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Contents

Original Papers

Web-Based Treatment Program Using Intensive Therapeutic Contact for Patients With Eating Disorders: Before-After Study (e12) Elke ter Huurne, Marloes Postel, Hein de Haan, Constance Drossaert, Cor DeJong.	3
Web-based Intervention to Promote Physical Activity by Sedentary Older Adults: Randomized Controlled Trial (e19) A. Irvine, Vicky Gelatt, John Seeley, Pamela Macfarlane, Jeff Gau.	18
Influence of Delivery Strategy on Message-Processing Mechanisms and Future Adherence to a Dutch Computer-Tailored Smoking Cessation Intervention (e28) Nicola Stanczyk, Rik Crutzen, Catherine Bolman, Jean Muris, Hein de Vries.	34
Effectiveness of a Self-Guided Web-Based Cannabis Treatment Program: Randomized Controlled Trial (e26) Sally Rooke, Jan Copeland, Melissa Norberg, Donald Hine, Jim McCambridge.	48
Cost-Effectiveness of a New Internet-Based Monitoring Tool for Neonatal Post-Discharge Home Care (e38) Valentina Isetta, Carme Lopez-Agustina, Esther Lopez-Bernal, Maribel Amat, Montserrat Vila, Carme Valls, Daniel Navajas, Ramon Farre.	6 2
Effects of Internet Popular Opinion Leaders (iPOL) Among Internet-Using Men Who Have Sex With Men (e40) Nai-Ying Ko, Chao-Hsien Hsieh, Ming-Chi Wang, Chiang Lee, Chun-Lin Chen, An-Chun Chung, Su-Ting Hsu.	90
Queer as F**k: Reaching and Engaging Gay Men in Sexual Health Promotion through Social Networking Sites (e25) Alisa Pedrana, Margaret Hellard, Judy Gold, Nadine Ata, Shanton Chang, Steve Howard, Jason Asselin, Olivia Ilic, Colin Batrouney, Mark Stoove.	99
Misleading Health-Related Information Promoted Through Video-Based Social Media: Anorexia on YouTube (e30) Shabbir Syed-Abdul, Luis Fernandez-Luque, Wen-Shan Jian, Yu-Chuan Li, Steven Crain, Min-Huei Hsu, Yao-Chin Wang, Dorjsuren Khandregzen, Enkhzaya Chuluunbaatar, Phung Nguyen, Der-Ming Liou.	115
Impact of Internet Use on Loneliness and Contact with Others Among Older Adults: Cross-Sectional Analysis (e39) Shelia Cotten, William Anderson, Brandi McCullough.	128

Web 2.0 Chronic Disease Self-Management for Older Adults: A Systematic Review (e35) Michael Stollefson, Beth Chaney, Adam Barry, Emmanuel Chavarria, Bethany Tennant, Kim Walsh-Childers, P.S Sriram, Justin Zagora.	141
Internet-Based Recruitment to a Depression Prevention Intervention: Lessons From the Mood Memos Study (e31) Amy Morgan, Anthony Jorm, Andrew Mackinnon.	155
Dental Fear and Anxiety in Children and Adolescents: Qualitative Study Using YouTube (e29) Xiaoli Gao, SH Hamzah, Cynthia Yiu, Colman McGrath, Nigel King.	184
How "Community" Matters for How People Interact With Information: Mixed Methods Study of Young Men Who Have Sex With Other Men (e33) Tiffany Veinot, Chrysta Meadowbrooke, Jimena Loveluck, Andrew Hickok, Jose Bauermeister.	195
If We Offer it, Will They Accept? Factors Affecting Patient Use Intentions of Personal Health Records and Secure Messaging (e43) Ritu Agarwal, Catherine Anderson, Jesus Zarate, Claudine Ward.	216
ICDTag: A Prototype for a Web-Based System for Organizing Physician-Written Blog Posts Using a Hybrid Taxonomy-Folksonomy Approach (e41) Yamen Batch, Maryati Yusof, Shahrul Noah.	230
Measuring Actual eHealth Literacy Among Patients With Rheumatic Diseases: a Qualitative Analysis of Problems Encountered Using Health 1.0 and Health 2.0 Applications (e27) Rosalie van der Vaart, Constance Drossaert, Miriam de Heus, Erik Taal, Mart van de Laar.	253
What Do Electronic Health Record Vendors Reveal About Their Products: An Analysis of Vendor Websites (e36) Natalie Yeung, Alejandro Jadad, Aviv Shachak.	270
Eight Questions About Physician-Rating Websites: A Systematic Review (e24) Martin Emmert, Uwe Sander, Frank Pisch.	286

Review

A Systematic Review of Web-Based Interventions for Patient Empowerment and Physical Activity in Chronic Diseases: Relevance for Cancer Survivors (e37) Wilma Kuijpers, Wim Groen, Neil Aaronson, Wim van Harten.	72
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Tutorial

Single-Case Experimental Designs to Evaluate Novel Technology-Based Health Interventions (e22) Jesse Dallery, Rachel Cassidy, Bethany Raiff.	167
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Original Paper

Web-Based Treatment Program Using Intensive Therapeutic Contact for Patients With Eating Disorders: Before-After Study

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Abstract

Background: Although eating disorders are common in the Netherlands, only a few patients are treated by mental health care professionals. To reach and treat more patients with eating disorders, Tactus Addiction Treatment developed a web-based treatment program with asynchronous and intensive personalized communication between the patient and the therapist.

Objective: This pilot study evaluated the web-based treatment program using intensive therapeutic contact in a population of 165 patients with an eating disorder.

Methods: In a pre-post design with 6-week and 6-month follow-ups, eating disorder psychopathology, body dissatisfaction, Body Mass Index, physical and mental health, and quality of life were measured. The participant's satisfaction with the web-based treatment program was also studied. Attrition data were collected, and participants were classified as noncompleters if they did not complete all 10 assignments of the web-based treatment program. Differences in baseline characteristics between completers and noncompleters were studied, as well as reasons for noncompletion. Furthermore, differences in treatment effectiveness, treatment adherence, and baseline characteristics between participants of the three major eating disorder diagnostic groups EDNOS (n=115), BN purging (n=24), and BN nonpurging (n=24) were measured.

Results: Of the 165 participants who started the web-based treatment program, 89 participants (54%) completed all of the program assignments (completers) and 76 participants (46%) ended the program prematurely (noncompleters). Severe body dissatisfaction and physical and mental health problems seemed to have a negative impact on the completion of the web-based treatment program. Among the participants who completed the treatment program, significant improvements were found in eating disorder psychopathology ($F=54.6$, $df = 68$, $P<.001$, $d=1.14$). Body dissatisfaction, quality of life, and physical and mental health also significantly improved, and almost all of these positive effects were sustained up to 6 months after the participants had completed the web-based treatment program. Body Mass Index improved only within the group of participants suffering from obesity. The improvement in eating disorder psychopathology occurred in all three eating disorder diagnostic groups, and the percentage of completers did not differ significantly between these groups. Participants' satisfaction with the treatment program, as well as with their therapist, was high, and participants indicated that they would recommend the program to other patients with eating disorders.

Conclusions: The results of this study suggest that the web-based treatment program has the potential to improve eating disorder psychopathology in patients with different types of eating disorders.

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KEYWORDS

Eating disorders; eHealth; Internet; Web-based treatment; Intensive therapeutic contact; Program evaluation; Treatment effectiveness.

Introduction

Approximately 1% of the young female population suffers from bulimia nervosa (BN) and 0.3% from anorexia nervosa (AN). The prevalence of binge eating disorder (BED) is at least 1% of the adult population [1]. Furthermore, a large segment of the population suffers from an eating disorder not otherwise specified (EDNOS) [2,3]. Yet despite the severe psychological, physical, and social consequences of eating disorders, only 6% of the patients with BN and 33% of the patients with AN are treated by mental health care professionals in the Netherlands [1]. Patients often do not ask for help themselves because of, for example, feelings of shame, a lack of awareness, ambivalence about the need for treatment, or a positive attitude towards their eating disorder behavior [4-7]. Most patients have suffered from severe eating disorders for many years before they eventually receive treatment. The Internet, which offers widespread access to information and has resulted in increasing usage among individuals, has already proven to be a suitable medium to offer effective interventions for patients with different kinds of psychological disorders, including alcohol abuse [8-11], depression [12-14], anxiety disorders [13,14], posttraumatic stress [15], and panic disorder [16,17]. The advantages of web-based interventions, such as anonymity and 24-hour access from any location, fit the needs of patients with eating disorders as well [5,18-21]. However, the number of studies on web-based interventions for adult patients with eating disorders is limited: existing studies focus primarily on prevention rather than treatment [22-30]. Moreover, most studies involve self-help or minimal contact interventions [31-34], whereas research has shown that intensive contact with a therapist is more effective [8,13,35-37]. There are also web-based interventions that focus exclusively on weight reduction in overweight and obese adults but not on other relevant eating disorder characteristics [38-40].

To our knowledge, only three web-based treatments using intensive therapeutic contact have been studied. One intervention included a 3-month email therapy, consisting of one or two emails sent per week by an online therapist [41]. The results of a Randomized Controlled Trial (RCT) showed that this email therapy significantly reduced the number of patients fulfilling DSM-IV eating disorder criteria, compared to a waiting list control group. However, almost identical results were found for patients who participated in a writing intervention with minimal therapeutic contact [41]. Another intervention consisted of eight weekly 90-minute group chat sessions led by a trained therapist [42]. This intervention proved to be effective in improving body image and eating attitudes and behaviors in patients with high body dissatisfaction, compared to a control group. However, the improvements in the chat intervention group were not as significant as the improvements in a face-to-face treatment group at the end of treatment. Due to continued improvements in the chat intervention group, there were almost no significant differences between the chat

intervention and the face-to-face treatment group at 6-month follow-up [42]. The third web-based intervention using intensive therapeutic contact that was studied included a 20-week Internet-delivered Cognitive Behavioral Therapy (CBT) program, using 25 scheduled asynchronous therapist feedback moments, which proved to be effective in patients with bulimic symptoms [43]. Participants of the web-based intervention group reported clinically relevant reductions in bulimic symptoms, and those reductions were substantially greater at posttreatment compared to the reductions in the bibliotherapy group and the waiting list control group. One year after the treatment, the differences between the web-based intervention and the bibliotherapy were no longer significant due to improvements in the bibliotherapy group [43].

Despite the mainly positive results of these studies, only the asynchronous, therapist-guided treatment program is available in the Netherlands. The recently published effects of this intervention have been studied in patients with high body dissatisfaction and bulimic symptoms, but not in patients with the different DSM-IV eating disorder diagnoses (AN, BN, and EDNOS, including BED). Patients with AN are even excluded from all three web-based treatments; all that exists is an Internet-based relapse prevention program for AN patients who have already been discharged from in-patient therapy [44] and a successful online intervention for the carers of AN patients [45]. To offer all eating disorder patients in the Netherlands the possibility to participate in a low threshold online therapy, we developed a new web-based intervention.

The intervention consisted of a website, an online forum, and a web-based treatment program. The website [46] was freely accessible for everyone and included concise information about eating disorders and related topics alongside a detailed description of the treatment program (sign-up procedure, content, aims, and costs). All visitors were free to decide whether they wanted to sign up for the web-based treatment program. Visitors to the website also had access to the online forum, where they could exchange ideas and experiences with fellow sufferers. In addition, registered participants of the web-based treatment program could log in to their personal online dossier via the website. During the treatment program, patients and therapists communicated asynchronously, solely via the Internet. Patients retained the same therapist, who could be identified by a name and a photograph in the patient's online dossier. No face-to-face or telephone contact took place during the web-based treatment program, unless patients explicitly requested this. The intensive and personalized interaction between patients and therapists was an essential element of the program and set it apart from other online self-help programs. The asynchronous communication resembled email contact but took place within the framework of a safe and secure web-based application. Asynchronous contact was chosen because the time delay between the responses gave patients more autonomy to decide when to participate in treatment. They also had the opportunity to think carefully about the response they wished

to give to their therapist. The content of the treatment program was based on the Dutch Multidisciplinary Guideline for Eating Disorders [7] and the latest insights regarding the treatment of eating disorders [6]. The online format, the design, and the technical aspects of the program were comparable with the successful web-based intervention for problem drinkers [8,47].

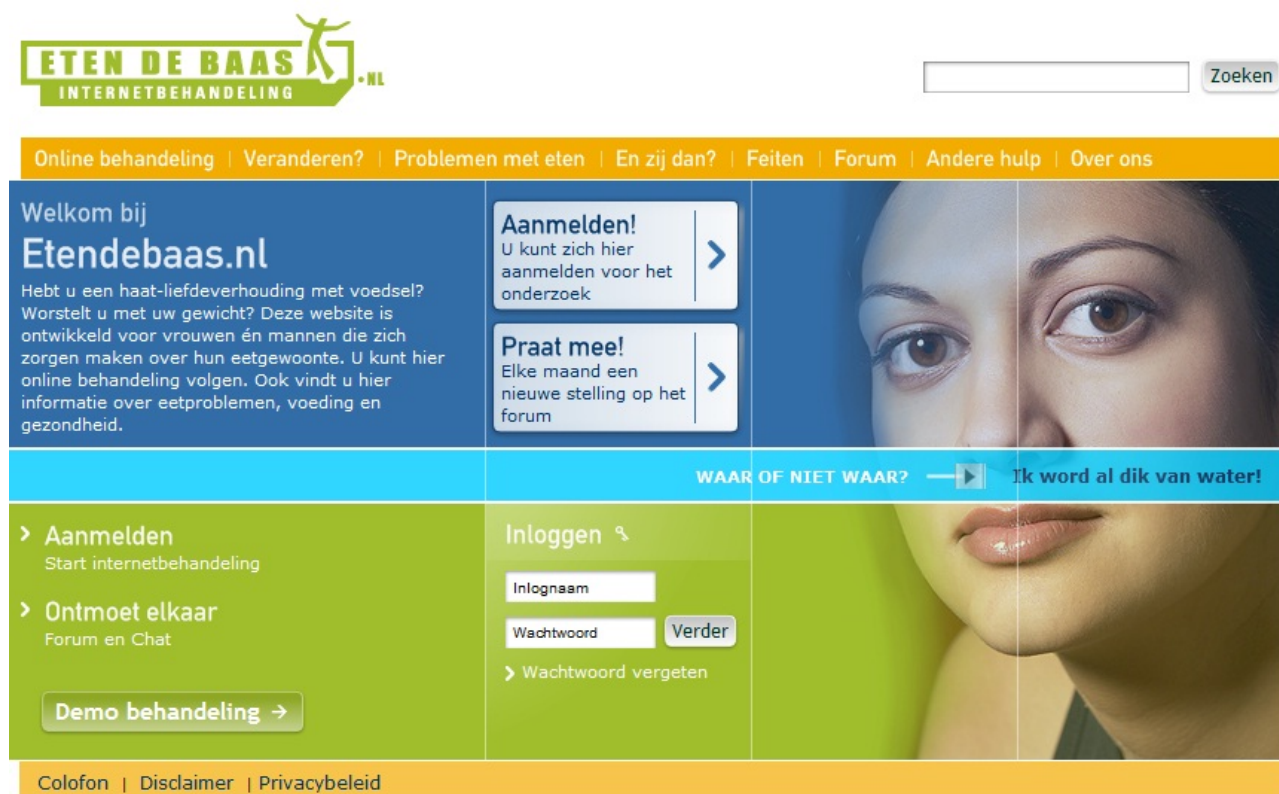
The aim of this pilot study was to evaluate adherence to, and the effectiveness of, the web-based treatment program and also patients' satisfaction with the program and their therapist, respectively. Differences in adherence, appreciation, and the effects of the web-based treatment between patients with a different eating disorder diagnosis were also investigated.

Methods

Participants and Procedure

The participants consisted of 165 adults who visited the website [46] (see Figure 1) and decided to sign up for the web-based treatment program between January 25 and December 31, 2010.

Figure 1. Homepage of the website.



Intervention

The structured, two-part, web-based treatment program was based on the principles of cognitive behavioral therapy (CBT) [19,48,49] and motivational interviewing (MI) [50,51]. Psycho-education, cognitive restructuring, self-control techniques, and exposure techniques were applied during the treatment program. The main aim of the program was to improve eating disorder psychopathology and to reduce body dissatisfaction. The average duration of the treatment program was about 15 weeks. Patients mostly maintained regular contact (1 or 2 times a week) with their therapist, and the therapist

The website was written for a general audience and all eating disorder diagnostic groups in order to reach a broad cross-section of the public and to recruit as many patients as possible for the web-based treatment program. The website and treatment program were promoted through various sources including relevant health care institutions, eating disorder-related websites, and a national press statement that resulted in newspaper, journal, and radio and television coverage. To sign up, participants provided personal data including their email address and information about their General Practitioner (GP) (to enable reimbursement of the treatment program by the health insurer). Participants were also informed about the terms and conditions of the treatment, after which they gave consent to participate by checking a box to indicate that they had read and understood the terms and conditions. Participants were then asked to choose a username and password and to fill in the baseline questionnaire. In total, 173 participants signed up for the treatment program although 8 (5%) did not start the program. Therefore, data from only 165 participants are included in the analysis.

always responded within 3 working days to the messages of their patient. The therapists monitored the progress of the treatment program. In the event of irregular or limited contact (less than once a week), the therapist requested the patient to keep in touch regularly. Patients could access the web-based treatment program in their personal environment at any time they wished. By logging in to their personal dossier (see Figure 2), they had access to the messages sent by the therapist. These messages were personalized, although preprogrammed text parts were also used for the analogous parts of the program, eg, the explanation of an assignment. The therapist sent all assignments

as attachments to their messages. Patients also had the option to request a face-to-face meeting or telephone contact.

The first part of the web-based treatment program included 4 assignments and at least 7 contact moments between the patient and the therapist, focusing on the analysis of the patient's eating behavior. Patients were asked to register their daily eating behavior, analyze their eating situations, and describe the advantages and disadvantages of their eating problem. At the end of Part 1, the patients received personal advice from their therapist, who in turn obtained expert advice from the multidisciplinary team, which consisted of treatment staff, a doctor specialized in addiction, a psychiatrist, a psychologist, a dietitian, and supervisors. The second part started with setting a goal for eating behavior, exercising patterns, weighing, and compensatory behaviors. This part involved 6 assignments and at least 14 contact moments geared towards helping the patient reach the set goals and desired behavioral change. Examples of the assignments were: changing thought patterns, changing behavior patterns, improving the patient's self-image, and

writing a relapse prevention plan. If patients did not complete all 10 assignments, they were considered to be noncompleters.

All of the therapists involved had a Bachelors degree in nursing or social work or a Masters degree in psychology. All therapists followed an intensive training program that focused on motivational writing skills, the content and implementation of the treatment protocol, and the technical aspects of delivering the intervention. The training program included 2 days of theoretical information and practice-oriented assignments (eg, writing a response to a message received from a patient). After the training program, all therapists went on to complete a full treatment program with a test patient before they could start as an online therapist. They were subsequently supervised for a period of 3 months. If the trainers positively evaluated the therapists at this point, the therapists received a certificate for completing the training program. When the trainers judged a therapist to be unsuitable to work with the web-based treatment program, the training program was terminated prematurely.

Figure 2. Participant's personal online dossier.

The screenshot displays a web-based interface for a patient's online dossier. At the top right, the logo for 'Eeten de Baas' is visible, with the text 'INTERNETBEHANDELING'. Below the logo, there are buttons for 'Nieuw bericht', 'a → A', and 'Afsluiten'. The main content area is divided into several sections:

- Therapist Profile:** A small profile picture of a woman is shown next to the text 'Je hulpverlener: Zerline de Boer'.
- Navigation:** A 'Handleiding' button with a question mark icon is located at the top left.
- Task List:** A yellow button labeled 'Eetdagboek' with a calendar icon and the text 'laatste registratiedatum: 18-03-2012' is present. Below it is a 'Print lege lijst' button.
- Checklist:** A vertical list of tasks with green checkmarks indicating completion:
 - Intake
 - Welkom
 - Eetdagboek bijhouden
 - Momentbeschrijvingen
 - Situaties analyseren
 - Voordelen, nadelen
 - Overeten
 - Top drie
 - Meten en weten
 - Doel stellen
- Message List:** A table with columns 'Onderwerp' and 'Datum'. The messages are:

Onderwerp	Datum
Afsluiting behandelfase	25-11-2011 20:43
Actieplan	25-11-2011 20:15
Goed inzicht	25-11-2011 20:06
Stof tot nadenken: de fasen van verandering	25-11-2011 19:58
Stof tot nadenken: op eigen kracht verder	25-11-2011 19:57
Beslissingen	25-11-2011 19:45
Kwaliteiten en sterke punten	25-11-2011 19:29
Stof tot nadenken: de gewone eetbui	25-11-2011 19:24
Stof tot nadenken: nee zeggen	25-11-2011 19:23
Wie ben ik	25-11-2011 18:52
Geen succesmomenten?	25-11-2011 17:32
Stof tot nadenken: ben jij zelf je grootste criticus?	25-11-2011 17:27
Oefeningen: ademhaling en ontspanning	25-11-2011 17:27

Outcome Measures

Participants completed online self-report measurements at baseline, posttreatment, 6-week and 6-month follow-ups. From the participants who prematurely ended the program, only baseline data were available as the measurement points linked to the treatment sessions.

The primary outcome measure of this pilot study was eating disorder psychopathology, which was assessed by using the Eating Disorder Examination Questionnaire (EDE-Q) [52,53]. The EDE-Q is a 36-item self-report scale that focuses on the previous 28 days to assess key behavioral and attitudinal features

of eating disorders and the severity of the psychopathology of eating disorders. It consists of 4 subscales measuring 4 eating attitudes: Restraint, Eating Concerns, Shape Concerns, and Weight Concerns. The items were scored on a 7-point Likert-type scale ranging from 0 to 6. A higher score indicates a higher level of eating disorder psychopathology.

Secondary outcome measures were Body Mass Index (BMI), body dissatisfaction, physical health, mental health, and quality of life. BMI was measured by dividing the participants' self-reported body weight in kilograms by the participants' self-reported height in meters squared. Body dissatisfaction was measured using the 20-item Body Attitude Test (BAT) [54-57],

which assesses the subjective perception and attitude of the participant towards his or her own body. The items were scored on a 6-point Likert-type scale ranging from 0 to 5. A higher score represents greater body dissatisfaction. A score above 36 indicates clinically significant disturbance. Physical health was assessed using the Maudsley Addiction Profile Health Symptom Scale (MAP-HSS): a 10-item self-report scale measuring physical complaints [58]. Each item was scored on a 5-point Likert-type scale ranging from 0 to 4. Because the MAP-HSS measures only general physical complaints, 15 additional eating disorder-specific physical complaints were added: dizziness/fainting; insomnia; hoarseness; sore throat; palpitations; diarrhea; constipation; hair loss/brittle hair; downy hair on face, arms, chest or back; fluid accumulation in the legs; dry/scaly skin; rapidly cold; dental problems; damaged back of the hand; and swollen glands. These items were scored on the same 5-point Likert-type scale. The total score of physical complaints was determined by dividing the sum of the scores on the 10 MAP-HSS items and the 15 additional items by the total number of items ($n=25$). A higher score represents a higher level of physical health problems. The 21-item Depression Anxiety Stress Scale (DASS-21) [59] measured the three related negative emotional states of depression, anxiety, and stress. Each item was scored on a 4-point Likert-type scale ranging from 0 to 3. A higher total score indicates a higher level of mental health problems. Quality of life was measured using the visual analogue scale of the EuroQol-5D (EQ-5D VAS) ranging from 0 (worst imaginable health state) to 100 (best imaginable health state). A higher score represents a higher quality of life.

Other measures at baseline included demographic characteristics, motivation for participating in the web-based treatment program, eating disorder diagnosis, previous treatment for eating disorders, and previous treatment for psychological problems. Demographic characteristics included age, gender, level of education, employment, and their daily routine. Participants were categorized as “higher educated” when they had a Bachelors or Masters degree. Participants’ motivation for participating in the web-based treatment program was measured with the question: “Why have you opted for the web-based treatment?” Possible answers were: (1) “I can do this on my own time”, (2) “I can do this from the confines of my own personal environment”, (3) “I can retain my anonymity”, (4) “I prefer contact via the Internet”, (5) “On the advice of a doctor/therapist”, and (6) “For another reason, namely ...” (free text response). Eating disorder diagnosis was determined using self-report questions based on the DSM-IV-TR criteria of eating disorders. The MINI-Plus interview [60,61] was used as a guideline in the development of this self-report questionnaire.

At posttreatment, participants’ satisfaction with the program and their therapist was measured. Participants were asked which aspects of the treatment program they found most important, as well as how pleasant, personal, and safe they considered the communication with their therapist. Participants were also asked if web-based treatment was effective for them and if they would recommend the intervention to others. Participants had to rate the treatment program and their therapist on a scale from 0 (very low) to 10 (very high). Finally, they also had the possibility of providing additional comments.

Analysis

A pre-post design was used to compare baseline data with outcome measures after completing the web-based treatment program. Multilevel modeling with SPSS, version 18, was used to determine improvement from baseline to posttreatment for the outcomes of interest. Repeated analyses of the outcome measures allowed for the inclusion of all participants, regardless of missing data, over time. For all outcomes, Cohen’s d effect sizes were calculated to analyze the strength of the observed effects [62]. Differences among the diagnostic groups and between completers and noncompleters were analyzed using chi-square tests for ordinal and nominal variables and one-way ANOVA (diagnostic groups) or independent sample t tests (completers/noncompleters) for scale variables.

Results

Participants

Table 1 presents the baseline characteristics of the 165 participants who enrolled in the pilot study. Of these participants, 98% ($n=161$) were female, 68% ($n=113$) were employed, and 42% ($n=69$) had a higher level of education. Of the participants ($n=115$), 70% fulfilled the criteria for EDNOS, 15% ($n=24$) for BN nonpurging, 15% ($n=24$) for BN purging, and 1% ($n=2$) for AN restrictive. Most participants had suffered from their eating disorder for many years, but 75 participants (45%) had never been in treatment before (eg, individual contact with a dietitian or a psychologist, admission to a clinic or hospital, or group therapy). However, 65% of the participants ($n=108$) had been in treatment for other mental health problems, mostly for depression or anxiety. The main reasons for participants to choose web-based treatment were that they could participate in the program on their own time and within their own personal environment.

We compared baseline characteristics among the three major diagnostic groups: EDNOS, BN nonpurging, and BN purging. Unfortunately, no separate analysis could be conducted for the AN diagnostic group because the pilot study included only 2 participants with AN. The differences between the three diagnostic groups, EDNOS, BN nonpurging, and BN purging, are presented in Table 1. Regarding demographic variables, we found that participants with BN purging were the youngest and participants with EDNOS the oldest. The percentage of participants who were employed was also the lowest in the BN purging group and the highest in the EDNOS group. For illness-related variables, significant differences were found for BMI, prior care for eating disorder, eating disorder psychopathology, quality of life, and mental and physical health. Participants in the BN purging group had received care for their eating disorder less frequently but experienced more physical and mental health problems than participants in the EDNOS and BN nonpurging groups. Eating disorder psychopathology was less severe among the participants with EDNOS; these participants had lower scores on the subscales “Restraint” and “Eating Concern”. Quality of life was highest among participants with BN nonpurging.

Table 1. Participant characteristics at baseline and differences between diagnostic groups.

Variable	Overall	EDNOS ^a	BN NP ^b	BN P ^c	Analysis	
	n=165	n=115	n=24	n=24	<i>F</i> value / χ^2	<i>P</i>
Female, n (%)	161 (98%)	111 (97%)	24 (100%)	24 (100%)	1.71	.43
Age (years), mean (SD)	35.3 (11.0)	36.6 (10.2)	33.1 (11.4)	30.9 (13.1)	3.41	.04
Employed, n (%)	113 (68%)	87 (76%)	15 (63%)	11 (46%)	8.92	.01
Higher education	69 (42%)	53 (46%)	9 (38%)	6 (25%)	4.01	.14
Regular daily routine, n (%)	123 (75%)	87 (76%)	20 (83%)	15 (63%)	2.90	.23
Prior care eating disorder, n (%)	90 (55%)	68 (59%)	14 (58%)	6 (25%)	9.53	.009
Prior care psychiatric problems, n (%)	108 (65%)	77 (67%)	16 (67%)	13 (54%)	1.46	.48
Body Mass Index, mean (SD)	29.1 (9.2)	31.2 (9.4)	26.4 (6.7)	22.8 (5.3)	11.12	<.001
Eating disorder psychopathology, mean (SD)^d	3.4 (1.0)	3.2 (1.1)	3.8 (0.9)	3.8 (0.8)	5.42	.005
Restraint	2.5 (1.6)	2.1 (1.5)	3.1 (1.6)	3.5 (1.3)	11.22	<.001
Eating concern	3.0 (1.3)	2.8 (1.3)	3.3 (1.0)	3.4 (0.9)	4.14	.02
Shape concern	4.3 (1.3)	4.2 (1.3)	4.5 (1.2)	4.3 (1.2)	0.67	.51
Weight concern	4.0 (1.2)	3.9 (1.2)	4.3 (1.1)	4.0 (1.4)	1.28	.28
Body dissatisfaction, mean (SD)^e	60.5 (16.7)	61.0 (15.8)	62.1 (16.9)	55.5 (20.4)	1.21	.30
Quality of life, mean (SD)^f	59.4 (16.6)	59.1 (16.3)	67.4 (13.7)	53.3 (18.5)	4.61	.01
Mental health, mean (SD)^g	38.5 (19.8)	36.6 (20.0)	36.3 (16.0)	47.8 (19.7)	3.42	.04
Physical health, mean (SD)^h	2.1 (0.5)	2.0 (0.5)	2.1 (0.5)	2.4 (0.5)	6.33	.002

^aEDNOS = eating disorder not otherwise specified.

^bBN NP = bulimia nervosa nonpurging.

^cBN P=bulimia nervosa purging.

^dEating Disorder Examination – Questionnaire (EDE-Q).

^eBody Attitude Test (BAT).

^fEuroQol-5D visual analogue scale (EQ-5D VAS).

^g21-item Depression Anxiety Stress Scale (DASS-21).

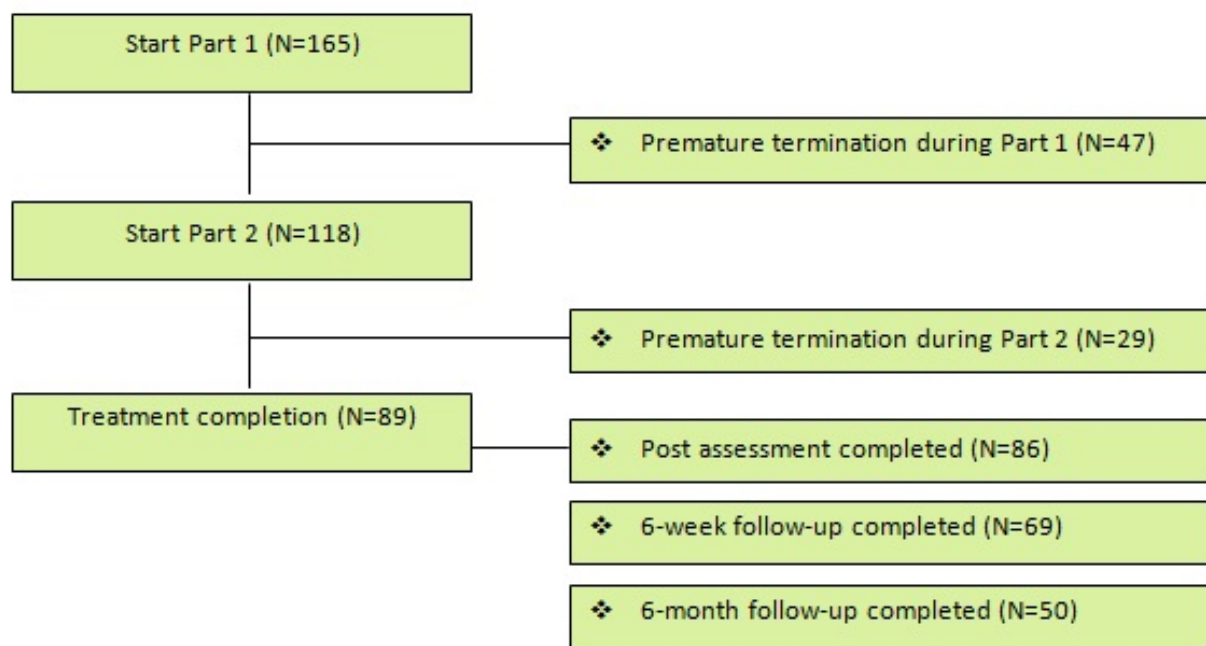
^hTotal score consisting of Maudsley Addiction Profile Health Symptom Scale (MAP-HSS) and 15 additional eating disorder-specific physical complaints.

Intervention Usage and Missing Data

More than half of the participants (n=89, 54%) completed all of the treatment sessions (completers), and 118 participants (72%) completed Part 1 of the program. Figure 3 provides an overview of the participant flow. Of the 76 participants (46%) who did not complete the entire program (noncompleters), the reasons for dropping out were mostly unknown. The 23 noncompleters (14%) who did provide a reason for stopping the treatment program mentioned a personal situation unrelated to the treatment (n=9), discomfort with the treatment protocol

(n=6), discomfort with treatment via the Internet (n=4), satisfaction with the achieved results (n=2), or something else (n=2). The therapist discharged one participant due to the seriousness of her problem. The postassessment was completed by 86 of the 165 participants (52%), and the 6-week and 6-month follow-ups were completed by 69 participants (42%) and 50 participants (30%), respectively. There were no significant differences between the diagnostic groups in terms of the percentage of completers and noncompleters ($\chi^2 = 2.95$; $df = 2$; $P = .23$).

Figure 3. Participant flow.



Completers Versus Noncompleters

We compared baseline characteristics between completers and noncompleters (Table 2). Almost all of the demographic characteristics did not differ significantly between those two groups, except for their daily routine. Completers more often

had a regular daily routine than noncompleters. Regarding illness-related variables, noncompleters were more dissatisfied with their bodies and experienced a lower quality of life and more physical and mental health problems. The completers and noncompleters did not differ with regard to diagnosis, BMI, or eating disorder psychopathology.

Table 2. Differences in baseline characteristics between completers and noncompleters.

Variable	Completers	Noncompleters	Analysis	
	n=89	n=76	<i>t</i> value / χ^2	<i>P</i>
Female, n (%)	88 (99%)	73 (96%)	1.38	.34
Age (years), mean (SD)	36.8 (11.2)	33.5 (10.5)	1.94	.054
Employed, n (%)	65 (73%)	48 (63%)	1.85	.17
Higher education	40 (45%)	29 (38%)	0.88	.35
Regular daily routine, n (%)	75 (84%)	48 (63%)	9.63	.002
Prior care eating disorder, n (%)	51 (57%)	39 (51%)	0.59	.44
Prior care psychiatric problems, n (%)	58 (65%)	50 (66%)	0.01	.93
Body Mass Index, mean (SD)	28.3 (7.9)	30.0 (10.5)	-1.19	.23
Eating disorder psychopathology, mean (SD) ^a	3.4 (1.0)	3.5 (1.0)	-0.40	.69
Restraint	2.6 (1.5)	2.3 (1.6)	1.32	.19
Eating concern	2.9 (1.2)	3.1 (1.3)	-0.88	.38
Shape concern	4.2 (1.3)	4.4 (1.2)	-0.79	.43
Weight concern	3.9 (1.2)	4.1 (1.2)	-1.35	.18
Body dissatisfaction, mean (SD) ^b	57.8 (15.6)	63.8 (17.5)	-2.33	.02
Quality of life, mean (SD) ^c	62.2 (14.8)	56.3 (18.1)	2.28	.02
Mental health, mean (SD) ^d	34.2 (17.9)	43.5 (20.8)	-3.10	.002
Physical health, mean (SD) ^e	1.9 (0.5)	2.3 (0.5)	-4.54	<.001

^aEating Disorder Examination – Questionnaire (EDE-Q).

^bBody Attitude Test (BAT).

^cEuroQol-5D visual analogue scale (EQ-5D VAS).

^d21-item Depression Anxiety Stress Scale (DASS-21).

^eTotal score consisting of Maudsley Addiction Profile Health Symptom Scale (MAP-HSS) and 15 additional eating disorder-specific physical complaints.

Effectiveness of the Intervention

Table 3 presents the mean and standard deviations on the outcome measures of this pilot study. Eating disorder psychopathology significantly improved ($F=54.6$, $df = 68$, $P<.001$, $d=1.14$) with medium to large effect sizes (from $d=.47$ to $d=1.17$). We also found significant improvements in body

dissatisfaction, quality of life, and mental and physical health. Almost all of the treatment effects were sustained at the 6-week and 6-month follow-up measurements; only the improvement in quality of life was no longer significant 6 months after completing the treatment program. For BMI, the improvements were significant only for participants with obesity ($BMI > 30$). However, the size of the effect was small ($d=.20$).

Table 3. Treatment outcomes for all participants.

Variable	Pretreatment		Posttreatment			Follow-up at 6 months			Overall effect ^a			
	Mean	SD	MD ^b	SD	<i>P</i>	MD ^b	SD	<i>P</i>	<i>F</i>	df	<i>P</i>	Effect size ^c
Eating disorder psycho-pathology^d	3.4	1.0	1.4	1.2	<.001	1.2	1.4	<.001	54.6	68	<.001	1.14
Restraint	2.5	1.6	0.9	1.8	<.001	0.7	1.5	.001	11.7	70	<.001	0.47
Eating concern	3.0	1.3	1.6	1.4	<.001	1.2	1.5	<.001	55.6	70	<.001	0.95
Shape concern	4.3	1.3	1.6	1.5	<.001	1.5	1.8	<.001	39.6	67	<.001	1.17
Weight concern	4.0	1.2	1.4	1.5	<.001	1.3	1.6	<.001	41.6	68	<.001	1.11
Body dissatisfaction^e	60.5	16.7	15.3	13.6	<.001	14.5	17.1	<.001	40.8	67	<.001	0.86
BMI^f												
< 18.5	16.9	1.3	-0.6	0.9	.29	-0.3	0.6	1.00	3.8	9	.05	0.02
18.5-25	21.1	1.7	0.1	1.1	.99	0.7	1.8	.34	1.6	18	.22	0.39
25-30	27.8	1.5	0.4	1.0	.66	0.7	1.9	.67	0.9	14	.48	0.46
> 30	36.4	7.2	1.1	1.9	.01	1.5	2.1	.01	4.7	26	.01	0.20
Quality of life^g	59.4	16.6	-9.6	17.8	<.001	-6.8	20.5	.08	13.3	71	<.001	0.32
Mental health^h	38.5	19.8	12.8	16.1	<.001	11.0	17.9	<.001	21.8	70	<.001	0.56
Physical healthⁱ	2.1	0.5	0.3	0.3	<.001	0.2	0.3	<.001	36.8	67	<.001	0.39

^aTreatment outcomes were measured with Repeated Measures and Mixed Model analysis.

^bMD = Mean Difference; positive MD scores indicate a decrease in baseline scores and negative MD scores indicate an increase in baseline scores.

^cEffect sizes were measured with Cohen's *d* using MD at 6-months follow-up and baseline SD.

^dEating Disorder Examination – Questionnaire (EDE-Q).

^eBody Attitude Test (BAT).

^fBMI indexes below 18.5 indicate underweight, 18.5 to 25 healthy weight, 25 to 30 overweight, and over 30 obesity.

^gEuroQoL-5D visual analogue scale (EQ-5D VAS).

^h21-item Depression Anxiety Stress Scale (DASS-21).

ⁱTotal score consisting of Maudsley Addiction Profile Health Symptom Scale (MAP-HSS) and 15 additional eating disorder-specific physical complaints.

Analyses for individual diagnostic groups showed that eating disorder psychopathology significantly improved in the EDNOS group and that this improvement was sustained up to 6 months after completion of the web-based treatment program (Appendix 1). Participants from the EDNOS group also improved on all secondary outcome measures, and the effect sizes for all outcome measures were medium to large (from $d=.45$ to $d=1.29$). Participants from the BN nonpurging group also improved on most primary and secondary outcome measures with generally medium to large effect sizes, but the differences between the separate measuring moments (pretreatment and posttreatment, and pretreatment and follow-up at 6 months) were not significant for this group. Analyses for the participants from the BN purging group showed significant improvements in eating disorder psychopathology from pretreatment to posttreatment, but those improvements did not maintain at the 6-month follow-up. For all secondary outcome measures, positive trends were found at posttreatment; however, those improvements were not statistically significant and did not remain 6 months after treatment completion.

Participant's Satisfaction With the Intervention

Participants who completed the postassessment ($n=86$, 52%) were satisfied with the program and the contact they had with the therapist. Most participants ($n=72$, 84%) found web-based treatment to be an effective method for treating eating disorders and nearly all of the participants ($n=78$, 91%) stated that they would recommend the program to others. The support of the therapist was considered to be one of the most valuable and important components of the program. Most participants considered the online contact with the therapist to be pleasant ($n=77$, 90%), personal ($n=61$, 71%), and safe ($n=82$, 95%). The assignment "Changing thoughts" and the daily registration in the eating diary were also evaluated as very worthwhile and important. On a scale from 0 to 10, participants evaluated the treatment program with a 7.8 (SD 1.2) and their therapist with an 8.4 (SD 0.9). These evaluations did not differ among the three diagnostic groups (treatment program: $F=0.01$, $df=2$, $P=1.00$; therapist: $F=0.15$, $df=2$, $P=.86$). The most common criticisms were that the treatment program was too short ($n=5$), the therapist's messages were sometimes too standard and impersonal ($n=4$), and the treatment sessions sometimes followed on from each other too quickly ($n=3$).

Discussion

Principal Results and Comparison With Prior Work

This pilot study showed that the web-based treatment program successfully changed the eating disorder psychopathology in patients with eating disorders and that these improvements were sustained at 6-week and 6-month follow-ups. Participants also indicated that they had become more satisfied with their bodies and that their physical and mental problems had decreased during the treatment program. Participants evaluated the program positively, with the support of the therapist rated as the most important element. Participants experienced the personal online contact with their therapist as pleasant, personal, and safe. On a scale from 0 to 10, they evaluated their therapist with an 8.4.

The improvement in eating disorder psychopathology in our pilot study is consistent with the results of other web-based interventions with intensive therapeutic contact, although our effect sizes seem to be somewhat larger [42-43]. We did not find a significant improvement in BMI for participants who were underweight (BMI < 18.5) and overweight (BMI = 25-30). Although the web-based treatment did not focus primarily on weight improvement, the underlying idea is that the improvement of eating disorder psychopathology will improve BMI. In the present study, there is only limited evidence for this among the participants with obesity (BMI > 30). Further research would be required to investigate how BMI changes can be achieved for all participants who are either underweight or overweight.

The attrition rate in our pilot study was 46%. Because of the linear design of our treatment program, nonusage attrition (program adherence) and dropout attrition (study adherence) were the same in our study. According to a systematic review on adherence to, and the effectiveness of, web-based therapies, it is often difficult to compare the attrition rate of interventions because of the large variation in the reporting of those results [63]. This also applies to the attrition rate of our study compared to the attrition rate of other web-based interventions for patients with eating disorders. For example, Paxton et al reported a nonusage rate of 16% for their web-based group chat intervention; however, they considered participants to be completers when they had attended only four of the eight intervention sessions [42]. In addition, Carrard et al reported a low dropout attrition rate (25%), but a high nonusage attrition rate (69%) [33]. Robinson and Serfaty, however, described only the dropout attrition rate in their study (47%). It is therefore not clear whether patients participated actively in the email therapy [41]. Ruwaard et al reported a nonusage attrition rate of 26% and a dropout attrition rate of 17% for their asynchronous web-based intervention [43]. One possible explanation for the lower attrition rates in this study might be selection bias due to the randomized design and the exclusion criteria of that study, with more than 60% of the participants stopping or being rejected even before randomization [43].

Completers and noncompleters differed significantly on several baseline characteristics. The baseline physical and mental health as well as participants' satisfaction with their body seemed to

play an important role in completing the web-based treatment program. Although little research has examined differences between completers and noncompleters of treatments for eating disorder patients (especially for web-based treatments), other studies have suggested that the risk of noncompletion increases with an increase in the severity of other health problems and comorbidity [64]. Therefore, the web-based treatment program can be seen as an important and accessible first step within the stepped-care principle, while participants who need more help will be referred to a more intensive form of treatment. However, further research into the factors that influence the completion of the treatment program is needed.

The web-based treatment was available for patients with all eating disorders; however, as expected based on prevalence rates, most of the participants (70%) fulfilled the criteria for EDNOS (including BED). Almost all of the other participants met the criteria of BN, with half of them belonging to the purging subtype and the other half to the nonpurging subtype. Only 2 participants fulfilled the criteria of AN. The low number of participants with AN can be a result of the recruitment strategy, as it focused on eating disorders in general and not on specific diagnostic groups. In addition, the lower prevalence of AN compared to the other eating disorder diagnostic groups might also be a reason for the limited number of patients with AN in our pilot study. However, the benefits of the web-based treatment program, such as the high degree of anonymity and the increased convenience, are particularly applicable for patients with AN. As such low-threshold forms of treatment for this particular target group are still missing from the current treatment services in the Netherlands, it is important to recruit more patients with AN for the web-based treatment program in the future. However, the recruitment should then be more focused on places where patients with this particular diagnosis can be found (eg, informative websites and forums for patients with AN, patient associations, health centers, general practitioners' surgeries, and schools), and the message of the recruitment should also be more tailored for this target group.

As the pilot study included only 2 participants with AN, no separate analysis could be conducted for this group. Between the other diagnostic groups (EDNOS, BN purging, and BN nonpurging), we found significant differences regarding several demographic and illness-related variables. The differences in age and employment are not surprising as BN often occurs in young women (some of whom are still studying), while BED has a much broader age range. The differences in BMI and eating disorder psychopathology can be explained by the diagnosis, as participants with BN have compensatory behaviors that are related to body weight and eating disorder psychopathology. The study found no significant differences between the diagnostic groups related to treatment adherence and satisfaction with the program. In addition, eating disorder psychopathology improved within each diagnostic group. Therefore, the web-based treatment program seems feasible for patients with BN, as well as patients with EDNOS, including BED. However, some differences were evident among the diagnostic groups. These differences might be explained by the large differences in numbers between the three groups. It would

be interesting to further investigate these differences among larger patient groups in order to draw reliable conclusions.

Limitations

The pilot study has several limitations. As previously mentioned, almost half of the participants did not complete all of the treatment sessions provided through the program. Consequently, no posttreatment and follow-up data were available from the noncompleters, as these questionnaires were completed after the last treatment session. Therefore, we do not know whether these patients benefited from participating in the treatment program. We have chosen a linear model, as the treatment program is most effective with a specific order of treatment steps, and this model is also useful in working with homework assignments and tailored feedback. However, the lack of information about noncompleters of the intervention is a real disadvantage. We recently started a randomized controlled trial (RCT) to study the efficacy of the web-based treatment program. In the RCT, the web-based application has been modified so that the measurements are no longer linked to the treatment steps. Consequently, posttreatment and follow-up data will be available from both completers and noncompleters. The reasons for noncompletion and the characteristics of noncompleters, as well as their satisfaction with the treatment program and therapist, will also be investigated in the RCT.

Another limitation is that we cannot attribute the observed improvements exclusively to the web-based treatment program due to the nonrandomized design of the study. The RCT will therefore provide more insights into the effectiveness of this intervention. The results and our experiences of this pilot study were the foundation for the development of the RCT. As mentioned before, the web-based application has been modified to differentiate between the research questionnaires and the treatment steps. Study adherence and treatment adherence can therefore be distinguished. In addition, patients with BED will not be included in the EDNOS group in the RCT, but they will

comprise an individual diagnostic group based on the BED DSM-IV-TR research criteria. Furthermore, patients with AN and male patients will be excluded, as these groups were a minority in this pilot study and it is not feasible to recruit enough patients within the RCT to be able to make statements about these individual patient groups. However, since the web-based treatment program has been developed for all patients with eating disorders, and we do not want to exclude male patients and AN patients, we will offer them the possibility to participate in the regular treatment program without participating in the RCT. Finally, in the RCT more attention will be paid to completing all research questionnaires to enlarge study adherence. The researcher will actively approach participants via email and phone and will request that they fill in all of the research questionnaires. This will also be stimulated with an incentive of €10.00 for each completed research questionnaire.

A last limitation of this pilot study concerns the reliability of some measurements. Although validated self-report instruments were used, clinical interviews might be more preferable. In addition, a direct measurement of the participants' height and weight is more desirable than self-reported height and weight [65], but because all communication with participants occurred via the Internet, this was not possible in the present study.

Conclusions

This pilot study indicated that the web-based treatment program with intensive therapeutic contact is an acceptable intervention for patients with eating disorders. Participants evaluated the program positively, and the results after completing treatment were promising. Eating disorder psychopathology and body satisfaction improved significantly, as did mental and physical health. The web-based treatment program also resulted in an improvement in the quality of life. A randomized controlled trial has recently been started to provide more scientific evidence for the efficacy of this web-based intervention.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Treatment outcomes for individual diagnostic groups.

[PDF File (Adobe PDF File), 110KB - [jmir_v15i2e12_app1.pdf](#)]

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Abbreviations

AN: anorexia nervosa
BAT: Body Attitude Test
BED: binge eating disorder
BMI: body mass index
BN NP: bulimia nervosa nonpurging
BN P: bulimia nervosa purging
CBT: cognitive behavioral therapy
DASS-21: Depression Anxiety Stress Scale
DSM-IV: Diagnostic and Statistical Manual of Mental Disorders, 4th revision
EDE-Q: Eating Disorder Examination Questionnaire
EDNOS: eating disorder not otherwise specified
EQ-5D VAS: EuroQol-5D visual analogue scale
MAP-HSS: Maudsley Addiction Profile-Health Symptom Scale
MI: motivational interviewing
MINI-Plus: Mini International Neuropsychiatric Interview Plus
RCT: randomized controlled trial

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Original Paper

Web-based Intervention to Promote Physical Activity by Sedentary Older Adults: Randomized Controlled Trial

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Abstract

Background: Physical activity (PA) for older adults has well-documented physical and cognitive benefits, but most seniors do not meet recommended guidelines for PA, and interventions are lacking.

Objectives: This study evaluated the efficacy of a 12-week Internet intervention to help sedentary older adults over 55 years of age adopt and maintain an exercise regimen.

Methods: A total of 368 sedentary men and women (M=60.3; SD 4.9) were recruited, screened, and assessed online. They were randomized into treatment and control groups and assessed at pretest, at 12 weeks, and at 6 months. After treatment group participants rated their fitness level, activity goals, and barriers to exercise, the Internet intervention program helped them select exercise activities in the areas of endurance, flexibility, strengthening, and balance enhancement. They returned to the program weekly for automated video and text support and education, with the option to change or increase their exercise plan. The program also included ongoing problem solving to overcome user-identified barriers to exercise.

Results: The multivariate model indicated significant treatment effects at posttest ($P=.001$; large effect size) and at 6 months ($P=.001$; medium effect size). At posttest, intervention participation showed significant improvement on 13 of 14 outcome measures compared to the control participants. At 6 months, treatment participants maintained large gains compared to the control participants on all 14 outcome measures.

Conclusions: These results suggest that an online PA program has the potential to positively impact the physical activity of sedentary older adult participants. More research is needed to replicate the study results, which were based on self-report measures. Research is also needed on intervention effects with older populations.

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KEYWORDS

physical activity; older adults; Internet; sedentary; multi-week; exercise

Introduction

Physical activity (PA) for older adults increases active life expectancy while limiting the development and progression of disabling conditions and chronic disease [1]. PA is associated with decreased depression [2], improved mental well-being [3,4] and decreased risk of functional decline [5,6]. It enables

seniors to maintain their mobility, to improve muscle strength, and to prevent falls [1,7-9]. While results have been mixed, emergent research links vigorous physical activity with reduced risk for cognitive decline [10-12]. The American College of Sports Medicine recommends that PA programs for seniors include endurance, flexibility, strengthening, and balance enhancement exercises, and that seniors engage in 30 minutes

of moderate exercise at least 5 days per week [1,8]. Unfortunately, 39% of adults age 65 and older do not meet recommended PA guidelines [8], 33% report no leisure-time physical activity [13], and there is a lack of interventions targeting sedentary behavior [14].

Although the most effective PA intervention mediators are yet to be determined, theory-based behavioral interventions promoting adoption of exercise as a lifetime habit are recommended [6,14-16]. Some studies suggest that participants need to be active for a minimum of 12 weeks to reap the benefits and develop an exercise routine [17-19]. Home-based PA interventions have produced positive results [20-22], while requiring fewer professional resources compared to community or institution-based programs [23].

Computer-technology with multimedia interfaces has the potential to provide cost-effective personalized home PA interventions [6,24,25]. Early research has examined the relative efficacy of various computerized PA approaches including the use of telephone [26-29], print [16,30-34], and handheld computer technology [35]. As new applications and hardware are developed or updated (eg, iPhones, Droids, iPads), more options are becoming available with 4G telecommunications technology. The benefits of interactively tailored interventions has been supported by some [36-38], but not all research [39]; however, interactive programming that tailors the programming to match the users' personal preferences also is a promising PA approach [40,41]. In sum, new technological developments offer multiple options for individualized PA interventions on desktop computers and mobile devices, but this is still an emerging field of research that has focused so far on young to middle-aged adults [6,16,24,25,42].

Shaping a PA intervention to an older adult audience requires a thoughtful approach because seniors may have decade-old habits and attitudes to change, and they may have functional limitations due to age or medical conditions. Further, based on rates of Internet adoption, seniors may be less prone than younger age groups to adopt new technological approaches, but the tide is changing as baby boomers age and use of the Internet becomes more commonplace. While seniors have been the slowest age group to use the Internet, they have been the fastest growing population segment in recent years, and as of April 2012, 53% of American adults aged 65 and older use the Internet or email, and 70% of them use the Internet daily [43]. Thus, use of computer technology to deliver a senior PA program has increasing potential. In a literature search, however, we could find no research involving stand-alone, theory-driven, Internet PA interventions for seniors that may tap into this potential. Given the success of Web interventions to influence low-fat eating habits [44], tobacco use [45], family caregiver behavior [46], and the exercise habits of sedentary employees [47], among others, we hypothesized that a stand-alone Web-based intervention could influence the PA of older adults as well.

The intervention in this research was based on the theory of planned behavior [48,49], which posits that attitude toward a behavior, social norms, and perceived behavioral control (ie, self-efficacy [50-52]) lead to behavioral intention and change. Considerable empirical evidence supports the significance of

self-efficacy in the adoption and maintenance of health-promoting exercise behaviors for adults generally, for example, [53,54] and older adults in particular [55-59]. Thus, the more positive the attitude and subjective norm and the greater the perceived behavioral control, the stronger the intention to perform the behavior [48,49]. Interventions based on this theory have recently been shown to produce large effects on behavior in Web-based interventions [16].

Consequently, the program was designed to provide information and support that would enhance knowledge, attitudes, self-efficacy, and behavioral intentions to participate in exercise activities on a regular basis. Using the criteria recommended for theoretically driven web exercise programs by Doshi and colleagues [14], the intervention included: general assistance, tailored assistance and feedback, self-assessment, and general information, all combined within a gain-framed messaging framework [60,61].

Stage of change theory [62,63] suggests that readiness to change a behavior is predicted by series of stages. These stages include: precontemplation (not considering changing); contemplation (thinking about changing); decision or preparation (definite plans to change); action (beginning change); and maintenance. Encouraging step-wise movement along the continuum of change is thought to lead to enhanced self-efficacy, as well as greater compliance and participation in a behavior change activity. While stage theory is a popular intervention approach in health promotion, it has had mixed results in exercise research. Marcus et al [64] and Calfas et al [65] showed positive intervention effects from stage-matched interventions, but other research has not shown similar effects [21,66,67]. In the research reported here, we viewed stage-matched messages as unnecessary. The program focused on the action-focused messages and social support for all user choices.

In this study, we developed and tested a stand-alone 12-week Internet intervention designed to improve self-reported PA of sedentary older adults. The randomized design (Clinicaltrials.gov NCT01579240) evaluated self-reported changes in exercise across four domains: endurance, stretching, strengthening, and balance. We hypothesized that the intervention would be linked to improvement in the above PA domains and to theoretically relevant mediators of behavior change (eg, attitudes, self efficacy, behavioral intentions) and that user acceptance would be positive. This was a "real-world" effectiveness trial [24,68] in the participants' setting of choice, as opposed to an efficacy trial in a more controlled gym or laboratory setting.

Methods

Intervention Program

The intervention, entitled *Active After 55*, was a multiple-visit Internet program to enhance functional ability, mobility, and physical activity of older adults. Using text and video messages integrated with interactive values clarification and goal-setting activities, it helped users develop a self-tailored exercise plan (eg, by type, intensity, frequency, duration, and schedule) consisting of four activities: endurance, stretching,

strengthening, and balance enhancement. Our rationale for a self-tailored approach was based on formative research in this and a previous Web PA study with sedentary individuals [47] and on the theoretical benefits of behavioral control espoused in the theory of planned behavior [50-52]. We also felt that program users being supported and assisted as they set up their own PA prescription might feel ownership, which might improve program engagement and decrease attrition.

The interactive framework was developed in consultation with professionals experienced in the design and implementation of research-based exercise programs for older adults. Care was taken to include only exercises that the participants could do safely on their own with minimal equipment.

Active After 55 was designed as a browser format, and it did not control the participants' actions with mandatory linear pathways. The home page had links to *Personal Activity Planning* (ie, developing a personal exercise prescription), *The Health Value of Exercise, Overcoming Obstacles* (ie, dealing with barriers to exercising), *Tracking Progress* (ie, charting activities and frequency of exercise), *Staying Motivated* (ie, tips and personal stories of how individuals made exercise a habit), *Safety Tips* (ie, avoiding injuries), *Disease Specific Recommendations* (ie, tips on exercising with diseases such as arthritis, osteoporosis), and a library with additional related articles and tip sheets. After logging in, participants were encouraged to visit the section on *Personal Activity Planning*, but they were not required or later prompted to do so.

At the initial 1-hour start-up session, *Active After 55* assisted users in designing a personalized PA program. With 11 subsequent weekly sessions, lasting at least 10-15 minutes or more in length, the content logically built on the previous session, with new exercises or advanced challenges of the same exercise added over time. A narrator and personal coach presented video-based educational content with bulleted text teaching points and interactive knowledge-building content. Onscreen titles, bullets, and printable text articles were written at a grade 6-8 reading level. Each exercise was introduced with text instruction and offered optional video demonstrations employing a diverse cast of older adults.

During the first visit, participants were asked to identify their personal goals and their perceived benefits of increased exercise. Users provided information on their recent exercise history and then categorized themselves (ie, Beginner, Intermediate, Advanced) for each of the four activity types. Next, the program helped the user build a tailored weekly exercise plan for each activity type (eg, Beginner stretching: 5 stretches, 3 days per week; Intermediate endurance: 30 minutes per day, 5 days per week). Given the sedentary target population, the program was not designed to provide aerobic exercise. Since we could not control for inaccurate self-categorization of fitness level (eg, sedentary individual selects Advanced for a category), the activities were designed conservatively. That is, Advanced levels were slight increases in frequency or duration from Intermediate

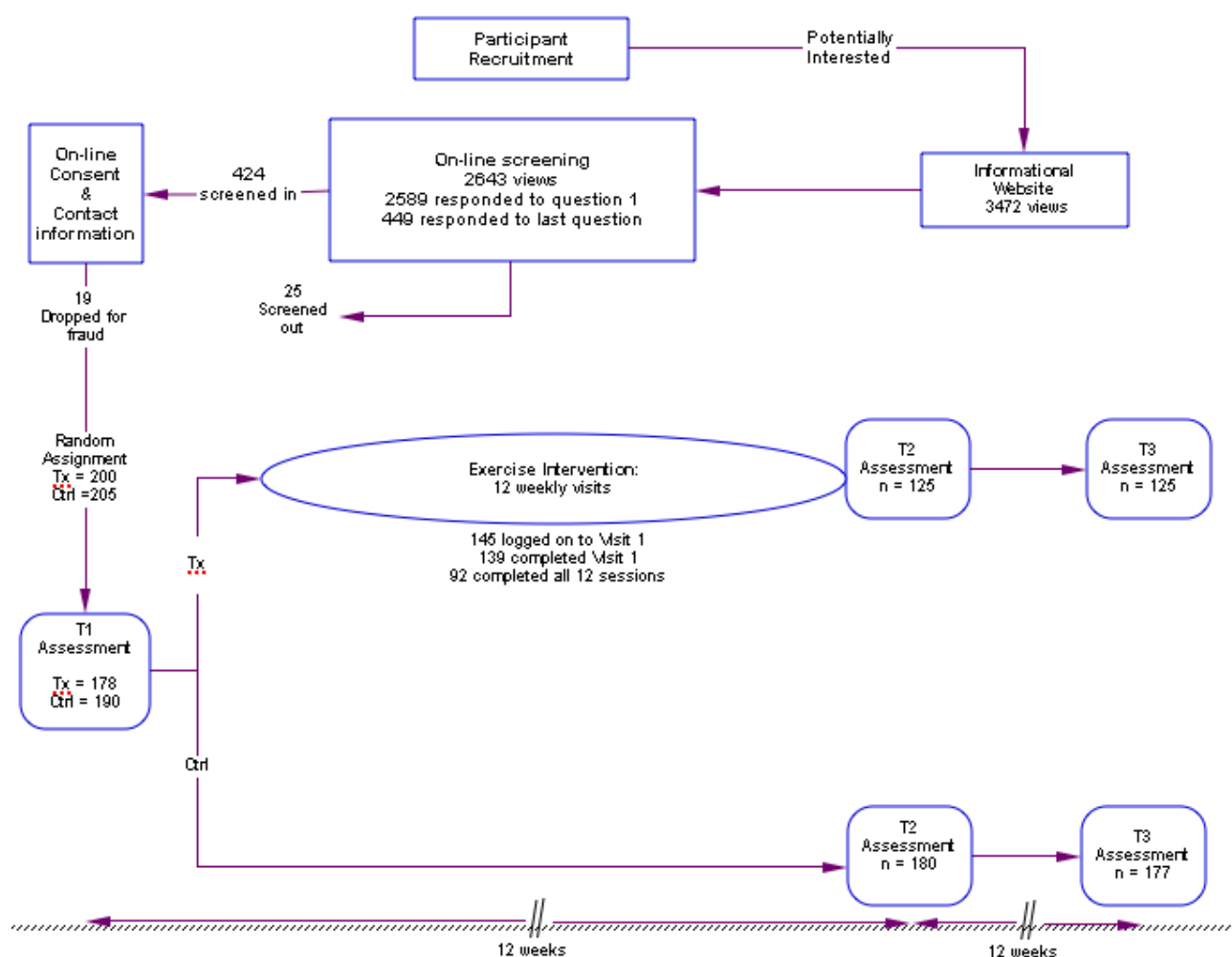
levels, and participants were encouraged by text on their printouts to postpone finishing an activity if it seemed too difficult.

For each activity type, users committed to exercises (eg, type of stretches from a list; type of endurance activity from a list) and scheduled the days of the week when they would do each one. For each of the four activity types, users responded to multiple-choice questions about their confidence in achieving their exercise plan for the following week. If they were not confident, they were interactively asked to adjust either the intensity or duration of that exercise (eg, stretching: decrease number of stretches or days per week; endurance: decrease number of days or minutes per day), and they were queried until they interactively expressed confidence that they could meet their weekly commitment. Users also were encouraged to print the schedule for their reference. The printout included personal goals, next week's exercise plan and blank exercise tracking sheets, guidelines, and safety tips for each activity type. Finally, the session was summarized by the video narrator who extolled the benefits of following the exercise plan and invited the user back in a week for the next session. While participants could visit the website as often as they liked (eg, to read articles or print out personal exercise plans linked to the user's ID and password), the next program session was available no sooner than 1 week after the completion of the previous session.

At return visits, users were welcomed back and given video and text support for returning. Based on an interactive self-report about success in adhering to exercise commitments from the previous session, users were appropriately praised and encouraged to continue their efforts. For those who reported no progress, the coach's message was upbeat, offering praise for coming back, and encouragement to try again. At each visit, the user was offered tailored video support on overcoming self-identified exercise barriers (eg, too tired, lack motivation, lack skills, etc). Each week, new educational material was presented to engage users and enhance their knowledge about how to make exercise a habit over time. Based on the user's self-reported progress and motivation, changes to the exercise plan from the previous week were recommended, if appropriate. As before, the users selected exercise amounts and schedules for each activity and affirmed their confidence to meet the commitments. At the 12th visit, users were encouraged to maintain their exercise program into the future, making it a habit.

Research Design

The study was a randomized controlled trial on the Internet with three assessments: pretest (T1), postintervention at 12 weeks after pretest (T2), and 6-month follow-up (T3; see [Figure 1](#)). After screening into the study and agreeing to the online informed consent, participants were automatically randomized into a treatment (Tx) group, which used the Internet PA intervention, and a control (Ctrl) group, which did not have access to the intervention.

Figure 1. Research design with participation level from recruitment to T3 assessment.

Recruitment

After approval by an Institutional Review Board for protection of human subjects (IRB), the study was conducted entirely on the Internet. Participants were recruited via a mixture of online recruitment strategies (eg, listservs, advertising on a website for seniors), flyers, newsletters, and announcements supported by service agencies, senior centers, and worksites. Interested individuals linked to an information website, which offered a link to an online screening questionnaire to determine eligibility (Figure 1). Page views included a total of 3472 on the information website, 2643 on the first screening-questions page, 2589 responses to the first screening item, 449 responses to the last screening item, with 405 individuals ultimately qualifying for the research. This was a rolling recruitment, ie, recruitment was initiated before the intervention was ready for use, with screened-in participants asked to wait, and recruitment continued for 21 days after the T1 assessment and intervention program became available. The average time between participant consent and starting the T1 assessment was 29.1 days (SD 14.8).

Participant Screening

The online screening questionnaire asked respondents a total of 14 questions about current PA levels (ie, frequency and duration of exercise), desire to exercise more (ie, yes/no),

demographics (ie, age, gender, race/ethnicity, employment status, computer use), a working email address, and access to a computer Internet connection. Participants were required to be at least 55 years of age, with a reported desire to engage in more PA. Maximum self-reported exercise levels were: (1) no more than 60 minutes per week of moderate exercise, defined as exercise that increases heart rate, with (2) no bouts of continuous exercise lasting 35 minutes or more. Each respondent answered questions from the 7-item Par-Q [69], which is designed as the minimal standard for entry into a moderate-intensity exercise program.

Individuals who qualified for the study read and agreed to an online informed consent. They then provided contact information, which was checked for fraud before they were randomized by the database into Tx and Ctrl groups. Blinding of the research team to the participants' research condition was unnecessary.

Our previous Internet research has found a few applicants who attempted to screen-in to a study by providing false information. Consequently, in this study, participant data were checked against our database of about 6000 records from previous Internet study applicants, for fraudulent information (eg, same name or IP address shows inconsistent age, gender, or ethnicity).

Screened-in participants providing suspicious data were telephoned, and if the inconsistencies were not resolved, the individual was excluded from the study. A total of 38 were dropped from the study, including 19 before T1, who were not randomized, and 19 after randomization (13 Tx; 6 Ctrl) who were discovered between T1-T3 and were then dropped from the study. Personal privacy was protected with unique user ID and passwords once a participant was accepted into the study and provided contact information. Only passwords provided to Tx participants could link to the intervention.

Procedures

After completing T1, Tx group participants were mailed a web-enabled CD-ROM (WECD) and emailed log-in information to the *Active After 55* intervention website. Use of the WECD was designed to provide broadband quality video, even from computers with dial-up Internet connections. The WECD, played from the CD-ROM drive of the participant's computer, contained video with necessary programming code so that specific video elements (eg, an explanation by the coach; an exercise demonstration) were seamlessly integrated into the program presentation, while being controlled by Internet commands from the research host.

Tx group members were asked by a flyer in the WECD mailer to visit the website within a week. One week after a visit to *Active After 55*, an email was sent informing the participant that the next session was now available. The email prompts continued weekly thereafter until the 12 sessions were complete. Twelve weeks after submitting the T1 assessment, all Tx participants who had completed at least Session 1, and all Ctrl participants were emailed a link to the T2 survey. Individuals who had not submitted the T1 assessment or who asked to discontinue participation were dropped from the study. After completion of T2, any Tx participants still in the process of completing the 12 weekly sessions were encouraged to continue using the program until they had completed all sessions.

Twelve weeks after T2, and 6 months after T1, all participants still enrolled in the study were emailed a link to the T3 assessment. After completion of T3, Ctrl participants and individuals who initially were screened out of the study, but who expressed interest in using the site, were emailed a link to access the *Active After 55* website. They were given free access for 6 months.

The protocol for prompting individuals who failed to submit surveys or to complete intervention visits included up to 5 emails over a 1-month time period. They were followed by a single phone call attempting to verify that technical difficulties were not responsible for the lack of participant communication. The individual was then dropped from the study if participation was not re-established. This protocol was developed with the approval of our IRB in other studies. We believe that it allowed for contentious follow-up of consented participants without undo harassments.

All participants were mailed a \$25 check after submitting each survey. Participants in the Tx group did not receive a financial incentive to use the intervention website.

Measures

The T1, T2, and T3 assessments were adapted from our previous Internet research on sedentary factory workers [47], which had satisfactory psychometrics. The items were identical for all participants with the exceptions that demographic questions were asked at T1 only, and Tx group participants were asked to respond to items on website usability and program satisfaction at T2. As noted above, the assessment items were designed to measure program-linked changes on participants' physical activity, as well as on theoretical constructs that have been shown in previous research to be related to the initiation and maintenance of exercise.

Physical Activity Status

Each participant's self-reported current activity level was measured with 2-item sets addressing the frequency and duration of intentional physical activities that included: (1) cardiovascular activities to increase heart rate (eg, walking briskly, swimming, bicycling, or mowing the lawn), (2) stretching activities to improve flexibility, (3) strength building activities, and (4) balance enhancement activities. For each category, one item asked "In a typical week, how many days do you intentionally...?", and a pull-down menu offered choices between 0-7 days a week. The second statement asked "How many minutes do you typically ... on each of those days?" and a pull-down menu offered choices of from 5-60+ minutes in 5-minute increments. Items were scored to reflect minutes per week of each activity. Scores showed substantial skew, so a log to base 10 transformation was applied.

Other Physical Activities

For a sedentary individual, an increase in the number of physical activities, even if they were not categorized as intentional exercise, would indicate an improvement over a sedentary lifestyle. Participants were asked to report on activities they engaged in during the previous week. They were presented with a list of 16 typical physical activities of older adults: yard work, housework, doing exercises, toe raises or stretches, dancing alone as a physical activity, going for a walk for 10 minutes or more, using the stairs instead of an elevator, parking farther away from the store, exercising with others, playing with children, attending activity classes, dancing/square dancing, bowling or other active games, going to a museum, park, or mall, playing golf, and other physical activities. A count of the number of activities engaged in during the previous week was computed for analysis.

SF-12

The SF-12 is a 12-item survey that has proven useful in monitoring health outcomes [70]. The SF-12 achieved a multiple R-squared of .918 in predictions of the SF-36 Mental Component Summary Score, which has been validated extensively in research studies. Based on a 4-week recall, the SF-12 items include four physical components: general health (1 item), physical functioning (2 items), role limitations due to physical health problems (2 items), and bodily pain (1 item); and four mental components: vitality (1 item), social functioning (1 item), role limitations due to emotional issues (2 items), and general mental health (2 items). Two summary component

scores were created for analysis: Physical Component Summary (Cronbach alpha = .82) and Mental Component Summary (Cronbach alpha = .83).

BMI

The Body Mass Index (BMI) has been used as a way to classify sedentary (physically inactive) individuals with an average body composition by the World Health Organization (WHO) [71]. An individual's BMI is calculated using weight divided by the square of their height. According to the International Classifications (WHO [72]), a BMI greater than 25 is considered overweight and above 30 is considered obese. A limitation of using BMI is that it accounts for weight, but not for differences in body composition [69].

Attitudes and Knowledge

The theory of planned behavior suggests that an individual's attitude and knowledge will shape self-efficacy and intention [48,49]. The line between some attitudinal and knowledge items is blurred, and many attitudinal items might also be considered knowledge items and vice versa. For instance, a statement such as "It's best to increase activity levels slowly," might be construed as an opinion or a fact. Therefore, 16 attitudinal items and 5 knowledge items designed to assess program specific content were analyzed as a single-scale score (Cronbach alpha = .91). Items were presented as agree-disagree statements on a 5-point rating scale (1 "Strongly Disagree" to 5 "Strongly Agree"). Attitudinal items addressed opinions and philosophies (eg, the emotional and psychological benefits of exercise; the importance of doing different types of exercise, use of personal strategies to stay active such as sitting less, being active all day, and looking for ways to be active). Knowledge items included information about the benefits of exercise for chronic conditions and avoiding falls, the value of stretching for arthritis, recommended daily activity goals (ie, 30 minutes moderate exercise, most days). For analysis, items were re-coded so that a higher score indicated a more positive attitude or accurate knowledge toward exercise.

Behavioral Self-Efficacy

The importance of behavioral self-efficacy to exercise adherence is supported by both social cognitive theory [50,51] and the theory of planned behavior, eg, [73,74]. Five items asked participants how confident were they that in the next month they could, if they wanted to, "be more physically active on a regular basis", "be physically active most days of the week", "intentionally do 30 minutes of physical activity in your typical day", "develop a physical activity plan that would meet your needs", and "consistently do 4 types of physical exercises (endurance, stretching, strengthening, and balance)". Responses were measured with a 5-point rating scale (1 "Not at all confident" to 5 "Extremely confident"; Cronbach alpha = .94).

Behavioral Intention

The theory of planned behavior suggests that behavioral intentions can predict exercise behavior [75]. Five items asked participants to indicate in the next month how likely they would be to "be physically active most days of the week", "be physically active for 30 minutes or more a day, 5 days per week", "develop a physical activity plan that would meet your

needs", "consistently do 4 types of physical exercises (endurance, stretching, strengthening, and balance)", and "intentionally do 30 minutes of physical activity in your typical day." Responses were measured with a 5-point rating scale (1 "Very unlikely" to 5 "Very likely;" Cronbach alpha = .93).

Motivation

We found no research to adequately measure the motivation of sedentary individuals to exercise, but improvement on this variable should be linked with an increase in PA. Consequently, we adapted the motivation item used by Irvine et al [47] in Internet intervention research on sedentary workers. A single item asked "How motivated are you to be physically active in your daily life?" It was measured on a 5-point rating scale (1 "Not at all motivated" to 5 "Extremely motivated").

Ability to Exercise

A positive change in perceived ability of an individual to perform day-to-day activities was hypothesized to be a measure of improved physical fitness. To assess these capabilities, scales from previous research, eg, [76-79] were adapted into a list of 14 activities that included cardiovascular (eg, walking up two flights of stairs, heavy household chores), strength (eg, lift and carry 10 lb of groceries), balance (eg, balance on one foot for 10 seconds), and stretching (eg, reach into a high cupboard). Participants were asked to rate the difficulty to do each behavior. Responses were given on a 4-point rating scale (1 "Easy to do," 2 "Somewhat difficult", 3 "Difficult," 4 "Can't do;" Cronbach alpha = .90)

Barriers to Exercise

One goal of the intervention was to change perceptions about possible barriers to participating in physical activity, which research suggests are the reasons many individuals fail to adopt and/or maintain exercise habits, eg, [80,81]. Our previous Internet research on sedentary factory workers [47] compiled a list of 15 barriers to exercise, which showed significant improvement at 30-day follow-up. The list from that study and barriers derived from our unpublished Internet survey of older adults was adapted for this research. The 13 potential barriers included lack of willpower, no one to exercise with, fear of injury, lack of skills, lack of time, bad weather, no safe place, lack of social support, finances, being out of town, too old and out of shape, dislike of sweat, and exercise is boring. Participants were asked to rate how likely each barrier was to prevent them from being physically active in the next week. Responses were given on a 5-point rating scale (1 "very unlikely" to 5 "very likely") and combined to form a single-scale score (Cronbach alpha = .88).

Stage of Change

If the research intervention was successful, a progression of participants along the continuum of change would be expected. Stage of change (SOC), ie, precontemplation, contemplation, action, maintenance, which assesses an individual's readiness to adopt new behavior, was measured using four items developed by Marcus, Rossi, Selby, Niaura, and Abrams [82]. A definition of physical activity was provided that included increased heart rate and breathing. Four items were presented: "I am currently physically active (Yes/No)", "I intend to become

more physically active in the next 6 months (Yes/No)", "I am currently engaged in regular physical activity (Yes/No)", and "I have been regularly physically active for the past 6 months (Yes/No)". This instrument had a 2-week Kappa index of reliability of .78 and was correlated with measurements of self-efficacy and intentions [83-85] and with the Seven Day Recall Physical Activity Questionnaire [86].

User Satisfaction

User acceptance of the intervention was measured with ratings of perceived satisfaction. Tx group participants responded to additional items relating to their subjective opinions of the *Active After 55* program, including satisfaction, ease of use, helpfulness of the overall information, helpfulness of the articles, and willingness to recommend the program to a friend. For each item, participants were asked to rate their opinions on a 7-point rating scale (1 "Not at all..." to 7 "Extremely..."). A final item asked for opinions on the number of sessions, with a 5-point Likert scale from 1 "Needed many more" to 5 "Far too many".

Results

Participants

A total of 405 participants, including 200 Tx and 205 Ctrl group participants were randomized into the study after consenting, and a total of 368 participants completed the T1 assessment including Tx (n=178) and Ctrl (n=190; Appendix 1) conditions. The sample included 69% female and had a mean age of 60.3 years (SD 4.9). Average BMI was 28.9 (SD 6.7), indicating that the participants, as a group, were considered overweight [69]. They self-identified to be 59% Caucasian, with 41% from other racial and ethnic groups. Most (82%) had at least some college education, 73% had a family income >\$40,000/year, and 56.9% were employed. A total of 70% of participants reported using the Internet more than 7 times per week, and 71% emailed more than 7 times per week.

Baseline Equivalency and Attrition Analysis

The two experimental groups were compared on baseline characteristics and pretest outcome measures. With respect to baseline characteristics, the only significant difference was obtained for race/ethnicity: compared to the Ctrl participants, Tx participants were less likely to be Caucasian, ie, 53% vs. 64%; chi-square (1, N=368) = 4.46, $P=.035$. Given this significant difference, the main outcome analysis included race/ethnicity as a between-subjects factor. The two conditions did not differ significantly on any of the 13 numeric outcome measures or the Stage of Change groups.

Over the course of the study, a total of 84 (62 Tx; 22 Ctrl) of the 405 randomized participants were unresponsive to repeated prompts and were dropped from the study, and 19 participants (13 Tx; 6 Ctrl) were removed as fraudulent during the 6-month period between T1-T3 assessments. Of the Tx group participants, only 145 of the 178 who submitted the T1 assessment logged on to initially use the intervention, and 6 of those participants did not complete Visit 1. A total of 92 (73.6%) of those completing T3 assessments (ie, 51.7%) from the T1 Tx group completed all 12 sessions.

Thus, out of the 178 Tx Group participants at T1, 125 (70.2%) eventually remained in the study to T3. A total of 305 participants (125 Tx group; 180 Ctrl group) submitted a T2 assessment, and 302 (125 Tx group; 177 Ctrl group) submitted a T3 assessment. Overall, T1-T3 attrition was (368-302)/368 = 17.9%.

A significantly higher attrition rate was obtained for the Tx condition compared to the Ctrl condition with 30% vs. 7%; chi-square (1, N=368) = 32.84, $P<.001$. In addition, significantly higher rates of attrition were obtained for male vs. female participants with 25% vs. 15%; chi-square (1, N=360) = 4.51, $P=.034$, race/ethnic minority vs. Caucasian participants at 26% vs. 12%; chi-square (1, N=368) = 32.84, $P<.001$, and those who reported less frequent baseline computer usage, ie, 1-2 times per week = 46%, 3-4 times per week = 44%, 5-6 times per week = 12%, 7 times per week = 14%, 8 or more times per week = 15%; chi-square (4, N=361) = 20.83, $P<.001$. Participants who dropped out of the study after T1 (n=65) were also compared to those who continued participating (n=302) on the pretest outcome measures. Compared to the participants who completed either T2 or T3 assessments, those who dropped out had significantly lower means on the attitudes/knowledge scale at 3.8 vs. 4.1; $t(365) = 3.26$, $P=.001$, ie, attriters had poorer attitudes/knowledge at T1 and significantly higher mean levels for the barriers to exercise scale at 2.7 vs. 2.4; $t(365) = 2.86$, $P=.005$. However, no condition-by-attrition interactions were found to be significant for any of the T1 measures, ie, attriters did not differ across experimental condition on the T1 measures.

Missing Data and Imputation

Rates of missing study outcomes ranged from 0-1% at T1, 18-21% at T2, and 19-22% at T3. The full-information maximum likelihood estimators assume data are at least missing at random (MAR). It is not possible to know for sure that data are MAR because information about the value of the missing data is not available. However, given the abovementioned significant associations between attrition and study outcomes at baseline, the MAR assumption appears less tenable. Therefore, the main outcome analyses were conducted with (1) available data (ie, "complete cases", n=294 to 300, dependent outcome), and (2) one fully-imputed dataset that included all 368 study participants. Since the inclusion of additional predictors in the imputation model can reduce bias and make the MAR assumption more plausible [87-89], in addition to the all study outcomes, the imputation model also included all study demographic characteristics.

Sequential regression multiple imputation (SRMI [90]) was used to generate the dataset using the IVEware software V0.2 [91]. SRMI specifies a multivariate model by separate conditional models for each incomplete variable allowing for imputation of variables with different distributional properties. For the current study, three models were specified: a normal linear regression model for continuous variables, a logistic regression model for binary variables, and a generalized logit regression model for variables with more than two categories.

Results indicate that the available data approach and imputed data approach resulted in a similar pattern of results. Following

the intent-to-treat approach, results from the imputed model are reported below.

Program Usage

As mentioned, 125 (70%) of the original Tx group remained in the 12-week study. The mean number of visits to the website for these individuals was 15.2 visits (SD 9.02). The mean total time spent using the program summed across all visits was 123.4 minutes (SD 185.98), and the mean time spent per visit was 9.66 minutes (SD 10.48). Participants each accessed an average of 2.92 (SD 4.30) program segments designed to help overcome specific perceived barriers to exercise.

Pretest-Posttest Change

A 2 x 2 (condition by race/ethnic minority status) MANCOVA was conducted on the posttest outcome measures in which the pretest outcome measures were included as covariates. The dependent measures included: (1) physical activity measures, (2) SF-12 physical and mental composite measures, (3) BMI, and (4) psychosocial measures (Appendix 2).

An overall multivariate model was tested at posttest, followed by univariate models for each outcome measure. Partial eta-square was used as the estimate of the effect size; values of .01, .06, and .14 represent small, medium, and large effect sizes, respectively [92]. The multivariate model at posttest was significant in which the Tx participants were found to have large gains compared to the Ctrl participants, $F(14, 337) = 4.81$, $P = .001$, eta-square = .17 (Table 1). As can be seen in Table 1, the Tx Group differed significantly from the Ctrl participants on 13 of the 14 outcome measures. The only measure not showing significant T1-T2 change was BMI. The outcome measures with medium effect sizes or larger include cardiovascular exercises min/wk (eta-square = .07), stretching exercises min/wk (eta-square = .07), strength exercises min/wk (eta-square = .11), balance exercises min/wk (eta-square = .09), number of activities (eta-square = .07), behavioral intentions to exercise (eta-square = .10), and motivation to exercise (eta-square = .06). Neither the multivariate main effect for race/ethnicity nor the condition-by-race/ethnicity interaction effect was significant.

Table 1. ANCOVA results for the outcome measures.

Outcome measure/ Condition	T1-T2 condition effect			T1-T3 condition effect		
	<i>F</i> test	<i>P</i>	Eta ² a	<i>F</i> test	<i>P</i>	Eta ² a
Cardiovascular activities	26.32	<.001	.067	19.38	<.001	.050
Stretching activities	25.71	<.001	.070	23.36	<.001	.060
Strengthening activities	42.70	<.001	.105	19.03	<.001	.050
Balance activities	37.26	<.001	.092	32.37	<.001	.081
Activities min/wk	25.4	<.001	.068	17.98	<.001	.049
SF-12 physical	5.19	.023	.015	7.56	.006	.021
SF-12 mental	11.41	.001	.032	9.51	.002	.026
BMI (kg/m ²)	1.04	.309	.003	4.42	.036	.012
Attitudes/Knowledge	10.16	.002	.028	8.57	.004	.024
Self-efficacy	9.08	.003	.025	13.05	.001	.036
Behavioral intentions	38.99	<.001	.1	23.38	<.001	.063
Motivation to exercise	21.22	<.001	.057	22.47	<.001	.06
Ability to exercise	4.14	.043	.012	6.85	.009	.019
Barriers to exercise	8.67	.003	.024	8.26	.004	.023

^a Partial eta-square (effect size): .01 small, .06 medium, .14 large.

Pretest-Follow-Up Change

To examine the maintenance of program effects at follow-up, an overall 2 x 2 MANCOVA model was tested comparing the two conditions on the follow-up outcome measures, controlling for pretest measures, followed by univariate ANCOVA models. The multivariate model at follow-up was significant in which the Tx participants were found to maintain large gains compared to the Ctrl participants, $F(14, 337) = 3.08$, $P < .001$, eta-square = .11. The Tx group differed significantly from the Ctrl participants on all of the 14 outcome measures (see Appendix 2). The outcome measures with medium effect sizes or larger include stretching exercises min/wk (eta-square = .06), balance

exercise min/wk (eta-square = .08), behavioral intentions to exercise (eta-square = .06), and motivation to exercise (eta-square = .06). Although there was a significant multivariate main effect of race/ethnicity status with $F(14, 337) = 1.96$, $P = .020$, eta-square = .08, the condition-by-race/ethnicity interaction effect was not significant. Compared to race/ethnic minority participants, Caucasian participants reported significantly lower follow-up mean scores for self-efficacy at 3.6 vs. 3.9; $F(1, 350) = 5.05$, $P = .025$, eta-square = .01, behavioral intentions at 3.6 vs. 4.0; $F(1, 350) = 5.39$, $P = .021$, eta-square = .02, and motivation at 3.3 vs. 3.8; $F(1, 350) = 12.05$, $P < .001$, eta-square = .03.

Stages of Change Analysis

Stage of change groupings are compared in Table 2, and it is curious that even though all of the participants were screened to be at a maximum of 40% of recommended minimums for weekly exercise [7], 29% of Tx and 21% of Ctrl participants reported being in the maintenance stage at pretest. The two

conditions were compared using contingency table analyses at pretest, posttest, and follow-up. They did not differ significantly at pretest, but significant effects were obtained at posttest and follow-up. Compared to Ctrl participants, a larger proportion of Tx participants were found to be in the Action and Maintenance stages at both posttest and follow-up.

Table 2. Stages of change groups by condition at T1, T2, and T3.

	Pre-contemplation		Contemplation		Preparation		Action		Maintenance	
	N	%	N	%	N	%	N	%	N	%
T1^a										
Treatment	3	2	91	52	24	13.6	7	4	51	29
Control	3	2	97	52	37	19.8	11	6	39	21
T2^b										
Treatment	–	–	14	11	19	15.4	28	23	62	50
Control	8	5	57	33	24	13.9	19	11	65	38
T3^c										
Treatment	1	1	16	13	15	12	13	10	80	64
Control	4	2	46	26	30	17	17	10	79	45

^a Chi square (4, N=363) = 5.12, $P=.275$.

^b Chi square(4, N=296) = 28.79, $P=.001$.

^c Chi square (4, N=301) = 13.61, $P=.009$.

Dose-Response Analysis

A dose-response analysis was conducted to examine whether the level of exposure to the program was significantly associated with pretest-posttest change in the outcome measures for the participants assigned to the treatment condition. A composite dose measure was created by standardizing the total time spent across all sessions, the number of page views, and the number of sessions, and computing the mean value of the three standardized scores (Cronbach alpha = .79). A composite outcome measure was created by calculating pretest-posttest gain scores for each of the 13 outcome measures, standardizing each gain score, and computing the mean value of the standardized gain scores (Cronbach alpha = .85). The correlation between the composite dose measure and the composite gain score was significant, $r=.22$, $P=.014$. Thus, a higher level of program utilization was associated with significantly greater change in outcome, which provides further support for the internal validity of the study.

User Acceptance

On a 7-point scale (eg, not at all satisfied – extremely satisfied), participants reported they were quite satisfied with the program (M=5.6, SD 1.3), the program was very easy to use (M=5.9, SD 1.2), the overall information was very helpful (M=5.9, SD 1.2), the articles provided by the program were very helpful (M=5.7, SD 1.3), and they would be very likely to recommend the program to a friend or family member (M=5.7, SD 1.4). On a 5-point scale to determine opinions about the number of sessions, 89 participants (70%) rated “Just Right,” and 27 (21%) rated “A few too many”.

Discussion

This randomized effectiveness trial to evaluate the *Active After 55* Web program indicates that the intervention positively impacted the physical activity of sedentary older adults, and it was well received. The hypotheses were that the intervention would be linked to changes in the exercise domains of endurance, stretching, strengthening, and balance and that it would be linked to theoretically relevant mediators of behavior change. The findings were very consistent across an array of measures, with a large multivariate effect size at posttest and a medium multivariate effect size at 6-month follow-up. The Tx group showed significant improvement on 13 of 14 outcomes at posttest and on all 14 outcomes at follow-up (Table 1). Taken together, the results suggest that the intervention had an impact on the self-reported PA of this sample of sedentary older adults, a group that might be expected to be difficult to change.

The strength of the results presented here may actually be diluted somewhat by the measurement process. Treatment subjects who were late completing courses or had stopped taking them were exposed to relatively less of the intervention before the T2 assessment. Additionally, the Ctrl group results generally improved over time, possibly indicating that the assessment process might have brought about reactive effects. Just being exposed to those questions might have sensitized the Ctrl group to improve their level of physical activity and related cognitions.

While defining and identifying a sedentary population of older adults is an inexact science, the screening was designed to disqualify any applicant who engaged in moderate exercise for more than 60 minutes per week, which is 40% of the minimum

recommended level [1,7]. The mean BMI value of 28.9 (kg/m²) for the participants (Appendix 1) is in the “overweight” category [93]. While being overweight does not of itself indicate that an individual is sedentary, excess weight is often linked with insufficient exercise [7,94,95]. Thus, those who tested the *Active After 55* program seemed to have at least one of the characteristics of sedentary users for which it was designed.

The fact that 92 of the 139 participants (66%) who completed Visit 1 finished all 12 sessions without payment to do so, suggests that the PA intervention was engaging enough for a majority to follow through for 12 weeks. This is a very positive sign, but we found no attrition results from comparable Web research against which to measure our results. As indicated by the dose-response analysis, greater program utilization resulted in greater change in outcomes, which has been reported by other [47,96], but not all [97] Internet PA studies. However, understanding the dose response relationship between improved outcomes and program engagement is complicated by participant attrition [24].

Dropouts in this study had lower attitude/knowledge scores about the benefits of exercise, and they had higher perceptions of barriers to exercise. While the results presented here must be viewed cautiously until validated by other research, they might offer a hint as to why sedentary individuals fail to start to engage in a Web PA program. Other research attributes attrition from PA programs to unrealistic participants’ expectation [98], demographics, and physical characteristics [99], low intention to change [32], time requirements [100], and various perceived barriers to exercise [101]. An alternative supposition for dropouts related to Internet PA programs is offered by the work of Christensen and colleagues, which suggests that some individuals, described with terms such as *e-attainer* [102] or *one hit wonders* [103], benefit from only brief exposure to Internet interventions. That is, participants meet their own Web program participation goals, which do not match those of the researcher(s). Thus, imputing baseline levels for dropouts or looking only at participants who complete a program may confound the dose-response relationship, which also might be related to participant motivation or program engagement [24]. More research is clearly needed to examine the influence of different intervention components on engagement and effectiveness with PA websites [104,105], which might help tease out techniques to improve outcomes and decrease attrition [24].

This research also presents data on recruitment success using an informational website and automated online screening (Figure 1). While 3472 views of the informational website led to 2589 responses to the first screening question, only 449 (17.3%) respondents completed the questionnaire. Why more potential participants did not complete the 14-item questionnaire, which did not request sensitive information and was designed to require less than 5 minutes to complete, is unclear.

Also of potential interest to other researchers is the incidence of fraud reported here. Of the 424 individuals who screened in and agreed to the informed consent, 19 were dropped because of fraudulent information before being randomized, and another 19 subjects were discovered to be fraudulent and were dropped

between T1-T3. Thus, 9% of those who screened in provided false information. We have experienced roughly similar numbers in other Internet studies, causing us to set up our fraud database to cross-check participant information. Some individuals are repeat offenders, and we even had one fraudulent participant in another study complain to us when confronted on the telephone that removal from a study constituted mistreatment by us because she said, “I’m only trying to make a living.” We believe that the potential for fraudulent participation in research studies on the Internet is an important issue, but we are aware of no research into the frequency of occurrence or steps to minimize it.

Limitations

The current results must be viewed cautiously because we have no evidence that the participants actually engaged in PA or provided accurate information. Additionally, some of the measures were not validated in other research, physical functionality was not measured beyond the SF-12 physical sub-scale, and the follow-up period was somewhat limited (ie, 6 months). Follow-up studies of 1-2 years, using participant exercise logs and verifiable measures of PA (eg, treadmill testing; 6-minute walk testing), and functionality (eg, Physical Functional Performance Test [106]; AM-PAC Physical Mobility, and Personal Care scales [107]) would provide greater confidence in the intervention effects. Also, the assessment measures were self-reported making them potentially subject to social desirability bias [108]. Some research, however, suggests self-report measures of PA and more objective measures such as treadmill testing may be in rough concordance [109]. Another concern is the discrepancy between the initial screening of participants, which limited participants to a maximum of 60 minutes of exercise per week, and the amounts of PA reported at T1 (eg, Tx: 53.7 min/wk, SD 73.5; Ctrl: 47.5 min/wk, SD 55.6; Appendix 2), which put many participants near or perhaps over the maximum allowable limits at baseline. Despite all these potential shortcomings, however, Tx participants showed significant improvement compared to the Ctrl group, which is a promising outcome.

Participants were a relatively young population of older adults (ie, M=60 years of age), and they tended to be employed, educated, and frequent computer users with at least a middle-class income. Less educated, lower income, rural, and ethnic populations might be less likely to have Internet in their homes [110], and this approach would obviously be inapplicable for seniors who do not use computers. While seniors are the fastest growing demographic online [43], research is needed to determine if the results of this study generalize to even older generations and to other demographic categories.

The higher attrition rate among treatment participants compared to control participants is another limitation that may have biased the study findings. However, because experimental conditions did not interact significantly with any of the baseline participant characteristics in predicting study attrition, the potential confounding due to differential attrition would appear to be minimal. Furthermore, the use of maximum likelihood estimation for missing data would help to reduce potential biases associated with study attrition.

Conclusions

Despite limitations, this research demonstrates that a theoretically based stand-alone Internet exercise program that tailors content according to users' preferences and interests can increase self-reported PA and be well received by sedentary older adults. This type of intervention can be available to users 24/7 on the Internet, making it a potentially cost-effective PA

tool that can reach large numbers of people. The results are impressive considering that the study was not conducted as part of a larger health promotion campaign, which might have provided additional support and encouragement for the participants and which might have decreased attrition. Still, more research is needed to understand factors associated with using Internet interventions to maintain engagement in PA over time.

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Conflicts of Interest

Blair Irvine was the grant PI. He is employed as a Research Scientist at ORCAS, a health care technology company that creates self-management programs to improve physical and emotional well-being. The software is not for sale, and he and the other authors derive no financial benefit from development of the software or from publication of this research.

Multimedia Appendix 1

Demographic information for participants.

[\[PDF File \(Adobe PDF File\), 23KB - jmir_v15i2e19_app1.pdf \]](#)

Multimedia Appendix 2

Pretest, posttest, and follow-up descriptive statistics (untransformed values are reported for cardiovascular activities, stretching activities, strengthening activities, and balance).

[\[PDF File \(Adobe PDF File\), 43KB - jmir_v15i2e19_app2.pdf \]](#)

Multimedia Appendix 3

CONSORT-Ehealth Checklist V1.6.2 [111].

[\[PDF File \(Adobe PDF File\), 987KB - jmir_v15i2e19_app3.pdf \]](#)

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Original Paper

Influence of Delivery Strategy on Message-Processing Mechanisms and Future Adherence to a Dutch Computer-Tailored Smoking Cessation Intervention

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Abstract

Background: Smoking tobacco is one of the most preventable causes of illness and death. Web-based tailored smoking cessation interventions have shown to be effective. Although these interventions have the potential to reach a large number of smokers, they often face high attrition rates, especially among lower educated smokers. A possible reason for the high attrition rates in the latter group is that computer-tailored smoking cessation interventions may not be attractive enough as they are mainly text-based. Video-based messages might be more effective in attracting attention and stimulating comprehension in people with a lower educational level and could therefore reduce attrition rates.

Objective: The objective of the present study was to investigate whether differences exist in message-processing mechanisms (attention, comprehension, self-reference, appreciation, processing) and future adherence (intention to visit/use the website again, recommend the website to others), according to delivery strategy (video or text based messages) and educational level, to a Dutch computer-tailored smoking cessation program.

Methods: Smokers who were motivated to quit within the following 6 months and who were aged over 16 were included in the program. Participants were randomly assigned to one of two conditions (video/text CT). The sample was stratified into 2 categories: lower and higher educated participants. In total, 139 participants completed the first session of the web-based tailored intervention and were subsequently asked to fill out a questionnaire assessing message-processing mechanisms and future adherence. ANOVAs and regression analyses were conducted to investigate the differences in message-processing mechanisms and future adherence with regard to delivery strategy and education.

Results: No interaction effects were found between delivery strategy (video vs text) and educational level on message-processing mechanisms and future adherence. Delivery strategy had no effect on future adherence and processing mechanisms. However, in both groups results indicated that lower educated participants showed higher attention ($F_{1,138}=3.97$; $P=.05$) and processing levels ($F_{1,138}=4.58$; $P=.04$). Results revealed also that lower educated participants were more inclined to visit the computer-tailored intervention website again ($F_{1,138}=4.43$; $P=.04$).

Conclusions: Computer-tailored programs have the potential to positively influence lower educated groups as they might be more involved in the computer-tailored intervention than higher educated smokers. Longitudinal studies with a larger sample are needed to gain more insight into the role of delivery strategy in tailored information and to investigate whether the intention to visit the intervention website again results in the ultimate goal of behavior change.

Trial Registration: Netherlands Trial Register (NTR3102).

KEYWORDS

computer tailoring; smoking cessation; message-processing mechanisms; e-loyalty; future adherence

Introduction

During the last decade, an increasing number of people used the Internet to obtain health-related information. In the field of health promotion, the Internet has become an important medium for the delivery of behavioral change interventions [1,2]. Health professionals have started to deliver several lifestyle behavior interventions through the web, including interventions aimed at smoking cessation [3], nutrition behavior [4], and physical activity [5,6].

A successful interactive strategy consists of computer-tailored interventions [7] through which individuals receive personalized information and feedback on health behavior and motives for this behavior. Tailored health messages are based on a person's answers to a questionnaire on individual characteristics related to health behavior. Current research has shown the superiority of tailored materials over existing standard materials [8,9]. In the field of smoking cessation, recent studies have revealed computer-tailored smoking cessation interventions to be more effective than non-tailored interventions [9,10]. Yet, as with many eHealth interventions, smoking cessation interventions delivered via the Internet have high attrition rates, especially among people with lower education [11,12]. However, less educated people are often those who smoke more cigarettes [13] and show higher nicotine addiction rates, less quit-attempts, and more relapses compared to people with a higher level of education [14,15]. Past research in the Netherlands has shown that smoking prevalence was significantly higher among less educated people (29%) compared to people with a higher level of education (20%) [13]. Smokers of lower socioeconomic status (LSES) are therefore a highly relevant target group for using these computer-tailored programs. Hence, it is important to investigate how attrition rates among lower educated groups can be reduced and how computer-tailored interventions can be optimized to attract groups of different education levels.

A possible reason for the high attrition rates in computer-tailored interventions is that they rely heavily on text-based messages. Research suggests that video-based messages might be more effective in attracting attention and stimulating comprehension in people with a lower educational level [16,17]. Furthermore, video-based messages have been shown to require less mental effort and may help the person focus on the core elements of the message [18,19]. It is therefore conceivable that video-based messages may be better for reaching lower educated groups and realizing behavior change. Additionally, higher educated groups may benefit more from in-depth processing and accordingly may be stimulated more by text-based messages [20].

Recent research examining computer tailoring identified different underlying message processing-mechanisms that play an important role in enhancing health communication [21]. In tailored communication, five important message-processing mechanisms have been identified: attention, comprehension,

processing, self-reference, and appreciation. Attention refers to the ability to focus on the receiving message. Due to the fact that paying less attention to a message lowers the overall effect, one purpose of tailored material is to increase the attention to the message. A recent study has shown stronger attention processes in people reading tailored material [22]. Comprehension refers to the ability to understand the content of the message. Past studies have shown that the better the message was matched to personal attributes and preferences, the more the message was understood and remembered [23,24]. A psychological theory that has been used to explain the effects of tailoring is the Elaboration Likelihood Model (ELM). This theory states there are two processing routes, the peripheral and the central. Related to this theory, personally relevant messages are processed by the "central route" and therefore take more effort to process [25]. The idea of tailoring is to increase the perceived relevance of the message in order to elicit a careful consideration of the message, which leads to a deeper impact of the received content. Indeed, a study about weight loss information indicated participants engaged in deeper processing of tailored information when compared to non-tailored information [26]. Besides effortful processing, a further aim of tailoring is to stimulate self-referential thinking. Self-referential thinking refers to the ability to refer the given information to one's own situation. For example, tailored weight loss materials have been shown to encourage participants to link the information to their own situation [26]. Furthermore, it is also theorized that tailoring influences the appraisal of a message. Tailored materials may enhance the feeling of being well understood and would therefore lead to more appreciation compared to non-tailored information. To sum up, tailoring is used to increase the relevance of a health message by stimulating attention, comprehension, and the overall depth of message processing. The effects of tailoring on message-processing mechanisms might be further increased by the use of a suitable delivery strategy. However, as already indicated, these possible effects might be different for people with a lower or higher educational level.

To our knowledge, no previous studies have empirically examined the effects of delivery strategies (video vs text) and their impact on message-processing mechanisms among different educational groups. The first aim of this paper was to explore whether there exist differences in message-processing mechanisms according to delivery strategy (video or text based messages) and educational level. Past research has shown that information processing in lower educated groups was less profound and more influenced by visual than textual information [27]. Based on this, it was expected that tailoring would result in deeper information processing in lower educated smokers who received the video-based messages. In contrast, it was expected that the effects of tailoring would increase for higher educated smokers who received the text-based messages.

Additionally, eHealth research has acknowledged the importance of user experience of the intervention website. User experience refers to what a person thinks and feels during and after being exposed to a website [28]. Past research demonstrated the importance of user experiences (eg, trustworthiness, enjoyment) with regard to revisiting the website [29]. A positive user experience is related to an increased website use [28], resulting in future adherence [30]. Future adherence can comprise two components: (1) the intention to revisit an Internet-delivered intervention, and (2) recommending an Internet-delivered intervention to others [30]. Internet-delivered interventions and especially computer-tailored interventions often consist of several modules/feedback sessions. Since several sessions are often necessary to achieve behavior change in the long run [31,32], it is important to know whether people would like to revisit the intervention website. People with a high intention to revisit the website intervention might be likely to follow further important parts/sessions of the intervention and could therefore benefit more from the intervention than people leaving the program after their first visit. Next, it is important to know whether people would recommend the Internet-delivered intervention to others since previous studies demonstrated that the “word of mouth” strategy is effective in order to increase the use of eHealth interventions [33]. In order for web-based interventions to have an impact on public health, it is important that the intervention is also disseminated by the target population [34]. Now that computer-tailored interventions have become an increasingly popular strategy in the field of smoking cessation interventions, it is important to examine whether future adherence of computer-tailored intervention websites is influenced by delivery strategy (video vs text) and whether these effects vary among different educational groups.

The second aim of this study was to investigate whether there exist differences in future adherence according to delivery strategy (video or text based messages) and educational level. It was expected that future adherence would increase in lower educated smokers who received the video-based messages; whereas, we expected the same effects for higher educated smokers who received the text-based messages.

In summary, the current study was designed to assess whether a different delivery strategy (video vs text) interacted with educational level on message-processing mechanisms and future adherence of a Dutch computer-tailored smoking cessation program.

Methods

Background

This study aims to provide an in-depth exploration of the effects of video and text computer tailoring on message-processing mechanisms, which are also tested within the currently tested RCT [35]. Hence, the sample and the study we describe in this

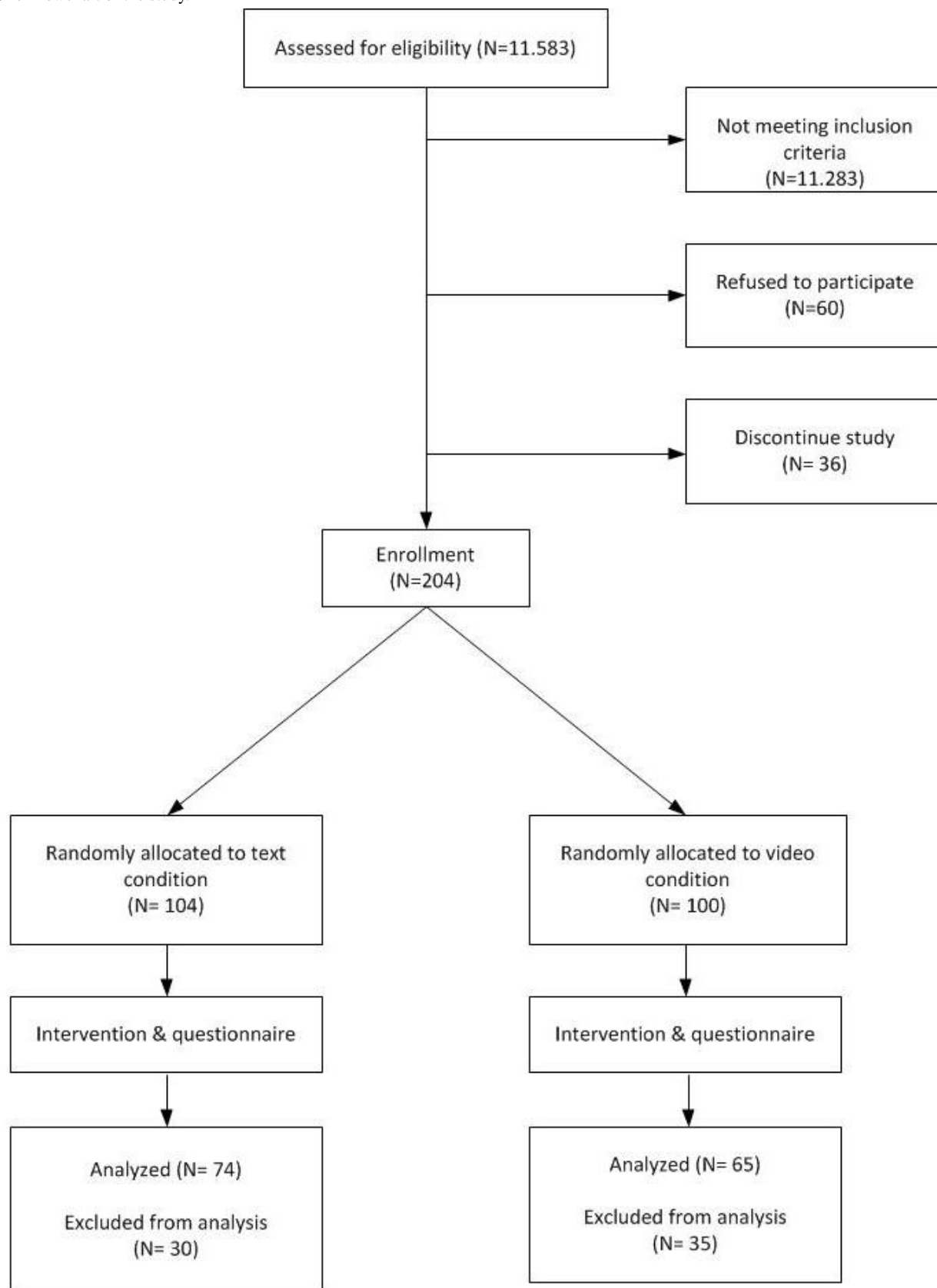
paper are different from the currently tested RCT. The described study uses only one session of the intervention tested within the RCT to test a different hypothesis (ie, differences between video/text on outcome measures regarding message-processing mechanisms and future adherence, which are not directly related to health, and not the hypothesis stated in the RCT protocol concerning the effect on smoking cessation) and was therefore not registered as a trial.

Sample

Participants for this study were recruited in May 2011 through the Dutch Internet research agency Flycatcher [36]. From this panel, a sample of potential participants (N=11,583) was approached to fill in a short web-based questionnaire about their smoking behavior, their motivation to quit, and their educational level. The main purpose of this pre-analysis was to include participants who smoked only at the time of the study inclusion, were aged 16 years or older, were motivated to quit, and could be categorized as lower or higher educated participants. They were first asked to indicate whether they smoked. Participants who indicated they smoke were next asked to indicate how often they smoked ranging from daily to once a month or less. Motivation to quit smoking was measured by one item assessing whether the participant intended to quit smoking in the future on an 8-item scale ranging from “definitely not” (1) to “definitely yes” (8). All participants who at least indicated that they were most likely (6) to quit in the near future were categorized as motivated. Educational level was divided into low (primary, basic vocational, lower general school), intermediate (higher general secondary education, preparatory academic education, medium vocational school) and high (higher vocational school or university level). Only participants with a low or high educational level (categorized to the standards of Statistics Netherlands) were invited to take part in the study [37]. In total, a random sample of panel members (N=300) who met these inclusion criteria was invited to participate in the study.

From this sample, 240 clicked on the link of the intervention website and agreed to participate in the study (response rate: 80%); 36 participants did not fill out the questionnaire resulting in a sample of 204 participants who finished the study (retention rate: 85%). From these 204, only smokers who stayed more than 5 minutes on the intervention website (n=139) were included in the main analysis. We used this inclusion criterion since a minimum of 5 minutes is needed to process the information in both conditions. In order to test our hypotheses on message-processing mechanisms and future adherence correctly, we found it necessary to include only smokers who thoroughly completed the program. This resulted in a sample of 139 participants (see Figure 1). As an additional strategy, we also conducted an intention-to-treat analysis of the data from all participants, also including those who stayed less than 5 minutes on the website.

Figure 1. Flowchart of the study.



Procedure

After signing up for participation and giving online informed consent, all included smokers were exposed to the website of a Dutch smoking cessation computer-tailored intervention [38].

Participants were informed that they were able to discontinue their participation in the study at any time without any consequences. Smokers were randomly allocated to either the text condition or the video condition. Allocation to the two conditions was executed by the Tailor Builder computer

software program (OSE, Sittard, the Netherlands). This software was developed for the execution of different web-based tailored interventions [39]. Smokers had to follow only one session of the currently tested computer-tailored smoking cessation intervention. After completing this session, they were asked to fill out a web-based questionnaire assessing message-processing mechanisms and the intention to revisit the website and recommend it to others.

Content

Intervention

The computer-tailored smoking cessation intervention was based on the I-Change model [40]. Participants in the text condition received computer-tailored text messages, whereas participants in the video condition received computer-tailored video messages. In the text condition, participants were presented text phrases without any further graphics or animations. For the video condition, the text-driven messages were translated into narrated video-driven messages that had a news-driven format with different adults delivering the tailored messages. We used

simple videos without any other animation effects such as cartoons, hyperlinks, etc. In the video condition, the same tailored advice was used as in the text condition. The only difference between the two conditions was the strategy of delivery; the content of the advice was the same in both conditions (see Figures 2 and 3). Feedback messages were based on a participant's answers to a questionnaire and tailored to their individual characteristics, such as their beliefs towards smoking, their intention to quit, and their overall smoking behavior. The session that smokers had to follow in this study was intended to increase participants' motivation to quit smoking and to encourage smokers to quit smoking in the near future. First, smokers received three tailored feedback messages on their perceived advantages and disadvantages of quitting. Next, one piece of advice was offered with respect to participants' perceived social support. Last, one piece of tailored advice was provided on their perceived self-efficacy to quit smoking. A detailed description of the different intervention components that are assessed in the currently tested RCT are reported elsewhere [35].

Figure 2. Screenshot of personal advice from the video condition.

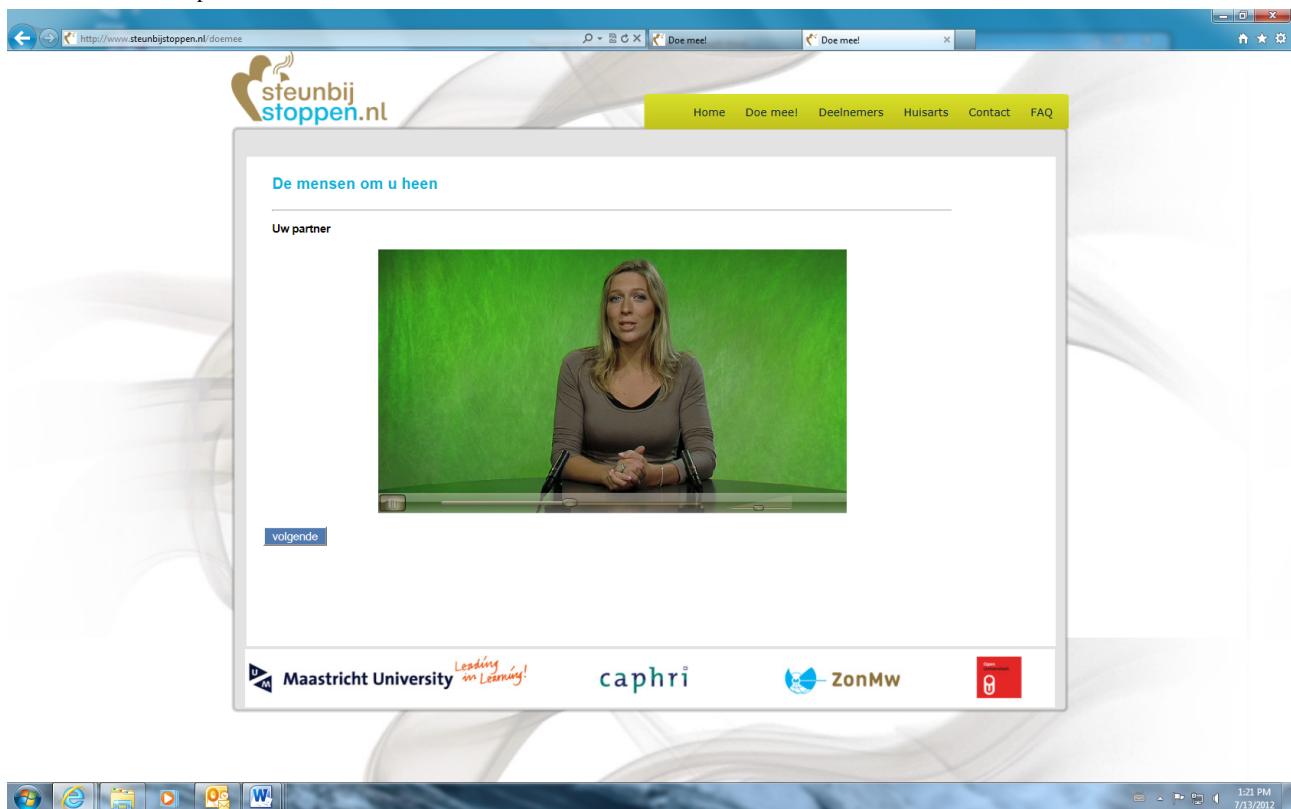
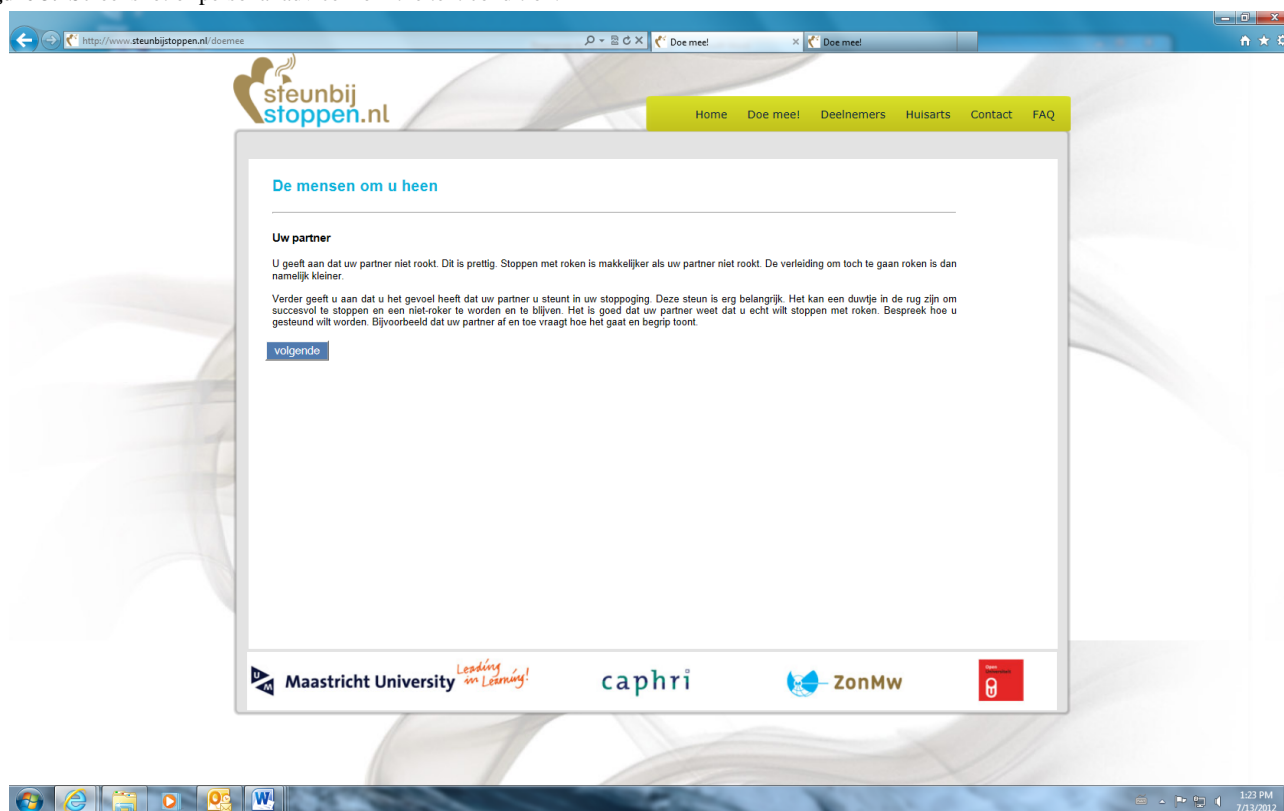


Figure 3. Screenshot of personal advice from the text condition.



Measures

The following demographic variables were measured: age, gender (0=male; 1=female), and educational level (0=low; 1=high) [37]. Furthermore, time spent on the intervention website was logged by the program system in minutes and seconds.

Addiction level was measured by 6 items using the Fagerström Test for Nicotine Dependence (FTND), asking participants how many cigarettes they smoked per day, at which time points, and whether they had difficulties not smoking in smoke-free places. The answers were converted into an overall sum score (0=not addicted; 10=highly addicted) [41].

Readiness to quit smoking was measured by one item asking participants whether they intended to quit smoking, resulting in 6 categories (6=yes, within the following month; 5=yes, within 1-3 months; 4=yes, within 4-6 months; 3=yes, within 1 year; 2=yes, within 1-5 years; 1=yes, but not within the following 5 years) [42,43].

Cognitive processing (eg, "I like tasks where I do not have to think much", assessing to what extent people engage in effortful processing) was measured by 6 items on a 5-point scale of the Heuristic Systematic Processing Questionnaire ranging from 5, "I totally agree" to 1, "I totally disagree" (Cronbach alpha=.74) [44].

Future adherence was measured by two concepts: intention and recommendation. *Intention to revisit* (eg, "It is likely that I will visit the website again in the future") was measured by 3 items on a 7-point scale, ranging from 7, "I totally agree" to 1, "I totally disagree" (Cronbach alpha=.91). *Recommendation to*

others (eg, "It is likely that I will recommend this website to others") was measured by 3 items on a 7-point scale ranging from 7, "I totally agree" to 1, "I totally disagree" (Cronbach alpha=.97) [30,45].

User experiences (also known as user perceptions) [30] were measured by four concepts: trustworthiness, enjoyment, active trust, and design aesthetic. *Trustworthiness* (eg, "I trust the information presented on this website") was measured by 3 items on a 7-point scale ranging from 7, "I totally agree" to 1, "I totally disagree" (Cronbach alpha=.87). *Enjoyment* (eg, "I found my visit to this website enjoyable") was measured by 3 items on a 7-point scale ranging from 7, "I totally agree" to 1, "I totally disagree" (Cronbach alpha=.92). *Active trust* (eg, "I would act on the information presented on this website if needed") was measured by 3 items on a 7-point scale ranging from 7, "I totally agree" to 1, "I totally disagree" (Cronbach alpha=.91). *Design aesthetic* (eg, "The whole design of the website/program is attractive") was measured by 3 items on a 7-point scale ranging from 7, "I totally agree" to 1, "I totally disagree" (Cronbach alpha=.93) [30].

Tailored-processing mechanisms were measured by five concepts. *Attention* for the tailored advice (eg, "The advice was interesting") was measured by 4 items on a 7-point scale ranging from 7, "I totally agree" to 1, "I totally disagree" (Cronbach alpha=.89). *Comprehension* of the advice (eg, "The advice was clear to me") was measured by 4 items on a 7-point scale ranging from 7, "I totally agree" to 1, "I totally disagree" (Cronbach alpha=.91). *Self-reference* towards the advice (eg, "The advice was personally relevant for me") was measured by 4 items on a 7-point scale ranging from 7, "I totally agree" to 1, "I totally disagree" (Cronbach alpha=.91). *Appreciation* of

the advice (eg, “I appreciated the advice”) was measured by 3 items on a 7-point scale ranging from 7, “I totally agree” to 1, “I totally disagree” (Cronbach alpha=.94). *Processing* of the advice (eg, “The advice encouraged me to think more about smoking cessation”) was measured by 4 items on a 7-point scale ranging from 7, “I totally agree” to 1, “I totally disagree” (Cronbach alpha=.93) [21].

An overall grade for the advice was measured by 1 item asking participants to give an overall score for the provided advice from 1 (very bad) to 10 (very good).

Statistical Analysis

First, descriptive analyses were used to determine the sample’s characteristics. To test whether any baseline differences existed between the video and text condition, *t* tests were performed for interval scaled variables, whereas Chi-square tests were conducted for categorical variables. Additionally, the same analyses were executed to investigate whether baseline differences existed between higher educated and lower educated participants. Those variables that differed between condition and educational levels were included as covariates in all further analyses.

Second, two-way analyses of co-variance (ANCOVA) were carried out to assess whether any differences existed in message-processing mechanisms according to delivery strategy and educational level. The same analyses were executed to detect any differences in future adherence according to delivery strategy and educational level.

Last, a linear regression analysis was conducted to determine the unique predictive power of delivery strategy and educational level on future adherence when user experiences were included as independent predictors in the analysis. All analyses were conducted with SPSS 17.0.

In the main analyses, we used the sample of the 139 participants who stayed more than 5 minutes on the intervention website. These analyses were repeated using an intention-to-treat analysis of the data from all 204 participants to verify whether we did not introduce a selection bias by our restriction criterion.

Results

Sample Characteristics

There were no significant differences between participants in the video and text condition with regard to gender, educational level, age, cognitive processing, addiction level, and intention to quit smoking.

Participants in the video condition spent more time on the website in comparison with participants in the text condition ($t(137) = 5.06, P < .001$), most probably due to the fact that the video condition lasted slightly longer than the text condition. Age of participants included in the analysis varied from 20 to 72 years (mean 47.39; SD 11.94). Overall, men were slightly underrepresented (37.4%). A description of the overall sample at baseline can be found in [Table 1](#).

Table 1. Sample characteristics of adult Dutch smokers (N=139).

	Overall sample	Text condition	Video condition	<i>P</i>
Gender, n (%)				.42
Female	87 (62.6 %)	44 (59.5%)	43 (66.2%)	
Male	52 (37.4%)	30 (40.5%)	22 (33.8%)	
Educational level, n (%)				.45
Low	68 (48.9%)	34 (45.9%)	34 (52.3%)	
High	71 (51.1%)	40 (54.1%)	31 (47.7%)	
Age, mean (SD)	47.39 (11.94)	46.66 (11.90)	48.22 (12.03)	.45
Cognitive processing, mean (SD)	3.56 (0.61)	3.55 (0.62)	3.57 (0.60)	.83
FTND score (1-10), mean (SD)	3.57 (2.54)	3.41 (2.52)	3.75 (2.57)	.43
Readiness to quit, n (%)				.93
Within 1 month	26 (18.8%)	14 (19.2%)	12 (18.5%)	
Within 1-3 months	43 (31.25%)	22 (30.1%)	21 (32.3%)	
Within 4-6 months	28 (20.3%)	14 (19.2%)	14 (21.5%)	
Within 1 year	24 (17.4%)	12 (16.4%)	12 (18.5%)	
Within 1-5 years	15 (10.9%)	10 (13.7%)	5 (33.3%)	
After 5 years	2 (1.4%)	1 (1.4%)	1 (1.5%)	
Time spent on website (min), mean (SD)	8.11 (12.82%)	7.15 (9.82%)	7.81 (16.24%)	< .001

Table 2 shows that participants with either a high or low educational level did not differ with respect to condition, gender, readiness to quit smoking, and time spent on the website. However, educational level differed significantly with respect to age ($t(137)=1.90$; $P=.05$) and nicotine addiction ($t(136)=4.69$; $P<.001$).

Lower educated participants were older and more addicted to nicotine compared to higher educated participants. Participants with a higher educational level scored significantly higher on cognitive processing than those with a lower educational level ($t(137)=-5.00$; $P<.001$).

Table 2. Differences of characteristics between lower and higher educational levels (N=139).

	Overall sample	High level	Low level	<i>P</i>
Condition, n (%)				.45
Text	74 (53.2%)	40 (56.3%)	34 (50.0%)	
Video	65 (46.8%)	31 (43.7%)	34 (50.0%)	
Gender, n (%)				.39
Female	87 (62.6%)	42 (59.2%)	45 (66.2%)	
Male	52 (37.4%)	29 (20.9%)	23 (33.8%)	
Age, mean (SD)	47.39 (11.94)	45.52 (13.63)	49.34 (9.60)	.05
Cognitive processing, mean (SD)	3.56 (0.61)	3.79 (0.56)	3.31 (0.57)	<.001
FTND score (1-10), mean (SD)	3.57 (2.54)	2.65 (2.45)	4.54 (2.27)	<.001
Readiness to quit, n (%)				.109
Within 1 month	26 (18.8)	17 (23.9%)	9 (13.4%)	
Within 1-3 months	43 (31.2%)	27 (38.0%)	16 (23.9%)	
Within 4-6 months	28 (20.3%)	12 (16.9%)	16 (23.9%)	
Within 1 year	24 (17.4%)	8 (11.3%)	16 (23.9%)	
Within 1-5 years	15 (10.9%)	6 (8.5%)	9 (13.4%)	
After 5 years	2 (1.4%)	1 (1.4%)	1 (1.5%)	
Time spent on website, mean (SD)	12.82 (8.11)	13.49 (9.92)	12.13 (5.62)	.33

Differences in Message-Processing Mechanisms

To test possible interaction effects of delivery strategy and educational level on message-processing mechanisms, ANOVAs were conducted using each of the five message-processing measures as dependent variables. For the five measures, no interaction effects were found between delivery strategy and educational level. Subsequently, main effects of delivery strategy were tested on message-processing measures. As shown in Table 3, none of the measures approached significance. Furthermore,

main effects of educational level were tested on message-processing measures. As shown in Table 4, lower educated participants devoted more attention to the tailored advice compared to higher educated participants ($F(1,138)=3.97$; $P=.05$). Also, the extent to which participants processed the information was shown to be higher among lower educated groups ($F(1,138)=4.58$; $P=.04$). No differences between lower and higher educated smokers could be found with regard to understanding, self-reference, appreciation, and the overall grade for the advice.

Table 3. Differences in variances of delivery strategy with regard to message-processing mechanisms (N=139).

Delivery strategy	Text group Mean (SD)	Video group Mean (SD)	<i>F</i>	<i>P</i>	η^2
Attention	4.85 (1.43)	4.83 (1.28)	.00	.97	.000
Comprehension	5.50 (1.12)	5.41 (1.04)	1.15	.29	.008
Self-reference	4.93 (1.47)	4.97 (1.20)	.06	.81	.000
Appreciation	5.23 (1.43)	5.08 (1.32)	.40	.53	.003
Processing	4.56 (1.54)	4.83 (1.38)	.97	.33	.007
Grade advice	7.19 (1.36)	6.91 (1.56)	1.89	.17	.014

Table 4. Differences in variances of socioeconomic status with regard to message-processing mechanisms (N=139).

Educational Level					
	High level	Low level Mean (SD)	F	P	η^2
Attention	4.51 (1.46)	5.21 (1.14)	3.97	.05	.029
Comprehension	5.41 (1.16)	5.54 (0.98)	.02	.67	.001
Self-reference	4.74 (1.42)	5.19 (1.23)	2.10	.15	.016
Appreciation	4.88 (1.50)	5.47 (1.16)	1.75	.19	.013
Processing	4.32 (1.53)	5.09 (1.31)	4.58	.04	.033
Grade advice	6.92 (1.46)	7.21 (1.54)	1.45	.23	.011

Differences in Future Adherence

To test for possible interaction effects of delivery strategy and educational level on future adherence, ANOVAs were conducted using each of the two measures as dependent variables. For both measures, interaction effects between delivery strategy and educational level were found to be insignificant. Next, main effects of delivery strategy were tested on future adherence. As

shown in [Table 5](#), the two measures did not approach significance. Furthermore, main effects of educational level on future adherence were conducted. As shown in [Table 6](#), lower educated participants had a higher intention to visit the website again compared to participants with a higher educational level ($F(1,138)=4.43$; $P=.04$). Recommending the website to others did not differ among lower and higher educated smokers.

Table 5. Differences in variances of delivery strategy with regard to future adherence (N=139).

Delivery strategy					
	Text group Mean (SD)	Video group Mean (SD)	F	P	η^2
Intention	4.61 (1.58)	4.54 (1.61)	.00	.95	.000
Recommendation	4.65 (1.63)	4.74 (1.58)	.03	.87	.000

Table 6. Differences in variances of socioeconomic status with regard to future adherence (N=139).

Educational level					
	High level Mean (SD)	Low level Mean (SD)	F	P	η^2
Intention	4.23 (1.76)	4.96 (1.28)	4.43	.04	.032
Recommendation	4.37 (1.72)	5.05 (1.41)	2.72	.10	.020

Predictors of Future Adherence

In order to test whether delivery strategy, educational level, age, smoking dependency, cognitive processing, and time spent on the website were independent predictors of future adherence, multiple regression analysis was executed. User experiences were included as well as independent predictors in the analysis to determine the unique predictive power of delivery strategy

and educational level in addition to user experiences. Therefore, the first model consisted of user experiences. Second, we investigated whether these results would change after controlling for delivery strategy, educational level, age, gender, and smoking behavior. Results of the multiple regression analysis are presented in [Table 7](#). User experiences did not alter the observed results.

Table 7. Multiple regression analysis for future adherence (N=139).

Predictor variable (Beta)	Intention	Recommendation
Trustworthiness	-.145	-.093
Enjoyment	-.057	-.171
Active trust	-.544 ^b	-.487 ^b
Design aesthetics	-.128	-.158 ^b
Condition	-.053	-.010
SES	-.156	-.032
Age	-.086	.017
Gender	-.061	-.028
Smoking dependency	-.008	-.015
Cognitive processing	.015	-.033
Time on the website	.006	.075
R square	.697	.721

^a $P < .01$.^b $P < .05$.

Intention-to-Treat Analysis

The intention-to-treat analysis revealed no different results with regard to sample characteristics. For both, message-processing mechanisms and future adherence interaction effects between delivery strategy and educational level were found to be insignificant. Next, main effects of delivery strategy and educational level were tested on message-processing mechanisms and future adherence. We found a significant difference between the two message methods only regarding the concept of comprehension. Participants in the text condition showed a higher comprehension of the tailored messages compared to people in the video condition ($F(1,201)=4.34$; $P=.04$). However, the results of this analysis should be carefully interpreted since people staying less than 5 minutes on the website could not possibly have read the advice in-depth.

Discussion

The first objective of the present study was to investigate whether differences exist in message-processing mechanisms according to delivery strategy and education level for a computer-tailored smoking cessation intervention. Results revealed that delivery strategy did not interact with education on message-processing mechanisms. This means that delivery strategy had no influence on the processing of the message by participants with different educational levels. Moreover, the processing of the tailored information did not differ between the two conditions. The idea that the processing of computer-tailored information would depend on the delivery strategy did not hold for this computer-tailored intervention. This conclusion is in line with results found in a recent study concerning physical activity, which demonstrated no differences between video- and text-generated computer-tailored messages [46]. One explanation for these findings may be the exposure time of the intervention. Participants may have needed to follow more than one session of the intervention in order to detect

differences between the two delivery modes. Next, our findings revealed that lower educated smokers paid more attention to the tailored advice and seemed to process information more deeply. As such, lower educated smokers seemed to be more involved in the computer-tailored intervention than higher educated smokers. The findings imply that the current intervention session succeeded in approaching those smokers in the general population who might profit the most from these computer-tailored interventions. Our findings correspond with those from a recent study that found that lower educated participants were more likely to finish a module of a computer-tailored lifestyle intervention [47]. We did not find other differences between educational groups with respect to the other message-processing mechanisms: comprehension, self-reference, and appreciation, which is contrary to previous research that did find higher appreciation rates of computer-tailored advice among lower educated participants [48].

The second objective of this study was to examine whether differences exist in future adherence (intention to revisit, recommend the website to others) with regard to delivery strategy and education. The results revealed no interaction between delivery strategy and education on the intention to adhere; implying that a different delivery strategy did not influence future adherence of lower and higher educated smokers. Again, delivery strategy was found to have no particular effect on future adherence. However, the results demonstrated that lower educated smokers were more inclined to revisit the website compared to higher educated smokers. Although not significant, our findings revealed a slightly better appreciation of the website by lower educated participants, which may have contributed to the positive intention to revisit the website. As already mentioned, this is in line with findings of a previous study that lower educated participants were more inclined to initiate a lifestyle program [47]. Additionally, our lower educated participants were slightly less motivated ($P < .11$)

to quit immediately, which also could explain a need for continued help to prepare them to quit in the future. Although lower educated smokers were more inclined to visit the website again, we could not find any educational differences with regard to recommending the website to others. As the results indicate that the “word of mouth” strategy might be not sufficient to recruit participants for Internet interventions, other recruitment strategies may also be needed such as recruitment through general practitioners [49]. A question raised by our results is why delivery strategy did not influence message-processing mechanisms and future adherence among different educational groups. One explanation could be that we recruited persons via an Internet research agency, which may have more innovative members that have already an open mind to Internet interventions. It might be possible that for those people, delivery mode did not differ that much. It is conceivable that delivery mode preference might have been different if we had recruited participants via other strategies, eg, newspaper advertisements. Furthermore, it might be possible that participants were not engaged by the design of the intervention components. The two conditions might have been presented in a more engaging way with further images, graphics, hyperlinks, and other animation effects. However, an important precondition for our experimental design was that the information of the video condition was contingent on the information provided by text condition to reveal the added effect of presenting information through a video format.

Our findings reveal that the tailored advice given was more positively evaluated by lower educated smokers. This outcome is in contrast with earlier studies indicating that web-based programs may result in a digital divide between lower and higher educated groups. Perhaps high Internet use among the Dutch (over 90%) may explain these effects [37]. Moreover, since our less educated smokers often show higher addiction rates, fewer quit attempts, and more relapses [14,15], approaching them via Internet may have added potential.

Study Limitations

The present study is subject to certain limitations. First, as with many health communication studies, we could not objectively assess quality of information processing as we could not measure it. Yet we did assess how long participants stayed on the website via server registrations and therefore could exclude all participants who briefly visited the intervention website and probably did not accurately process the given information. Second, our sample size was limited. Additional longitudinal research with a larger sample size is needed to investigate the role of delivery strategy in tailored information and to examine whether smokers will actually revisit the website and whether this will result in the ultimate goal of behavior change.

Conclusions

Delivery strategy did not play a role in the processing of the tailored information. Lower educated participants showed higher attention and processing levels. Lower educated participants were also more inclined to visit the intervention website again compared to higher educated participants. Due to the fact that all participants were members of an Internet research panel, the results can be applied only to people who are already regularly using the Internet. This study can be seen as an important first step to assess the influence of delivery strategy among different educational groups and especially among lower educated smokers in the Netherlands. Effective smoking cessation interventions are important to decreasing the gap between lower and higher educated smokers. Yet, longitudinal studies with larger sample sizes are needed to see whether these counterintuitive findings still hold true and to further assess additional aspects that we could not assess, such as actual revisit and long-term behavioral effects of the two strategies among lower and higher educated smokers in order to improve computer-tailored smoking cessation interventions.

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Conflicts of Interest

Hein de Vries is scientific director of Vision2-Health, a company that licenses evidence-based innovative computer-tailored health communication tools.

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Original Paper

Effectiveness of a Self-Guided Web-Based Cannabis Treatment Program: Randomized Controlled Trial

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Abstract

Background: Self-help strategies offer a promising way to address problems with access to and stigma associated with face-to-face drug and alcohol treatment, and the Internet provides an excellent delivery mode for such strategies. To date, no study has tested the effectiveness of a fully self-guided web-based treatment for cannabis use and related problems.

Objectives: The current study was a two-armed randomized controlled trial aimed at testing the effectiveness of *Reduce Your Use*, a fully self-guided web-based treatment program for cannabis use disorder consisting of 6 modules based on cognitive, motivational, and behavioral principles.

Methods: 225 individuals who wanted to cease or reduce their cannabis use were recruited using both online and offline advertising methods and were randomly assigned to receive: (1) the web-based intervention, or (2) a control condition consisting of 6 modules of web-based educational information on cannabis. Assessments of cannabis use, dependence symptoms, and abuse symptoms were conducted through online questionnaires at baseline, and at 6-week and 3-month follow-ups. Two sets of data analyses were undertaken—complier average causal effect (CACE) modeling and intention to treat (ITT).

Results: Two thirds (149) of the participants completed the 6-week postintervention assessment, while 122 (54%) completed the 3-month follow-up assessment. Participants in the intervention group completed an average of 3.5 of the 6 modules. The CACE analysis revealed that at 6 weeks, the experimental group reported significantly fewer days of cannabis use during the past month ($P=.02$), significantly lower past-month quantity of cannabis use ($P=.01$), and significantly fewer symptoms of cannabis abuse ($P=.047$) relative to controls. Cannabis dependence symptoms (number and severity) and past-month abstinence did not differ significantly between groups ($P>.05$). Findings at 3 months were similar, except that the experimental group reported significantly fewer and less severe cannabis dependence symptoms ($P<.05$), and past-month quantity of cannabis consumed no longer differed significantly between groups ($P=.16$). ITT analyses yielded similar outcomes.

Conclusion: Findings suggest that web-based interventions may be an effective means of treating uncomplicated cannabis use and related problems and reducing the public health burden of cannabis use disorders.

Trial registration: ACTRN12609000856213, Australian New Zealand Clinical Trials Registry.

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KEYWORDS

marijuana; Internet intervention; computer-assisted therapy; addiction; randomized controlled trial

Introduction

Cannabis is the most commonly used illicit drug in the developed world—1.9 million Australians, for example, reported using cannabis in 2010 [1]. Although once believed to be a relatively harmless substance, it is now known that approximately one out of 10 of those who ever use cannabis meet DSM-IV criteria for cannabis dependence at some point in time [2]. Heavy cannabis use is associated with poorer mental and physical health, lower educational achievement, and impoverished cognitive functioning [3]. In Australia, cannabis use accounted for 10% of the health burden relating to all illicit drug use in 2003, with only heroin and hepatitis C contributing more [4]. This entails a greater loss of disability-adjusted healthy life years than the loss attributed to suicide and self-inflicted injuries related to substance use. Other developed countries, such as the United States, have experienced similar rates of cannabis use and related problems [5].

Unfortunately, most individuals meeting diagnostic criteria for a cannabis use disorder do not seek professional treatment [2]. This can occur for a variety of reasons. First, many cannabis users are employed and unable to attend face-to-face sessions during working hours. Second, residents of remote areas or localities poorly serviced by public transport have difficulty traveling to regular sessions. Third, face-to-face therapy is economically burdensome and provision services frequently cannot meet demand [6]. Finally, many people hesitate to seek treatment due to concerns about confidentiality and being stigmatized [7]. These issues underscore the vital need for evidence-based treatments that are highly accessible, financially efficient, and have a high level of acceptability to consumers.

Internet-delivered treatments may assist in resolving these issues, offering several advantages, including bridging the gap between supply and demand for alcohol and drug therapists, being potentially more cost effective than face-to-face treatment, and having the ability to be accessed at most times and in most locations. Increased privacy largely addresses the issue of stigmatization. Additionally, where treatment is automated, it is consistently delivered in its intended manner [8].

Several computer programs and web-based interventions for substance use have recently been developed and tested for their efficacy. The treatments consist of components such as cognitive behavioral therapy (CBT) [9], chat forums [10], and normative feedback on substance use [11]. A recent meta-analysis of the efficacy of computer-delivered treatments for tobacco and alcohol use found that, overall, the treatments had a significant effect [12]. A nonrandomized study by Budney et al involving 38 participants found that a computerized intervention program with therapist support yielded similar reductions in cannabis use to a therapist-delivered intervention [13]. Tossman et al tested the effects of a therapist-assisted online treatment program for cannabis use in a randomized trial with high levels of attrition, finding significant effects on cannabis use reductions [14]. Sinadinovic et al found some evidence that an online brief intervention program was superior to assessment-only in assisting illicit drug users to reduce their substance use [15]. No previous study, however, has empirically tested the efficacy

of a fully self-guided web-based treatment for cannabis use and related problems.

Research Objectives and Hypotheses

In response to the absence of evidence-based fully self-guided online treatments for cannabis use, the authors developed the online program, *Reduce Your Use: How to Break the Cannabis Habit* [16]. The objective of the current study was to test the effectiveness of the program in assisting individuals who wished to reduce or stop their cannabis use. We hypothesized that at 6-week and 3-month follow-up assessments, relative to an information-only control group, individuals who were randomized to the intervention would report lower frequency of cannabis use (H1), lower quantity of cannabis use (H2), lower levels of cannabis dependence (H3), and fewer symptoms of cannabis abuse (H4). We further hypothesized that the intervention group would report higher rates of past-month abstinence at both follow-up points (H5).

Methods

Participants

Our power calculation was based on a projected effect size of $d=0.45$, as this was obtained for cannabis use frequency in the face-to-face treatment on which the intervention was based [17]. This required a total of 158 participants to achieve 80% power. However, given that web-based studies are prone to higher attrition rates than face-to-face treatments [18], we recruited a larger number of participants ($N=225$). Participants were recruited between April 2010 and May 2011.

Participants were primarily from Australia (64%); however, Google advertising also attracted participants from the United Kingdom (21%), the United States (10%), New Zealand (3%), and other countries (2%). Study participants were adults who were at least 18 years old and were English and computer literate in order to comply with study procedures. All participants had used cannabis at least once during the past month and expressed a desire to stop or reduce their cannabis use. Those who had received formal treatment for cannabis use or any other substance use within the past 3 months were excluded from the study, as were those who used another illicit drug weekly or more frequently, or who reported having a mental illness that would be likely to significantly interfere with their participation. This information was obtained first by asking the participant if they had any mental illness that would likely interfere with their participation, then by asking them if a doctor had diagnosed them with schizophrenia, schizoaffective disorder, or bi-polar disorder. Participants who answered yes to either of these questions were excluded from participation.

Procedures

Ethical approval for this study was given by the University of New South Wales (UNSW) Human Research Ethics Committee. Approval was granted to recruit participants both within Australia and elsewhere. Recruitment for the study commenced following in-house testing of the program, during which minor modifications were made and bugs were fixed. Advertisements seeking individuals who wished to reduce or quit their cannabis use via an online program were placed on the National Cannabis

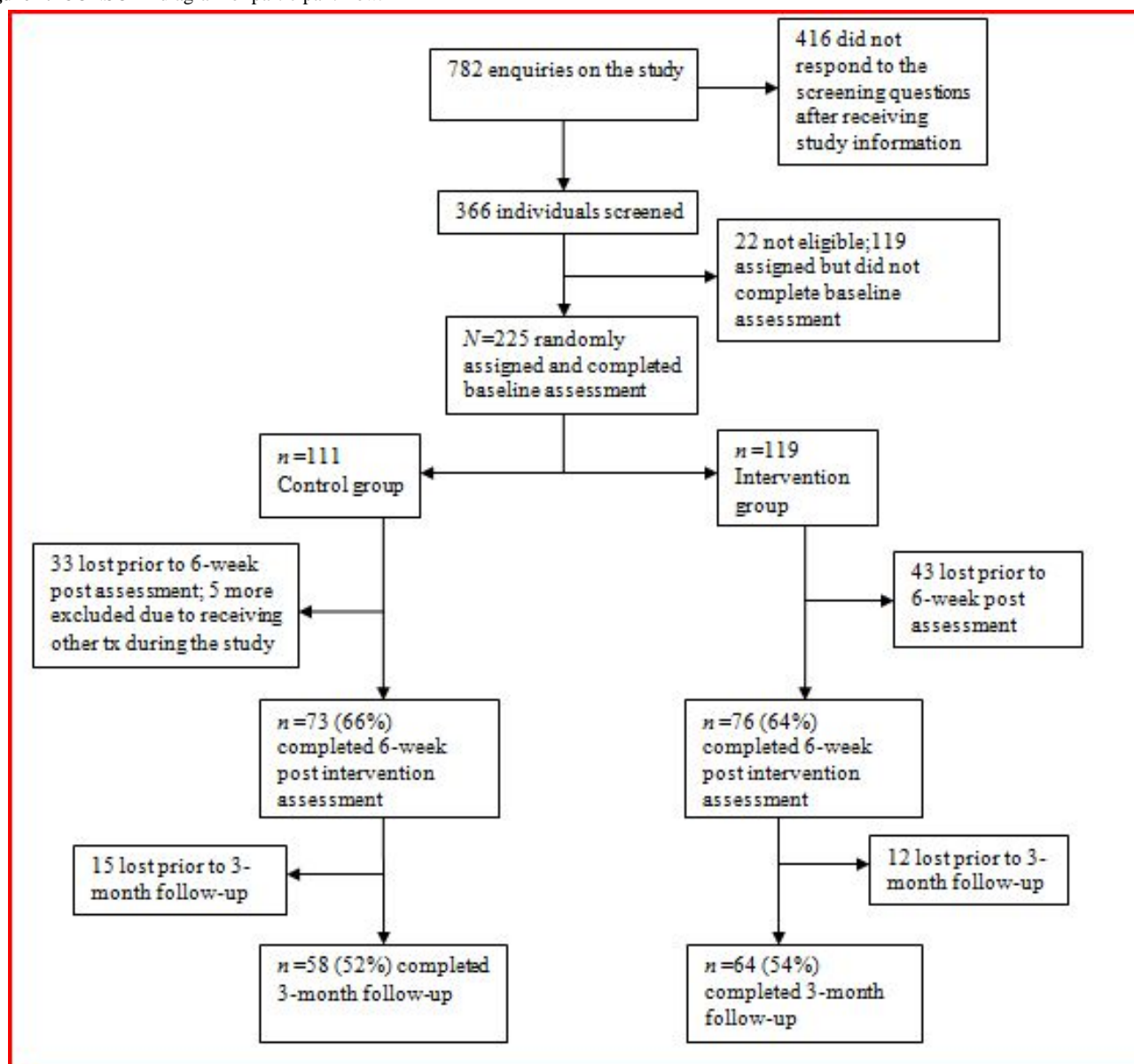
Prevention and Information Centre (NCPIC) website, online forums, Google, university bulletin boards, in newspapers, and at community health centers. NCPIC and UNSW affiliations were displayed on all advertisements. Interested individuals contacted the research team via email and were sent screening and study information materials by return email. Inclusion/exclusion criteria (aside from being 18 or older) were not stated on the advertisement, nor specifically noted during participant screening, to prevent individuals from providing false information in order to be eligible for the study. Compensation for completing assessments was not noted in the study advertisement but was noted in the participant information sheet, which participants received after contacting us to indicate their interest in the study.

Participants were informed that they would be randomly assigned to receive 6 modules of CBT or 6 modules of educational information. After responding to the screening questions and prior to completing the baseline assessment, those eligible for participation were randomly assigned by the first author. Assignment occurred through the drawing of one of two tokens from a box. The tokens were two different colours, representing the two study conditions. The token was replaced each time it was drawn, and the box shaken after each drawing; thus, the probability of allocation to either study condition was always 50%.

All participants were given a username and password-protected access to their respective websites. Data were stored on a secure server and password-protected computer. Participants assigned to the control condition were sent a link to an educational resource relating to cannabis use. Upon clicking this link, entry to this website occurred via checking an informed consent box and completion of the baseline assessment questionnaire. Participants assigned to the experimental condition were similarly sent a link to the intervention website, which contained the baseline assessment questions prior to accessing the remainder of the website. After this point, routine study procedures were fully automated. No further contact was made with participants for 6 weeks, at which point they were contacted by an automatically generated email that requested completion of follow-up data by returning to the website. Participants who did not respond were sent up to 3 reminder emails on a weekly basis. A researcher telephoned Australian participants who did not respond to these email requests and asked them to log in to the website and complete the assessment.

Three months post randomization, participants were contacted in the same manner as described for the 6-week follow-up. Participants completing each research assessment were given a gift voucher worth \$30 AUD (Australian participants) or \$30 AUD via PayPal (participants from other countries). Those assigned to the control condition were sent a link to the intervention website at the conclusion of the study. [Figure 1](#) shows a CONSORT [19] diagram describing participant flow.

Figure 1. CONSORT diagram of participant flow.



Interventions

The intervention website, *Reduce Your Use: How to Break the Cannabis Habit* (Figure 2), is a newly developed intervention, largely based on a face-to-face brief treatment previously found to be effective for problematic cannabis use [17]. The face-to-face treatment was informed by the principles of CBT and motivational interviewing (MI) and was specifically based on previous cognitive-behavioral interventions with known efficacy in managing substance use [20,21]. The web adaptation was also informed by other web-based interventions targeting substance use that used automated feedback [22]. The website contains 6 core modules, which are undertaken sequentially at intervals chosen by the participant. These are briefly summarized in Appendix 1. Feedback on the participant's progress is available throughout the sequence via graphing of cannabis use through the program and detailed feedback on changes in use

and related factors such as attitude toward cannabis, goal setting, and weekly expenditure on cannabis. The website also features a personalized folder for the participant, blogs from former cannabis users, quick assist links, and weekly automatically generated encouragement emails. Individuals using the website have the option of reading its text or watching a video of an actor speaking the text.

The control condition website contains information about cannabis and consists of 6 sections, with content as follows: (1) What is cannabis? (2) Cannabis potency, (3) Cannabis and the law, (4) Cannabis in the workplace, (5) Cannabis and aggression, and (6) Cannabis and driving. The information provided does not contain any content aimed at building skills or changing motivation or other aspects of thinking about cannabis, nor in supporting actual behavior change attempts. Participants did not need to read the sections in sequential order, and we did not monitor the number of sections each participant read.

Figure 2. Screenshot of the intervention.

Reduce your use:
How to break the cannabis habit

View as Text My Documents Quick Assist

On how many days in the previous week did you smoke cannabis?
2 days

What was the average number of joints or cones you smoked on each day?
3 joints

Continue >

QUICK FEEDBACK YOU SMOKED ON A TOTAL OF 2 DAYS IN THE LAST WEEK

Pre-Assessment Feedback and Motivation Smoking Urges and Withdrawal Changing Your Thinking Coping Strategies and Skill Enhancement Activities and Interpersonal Skills Relapse Prevention and Lifestyle Post-Assessment Six Month Post-Assessment

Outcome Evaluation and Measures

Trial outcomes were assessed 6 weeks and 3 months post randomization. If participants completed 1 module per week as recommended, the 6-week follow-up approximates a short-term posttreatment assessment. Participants may not have completed all modules or completed them more quickly than in 6 weeks. The reference period for all measures at all assessment points was the past month. There was no blinding of participants, who were thus aware that they had an equal probability of being assigned to the intervention or the educational website. Outcome data collection was automated, negating the need to blind researchers.

Days of cannabis use over the past month and past-month quantity of cannabis use were primary outcomes measures. These were assessed using the Timeline Follow-Back method (TFLB) [23], adapted to measure standard cannabis units (SCUs), where a regular-sized joint or 3 cones equals 1 SCU [24]. As well as the extensively validated frequency measure, quantity estimates from the TFLB have been found to be reliable [25]. Although the TFLB is a somewhat complex measure, previous research supports the validity of its use over the Internet [26]. Other outcomes included past-month abstinence, number and severity of past-month cannabis dependence symptoms, and past-month number of cannabis abuse symptoms. Cannabis dependence severity was measured using the Severity of Dependence Scale (SDS) [27]. Number of cannabis dependence and abuse symptoms were assessed using the

GAIN-I (Global Appraisal of Individual Needs - Initial) [28]. Participants also indicated the age at which they initiated cannabis use and provided basic demographic information.

Participants in the intervention group completed questions relating to their compliance and engagement with the program during the 6-week assessment. These included 1-4 ratings for the questions: "How closely did you follow the content of each module?" (1 = not closely at all, 4 = very closely), and "To what extent did you carry out the website's skill-building tasks?" (1 = did not do any of the tasks, 4 = did all of the tasks). Participants also were asked how many of the 6 modules they completed. In addition to providing information relating to compliance, participants in the intervention group rated their satisfaction with each module out of 10 and also completed the Client Satisfaction Questionnaire (CSQ-7) [29]. This included 7 items relating to satisfaction with the program, eg, "How would you rate the quality of the service you have received? To what extent has our program met your needs?" Items were rated on a 4-point scale, with higher ratings indicating higher satisfaction. Each measure in the assessment was placed on a single screen; thus, the number of items per page varied, depending upon the measure.

Data Analysis

Statistical significance was defined as a two-tailed *P* value below .05. Complier average causal effect (CACE) analysis, performed using Mplus software [30], was employed for continuous outcome measures. CACE contrasts study outcomes

for treatment group participants who are classed as compliers relative to participants in the control group who would have complied had they been assigned to the treatment group (see articles by Connell [31] and Jo et al [32] for a more detailed explanation of how “would be” compliance in the control condition is operationalized as a latent variable and for further information on CACE procedures). Standard assumptions were met with regard to the use of CACE analysis in the current study.

For our analyses, we defined a noncomplier as a participant who completed only 1 module or less and/or indicated that they did not follow the intervention at all closely, and/or failed to complete any of the skill-building exercises, and/or failed to complete at least some of the 6-week postintervention assessment or at least some of the 3-month follow-up assessment. The rationale behind selecting a cut-off of 1 module was that participants who completed more than 1 module returned to the program at least once.

CACE has been recommended for use in RCTs, where noncompliance and attrition are extremely common [18,31]. It has also been argued that the notoriously high rate of attrition associated with web-based intervention studies deems it necessary to employ analyses that estimate the efficacy of the intervention on individuals who actually use it [18]. Therefore, CACE was considered appropriate as the primary analysis in the current study. This decision was not made a priori; rather, it was made due to the observed level of missing data. A missing values analysis showed that data were missing completely at random (Little’s MCAR test $\chi^2 = 194.21, P = .66$). The CACE analysis addressed missing data by imputing missing values on continuous variables. The procedure used for imputation was PASW 17’s Expectation Maximization (EM) imputation procedure. This is a maximum likelihood approach that uses an iterative algorithm to estimate the parameters of the complete dataset [33].

In light of attrition from the study, conducting a traditional intention-to-treat analysis (ITT) with postintervention and follow-up data from all cases was not possible. Instead, EM

without CACE is also reported as the primary ITT analysis. This analysis employed between-groups repeated measures ANOVAs.

Listwise deletion (excluding participants who did not complete the relevant assessment) and last-score-carried forward analyses were also conducted in order to test outcomes as comprehensively as was feasible. These analyses were conducted through between-groups repeated measures ANOVAs. To avoid overcomplicating the results, outcomes of these two analyses are not reported in detail. Rather, a brief comparison of these findings and our primary analyses are presented in the Results section. While last-score-carried-forward analyses are often employed as a primary analysis in RCTs, we decided against this in the current study in light of several recent studies indicating that the technique can be vulnerable to bias where there are large amounts of missing data and thus should be avoided [34-36].

All between-groups analyses were conducted with the outcome variables adjusted for the baseline score. Other baseline variables previously found to be associated with continued cannabis use (age of cannabis use initiation, gender, and age) [37] were also entered into analyses as covariates.

Group differences in past-month abstinence were assessed in logistic regression models, performed on PASW 17 [38]. Additional analyses involved examining bivariate correlations among adherence/satisfaction and outcome variables. These also were conducted on PASW 17. Imputation was not used for these data.

Reporting

The research is reported in accordance with the E-CONSORT checklist [39] (see Appendix 2).

Results

Demographic characteristics and assessment data at baseline are presented in Table 1. Randomization was successful, with groups not differing significantly on any baseline variable.

Table 1. Baseline means (SD) or percentage scores on participant demographics and cannabis-related variables (N=225).

	Intervention (n=119)	Control (n=111)	<i>df</i>	<i>t</i>	χ^2	<i>P</i>
Age	31.88 (9.85)	30.18 (9.62)	224	1.33		.19
Gender (male)	59.7%	63.2%	1		0.30	.58
Age/initiation	16.31 (3.71)	16.22 (3.20)	224	0.20		.84
Frequency (days past month)	21.33 (8.24)	20.76 (8.68)	224	0.49		.62
Quantity (SCUs ^a past month)	79.28 (72.68)	70.66 (60.96)	224	0.99		.32
SDS ^b	13.97 (3.61)	13.78 (3.61)	224	0.37		.71
GAIN-dependence	4.47 (1.57)	4.40 (1.65)	224	0.36		.71
GAIN-abuse	2.61 (1.41)	2.43 (1.41)	224	0.96		.34

^a SCUs = standard cannabis units.

^b SDS = Severity of Dependence Scale.

Sixty-six percent (149 of 225) of participants completed the 6-week postintervention assessment, while 51% (122 of 225) completed the 3-month follow-up assessment. Five control group participants were excluded from the study because they reported receiving other professional treatment during the course of the intervention. No participants in the experimental group reported receiving additional treatment. Completion rates did not differ significantly between groups for either assessment

(*Ps*>.10). All but 2 participants who completed the 3-month assessment also completed the 6-week assessment (ie, only 2 participants did not complete the postassessment but completed the follow-up assessment). Table 2 shows outcomes for cannabis-related variables at 6 weeks and 3 months with EM imputation. Participants in both conditions reported significant change on all outcome variables after 6 weeks and maintained significant change after 3 months.

Table 2. Cannabis-related variables across assessments (N=225; imputation is not used for the Abstinence variable).

Variable	Intervention	Control	Intervention	Control	Intervention	Control
	Baseline	Baseline	6 weeks	6 weeks	3 months	3 months
	(n=111)	(n=119)	(n=76)	(n=73)	(n=64)	(n=58)
Frequency (days past month)	21.33 (8.24)	20.76 (8.68)	12.90 (8.47) ^a	14.87 (8.88) ^b	12.05 (8.99) ^a	14.11 (8.79) ^b
Quantity (SCUs ^c past month)	79.28 (72.68)	70.66 (60.96)	39.78 (44.97) ^a	46.16 (49.31) ^b	36.65 (44.85) ^a	39.25 (39.21) ^b
SDS ^d	8.97 (3.61)	8.78 (3.61)	7.31 (3.22) ^a	7.44 (3.56) ^b	5.70 (3.35) ^a	6.82 (3.31) ^b
GAIN-dependence	4.47 (1.57)	4.40 (1.65)	3.09 (1.69) ^a	3.21 (1.60) ^b	2.53 (1.67) ^a	3.10 (1.67) ^b
GAIN-abuse	2.61 (1.41)	2.43 (1.41)	1.60 (1.22) ^a	1.79 (1.37) ^b	1.24 (1.03) ^a	1.56 (1.24) ^b
Abstinence	N/A	N/A	9.3%	4.7%	12.4%	6.6%

^a Significantly different from intervention group baseline assessment (*P*<.001).

^b Significantly different from control group baseline assessment (*P*<.001).

^c SCUs = standard cannabis units.

^d SDS = Severity of Dependence Scale.

CACE Analyses With EM

A series of group comparisons employing CACE analyses, controlling for the previously noted covariates, are reported in Table 3. For the 6-week postassessment, there were 61 compliers and 68 noncompliers in the treatment group; for the 3-month follow-up, there were 53 compliers and 76 noncompliers in the treatment group. Hypothesis 1 predicted that at 6-week and 3-month follow-up assessments, participants in the intervention

group would report significantly lower cannabis use frequency than would participants in the control group. This hypothesis was supported, with between-group differences significantly favoring the experimental group at both postintervention and follow-up.

Hypothesis 2 predicted that at the 6-week and 3-month follow-up assessments, participants in the intervention group would report a significantly lower quantity of cannabis use than would participants in the control group. The hypothesis was partially

supported, with results showing significantly lower numbers of SCUs in the intervention group relative to the control group at the 6-week postassessment. This effect was, however, reduced somewhat by the 3-month follow-up, such that it no longer reached statistical significance.

Hypothesis 3 predicted that at 6-week and 3-month follow-up assessments, participants in the intervention group would report significantly lower levels of cannabis dependence than would participants in the control group. Group differences were not apparent after 6 weeks on either measure of cannabis

dependence; however, significant differences did emerge for both measures at the 3-month follow-up, providing support for a slight delay in effects on cannabis dependence.

Hypothesis 4 predicted that at 6-week and 3-month follow-up assessments, participants in the intervention group would report significantly fewer symptoms of cannabis abuse than would participants in the control group. This hypothesis was supported, with between-group differences on the GAIN abuse measure significantly favoring the experimental group at both assessment points.

Table 3. CACE analyses of cannabis outcome measures at 6-week and 3-month assessments (N=225; intervention group coded as 1, control group coded as 2).

Variable	<i>B</i>	<i>SE</i>	<i>P</i>	<i>d</i> ^a
6-weeks post				
Smoking days	3.82	1.67	.02	0.38
SCUs	24.86	9.78	.01	0.34
SDS	0.43	0.73	.56	0.08
GAIN-dependence	0.12	0.42	.78	0.04
GAIN-abuse	0.60	0.30	.047	0.27
3-month follow-up				
Smoking days	5.37	2.36	.02	0.31
SCUs ^b	11.84	8.45	.16	0.19
SDS ^c	2.37	0.84	.01	0.38
GAIN-dependence	0.99	0.50	.047	0.27
GAIN-abuse	1.05	0.40	.01	0.35

^a*d*= Cohen's *d*.

^b SCUs = standard cannabis units.

^c SDS = severity of dependence scale.

ITT Analyses With EM

An ITT analysis employing between-groups repeated measures ANOVAS and using EM imputation is reported in Table 4. All

significant outcomes found using CACE were replicated in these analyses, with the exception of the analysis examining cannabis abuse at the 6-week assessment, which marginally missed statistical significance ($P=.05$).

Table 4. ITT analyses with EM showing group x time interactions on cannabis outcome measures at 6-week and 3-month assessments (N=225; intervention group coded as 1, control group coded as 2).

Variable	<i>F</i>	<i>df</i>	<i>P</i>	<i>d</i> ^a
6-weeks post				
Smoking days	5.12	220	.02	0.30
SCUs ^b	6.31	220	.01	0.34
SDS ^c	0.50	220	.49	0.10
GAIN-dependence	0.43	220	.51	0.09
GAIN-abuse	3.82	220	.05	0.26
3-month follow-up				
Smoking days	5.88	220	.02	0.33
SCUs	3.49	220	.06	0.25
SDS	6.07	220	.01	0.33
GAIN-dependence	5.18	220	.02	0.31
GAIN-abuse	6.32	220	.01	0.34

^a*d* = Cohen's *d*.^bSCUs = standard cannabis units.^cSDS = severity of dependence scale.

Additional Analyses

Analyses using listwise deletion and last-score-carried-forward imputation were conducted as comparisons with the primary analyses. Several significant findings obtained in the primary analyses were replicated. The listwise deletion analyses found significant group x time interactions favoring the experimental group on smoking days at 6 weeks ($F(144) = 4.45, P = .04$), SCUs at 6 weeks ($F(142) = 5.08, P = .03$), and SDS at 3 months ($F(117) = 4.56, P = .04$). Other outcomes found to be significant in the primary analyses nonsignificantly favored the experimental group, with *P* values ranging from .05 to .17. Last-score-carried-forward analyses showed significantly lower SDS scores in the experimental group at 3 months ($F(220) = 5.62, P = .02$) and significantly lower cannabis abuse scores in the experimental group at 3 months ($F(220) = 5.32, P = .02$). Again, other outcomes found to be significant in the primary analyses showed nonsignificantly better results for the experimental group, with *P* values ranging from .08 to .15.

Past-Month Abstinence

The final study hypothesis predicted that at 6-week and 3-month follow-up assessments, participants in the intervention group would report significantly higher rates of past-month abstinence than those in the control group. At the 6-week post intervention assessment, the intervention group had a higher rate of abstinence (9.3%; 7/76) than did the control group (4.7%; 3/73), though the numbers were small and the difference not statistically significant (OR 2.53, $P = .10$). Likewise, at the 3-month follow-up, past-month abstinence was higher in the intervention group (12.4%; 8/64) compared with the control group (6.6%; 4 out of 58), with the difference missing the conventional threshold of statistical significance (OR 2.50, $P = .06$).

Process Analysis

Participants in the intervention group completed an average of 3.5 of the 6 modules. The percentage of participants who completed only the first module or less was 17.3%. The percentages of participants ceasing treatment after completing Modules 2-6 were 27.2%, 11.1%, 6.2%, 9.9%, and 28.4%, respectively. While we have reported participants' self-reports of number of modules completed, these were closely corroborated by the program's documentation of participant logins ($r = .87$). Number of modules completed was only significantly associated with one variable, reduction in past-month cannabis smoking days at both 6 weeks ($r = .25, P = .04$) and 3 months ($r = .32, P = .01$). Reported satisfaction with the program was generally high, with the mean score on the CSQ-7 being 3.41 (SD 0.64) out of a possible 4. Perhaps because of this, CSQ-7 scores were not significantly associated with any outcome variable (all P s > .07). Out of a possible 10, modules 1-6 received mean (SD) satisfaction ratings of 7.10 (2.21), 6.95 (2.28), 7.33 (2.47), 7.00 (2.47), 7.38 (2.61), and 7.85 (2.61), respectively.

Discussion

This study evaluated the effectiveness of the *Reduce Your Use: How to Break the Cannabis Habit* program in a fully automated environment. We tested the hypotheses that at 6-week and 3-month follow-up assessments, relative to a an information-only control group, participants who were randomized to the intervention would report lower frequency of cannabis use (H1), lower quantity of cannabis use (H2), lower levels of cannabis dependence (H3), fewer symptoms of cannabis abuse (H4), and higher rates of past-month abstinence (H5).

The first hypothesis was supported. Primary analyses conducted in relation to cannabis use frequency revealed a significantly lower number of past-month smoking days in the intervention group, after controlling for pre-intervention smoking days. Reductions in smoking days were substantial, with the intervention group reducing from 21.33 smoking days per month at baseline to 12.05 days at 3-month follow-up. This equates to a 43.5% reduction in smoking days per month for the treatment group. The control group reduced their smoking days from 20.76 at baseline to 14.11 at follow-up, representing a 32.0% reduction in smoking days. The outcome for the intervention group on cannabis use frequency is comparable to outcomes of several face-to-face treatments for cannabis at similar time points [40-42].

Hypothesis 2 was supported in part. Results showed significantly lower numbers of SCUs in the intervention group relative to the control group at 6 weeks in each analysis. However, by 3 months, this effect had reduced to a nonsignificant level. The intervention group reduced their past-month number of SCUs from 79.28 at baseline to 36.65 at 3 months, which equates to a 53.8% reduction in SCUs per month. The control group reduced from 70.66 at baseline to 39.25 at follow-up, which represents a 44.2% reduction in past-month SCUs.

Partial support was found for Hypothesis 3 regarding cannabis dependence. Interestingly, the effect on cannabis dependence symptoms appeared to be delayed, with both measures of cannabis dependence showing a nonsignificant effect at the 6-week assessment and both showing a significant effect in favor of the intervention group at 3 months in each analysis. This finding may suggest that the intervention has some effects that endure or strengthen over time [43]. It is also consistent with findings in face-to-face interventions, where concern over use, as measured in the SDS, has a long lag as participants take the time to become more established in, and less concerned about, their changed pattern of use [14]. However, a longer follow-up period would be required to investigate these possibilities.

The fourth hypothesis, relating to cannabis abuse, was partially supported, with the CACE analysis finding significant group differences at each assessment point, but the ITT analysis not reaching statistical significance at the 6-week analysis ($P=.05$). The trend in the expected direction suggests insufficient power may have affected the outcome of this analysis.

The final hypothesis, regarding abstinence, was not supported. Neither the post nor the follow-up assessment indicated significantly higher levels of abstinence among the intervention group relative to the control group. Rates of abstinence were lower than in several other intervention studies for cannabis [17,44,45], including the face-to-face intervention upon which the program is based [17], which achieved 20.8% abstinence in the intervention group at 3-month follow-up. This may in part reflect the intervention's focus on quitting *or* reducing cannabis use. It does, however, suggest that there is significant scope for improving online cannabis treatments to build rates of abstinence where that is the desired goal.

Findings of this study add to those of previous studies assessing computer-delivered treatments for cannabis, which have shown

that such treatments are valuable as an adjunct to in-person therapy [13,14]. This study further demonstrates that fully self-guided treatment delivered online can assist individuals to reduce their cannabis use.

Strengths and Limitations

This study has several important strengths. First, the intervention was designed to be fully self-guided, thus requiring minimal therapist input beyond the initial design of the program. Second, the program was able to reach a wide audience, both nationally and internationally. Third, continued operation and dissemination of the program can be achieved at low cost. Finally, this is an effectiveness study, designed to precisely estimate effects that may be obtained in real-world use outside of a research environment. These points engender confidence that the program will have positive effects as a free and publicly available cannabis treatment option. While rates of abstinence were lower than those achieved by highly trained clinicians using manualized interventions in traditional treatment settings, the significant reductions in the levels of cannabis use and related harms suggest that this web-based intervention offers great promise for reducing the public health burden of cannabis use.

There are also some important limitations to note in relation to the current study. First, the level of participant attrition was quite high with regard to completion of the treatment program as well as completion of assessments; however, high levels of attrition are the rule rather than the exception in web-based treatment studies. For example, online treatment programs have reported program completion rates as low as 0.5% and drop-out rates as high as 65% [18]. Finding ways of decreasing participant attrition in web-based studies should be an imperative for future related studies.

A second limitation is that the long-term effectiveness of the treatment program cannot be known with a 3-month follow-up period—future studies should contain provisions for longer durations of follow-up assessment with and without booster sessions. Similarly, findings on the effectiveness of this intervention are entirely restricted to the self-guided study context. It is possible that facilitation of uptake of such interventions may enhance their effectiveness. An additional limitation is that the study relied solely on self-report data for all outcome measures. With regard to our cannabis use outcome measures, however, there was little that could be done to rectify this as urinalysis was not possible in light of participation being open to individuals around Australia and elsewhere. Saliva analysis was not feasible due to funding and time constraints and is of questionable validity in the context of the current study. Finally, tobacco smoking was not taken into consideration as a factor that could influence success in reducing cannabis use and maintaining reductions. Future research would benefit from gauging the level of influence tobacco use exerts on cannabis use outcomes.

Implications and Future Directions

Findings of the current study provide support for further investigation of web-based treatment for cannabis use and related problems. Should these evaluations yield positive

outcomes, the availability of web-based treatment for cannabis use could lead to valuable and tangible developments in service delivery and treatment uptake. These could include an ease on the public health burden of cannabis use disorders, reductions in treatment waitlists, and increased uptake of treatment due to the high acceptability of online treatments to many users.

While there are many important areas of investigation for future studies, treatment adherence and retention are worthy of prominent consideration. In the current study, the average number of modules completed was 3.5 out of 6 and the retention rate at follow-up was 53%. This is lower than the average number completed in the face-to-face study upon which the current study is based (4.2 out of 6 modules), as well as the follow-up retention rate of 74%. There was some evidence of a relationship between adherence and treatment outcome, where number of modules completed did correlate with reduced frequency of use. Noncompletion of treatment in web-based studies is extremely common, and recent work suggests that additions to web-based intervention studies, such as brief weekly telephone check-ins [46] and use of incentives [47], can increase engagement with treatment as well as assessment completion rates. Future research on web-based studies addressing cannabis use could test whether additions such as these help to promote engagement and to reduce drop-out. Such methods may also lead to enhanced treatment outcomes. Increasing treatment satisfaction is another possible means of increasing treatment adherence. In the current study, satisfaction with the intervention was generally high as measured by the CSQ-7 and participant ratings of module quality. All modules received a rating of at least 7/10, with the exception of Module 2, which addressed coping with cravings and withdrawal symptoms. This is another area in which future web-based interventions could be improved. For example, the module included little information on sleep

problems, which one study recently found was the primary symptom associated with cannabis withdrawal [48].

There are few similar web-based interventions targeting substance use. In the alcohol field, *Down Your Drink* targeted anyone considering their drinking and did not require a decision to change to have been made prior to participation in the trial [49]. In contrast, an intervention known as *MinderDrinken* recruited help-seekers who had already made a decision to change [50]. Findings from the evaluation studies were positive for the latter study and negative for the former, with similarities in the content of the interventions themselves. Thus, it should be taken into consideration that findings of the current study may differ if the intervention program were to be used by non-help-seeking cannabis users. Future studies could examine whether online cannabis intervention programs have a significant impact on non-treatment-seekers.

Other important issues for future research include investigations of longer term effects of treatment, examining the effects of adaptations to suit varying demographics and cultures, and exploring the feasibility and impact of combining web-based treatment with face-to-face therapy.

Conclusions

Web-based treatments for substance use disorders are becoming increasingly available; however, up to this point, no completely self-guided web-based cannabis treatment has been tested in a randomized controlled trial. Outcomes of the current study suggest that *Reduce Your Use* holds promise in assisting individuals who wish to quit or reduce their cannabis use and also point to possible means of improving outcomes of web-based interventions for cannabis and other substance use disorders.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

The structure of Reduce Your Use: How to Break the Cannabis Habit.

[[PDF File \(Adobe PDF File\), 284KB - jmir_v15i2e26_app1.pdf](#)]

Multimedia Appendix 2

CONSORT EHEALTH Checklist V1.6.2 [51].

[[PDF File \(Adobe PDF File\), 590KB - jmir_v15i2e26_app2.pdf](#)]

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Abbreviations

CACE: complier average causal effect
CBT: cognitive behavioral therapy
CSQ: Client Satisfaction Questionnaire
EM: expectation maximization
GAIN: Global Appraisal of Individual Needs
ITT: intention-to-treat analysis
MI: motivational interviewing
NCPIC: National Cannabis Prevention and Information Centre
RCT: randomized controlled trial
SCU: standard cannabis units
SDS: Severity of Dependence Scale
TFBM: timeline follow-back method
UNSW: University of New South Wales

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Original Paper

Cost-Effectiveness of a New Internet-Based Monitoring Tool for Neonatal Post-Discharge Home Care

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Abstract

Background: The application of information and communication technologies in nursing care is becoming more widespread, but few applications have been reported in neonatal care. A close monitoring of newborns within the first weeks of life is crucial to evaluating correct feeding, growth, and health status. Conventional hospital-based postdischarge monitoring could be improved in terms of costs and clinical effectiveness by using a telemedicine approach.

Objective: To evaluate the cost-effectiveness of a new Internet-based system for monitoring low-risk newborns after discharge compared to the standard hospital-based follow-up, with specific attention to prevention of emergency department (ED) visits in the first month of life.

Methods: We performed a retrospective cohort study of two low-risk newborn patient groups. One group, born between January 1, 2011, and June 30, 2011, received the standard hospital-based follow-up visit within 48 hours after discharge. After implementing an Internet-based monitoring system, another group, born between July 19, 2011, and January 19, 2012, received their follow-up with this system.

Results: A total of 18 (15.8%) out of 114 newborns who received the standard hospital-based follow-up had an ED visit in the first month of life compared with 5 (5.6%; $P=.026$) out of 90 infants who were monitored by the Internet-based system. The cost of the hospital-based follow-up was 182.1€ per patient, compared with 86.1€ for the Internet-based follow-up.

Conclusion: Our Internet-based monitoring approach proved to be both more effective and less costly than the conventional hospital-based follow-up, particularly through reducing subsequent ED visits.

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KEYWORDS

Telemedicine; telenursing; Internet; neonatology; cost-effectiveness

Introduction

The economic policies of Western countries are increasingly pushing toward reductions in health care costs, especially

through the avoidance of unplanned hospital-based services. In this context, telemedicine is progressively becoming more widely used as a valuable technique for delivering nursing care, particularly in a patient's home, due to its capacity to provide

efficient, long-distance service. Besides reducing the costs and problems related to patients' need to travel to health facilities, telemedicine enhances patients' involvement in their own care and reinforces the nurse-patient relationship [1].

One nursing care area in which telemedicine applications are still little seen is neonatology. Monitoring newborns in the first weeks of life is critical for assessing adequate feeding and weight gain and identifying alterations such as hyperbilirubinemia [2]. Since postpartum hospitalization has been gradually shortening in length over the past years, there is more chance of newborns' parents/caregivers failing to recognize conditions requiring intervention, such as jaundice, dehydration, cardiac lesions, and serious infections [3-5]. Moreover, shorter hospital stays leave less time for the parental education and training that traditionally follow a baby's birth [2]. This problem may be aggravated by an inconsistent or poorly scheduled follow-up after hospital discharge. In fact, some recent data suggest that postdischarge care for newborns may actually have worsened [6,7]. One major consequence of this is unplanned use of health care services, including emergency department (ED) visits and hospital readmissions.

Therefore, it would be of great use to have a support tool that would provide a continuum of care during the first weeks of a newborn's life after going home [8]. Such a tool would facilitate contact and information-sharing between parents and specialized nurses, thereby enhancing parents' confidence and their involvement in their baby's care [9,10]. It would also be cost-effective, as it would relieve the pressure on the health care system caused by unplanned hospital-based care.

The aim of this study was to implement and evaluate an innovative postdischarge monitoring strategy for newborn patients involving a new Internet-based support system. This telemedicine tool (called "Babies at home") includes a web application that provides educational information about neonatal care to new parents, as well as baby monitoring via a questionnaire that parents fill in periodically and an email service that offers easy communication between parents and nurses.

To assess the effectiveness and financial viability of this new neonatal telemedicine service, a cost-effectiveness analysis was carried out by comparing this tool with the traditional hospital-based postdischarge follow-up. We hypothesized that an Internet-based support system for monitoring newborn patients after discharge from nursery would improve care, be well accepted by parents, and reduce unplanned health care, particularly ED visits.

Methods

The "Babies at home" web monitoring system (see [Figure 1](#) and [Multimedia Appendix 1](#) for translation to English) was designed, put into clinical service, and evaluated in a collaborative study involving the Neonatal Care Department of the Hospital de la Santa Creu i Sant Pau (HSP) of Barcelona and the Biophysics and Bioengineering Unit of the University of Barcelona. It has been in clinical use since July 2011 [11].

Figure 1. "Babies at home" home page screenshot.

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Petits a casa

Inici Consells per cuidar el nadó Enllaços útils Seguiment on line del nadó Qui som

Enhorabona pares, i gràcies per la vostra visita a "Petits a casa"!

Com a pares, i nosaltres com a professionals de la salut, sabem que el més important és la salut dels vostres fills.

Des de la Unitat Neonatal de l'Hospital de la Santa Creu i Sant Pau hem elaborat una pàgina on els bebès són els protagonistes i on trobareu consells, enllaços i respostes a les preguntes més freqüents relacionades amb la cura del nadó.

Feu servir el menú per navegar per les diferents seccions del lloc web.

Projecte desenvolupat amb la col·laboració de la Unitat de Biofísica i Bioenginyeria, Facultat de Medicina

UNIVERSITAT DE BARCELONA

Petits a casa - Hospital de Sant Pau - Barcelona 2011 - [Avis legal](#)

Study Population

We conducted a retrospective cohort study on newborn patients born between January 1, 2011, and January 19, 2012, in the HSP delivery rooms. Patients included in the study were consecutive low-risk newborns, specifically (1) late preterm newborns, born between 35 and 37 weeks of gestation, (2) babies weighing between 2200g and 2500g, (3) babies weighing between 2500g and 3000g who were the first children and received only breastfeeding, (4) babies weighing over 3000g who were the first children and/or received only breastfeeding and suffered a weight reduction of over 7% after birth, and (5) babies whose home was more than 40 km away from the hospital. Parents who were unable to communicate in written Spanish or Catalan or had no Internet access at home were excluded from the study.

Our study was based on a before/after design, which included one group of patients from before the implementation of the Internet-based follow-up and another from afterward. One group of babies (control group), born between January 1 and June 30, 2011, received the standard hospital postdischarge follow-up, which consisted of a hospital visit within 48 hours of the newborn's discharge. The other group (intervention group), born between July 19, 2011, and January 19, 2012, was monitored by the new Internet-based tool.

Internet-Based Monitoring System "Babies at home"

We developed the Internet-based monitoring tool "Babies at home" as a dynamic server-side website based on PHP language and MySQL database on a Linux/Apache server. All the development phases, from the structural design to the content formulation, evolved in close collaboration with the medical/nursing staff. The application comprises three main areas:

1. Free-access Area: open platform where all parents can find extensive high-quality information about baby care and useful links to breastfeeding and neonatal nursing association websites (see [Multimedia Appendix 2](#)).
2. Parents' Area: restricted area where only registered parents can access after authentication (see [Multimedia Appendix 3](#)). They are asked to answer twice a week a questionnaire from the neonatal nurses about the baby's conditions (weight, feeding, sleeping, body temperature, skin color, etc.), thereby covering the essential topics that nurses usually assess during hospital visits. All data are sent to a MySQL relational database stored in the secure environment of the hospital server. Parents have visual feedback of their baby's weight trend, plotted and continuously updated on the basis of the answers on the periodic questionnaires. Another important feature is the option of exchanging email messages with the nurses, making it possible to raise doubts and answer questions about baby care.
3. Staff Area: by logging in, neonatal nurses and pediatricians can access their special area, where they can monitor parents' answers to the questionnaires retrieved from the database, shown in dynamic Flash charts (see [Multimedia Appendix 4](#)). After evaluating the baby's data, nurses can write a message directly from the website to the parents to provide advice and comments about the newborn's care.

Once the patients' eligibility was established, the parents of the children participating in the study signed an informed consent form including a privacy protection statement, which was written with the endorsement of the hospital regulatory department. Before leaving the hospital, the latter were taught how to use the website and supplied with appropriate information, both general and specific, about baby care and also reassured about their capacity and commitment to take care of their baby at home. The neonatal nursing staff was in charge of both this initial training and the monitoring of the baby, undertaken by periodically checking parents' answers to the online questionnaire. In the event of any discrepancy in any parameter, nurses were able to contact the family by email or phone to check the newborn's conditions and address any possible problems in a suitable manner. Parents were also able to directly contact the nursing staff by email to ask questions and clarify any doubts about neonatal care. The baby's condition continued to be monitored until they achieved an appropriate weight and condition. At the end of the monitoring period, the parents were kindly invited to answer a final online survey to assess their level of satisfaction with the web service (see [Multimedia Appendix 5](#)). The survey consisted of 9 statements about the usefulness of the website contents and functions, and the possible answers were distributed on a Likert scale from 0 ("I strongly disagree") to 5 ("I strongly agree").

Outcomes

The main goal of our evaluation study was to assess the effectiveness of the new postdischarge Internet-based monitoring tool, which was evaluated in terms of the ED service used by the study population in the first month after discharge, before and after the implementation of the Internet-based follow-up. To this end, the parents were asked to preferentially use the ED of our hospital if an emergency visit was required and to report any visit to another ED. Accordingly, we performed a cost-effectiveness analysis from a social perspective. Our main outcome measures were (1) the follow-up cost per patient, (2) the rate of newborns who did not require an ED visit in the first month after birth, either because they did not need it or because the nursing support received via the Internet-based monitoring allowed them to avoid it, and (3) the incremental cost-effectiveness ratio (ICER) of the Internet-based follow-up compared to usual care. Another outcome of interest was the rate of ED visits. The ICER is commonly used in health economics and is a standard measure for cost-effectiveness analysis [12]. It represents a measure of the additional cost per unit of health gain, which in our case is one ED visit required by a newborn within the first month of life. The ICER is computed as follows: $ICER = (C_{IF} - C_{HF}) / (E_{IF} - E_{HF})$, where C_{IF} is the cost of the Internet-based follow-up strategy, C_{HF} is the cost of the hospital-based follow-up strategy, E_{IF} is the effectiveness of the Internet-based follow-up strategy and E_{HF} is the effectiveness of the hospital-based follow-up strategy. The effectiveness values were measured in terms of the avoidance of hospital-based care services.

Cost Measurements

We considered both direct and indirect costs for the cost-effectiveness analysis ([Table 1](#)). Immaterial costs were not

taken into account. Direct health costs were associated with the use of health care resources and were classified as ED visits, hospital visits, and nursing personnel costs related to the web monitoring. Information about the costs of ED and hospital visits and the nurses' hourly salary were provided by the administrative department of the hospital (which participates in the Catalanian Public Health Service). The average time taken to train newborns' families before leaving the hospital (10 minutes per family) and to perform the monitoring with the Internet-based tool (5 minutes per baby per day) was determined through interviews with the nursing staff in charge of it. Direct nonhealth costs corresponded to the travel expenses incurred by newborns' families to go to the hospital for ED or hospital visits. We also took into account indirect costs, such as opportunity costs related to parents' missed work time due to

those visits. We considered that just one parent came to the hospital with the child. The most frequent transportation mode for parents to come to the hospital for a visit (in the city center) was by car or taxi. Average transport costs were estimated, considering that the study population lived within the Barcelona district. These travel costs were calculated as an average between the taxi fare paid by a family living near the hospital (5-10€ approximately) and one paid ride from the city surroundings (45-50€ approximately). The cost of work time missed by the parents due to ED or hospital visits was calculated considering the average annual wage in Spain [13] and a regular weekly work time of 40 hours. We estimated an average of 3 hours lost for an ambulatory visit and 5 hours for an ED visit, considering the total sum of waiting, visit, and travel times.

Table 1. Direct and indirect costs included in the analysis (cost sources and ranges considered in the study are indicated).

	Cost, €	Range, %	Source
Direct Health Costs			
ED visit	127.2	±75	HSP
Hospital visit	85.4	±75	HSP
Nurse's hourly salary	33.0	±75	HSP
Direct Nonhealth Costs			
Transport to hospital	30.0	±75	Assumption
Indirect Costs			
Missed work hour	15.0	±75	Assumption

Statistical Analysis

Comparison of ED visit rates between patients who were monitored by the Internet-based system and those who received the standard hospital-based follow-up was made using Fisher's exact test.

Results

Study Groups

From January 1, 2011, to January 19, 2012, 931 newborns were discharged from the HSP nursery. Of these, 230 met the criteria to be included in the study. The study population was divided into two groups: (1) the postdischarge follow-up for 114 newborns consisted of a hospital visit within the 48 hours after discharge from January 1 to June 31, 2011 (control group), and (2) for 116 infants this was performed using the Internet-based system "Babies at home" from July 19, 2011, to January 19, 2012 (intervention group). Out of 116 families included in the

program, 90 (77.6%) participated actively until the end of their newborns' monitoring period and they were considered for the study. While each newborn from the control group received the standard hospital-based follow-up, in the intervention group, 32 infants needed a hospital visit due to neonatal or maternal pathology or because the nursing staff in charge of the Internet-based monitoring considered it appropriate.

Internet-Based Monitoring System and Parents' Satisfaction

Nursing staff received 382 answers to the online questionnaire (an average of 4.7 answers per patient) and 90 email consultations from parents (an average of 1 email per patient). Forty-eight percent of parents (N=43) answered the final satisfaction survey. Globally, they professed to be generally satisfied with the web service, showing a level of agreement of 4.3 ± 0.9 (mean \pm SD) to the first satisfaction survey statement, equivalent to an overall positive evaluation of the helpfulness of the "Babies at home" website (Table 2).

Table 2. Results of patients' satisfaction survey (mean \pm SD) where 0 means "I strongly disagree" and 5 means "I strongly agree".

Survey statement	Answer (mean \pm SD)
1. In general the Web service "Babies at home" was helpful.	4.3 \pm 0.9
2. The available information helped me take care of the baby.	4.3 \pm 0.8
3. The information available on the website could clarify my doubts.	4.1 \pm 0.9
4. The email service with nurses available on the website was useful.	4.6 \pm 0.9
5. The files and recommended links were useful.	4.0 \pm 1.0
6. The nurse's answers to my questions were useful.	4.7 \pm 0.9
7. The use of the website avoided visits to the primary care center.	31 (yes) – 72%
8. The use of the website avoided visits to the emergency department.	16 (yes) – 37%
9. I would recommend this website.	41 (yes) – 95%

ED Visits

According to the instructions given to parents, our ED was the only one visited during the study. Eighteen (15.8%) of the 114 newborns who received the standard hospital-based follow-up returned to the hospital's ED in the first month after birth compared with 5 (5.6%) of the group monitored by the Internet-based tool ($P=.026$).

Cost-Effectiveness Analysis

Considering the first month after discharge, 94.4% of the patients who received the Internet-based follow-up had no ED visits, compared with 84.2% of the control group patients. Our analysis revealed that the cost of the Internet-based follow-up per patient was 86.1€ while the hospital-based follow-up cost per patient was 182.1€ (Table 3). Therefore, the Internet-based follow-up strategy is said to be dominant because it is both less costly and more effective. The ICER of the Internet-based follow-up strategy compared with the standard hospital visit was -941.2€ which implies that society will save 941.2€ for every additional infant who does not have an ED visit in the first month of life.

The programming costs of the Internet-based tool corresponded to 1.5 person/month, ie, 7,500€ in a programmer's salary, including all taxes. Since the hospital already had the required computer and communication equipment, including a secure server, we only considered the cost of the programmer's salary for the tool development. With a savings of 96.0€ per patient follow-up, the Internet-based tool programming recovered its cost after 79 patients' follow-up—a figure that was attained within 6 months of the implementation of the new monitoring strategy.

One-way sensitivity analyses for ED visit cost, hospital visit cost, nurses' hourly salary, cost of families travelling to hospital and parents' missed work time revealed, within a plausible range of selection ($\pm 75\%$), that the Internet-based follow-up was still superior to the standard hospital-based follow-up. The tornado diagram in Figure 2 shows the impact of each cost parameters on ICER.

Varying the cost values simultaneously in two different cost scenarios, the Internet-based strategy was still dominant in comparison to the standard one (Table 4).

Table 3. Costs per infant and ICER of Internet-based follow-up for prevention of ED visits in the first month of life.

Strategy	Cost	Incremental cost	Effectiveness	Incremental effective- ness	ICER
Internet-based follow-up	86.1€	96.0€	0.944	-0.102	-941.2€
Hospital Visit	182.1€		0.842		

Figure 2. Tornado diagram showing the impact of cost parameters on ICER.

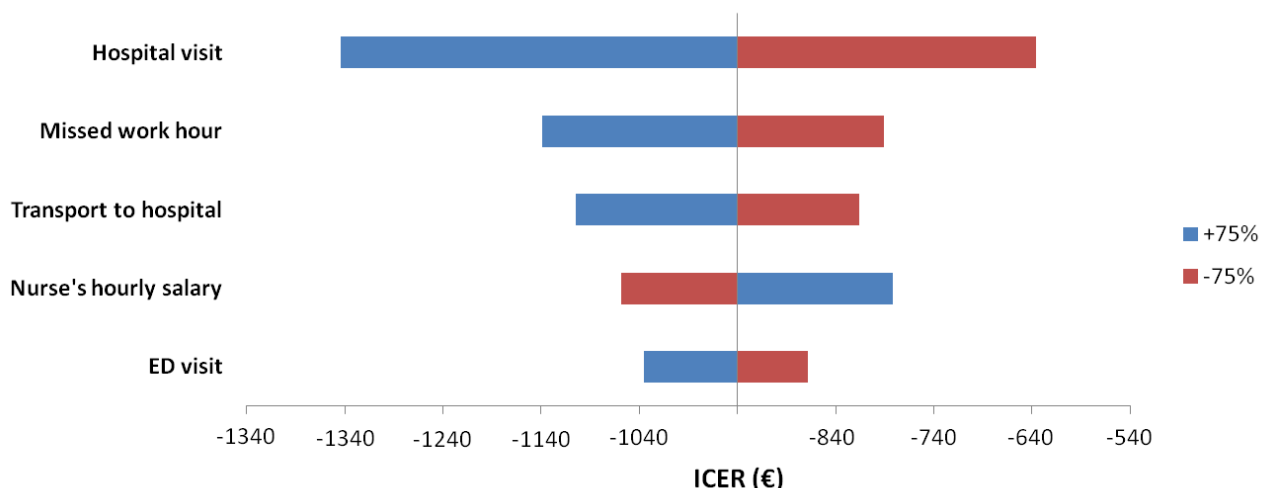


Table 4. Sensitivity analyses for two additional cost scenarios.

Costs (€)	Scenario +75%	Base case	Scenario -75%
Hospital visit	149.5	85.4	37.4
Missed work hour	26.3	15.0	6.6
Transport to hospital	52.5	30.0	13.1
Nurse's hourly salary	57.8	33.0	14.4
ED visit cost	222.6	127.2	55.7
Cost per patient	150.7-318.6	88.1-182.1	37.7-79.7
ICER	-1646.3	-941.2	-411.6

Discussion

Main Results

To our knowledge, this study is the first financial viability assessment of a telemedicine intervention in the neonatal postdischarge home care field. The results of the cost-effectiveness assessment provide support to the introduction of telemedicine services into routine clinical practice [14]. Specifically, the use of an Internet-based follow-up system to monitor low-risk newborns in the first month of life is both less costly and more effective than the usual hospital-based follow-up. This new monitoring approach resulted in a significant reduction in the subsequent use of hospital-based resources, such as ED visits, after discharge and a high level of parental satisfaction with the service. This reduction in ED visits can be considered not only a clear cost reduction for the health care provider but also an improvement in the newborn's clinical outcome after early discharge [15].

Besides providing high-quality educational contents about neonatal care to parents, "Babies at home" offers nursing staff a valuable and easy procedure for the home monitoring of newborns, as well as fast long-distance communication with families. An interactive website is a very convenient method, due to the wide availability of Internet-connected devices among health care consumers, especially in the homes of young families. Moreover, since usability and structural simplicity

were crucial to the development of the application, the training required by nurses and parents is minimal. Concerns about security and data confidentiality have been minimized, as this application was easily incorporated into the secure environment of the hospital server, in compliance with all the applicable legal regulations.

Other Outcomes

Our analysis focused on assessing the clinical effectiveness of our Internet-based monitoring approach during the first month of the newborn's life. Extending the assessed period to 2 months after birth, which is considered a postnatal phase, we found that 29 infants (25.4%) who received the standard hospital-based follow-up had an ED visit, compared with 7 (7.8%) of those monitored by the new Internet-based system ($P=.0014$). Since the Internet-based monitoring period was generally no longer than 1 month, we may conclude that our approach also had a positive impact on families' education and empowerment with respect to their babies' daily care and that this translated into a more pronounced decrease in the use of the ED.

Furthermore, this enhancement of parental education also had a positive effect on the continuance of breastfeeding, which is essential for babies' health and growth [16]. It has been widely demonstrated that the breastfeeding rate generally decreases by 10-20% within the first month of a baby's discharge [17,18]. Remarkably, the mothers included in the "Babies at home" program maintained the same breastfeeding rate after 1 month

as at discharge (60%), with no reduction at all. This success in avoiding a decrease in breastfeeding could be attributed both to the access the mothers had to the informative and educational items available on the website and to the fluid contact with nurses during the monitoring period.

Comparison With Previous Studies

In the last decade, the telemedicine concept has been expanded to nursing care because of its capacity to provide efficient long-distance health care. Most nurses recognize the contribution that information and communication technology, particularly the Internet, can make to both their practice and patients' understanding of their own health and care [19]. There are several examples of telenursing applications in the literature. Internet-based tools for chronic disease management, such as dyspnea in COPD patients [20], for educational intervention, such as Web-assisted tobacco control [21], or to support nurse-led triaging [22], are recent examples of successful telenursing applications using the Web.

In the neonatal care field, several telemedicine applications have been previously developed, particularly to bring real-time diagnoses to neonatal facilities without in-house trained specialists. These include the remote evaluation of digital images for retinopathy in prematurity screening [23,24], interventions for deaf or hard-of-hearing infants [25], the long-distance interpretation of echocardiograms [26], and neonatal teleconsultations in general [27].

Nevertheless, very few researchers have developed Internet-based tools for supporting families in the care of their newborns during the first days of life. One study described a program in which nurses provided updates to family members of Neonatal Intensive Care Unit (NICU) patients on the Internet [28]. The authors reported significant improvements in family satisfaction with NICU in the in-patient care of babies with very low birth weights and pointed out the need to extend this service to the postdischarge period. In another study, parents viewed real-time video images of their hospitalized newborns via an Internet browser or 3G cell phone [29]. Although no significant impact was found in terms of newborns' length of hospital stay, this virtual visiting was well accepted by families, suggesting the advisability of evaluating its role in improving postdischarge transition care.

Other Potential Clinical Applications

Thanks to its simplicity and versatility, our Internet-based neonatal monitoring system could be easily adapted to a wider range of application. First, its application could be useful in developing countries, where remote and poor places need simple and cheap technological interventions to give access to beneficial health services to those most in need [30]. Also, our tool could be effectively integrated into programs of neonatal postdischarge home assistance, which provide in-home support from clinical nursing specialists after infants' discharge [31] but are hampered by clinical and geographical constraints that render this service inaccessible to many families that could

otherwise benefit from it. An Internet-based monitoring tool could effectively overcome such limitations and give more families access to such programs.

Limitations

This was a retrospective study. Our Internet-based follow-up system was implemented as a possibly more efficient and cheaper monitoring strategy. The markedly improved efficiency of our new system was evident right from the start. Treating some patients with an efficient system, while randomizing others to an inefficient system, precluded any randomized controlled trial. Moreover, it was logistically impossible within the hospital guidelines and policies to run both postdischarge systems simultaneously.

It should be pointed out that the control and intervention groups were analyzed in two different periods of the year. However, the rate of ED visits should have not been affected by any seasonal bias taking into account that each of the two time windows (January-July and August-January) shared the same number of winter months. Actually, the main season-related causes of ED visits and hospitalizations in infants up to 1-month old are viral infections, such as respiratory syncytial and flu [32], which exhibit a well-known incidence distributed through the winter months [33].

One advantage of our study was the use of real data of clinical costs and effectiveness in terms of ED use. It is worth noting that, although these cost values were measured for a public university hospital in a big Spanish city, Barcelona, the positive results obtained in this study could easily be translated to other public or private health systems providing postnatal care, taking into account the results of the sensitivity analyses confirming the cost-effectiveness of the new telemedicine strategy in different cost scenarios.

Future Directions

"Babies at home" can be gradually expanded and optimized. To facilitate the assessment of some clinical parameters, such as a newborn's skin color, navel care, and correct breastfeeding, the web tool can be incorporated into a parent-nurse videoconference communication system. Also, the tool can be completely integrated into the hospital EHR system, so that the nursing staff in charge of web monitoring can easily access the patient's record, which would be automatically updated with the main clinical events and issues assessed during the telemonitoring.

Conclusion

Using the rate of ED visits and the costs for society, the cost of the Internet-based follow-up was shown to be much lower than that of the conventional hospital-based follow-up. Additionally, ED visits in the first month of patients' life decreased with the use of the Internet-based monitoring system. This telemedicine follow-up strategy proved absolute dominance (both more clinically effective and less costly) over the standard follow-up based on hospital visits.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Translation for "Babies at home" home page screenshot.

[[PDF File \(Adobe PDF File\), 329KB - jmir_v15i2e38_app1.pdf](#)]

Multimedia Appendix 2

Translation for "Tips for baby care" page in the free access area of "Babies at home" website.

[[PDF File \(Adobe PDF File\), 203KB - jmir_v15i2e38_app2.pdf](#)]

Multimedia Appendix 3

Translation for "Parents' area" access page screenshot.

[[PDF File \(Adobe PDF File\), 182KB - jmir_v15i2e38_app3.pdf](#)]

Multimedia Appendix 4

Translation for "Visualization of some of the parents' answers to the periodic questionnaire by dynamic Flash charts".

[[PDF File \(Adobe PDF File\), 379KB - jmir_v15i2e38_app4.pdf](#)]

Multimedia Appendix 5

Translation of Final online satisfaction survey.

[[PDF File \(Adobe PDF File\), 573KB - jmir_v15i2e38_app5.pdf](#)]

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Abbreviations

- ED:** emergency department
HSP: Hospital de la Santa Creu i Sant Pau
ICER: incremental cost-effectiveness ratio
NICU: Neonatal Intensive Care Unit

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Review

A Systematic Review of Web-Based Interventions for Patient Empowerment and Physical Activity in Chronic Diseases: Relevance for Cancer Survivors

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Abstract

Background: Patient empowerment reflects the ability of patients to positively influence their health and health behavior such as physical activity. While interactive Web-based interventions are increasingly used in various chronic disease settings to enhance empowerment and physical activity, such interventions are still uncommon for cancer survivors.

Objective: The objective of this study was to systematically review the literature regarding interactive Web-based interventions. We focused on interventions aimed at increasing patient empowerment and physical activity for various chronic conditions, and explored their possible relevance for cancer survivors.

Methods: Searches were performed in PubMed, Embase, and Scopus to identify peer-reviewed papers reporting on randomized controlled trials that studied the effects of Web-based interventions. These interventions were developed for adults with diabetes, cardiovascular disease, chronic obstructive pulmonary disease, heart failure, or cancer. Intervention characteristics, effects on patient empowerment and physical activity, information on barriers to and facilitators of intervention use, users' experiences, and methodological quality were assessed. Results were summarized in a qualitative way. We used the recommendations of the Institute of Medicine (IOM) regarding cancer survivorship care to explore the relevance of the interventions for cancer survivors.

Results: We included 19 papers reporting on trials with 18 unique studies. Significant, positive effects on patient empowerment were reported by 4 studies and 2 studies reported positive effects on physical activity. The remaining studies yielded mixed results or no significant group differences in these outcomes (ie, no change or improvement for all groups). Although the content, duration, and frequency of interventions varied considerably across studies, commonly used elements included education, self-monitoring, feedback/tailored information, self-management training, personal exercise program, and communication (eg, chat, email) with either health care providers or patients. Limited information was found on barriers, facilitators, and users' experiences. Methodological quality varied, with 13 studies being of moderate quality. The reported Web-based intervention elements appeared to be highly relevant to address the specific needs of cancer survivors as indicated by the IOM.

Conclusions: We identified 7 common elements of interactive, Web-based interventions in chronic disease settings that could possibly be translated into eHealth recommendations for cancer survivors. While further work is needed to determine optimal intervention characteristics, the work performed in other chronic disease settings provides a basis for the design of an interactive eHealth approach to improve patient empowerment and physical activity in cancer survivors. This may subsequently improve their health status and quality of life and reduce their need for supportive care.

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KEYWORDS

systematic review; Internet intervention; chronic disease; patient empowerment; physical activity; cancer survivor

Introduction

Due to improvements in cancer screening and treatment, the number of people living with cancer or that have been successfully treated for cancer is increasing rapidly [1]. Those people are often referred to as cancer survivors, and in the Netherlands this population is expected to increase from 419,000 in 2009 to 660,000 in 2020 [2]. Cancer survivors are increasingly approached as individuals with a chronic disease, with either on-going or intermittent impact on their health status and quality of life. Therefore, many of them need supportive and rehabilitative services to alleviate side effects of treatment and to cope with psychosocial problems such as fear of disease recurrence or with physical health problems such as a painful arm after breast cancer surgery. Furthermore, these services can be used for health promotion [3,4]. To minimize the time and costs involved with the need for such supportive care services in response to the raising number of cancer survivors, it may be useful to enhance patient empowerment.

Patient empowerment can contribute to control over patients' health and health behavior. It is frequently described as having knowledge about one's health, and being able and motivated to influence one's health [5]. It refers to well-informed patients taking responsibility for their own health, to as great an extent as possible, and the expected benefits of improved quality of life [6]. It is expected that increasing patient empowerment will result in a reduced need for support from the health care system, thus lowering health care costs [7,8].

Another factor that positively contributes to quality of life is physical activity. A number of studies have demonstrated many beneficial effects of physical activity on physical and psychosocial well-being, both during and after cancer treatment [9-11]. This suggests that empowering cancer survivors and enabling them to become or stay physically active is very likely to be beneficial for both the patients and the society.

A promising medium for facilitating patient empowerment and physical activity is the Internet. Easily accessible, up-to-date, and tailored information can be provided, often in an interactive way. For example, patients could be asked to provide information or pose questions via a questionnaire to trigger either standardized or tailored feedback from the health care system (given automatically or by a health care provider). The Internet is increasingly used for the delivery of these interactive interventions, both for healthy individuals [12] and those with chronic conditions [13]. For cancer survivors, other eHealth initiatives do exist, such as online support groups, online patient education programs [14,15], informative tools for decision support, and various mobile apps that could be used independent of provider activities. However, there are very few interactive websites that aim to empower cancer survivors, especially in the area of physical activity. Previously, researchers have reviewed Web-based interventions that aimed to increase either patient empowerment or physical activity level, with promising results [13,16]. These reviews included studies that were focused

primarily on healthy individuals (in some cases sedentary or overweight, [16]) or at increasing patient empowerment, but not physical activity levels, of individuals with chronic diseases [13]. In view of the increasing number of cancer survivors and the potential role that interactive Web-based interventions could play in stimulating empowerment and physical activity, it is important to learn from empirical evidence about the efficacy of such interventions in chronic diseases. Considering the comparable chronic nature of these diseases and cancer survivorship, it is plausible that interventions that contribute to managing chronic diseases other than cancer contain elements that are appropriate for cancer survivors as well.

This systematic review has 5 aims: (1) to describe the characteristics (content, length, frequency, duration) of interactive, Web-based interventions in diabetes, chronic obstructive pulmonary disease (COPD), (congestive) heart failure, cardiovascular disease, and cancer, (2) to summarize the effects of these interventions on patient empowerment and physical activity, (3) to identify barriers for and facilitators of the use of Web-based interventions and to describe users' experiences with such websites, (4) to assess the methodological quality of the studies reviewed, and (5) to evaluate the possible relevance of these interventions for cancer survivors.

Methods

Search Strategy

We searched the literature in PubMed, Embase, and Scopus. The main search strategy combined four concepts: patient empowerment, physical activity, information technology (IT), and type of chronic disease. For each concept, several search terms were used (see [Multimedia Appendix 1](#)). Because we also wanted to identify IT that focussed on either physical activity or patient empowerment, we also searched PubMed for the combination of patient empowerment, IT, and type of chronic disease, and separately for the combination of physical activity, IT, and type of chronic disease. As these searches resulted in many duplicates, this dual search strategy was not repeated in Embase or Scopus. To retrieve other relevant publications, we examined the reference lists of the selected publications and reviews that were excluded based on eligibility criteria.

Eligibility Criteria

We used the following inclusion criteria: (1) peer reviewed studies in English describing a randomized controlled trial (RCT), published between 1990 and November 20, 2012, (2) participants were adults and suffered from at least one of the following chronic diseases—cancer, diabetes, heart failure, cardiovascular disease, or COPD, (3) the intervention was Web-based and interactive, (4) the intervention group was compared to a similar patient group (receiving another intervention or usual care), and (5) the study included at least one outcome measure assessing patient empowerment and/or physical activity. For patient empowerment, relevant, related outcomes included self-efficacy, self-management, self-care

behavior, and self-control. For physical activity, relevant outcomes could be based on self-report (eg, by questionnaire or interview), performance tests, or observation (eg, accelerometer data).

Selection Method

The first author applied the eligibility criteria to the titles and abstracts. When the abstract was considered relevant or in case of ambiguity, two authors reviewed the full publication independently. In cases of disagreement, consensus was sought through discussion. When disagreement persisted, the judgement of a third reviewer was decisive.

Data Extraction

The following information was extracted from each publication: study characteristics (source and year of publication, country of origin, aim, and sample size), patient characteristics (type of disease, age, gender, comorbidities, computer experience, and Internet use), intervention characteristics (content, duration, frequency, compliance, and dropout rate), outcome measures (instruments used, and effects on patient empowerment and physical activity), information about barriers to and facilitators of intervention use, and users' reported experiences with the intervention. The first author independently extracted the data, and the second author checked the data extraction for 20% of the studies to determine inter-rater reliability. This was established by calculating the percentage of agreement. Consensus was reached by discussion. Due to the diversity of outcome measures, sample size, and intervention characteristics, it was not possible to conduct a formal meta-analysis.

Quality Assessment

The methodological quality of the studies was evaluated, but did not serve as an eligibility criterion. We used a list that was an adapted version of the Cochrane Collaboration Back Review Group [17], which was used previously in a systematic review of Internet-based physical activity interventions by van den Berg and co-workers. These authors modified the Cochrane list to better suit the type of studies they examined. For example, the Cochrane list contained the item "description of and acceptable dropout rate", which was changed into "description of dropout rate plus comparison of dropouts with completers". In addition, they deleted some items because they were not relevant for Web-based interventions [16]. For our review, one

additional change was made. "Long-term follow-up measurement" was defined as an outcome assessment more than 3 months after the post-intervention measurement. The final list of criteria included 13 items relating to the selection of patients, the intervention, outcome measurements, and statistics. The complete list can be found in Table 3, in which the outcomes of the methodological quality assessment are shown.

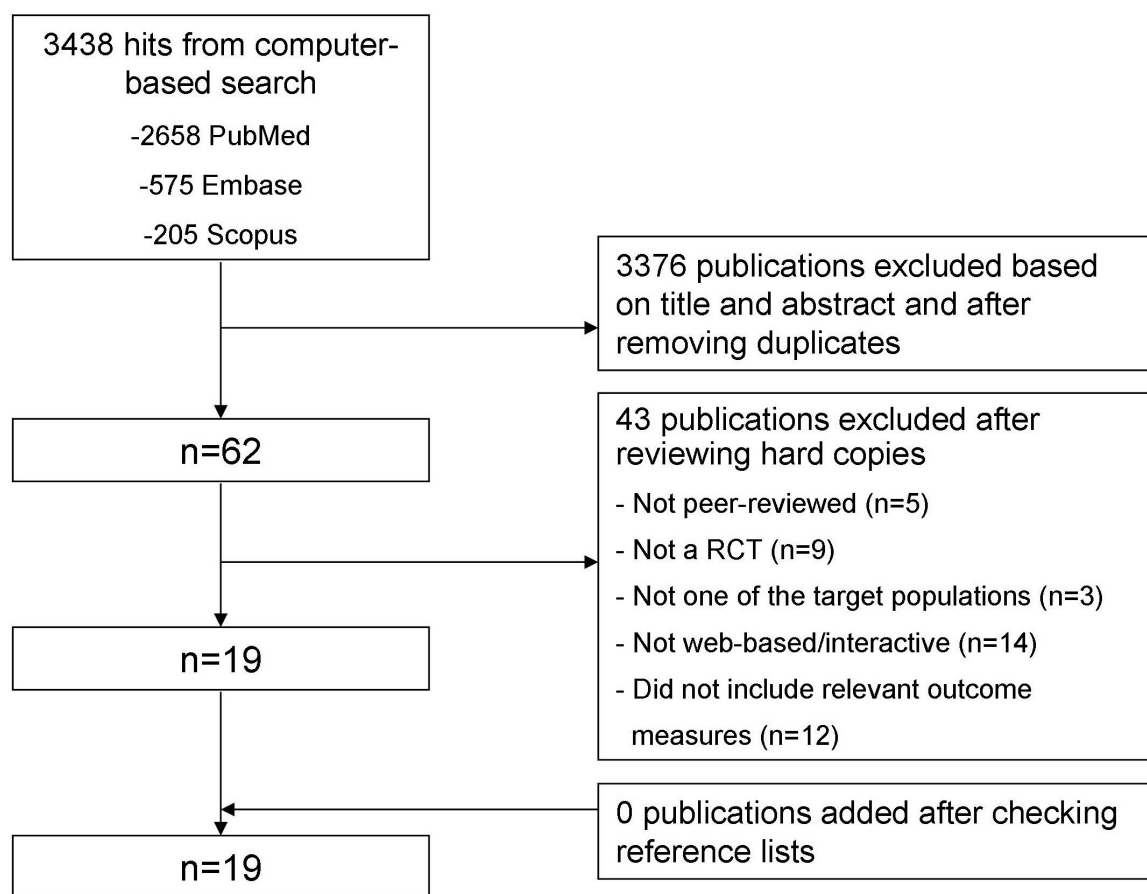
For each study, all criteria were scored with yes, no, or unclear, resulting in a maximum quality score of 13. In line with other researchers [16], we considered studies obtaining at least two-thirds of the total score (ie, ≥ 9 points) to be of high quality. Studies scoring 5 to 8 points were rated as moderate quality, and studies scoring lower than 5 points were rated as low quality. Quality assessment was performed by the first author, while the second author assessed the quality of a random sample of 4 studies. The inter-rater reliability was calculated as percentage of agreement on 52 aspects (4x13 criteria). Disagreements between researchers were discussed to reach consensus.

Evaluation of Potential Relevance for Cancer Survivors

To evaluate the relevance of the selected interventions for cancer survivors, we used the 5 factors included as characteristics of cancer survivorship identified by the Institute of Medicine (IOM): surveillance, management of late effects, rehabilitation, psychosocial support, and health promotion [4]. We evaluated whether the interventions reviewed could be mapped onto these 5 features of cancer survivorship care.

Selection of Publications

The initial search yielded 3438 hits. Based on titles and abstracts, 62 publications were selected. The full text of these 62 publications were reviewed, resulting in a selection of 19 publications that met all eligibility criteria [18-36]. A review of the reference lists of these publications, as well as the reference lists of the excluded reviews did not result in any additional studies. See Figure 1 for a flow chart of the selection process. For the cancer setting, we found 46 papers that met several of our inclusion criteria, but not all. Reasons for exclusion were diverse, varying from not being an RCT (eg, design papers or non-randomized pilot studies) to inappropriate outcome measures or not being Web-based and/or interactive (eg, a CD-ROM).

Figure 1. Flow chart of the search process.

Data Extraction

Reviewers' ratings were in agreement for 89.5% (68/76) of the data extraction elements from the sample. This can be considered as a high level of agreement according to the guidelines of Landis and Koch [37], and justified the decision to have only one of the authors carry out the data extraction for the remaining studies.

Study Characteristics

All papers were published in year 2000 or later, with most being published after 2005. The 19 publications described 18 unique studies; two papers by Glasgow et al described the same study at different assessment time-points (4 and 12 months, [21,22]). Twelve studies were conducted in the United States. The remaining studies took place in Canada (n=2), Korea (n=1), Norway (n=2), and Australia (together with the United States, n=1). Sample sizes at baseline varied between 15 and 1665. In the majority of RCTs, one group was exposed to a Web-based intervention and was compared to control group with usual care (n=7), an information only condition (n=2), an observational control group (n=1), a face-to-face intervention (n=1), both a print material intervention and usual care (n=1), or both a face-to-face intervention and an information only condition (n=1). In two RCTs, two intervention groups were compared with either control group with usual care or enhanced usual

care. In one RCT, two groups receiving a Web-based intervention were compared with an information only condition. Finally, in two RCTs, two intervention groups were compared. Those groups received the same basic intervention, but with a different focus (high vs low self-efficacy and lifestyle goals versus structured goals).

Patient Characteristics

Studies included patients with diabetes (n=11), heart failure (n=3), COPD (n=1), cardiovascular disease (n=1), cancer (n=1), and mixed patient groups (heart disease, lung disease, type 2 diabetes; n=1). The overall mean age of the participants was 60 years (SD 8.5 years, range 40-76 years). For the 18 studies that reported on gender, the median percentage of women was 53.1% (range 6.0%-73.3%). Individuals with comorbid conditions were excluded in 7 studies, and 6 studies provided information about comorbidity (eg, mean number of comorbid conditions). Only 6 studies collected information on participants' prior experience with computers and/or Internet use. Both computer experience and Internet use were assessed with a variety of self-reported questionnaire items, ranging from times per week to years of experience, making it difficult to compare across studies.

Intervention Characteristics

Intervention characteristics for both intervention and control groups are described in Table 1. The degree of detail provided

about the interventions varied greatly across studies. There was large variation in the duration, frequency, and content of the interventions. Duration varied between 1 month and 1 year (mean 23 weeks, SD 19 weeks). The intended frequency or intensity of the interventions was not clearly described in the majority of the papers. In some papers, a schedule for intervention use was proposed [23,25,36], whereas in other papers only information about actual use was reported (eg, number of logins, percentage of individuals that used the different intervention elements).

Although the content of the interventions differed, 7 key elements used in the majority of the interventions were identified, including interventions that had significant effects and those that did not. These elements were used in different combinations and were adapted to the specific patient population. The first element was *education*, which included information about various aspects of the chronic health condition such as medication, nutrition, exercise, coping, and symptom management, provided via electronic newsletters, pamphlets, slides, or a digital library with articles. The second element, *self-monitoring*, involved uploading or registration of data such as blood glucose levels, blood pressure, medication use, food intake, and exercise behavior. In the study of Nguyen and colleagues for example, individuals had to submit real-time information about dyspnea, cough, and sputum via their computer or smart phone [29]. This was often followed by the third element, *feedback/tailored information*. Based on the uploaded data, patients received individual feedback, which included individually tailored exercise advice, or a graphical overview of blood glucose levels for example. Other forms of tailored information included access to the medical record, medication reminders, and tips for overcoming personal exercise barriers. Fourth, interventions could include *self-management training*, involving lessons about the management of symptoms, psychosocial aspects, and fatigue. An important aspect of self-management training was goal setting. The fifth element, found only in interventions involving physical activity, was a *personalized exercise program* that was adapted on the basis of self-reported and/or objective physical activity data obtained before and during the intervention. The exercise programs took the individual's needs, preferences, and possibilities into account. In the study of McKay and co-workers for example, patients went through a 5-step process to select their personal motivators, goals, preferred activities and schedule, and to identify their personal barriers [27]. Elements 6 and 7 both involved *communication, either with health care providers or with fellow patients*, respectively, using communication routes like email, live chat, videoconferences, and discussion boards (forums). Communication with health care providers was often used for questions, encouragement, and emotional support, whereas communication with fellow patients was included to share experiences, exchange information, and provide support. Additionally, elements that were used in only some studies were an educational quiz and periodic reminders for website use.

The overall percentage of dropouts varied between 0.0% and 52.3% (median 17.5%). For the intervention groups (including the control groups that also received a Web-based program) the median dropout rate was 19.7% and for the control groups this was 14.0%. Compliance with the intended intervention varied between 36.6% and 96.0% for the 9 studies that reported on it. The remaining studies did not report compliance, but described aspects of website use, such as number of logins, percentage of people using a certain feature, minutes per session, or percentage of tasks completed. Intervention use varied greatly between studies and participants. All studies that monitored website use found a decline during the intervention period. There was no obvious relationship between dropout rates, compliance, and website use on the one hand, and patient and intervention characteristics on the other hand.

Outcome Measures

Table 2 presents patient empowerment and physical activity outcomes and dropout rates. A range of outcome measures was used (eg, different self-efficacy scales, diverse measures of different forms of physical activity).

A total of 13 studies included one or more patient empowerment measures. In 4 studies, patient empowerment increased significantly ($P<.05$) in the intervention group compared to usual care or observation [19,25,34,36], while in 3 studies this increase was reported for both groups [18,22,28] (ie, both the Web-based intervention group and the comparison group improved irrespective of receiving a Web-based, a face-to-face intervention or usual care). In the study of Nguyen et al for example, both the individuals receiving the Web-based intervention and those having personal contact improved on a measure of self-efficacy [28]. Two studies yielded mixed results, with 1 of 2 outcome measures showing a significant increase [24,35]. For example, Wangberg et al measured both self-efficacy and self-care behavior, but observed improvement only in the latter. The remaining 4 studies did not observe a significant change in patient empowerment [26,29,31,32] for either the intervention group or the usual care group.

Of the 14 studies that assessed physical activity, 2 reported significant improvement ($P<.05$) for the intervention group compared to usual care [33,36] (eg, an increase in the number of individuals who exercised regularly or in physical activity behavior). Increases in physical activity were found for both groups in 6 studies [21-23,27,28,30]. For instance, McKay et al compared their Web-based group with an information only approach. Both groups improved their moderate/vigorous exercise behavior as well as their walking performance. Three studies [24,26,29] found mixed results, with one of their outcome measures being non-significant and the others showing a significant increase. For example, Lorig et al found no change in aerobic exercise behavior but did observe an increase in stretch/strength exercise [26]. Finally, 3 studies did not find any effects on physical activity [18,20,25].

Table 1. Intervention characteristics.

Study	Patient group (sample size)	Study design	Intervention	Follow-up period
Artinian et al (2007)	Congestive heart failure (n=18)	Pilot RCT with an intervention group and a comparison group receiving usual care	Home care monitoring system: - pamphlet with education about self-care behavior - medication reminders - questions & response - registration of pill taking	3 months
Bond et al (2010)	Diabetes (n=62)	RCT with an intervention group and a comparison group receiving usual care	Focus on self-management and psychosocial well-being: - usual care - instructions (about issues regarding disease management) - interaction with study nurse - uploading data & receiving feedback - online educational discussion group - peer support via email and instant messaging	6 months
Glasgow et al (2003)	Type 2 diabetes (n=320)	RCT with 3 intervention groups and an Internet information only comparison group (library with articles, automated dietary goal setting, online assessments)	Aspects of information only and: (1) Tailored self-management training: - online professional suggesting tailored strategies - question and answer with dietician - blood glucose upload and dietary databases plus graphical feedback (2) Peer support: - exchange of information, coping strategies, and emotional support on a forum - live chat - 5 electronic newsletters (3) both 1 and 2	10 months
Glasgow et al (2010, 2011)	Type 2 diabetes (n=463)	RCT with 2 intervention groups and an enhanced usual care comparison group (health risk appraisal feedback, recommendations of preventive care behavior)	Self-management program with: (1) Minimal support: - goal selection - progress recording - feedback - community resources - quiz questions - motivational tips - periodic prompting (2) Moderate support: - aspects of minimal support - follow-up calls - invitation for a group visit with other participants	4 months and 12 months, respectively

Study	Patient group (sample size)	Study design	Intervention	Follow-up period
Kim & Kang (2006)	Type 2 diabetes (n=73)	RCT with an intervention group, a print-material comparison group (booklets with tailored exercise strategies), and a comparison group receiving usual care	Physical activity (PA) intervention: <ul style="list-style-type: none"> - general information - assessment tools for physical and psychological readiness for exercise - stage-based individual information about goal setting and exercise planning - question and answer board - interactive and animated features - exercise test (in the lab), followed by an individualized physical activity prescription 	12 weeks
Liebreich et al (2009)	Type 2 diabetes (n=49)	RCT with an intervention group and a comparison group receiving usual care	Website and counselling: <ul style="list-style-type: none"> - link to clinical practice guidelines for physical activity - interactive features (physical activity logbook, forum, email counselling) - education/tips - weekly topic (eg, goal setting, time management) 	12 weeks
Lorig et al (2006)	Heart & lung disease, type 2 diabetes (n=958)	RCT with an intervention group and a comparison group receiving usual care	Self-management program and usual care: <ul style="list-style-type: none"> - individual exercise program - management of symptoms, fatigue, emotions, problems - motivational email reminders - overview of medications - interaction with moderator - action planning - feedback 	12 months
Lorig et al (2010)	Type 2 diabetes (n=761)	RCT with 2 intervention groups (only difference was email support; analyzed together) and a comparison group receiving usual care	Self-management program: <ul style="list-style-type: none"> - 6 weekly sessions with different topics - bulletin board - exercise logs and monitoring tools - communication with facilitators 	18 months
McKay et al (2001)	Type 2 diabetes (n=78)	RCT with an intervention group and an information only comparison group (library articles, glucose tracking plus feedback)	PA intervention: <ul style="list-style-type: none"> - feedback on baseline activity levels - personalized PA program and PA database - personal coach counselling and support - communication with other intervention participants 	8 weeks
Nguyen et al (2008)	COPD (n=50)	RCT with an intervention group and a face-to-face intervention comparison group (same intervention components)	Self-management program: <ul style="list-style-type: none"> - education and skills training - tailored exercise planning - self-monitoring of symptoms and exercise - personalized feedback 	6 months

Study	Patient group (sample size)	Study design	Intervention	Follow-up period
Nguyen et al (2012)	COPD (n=125)	RCT with an intervention group, a face-to-face intervention group and a general health education comparison group (home visit, monthly face-to-face education sessions, phone calls with health information)	Self-management program (same components for online and face-to-face group): <ul style="list-style-type: none"> - dyspnea and exercise consultation at home (once) - individualized exercise plan - self-monitoring and reinforcement - education - skills training - peer interactions 	12 months
Richardson et al (2007)	Type 2 diabetes (n=35)	Pilot RCT with 2 intervention groups (with a focus on either lifestyle goals or structured goals)	Pedometer-based walking program with a focus on: <ol style="list-style-type: none"> (1) Lifestyle goals (targeting accumulated steps) <ul style="list-style-type: none"> - access to a personally-tailored Stepping Up to Health Web page - tailored motivational messages - tips about managing diabetes - automatically calculated goals (based on pedometer results) - feedback about performance toward goals (2) Structured goals (only targeting steps taken during bouts of at least 10 minutes with at least 60 steps per minute): <ul style="list-style-type: none"> - intervention see (1) 	6 weeks
Ross et al (2004)	Congestive heart failure (n=107)	RCT with an intervention group and a comparison group receiving usual care	Secure Web-interface to 3 features, and reminders for system use: <ul style="list-style-type: none"> - medical record - educational guide - messaging system 	12 months
Ruland et al (2012)	Breast and prostate cancer (n=325)	RCT with an intervention group and an information only comparison group	Self-management program: <ul style="list-style-type: none"> - self-monitoring plus tailored self-management support - information - communication with other patients and expert nurses - diary for personal notes 	12 months
Tomita et al (2009)	Heart failure (n=40)	RCT with an intervention group and a comparison group receiving usual care	Self-management program in addition to usual care: <ul style="list-style-type: none"> - informational support - recording vital signs and exercise - appraisal support (feedback) - emotional support 	12 months
Trief et al (2007)	Diabetes (n=1665)	RCT with an intervention group and a comparison group receiving usual care	Telemedicine case management: <ul style="list-style-type: none"> - access to educational materials - upload data on blood glucose and blood pressure readings - videoconference with a nurse case manager and dietician (to educate patients, facilitate goal setting/self-management, and discuss concerns) 	12 months

Study	Patient group (sample size)	Study design	Intervention	Follow-up period
Wangberg (2008)	Type 2 diabetes (n=60)	RCT with 2 intervention groups (with a focus on either high or low self-efficacy)	Self-care intervention tailored to either high or low self-efficacy: <ul style="list-style-type: none">- behavior exercises (including monitoring and graphic feedback)- information- quizzes with feedback- videos of peers- videos of lectures from health personnel	1 month
Zutz et al (2007)	Cardiovascular disease (n=15)	Pilot RCT with an intervention group and an observational control comparison group (no contact with either the research staff or the hospital)	Cardiac rehabilitation program: <ul style="list-style-type: none">- chat sessions with health care professionals- education sessions (slides)- monitoring of blood and exercise- group chat sessions	12 weeks

Table 2. Intervention outcomes and dropout rates.

Study	Patient empowerment outcome measure ^c	Patient empowerment outcomes ^{a,c}	Physical activity outcome measure ^c	Physical activity outcomes ^{a,c}	Dropout rate (overall)
Artinian et al (2007)	Revised Heart Failure Self-Care Behavior Scale	Self-care + ($P=.02$) ^e	6 Minutes Walking Test (6MWT)	Exercise performance - ($P=.42$)	0.0%
Bond et al (2010)	Diabetes Empowerment Scale	Self-efficacy + ($P<.05$) ^{b,e}	X	X	0.0%
Glasgow et al (2003)	X	X	Physical Activity Scale for the Elderly	Physical activity - ($P=.41$)	18.0%
Glasgow et al (2010)	Diabetes Self-Efficacy scale	Self-efficacy 4 months	Community Health Activities Model Program for Seniors Questionnaire	Caloric expenditure in physical activity	4 months 17.5%
Glasgow et al (2011)		X 12 months + ($P<.10$) ^{b, f}		4 months: + ($P=.04$) ^d 12 months: + ($P<.05$) ^{b,d}	12 months 22.7%
Kim & Kang (2006)	X	X	Self-report instrument adapted from the 7-day physical activity questionnaire (frequency, duration, intensity)	Metabolic equivalents (MET) x hours/week + ($P<.001$) ^d	0.0%
Liebreich et al (2009)	Likert scale (1-5); 12 items	Self-efficacy - ($P=.31$)	Godin Leisure-Time Exercise Questionnaire (GLTEQ)	MET minutes + ($P=.04$) ^d	10.3%
	Likert scale (1-5); 4 items	Behaviour capacity + ($P=.001$) ^d	GLTEQ	Unweighted minutes + ($P=.01$) ^d	
			Incorporated in GLTEQ (times/week, average time per session)	Resistance training - ($P=.06$)	
Lorig et al (2006)	Likert scale (1-10)	Self-efficacy - ($P=.06$)	Scale (0-4) measuring minutes of exercise per week	Stretch/strength exercise + ($P=.02$) ^d	18.8%
				Aerobic exercise - ($P=.70$)	
Lorig et al (2010)	Patient Activation Measure	Patient activation + ($P=.01$) ^d	A physical activities scale (minutes/week)	Aerobic exercise - ($P>.05$) ^b	15.8%
	Diabetes Self-Efficacy scale	Self-efficacy + ($P=.02$) ^d			
McKay et al (2001)	X	X	Behavioural Risk Factor Surveillance System	Moderate/vigorous exercise + ($P<.001$) ^e	12.7%
				Walking + ($P<.001$) ^e	
Nguyen et al (2008)	Single question on a 0- to 10- point response scale	Self-efficacy + ($P=.02$) ^e	Self-report (frequency & duration)	Endurance exercise + ($P=.001$) ^f	24.0%
				Strength exercise + ($P<.001$) ^f	
			List of 5 descriptions	Stages of change + ($P=.05$) ^f	
			6MWT	Exercise performance + ($P=.05$) ^d	
Nguyen et al (2012)	Single question on a 0- to 10- point response scale	Self-efficacy - ($P=.06$)	6MWT	Exercise performance + ($P<.001$) ^e	12.0%
			Incremental treadmill test	Exercise performance - ($P>.05$) ^b	

Study	Patient empowerment outcome measure ^c	Patient empowerment outcomes ^{a,c}	Physical activity outcome measure ^c	Physical activity outcomes ^{a,c}	Dropout rate (overall)
			Lifting a wooden dowel	Arm endurance + ($P=.04$) ^f	
			Self-report (frequency & duration)	Endurance duration + ($P=.04$) ^f Endurance frequency + ($P=.001$) ^e Strengthening frequency + ($P<.001$) ^f	
Richardson et al (2007)	X	X	Pedometer (Omron HJ-720IT)	Total steps + ($P=.003$) ^d Bout steps + ($P<.001$) ^d	14.0%
Ross et al (2004)	Kansas City Cardiomyopathy Questionnaire (self-efficacy domain)	Self-efficacy - ($P=0.08$)	X	X	24.0%
Ruland et al (2012)	Cancer Behavior Inventory version 2.0	Self-efficacy - ($P=.26$)	X	X	24.6%
Tomita et al (2009)	X	X	Self-reported frequency of exercise; participants exercising 2-3 times/week or more were seen as exercisers	Number of exercisers + ($P=.001$) ^d	19.8%
Trief et al (2007)	Diabetes Self-Efficacy scale	Self-efficacy + ($P<.001$) ^d	X	X	52.3%
Wangberg (2008)	Perceived Competence Scales Summary of Diabetes Self-Care Activities measure	Self-efficacy - ($P=.17$) Self-care behavior + ($P=.026$) ^d	X	X	45.9%
Zutz et al (2007)	Likert scoring	Self-efficacy (exercise-specific) + ($P<.05$) ^{b,d}	Minnesota Leisure Time Physical Activity Questionnaire Symptom-limited treadmill exercise stress test	Physical activity + ($P<.05$) ^{b,d} Exercise capacity + ($P<.05$) ^{b,d}	6.7%

^a+ is a positive effect; - is no effect

^bThe researchers did not provide specific *P* values.

^cX=not applicable

^dPositive effect for the Web-based intervention group(s) only

^ePositive effect for all groups (including usual care)

^fPositive effect for the Web-based intervention group(s) and other intervention groups

Barriers for and Facilitators of Intervention Use and Reported Users' Experiences

Five studies reported on perceived barriers, whereas no studies reported on perceived facilitators of the use of interactive, Web-based interventions. Perceived barriers were typically of a technical nature, including problems with Internet connection, slow loading of website, security concerns, discomfort with using the computer or Internet, and problems with related hardware (eg, PDA, monitor). Ten studies described some users' experiences, for example, satisfaction scores and a judgment of intervention content. In general, patient satisfaction was high.

The personalized nature of the interventions was often cited by participants as being important. In one study [31], nurses and physicians reported that their workload did not increase as a result of the intervention.

Methodological Quality

The concordance between reviewers in rating the methodological quality for the sample of papers evaluated was high (90.3% (47/52), [37]). For this reason, the first researcher independently performed the quality assessment for the remainder of the studies. The two papers of Glasgow that described the same study were judged together for methodological quality. Table

3 shows that 3 of 18 studies [21,22,28,29] obtained a score of 9 or higher, indicating good methodological quality. Two studies were of low quality [24,31] and the remaining studies were of moderate quality, with most studies scoring a 5 or 6. All studies specified eligibility criteria and employed a comparable timing of outcome assessment for the different groups. The majority of the studies reported dropout rates, including a comparison between completers and non-completers, and gave point estimates together with measures of variability. Only a minority of studies (maximum n=7) provided information about the

method of randomization, described their intervention explicitly, performed a power calculation and used an intention-to-treat approach to the data analysis. Most studies were unclear about concealing treatment allocation and blinding of the outcome assessor. In one study, groups were not similar at baseline, and for one study this was not clear. Only 2 studies described a long-term follow-up measurement. Because 12 out of 18 studies were of moderate quality, it was not possible to determine whether differences in outcomes were related to methodological quality.

Table 3. Methodological quality assessment. ^{a,b}

	1	2	3	4	5	6	7	8	9	10	11	12	13	Total score ^d
Artinian et al (2007)	√	X	?	√	X	√	?	√ ^c	X	√	X	X	√	6
Bond et al (2010)	√	X	?	√	X	X	√	√ ^c	X	√	√	X	√	7
Glasgow et al (2003)	√	X	?	√	X	X	?	√	X	√	√	X	√	5
Glasgow et al (2010, 2011)	√	√	?	√	√	√	?	√	X	√	√	√	√	10
Kim & Kang (2006)	√	X	?	√	X	X	?	√ ^c	X	√	X	X	√	5
Liebreich et al (2009)	√	X	?	X	X	√	?	X	X	√	X	X	√	4
Lorig et al (2006)	√	X	?	√	√	X	?	√	√	√	X	√	√	8
Lorig et al (2010)	√	√	?	√	X	X	?	√	√	√	X	√	√	8
McKay et al (2001)	√	√	?	√	X	X	?	√	X	√	X	X	√	6
Nguyen et al (2008)	√	√	√	√	√	√	√	√	X	√	X	√	√	11
Nguyen et al (2012)	√	X	X	√	√	√	√	√	X	√	√	√	√	10
Richardson et al (2007)	√	X	?	?	√	√	?	X	X	√	X	X	√	5
Ross et al (2004)	√	√	?	√	X	X	?	X	X	√	X	X	X	4
Ruland et al (2012)	√	√	?	√	X	√	?	X	X	√	√	√	√	8
Tomita et al (2009)	√	X	?	√	√	√	?	X	X	√	√	√	X	7
Trief et al (2007)	√	X	?	√	X	X	√	√	X	√	X	√	X	6
Wangberg (2008)	√	X	?	√	X	X	?	√	X	√	√	X	√	6
Zutz et al (2007)	√	X	?	√	√	√	?	X	X	√	X	X	√	6

^a1=specification of eligibility criteria; 2=method of randomization explained; 3=treatment allocation concealed; 4=groups similar at baseline; 5=explicit description of interventions; 6=description of compliance; 7=outcome assessor blinded; 8=description of dropout and comparison with completers; 9=long-term follow-up (> 3 months after post-intervention assessment); 10=timing of outcome assessment comparable; 11=sample size described with power calculation; 12=intention-to-treat analysis; 13=point estimates and measures of variability

^b√=reported item; X=unreported item; ?=unclear item

^cDropout rate was 0%

^dMaximum score was 13

Evaluation of Potential Relevance for Cancer Survivors

Our judgement of the relevance of the intervention elements for the cancer survivorship setting was based on their *Web-based* application (as opposed to their usefulness, in general). [Table 4](#) (the more cancer-related recommendations) and [Table 5](#) (the more health-related recommendations) show how these intervention elements could be mapped onto the recommendations for survivorship care as described by the IOM [4]. Five intervention elements contributed to all

recommendations, and two elements (personal exercise program and communication with fellow patients) would only be inappropriate for long-term follow-up/surveillance. The specific content of each element when adapted to the oncology setting depended on the recommendation for which it was used. For example, information provision will differ for surveillance versus healthy lifestyle recommendations. Similarly, a personal exercise plan for rehabilitation after surgery differs from an exercise plan that aims to enhance general physical activity levels.

Table 4. Proposed application of intervention elements that could enhance cancer survivorship care based on findings from this review (cancer-related recommendations).

Elements of Web-based intervention	Recommendations for survivorship care	
	Long-term follow-up/surveillance	Management of (late) effects
Education	Information about reasons for surveillance	Information about possible late effects of cancer treatment
Self-monitoring	Recommendations for self-screening Reporting results of self-screening	Upload of relevant vital signs (eg, pain scores, blood values)
Feedback/Tailored information	A personal follow-up schedule with frequency and type of screening	Advice for managing (late) effects as identified by self-monitoring data
Self-management training	Feedback on reported self-screening Training aimed at performing regular self-screening	Training to learn to cope with late effects of cancer treatment
Personal exercise program	X	Individual exercise advice to prevent or reduce (late) effects, taking into account a survivor's specific needs and preferences
Communication with health care provider	Possibility to ask questions about follow-up and self-screening	Possibility to ask questions about symptoms and how to deal with them
Communication with fellow patients	X	Share experiences and tips about managing (late) effects

^aX=application not relevant

Table 5. Proposed application of intervention elements that could enhance cancer survivorship care based on findings from this review (health-related recommendations).

Elements of Web-based intervention	Recommendations for survivorship care		
	Rehabilitation	Psychosocial support	Health promotion
Education	Information about the importance of and possibilities for rehabilitation	Information about possible psychosocial problems and possibilities to solve them	Information about the importance of and ways to obtain a healthy lifestyle (eg, physical activity, nutrition, smoking cessation)
Self-monitoring	Upload of relevant vital signs (eg, blood pressure, lung function) or exercise behavior (either self-reported or objective)	Questionnaire(s) measuring psychosocial aspects	Upload of relevant data such as food intake and exercise behavior
Feedback/Tailored information	Rehabilitation advice based on self-monitoring data	Advice for dealing with psychosocial problems as identified with questionnaires; following the stepped care principle	Health advice based on uploaded data; following the stepped care principle
Self-management training	Training to learn to sustain doing rehabilitation exercises	Training aimed at coping with psychosocial problems like anger, fear or frustration	Training aimed at obtaining and sustaining a healthy lifestyle
Personal exercise program	Individual exercise advice aimed at rehabilitation, taking into account a survivor's specific needs and preferences	Individual exercise advice, taking into account a survivor's specific needs and preferences	Individual exercise advice, taking into account a survivor's specific needs and preferences
Communication with health care provider	Possibility to ask questions about rehabilitation	Possibility to ask questions about psychosocial problems; receiving support	Possibility to ask questions about exercise advice
Communication with fellow patients	Share experiences and tips about rehabilitation	Share experiences and tips about dealing with psychosocial problems Provide support	Share experiences and tips about health behavior Provide support

Discussion

Principal Findings

In this paper we have systematically reviewed the empirical literature on Web-based interventions for people with diabetes, COPD, heart failure, cardiovascular disease, and cancer, and have evaluated their potential relevance for cancer survivors. Nineteen publications covering 18 unique studies were included in this review. The RCTs varied greatly in content, duration, and frequency. Significant, positive effects on patient empowerment were found in 4 studies and 2 studies reported positive effects on physical activity. The remaining studies reported mixed results or no significant differences between intervention and comparison groups (ie, either both groups or neither group improved) on these outcomes. The information we could obtain about barriers and facilitators for intervention use and users' experiences was limited. Nevertheless, we identified 7 elements that were common for the majority of interventions: education, self-monitoring, feedback/tailored information, self-management training, personal exercise program, and communication (with either health care providers or fellow patients). We were able to map these elements onto eHealth features for the recommendations for survivorship care of the IOM.

The 7 common intervention elements were used in different combinations and were adapted to the specific patient population. It is therefore not possible to make a judgment about the individual contribution of these elements to intervention outcomes. Future studies should be more structured, in order to determine the role of individual intervention elements and should also take the duration and frequency of interventions into account. In most studies no intervention schedule was prescribed. Rather, the intensity, frequency, and duration of website use were determined by the participants themselves. In contrast, structured rehabilitation programs usually have schedules to which patients are expected to adhere (eg, performing moderate intensity physical activity (running or cycling) for 30 minutes, 3 times a week, during a 12-week period). It is debatable whether Web-based interventions should or should not have a structured program, but it is conceivable that a certain combination of duration and frequency is optimal for achieving improved patient empowerment and physical activity. A recent review of Web-based interventions for type 2 diabetes [38] indicated that interventions of longer duration (more than 12 weeks) resulted in better outcomes, and it is likely that the same is valid for cancer survivors. However, future studies need to confirm this.

The relative importance and value of intervention elements, duration, and frequency on outcomes is not yet clear. Other factors may also have played a role in the large variation in patient empowerment and physical activity outcomes observed in the studies reviewed. These include the different measurement tools that were used within and between studies, different sample sizes and different periods between the start of the intervention and the post-intervention measurement. To facilitate future meta-analyses, new investigations should preferably use uniform outcome measures and time intervals for the outcome

assessment. The need for a uniform measure of patient empowerment was also pointed out in a paper that discussed the role of assessing patient empowerment in health care evaluation [39].

Another issue to be considered is that, in the majority of studies where no significant differences between groups were observed, significant, positive effects were found for all groups. In many of these studies, the comparison group(s) received an intervention as well. This may have limited the possibility of detecting an effect in favour of the Web-based interventions. More generally, it is becoming increasingly difficult to establish appropriate control groups, because the usual care situation is evolving rapidly. Although previous studies have shown that effects on knowledge and behavior change were higher for individuals using a Web-based intervention than for individuals using a non-Web-based intervention [40], more work is needed to determine whether this also applies to cancer survivors.

It would have been useful if the RCTs reviewed had provided more information on barriers and facilitators for intervention use. Insight into these factors is very important, because Web-based interventions are often characterised by high dropout rates [41]. Dropout can refer to patients being lost to follow-up or to patients not using the intervention. Bennett and Glasgow indicated that an important reason for dropout is loss of interest [42]. Furthermore, 2 literature reviews showed that peer support, counsellor support, email and phone contact, frequent website updates, record keeping, and individualized feedback were related to sustained intervention use (and conversely, to less dropout, [43,44]). Most of these components were present in the studies included in the current review. The mean percentage of dropouts in the Web-based intervention groups of the studies reviewed was 19.7%, which is comparable to the dropout rate found in another review (21.0%, [40]). More research on program adherence is needed. Or, in other words, it should be determined "what works and why" [44].

The assessment of the methodological quality of the studies reviewed suggests a number of areas in which there is room for improvement. Future RCTs in the field of Web-based interventions could be improved by clearly describing the method of randomization, concealment of treatment allocation, and an adequate description of sample size calculation. Additionally, researchers should preferably describe explicitly their intervention(s), including specific information about intervention elements, length, frequency, and duration. Studies should carry out the statistical analysis on an intention-to-treat basis (as opposed to only analyzing the participants who completed the intervention). This is important because participants who complete an intervention may differ from those who do not, as a result of which intervention effects may be over- or underestimated. Because it is often the goal to not only enhance patient empowerment and facilitate a physically active lifestyle in the short-term, but to sustain these outcomes over a longer period of time, it is important that RCTs include not only immediate post-intervention outcome assessment, but also longer-term follow-up assessments.

Web-based interventions are being developed at a rapid pace. This is also true for Web-based interventions for cancer

survivors. In this review we identified only 1 paper in the cancer field that met our eligibility criteria. Recently, however, positive results of a Web-based intervention to reduce depression in cancer survivors [45], and of a Web-based, tailored education program to reduce cancer-related fatigue and anxiety [46] have been reported. Several additional RCT's of Web-based interventions for cancer patients and survivors are currently on-going [47]. It is likely that in several years there will be sufficient, mature studies to facilitate a formal meta-analysis to more precisely determine the effects of Web-based interventions for both chronic diseases and cancer, rather than the more qualitative review presented here.

Although we identified 7 elements of eHealth interventions that may be relevant for cancer survivors, based on the available evidence, we could not determine which of these elements are the most important and effective. It was also unclear which combinations of intervention elements would be optimal. However, the benefit of the educational element for cancer survivors was supported by a review, which showed that cancer survivors who received sufficient information reported a better quality of life [48]. An emerging approach in cancer survivorship that may encompass or incorporate many of the intervention elements described in the eHealth literature is the use of a survivorship care plan. Such a plan includes a summary of the individual patient's diagnosis and treatment, as well as recommendations for appropriate follow-up care [4]. Currently, survivorship care plans are typically provided on paper, and

consequently are quite static documents. There is no reason why they cannot be adapted for eHealth use, including interactive elements.

Conclusion

In conclusion, our review suggests that Web-based, interactive interventions have a beneficial effect on patient empowerment and/or physical activity in people with various chronic conditions. Program elements that were frequently observed included education, self-monitoring, feedback/tailored information, self-management training, personal exercise program, and communication (with either health care providers or fellow patients). Although the results of these studies did not necessarily differ from those of traditional interventions, it is likely that the elements increased patient centeredness and efficiency of the interventions. Empowered individuals who are physically active are likely to have a better health status and quality of life, therefore the use of interactive Internet interventions in this field would appear promising. Further research is needed to establish optimal intervention characteristics and specific effects in cancer survivor populations. Future studies should also identify perceived barriers for and facilitators of the use of Web-based interventions. The studies that have been conducted in other chronic diseases are likely to constitute a basis for the development of an interactive, Web-based intervention to effectively empower the rapidly growing number cancer survivors.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Search strategy in PubMed.

[[PDF File \(Adobe PDF File\), 28KB - jmir_v15i2e37_app1.pdf](#)]

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Abbreviations

- 6MWT:** 6 Minutes Walking Test
- COPD:** chronic obstructive pulmonary disease
- GLTEQ:** Godin Leisure-Time Exercise Questionnaire
- IOM:** Institute of Medicine
- IT:** information technology
- MET:** metabolic equivalents
- PA:** physical activity
- RCT:** randomized controlled trial

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Original Paper

Effects of Internet Popular Opinion Leaders (iPOL) Among Internet-Using Men Who Have Sex With Men

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Abstract

Background: The Internet has become a popular venue for facilitating sex networking for men who have sex with men (MSM).

Objective: The study aimed to evaluate the effectiveness of Internet popular opinion leaders (iPOL) in disseminating information about the human immunodeficiency virus (HIV), increasing the frequency of HIV testing, and reducing risky behaviors among MSM in Taiwan.

Methods: A quasi-experimental study with a nonequivalent control website for comparison was used to estimate the effectiveness of iPOL. A community-level intervention, iPOL, was conducted at the Facebook social networking website and at top1069 as a control. The iPOLs actively disseminated HIV-related information via the platform of Internet opinion leaders and AIDS information center, and discussed and responded to questions or replied to Internet-using MSM.

Results: A total of 369 iPOLs posted 432 articles and 503 replies to others, influencing 959,088 persons on Facebook. A total of 1037 MSM, 552 (53.23%) from an intervention website and 485 (46.76%) from a control website, participated in the follow-up study survey (response rate 96%). At the 6-month follow-up after the intervention was conducted, MSM who visited the intervention website were more likely to receive HIV-related information (25.49% versus 10.47%, $P<.001$), discuss HIV issues with others (41.88% versus 23.79%, $P<.001$), review articles about HIV (90.58% versus 79.73%, $P<.001$), and be asked about or discuss HIV-related questions (51.11% versus 31.78%, $P<.001$) than those on the control website. In addition, MSM were more likely to have HIV tests within 6 months (43.89% versus 22.31%, $P<.001$) and consistently use condoms during anal sex with online sex partners than those using the control website (34.15% versus 26.19%, $P=.004$).

Conclusions: The study showed the feasibility and effectiveness of the iPOL intervention as an online HIV prevention program. These findings underscore the importance of disseminating HIV information online, as well as the challenges inherent in the efforts of iPOL to reduce HIV-related risky behaviors among Internet-using MSM.

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KEYWORDS

Internet, intervention studies, HIV prevention, Homosexuality, Male

Introduction

Finding male sex partners through the Internet has been associated with human immunodeficiency virus (HIV) and syphilis outbreaks among men who have sex with men (MSM) who meet online [1,2]. The Internet has become a significant venue for meeting MSM, who then engage in risky behaviors associated with HIV and sexually transmitted infection (STI) transmission [3,4]. The Asia Internet MSM Sex Survey in Taiwan reported that 73.9% of MSM had had sex with partners found online and that having sex with online partners was associated with a history of STIs, recreational drug use, and an increasing number of sexual partners [5]. The Internet has become a popular meeting place for MSM; thus, effective and targeted prevention programs should be developed to minimize the HIV transmission risk in the Internet era [6].

Information and communications technology has the potential to improve the quality and efficiency in HIV/STI prevention. The social network site, Facebook, has gained enormous popularity throughout the world, has created a mechanism for acquainting support from friends with same diseases [7], and provides a promising medium to deliver HIV/STI prevention messages to Internet users [8]. Online social network usage and the topics discussed on these networks were associated with HIV knowledge and risky sexual behaviors, and testing for STIs among homeless adolescents [9]. Homeless youth who used social networking websites, such as MySpace and Facebook, to connect with family members online were less likely to practice exchanged sex and more likely to report a recent HIV test, whereas youth connected to street-based peers online were more likely to practice exchanged sex [10]. The UCLA Harnessing Online Peer Education (HOPE) study used Facebook to scale the community popular opinion leader (C-POL) model to increase HIV prevention among African American and Latino MSM [11]. The Just/Us study aims to engage youth of color in sexual health education delivered via Facebook [12]. However, the findings of a few intervention studies that used Facebook as a medium for HIV prevention have not been reported yet. Because social media plays a more prominent role in the delivery of HIV/STI prevention intervention, more Internet-based HIV prevention research is required, particularly with changing behaviors among populations at high risk of contracting HIV/AIDS.

The Internet popular opinion leaders (iPOL) intervention for HIV/STI prevention was first designed in 2010 on Facebook for online Chinese MSM communities. The iPOL intervention was adapted from the popular opinion leader (POL) model, developed by Kelly in 1986 [13] and based on the diffusion of innovation theory [14]. The POL model posits that behavioral change is achieved when new risk-reducing methods for HIV prevention are disseminated by opinion leaders through their personal and social networks [15]. POL uses ethnographic techniques to systematically identify popular and socially influential members of the target population, then recruits and trains these popular individuals in how to communicate HIV risk reduction endorsement messages to peers during everyday conversations, and works with them to sustain their HIV prevention advocacy activities [16].

Computer technology-based HIV prevention interventions have been effective in decreasing the frequency of sexual behavior, the number of partners, and incidences of sexually transmitted diseases with an efficacy similar to more traditional human-delivered interventions [17]. Different from previous 1-way technology-based HIV prevention interventions [17], the iPOL is one type of community-level intervention using the Web 2.0 2-way communication format on Facebook to deliver HIV prevention messages for Internet-using MSM. Social networking websites, such as Facebook, hold great potential in adapting the POL intervention model on the Internet to diffusing HIV-related information among Internet-using MSM. MSM with a high degree of opinion leadership in the iPOL intervention are identified within existing online social networks and then trained in persuasive techniques and prevention messages to shape the behavior of their affiliated online network members [18].

Social networks provide a promising mechanism to deliver HIV prevention messages among Internet-using MSM. The Internet provides a more convenient approach to allowing MSM to answer questions anonymously and, therefore, maintain their privacy [19]. This study is the first Internet-based HIV intervention study in Taiwan to determine the effectiveness of iPOL in disseminating HIV-related information, increasing the frequency of anonymous HIV testing, and reducing risky behaviors among Internet-using MSM.

Methods

Study Design

A quasi-experimental study with a nonequivalent control website for comparison was used to estimate the effectiveness of iPOL among the Internet-using MSM population. The iPOL intervention was conducted from April through September 2011 at the Facebook social networking website and the top1069 website as a comparison.

Recruitment and Consent Procedures

Participants were recruited exclusively through online methods, primarily through Web banners on the top1069 website and electronic direct mailers sent through a network of gay community coalition partners on Facebook. Informed consent was requested from all participants on the first page of the questionnaire, and only those participants who said they were at least 18 years old and had had sex with a man in the past 12 months were given access. Approval to conduct the study was obtained from the Human Subjects Division Committee of National Cheng Kung University Hospital.

A cross-sectional online survey was used to collect baseline data of HIV-related behaviors at the intervention and comparison websites from October to November 2010. After the iPOL intervention had been implemented for 6 months, the same online survey was conducted from October to November 2011. During the baseline survey period, 2042 participants entered the survey. Of the 1692 (82.85%) participants who completed the baseline online survey, 1008 provided valid information for further analysis. After the 6-month intervention, 1079 men completed the follow-up online survey, excluding those aged

less than 18 years (n=32) and transgender individuals (n=10). A total of 1037 MSM, 552 (53.23%) from the intervention website and 485 (46.76%) from the control website, participated in the follow-up study survey.

Internet Popular Opinion Leaders Intervention

An online ethnographic study was carried out in virtual MSM communities in Taiwan. A series of Internet searches were conducted from January through March 2010 using 3 standard search engines (Google, Yahoo, and Ping), querying for traditional Chinese translations of terms including gay, homosexuals, AIDS, HIV, HIV and sexually transmitted diseases, and other relevant search terms of interest. We identified each online virtual MSM community based on interaction between MSM online users, electronic contents and replies posted within the community, and HIV/AIDS-related information dissemination serving the needs of venue MSM members. The iPOLs were recruited and recommended by networks of gay community coalition partners. The recommended eligible iPOLs were assessed by 6 questions about their opinion leadership [20] on HIV/STI information in the previous 3 months, including how they talked to their friends about HIV/STIs, how they gave information on HIV/STIs to their friends, how many people they told about HIV/STIs, how

likely they were to be asked about HIV/STIs, and how they would respond to their friends about HIV/STIs. A total of 369 men with a high degree of opinion leadership were selected as iPOL.

The 369 iPOL were trained by HIV/STI experts in the fundamentals of HIV prevention, social marketing strategies for dissemination of innovative ideas, and strategies of risk reduction and behavior change during a 12-week period in 2010. The online iPOL platform built on Facebook (Figure 1) was used to scale-up the influence of iPOLs on HIV prevention among Internet-using MSM. The iPOL platform uses the Web 2.0 2-way communication format on Facebook in which the iPOLs share and exchange news, video clips, reports, and opinions, and have the capability to connect with others over the Internet for advice and support. During the iPOL intervention period from April through September 2011, 2-way conversations related to risky behaviors on the online iPOL platform were reviewed by iPOLs, discussed, and reinforced at subsequent iPOL training sessions through the end of 2011. By the end of 2011, there were approximately 432 posts (including film clips, news, videos, personal accounts, and discussions on risky behavior), 503 comments, and 804 likes on the iPOL platform, with an estimated 959,088 people viewing the posts on the iPOL platform.

Figure 1. Sample iPOL platform on Facebook in 2012.



Measures

The online survey included demographic information on sex, age, residency, ethnicity, employment, education (primary or no formal education, secondary, tertiary, professional qualification, university, and postgraduate degree), partnership status (never married, opposite sex marriage, same sex marriage

or civil partnership, divorced, separated, and widowed), and sexual orientation. Participants were first asked whether they had heard about iPOL or the AIDS information center, followed by a series of questions about experiences discussing HIV-related issues with online friends, reading HIV-related posts on the Internet, and having online friends talk to them about HIV-related issues. They were asked about their HIV test

history (date and result of the last test), recreational drug use, history of STIs, and sexual behavior in the previous 3 months, including sexual behavior with males and females, the number of male and female sexual partners, sexual behavior with online partners, condom use behavior, unprotected anal intercourse (UAI), and use of the Internet to look for sex.

Analysis

Statistical analyses were performed with SPSS version 17.0 for Windows software (SPSS Inc, Chicago, IL, USA). HIV information distribution, HIV testing behavior, and risky behaviors were the main intervention outcomes. Intervention effects were assessed 6 months after the intervention. Between-group differences for primary behavior outcomes among Internet-using MSM were measured using chi-square tests at the 6-month follow-up. Mixed-effects logistic regression analysis, controlling for the baseline, was used to examine changes in HIV information dissemination, HIV testing

behavior, and risky behaviors between the intervention and comparison websites.

Results

Characteristics of the Study Participants

A total of 1037 men were recruited online, 499 (48.12%) from the intervention website and 538 (51.88%) from the comparison website. Significant differences in demographic characteristics were found between the comparison and treatment groups (Table 1). These differences were in age (men in the comparison group were younger), partnership status (a greater percentage of men in the comparison group were single), and education (those in the intervention group had slightly more years of education). Behavioral characteristics between the men in the comparison and intervention websites were similar, except that men enrolled in the intervention website were more likely to use recreational drugs, been diagnosed with STIs, and be HIV positive than those in the comparison website.

Table 1. Comparison of demographic and health characteristics between participants in the comparison and intervention (iPOL on Facebook) groups (N=1037).

Demographic and health characteristics	Total ^a	Intervention ^a n=499	Comparison ^a n=538	P value
Age (years), mean (SD)	24.8 (6.2)	25.8 (6.3)	23.8 (5.9)	<.001
Residency, n (%)				
North	476 (45.90)	231 (46.29)	245 (45.53)	.007
Middle	179 (17.26)	67 (13.42)	112 (20.81)	
South	345 (33.26)	184 (36.87)	161 (29.92)	
East/Archipelagos	37 (3.56)	17 (3.40)	20 (3.71)	
Education level, n (%)				<.001
High school or less	15 (1.44)	5 (1.00)	10 (1.85)	
Some college	214 (20.63)	70 (14.02)	144 (26.76)	
College	656 (63.25)	324 (64.92)	331 (61.71)	
Postcollege	152 (14.65)	100 (20.04)	52 (9.66)	
Partnership status, n (%)				<.001
Single	601 (57.95)	246 (49.29)	355 (65.98)	
Married (opposite sex)	11 (1.06)	8 (1.60)	3 (0.55)	
Civil partnership (same sex)	388 (37.41)	228 (45.69)	160 (29.73)	
Steady sex partner	37 (3.56)	17 (3.40)	20 (3.71)	
Sexual behavior, n (%)				
Had sex with females in the previous 3 months	39 (3.76)	17 (3.40)	22 (4.08)	.63
Sought sex on the Internet in the previous 3 months	765 (73.77)	361 (72.34)	404 (75.09)	.32
Had online sex partners in the previous 3 months	543 (52.36)	245 (49.09)	298 (55.39)	.046
Consumed recreational drugs in the previous 3 months	206 (19.86)	121 (24.24)	85 (15.79)	.001
Diagnosed with STIs in the previous 3 months	59 (5.68)	40 (8.01)	19 (3.53)	.002
HIV positive	51 (4.91)	40 (8.01)	11 (2.04)	<.001

^a May not add to total because of missing responses.

Effects of Internet Popular Opinion Leaders on Dissemination of HIV-Related Information

The iPOL intervention had significant effects on the dissemination of HIV-related information (Table 2). We found there was no difference in HIV information distribution between the comparison and intervention groups at baseline. At the 6-month follow-up after controlling for baseline data,

participants that visited the intervention website were more likely to access HIV-related information from iPOL or the AIDS information center (25.49% versus 10.47%, $P<.001$), to discuss HIV-related issues with online friends (41.88% versus 23.79%, $P<.001$), to read HIV-related posts on the Internet (90.58% versus 79.73%, $P<.001$), and to have online friends talking about HIV-related issues (51.11% versus 31.78%, $P<.001$) than those in the comparison group.

Table 2. Intervention effects on HIV information distribution among Internet-using MSM.

Outcome variables	Baseline ^a , n (%) n=1008		Follow-up, n (%) n=1037		χ^2_1	P value
	Intervention ^b n=501	Comparison ^b n=507	Intervention ^b n=499	Comparison ^b n=538		
Ever heard about iPOL or the AIDS information center on Facebook?						
No	N/A	N/A	269 (74.51)	453 (89.52)	34.1	<.001
Yes	N/A	N/A	92 (25.49)	53 (10.47)		
Discussed HIV-related issues with online friends						
No	444 (88.62)	461 (90.92)	290 (58.11)	410 (76.20)	38.6	<.001
Yes	57 (11.37)	46 (9.07)	209 (41.88)	128 (23.79)		
Read HIV-related posts on the Internet						
No	413 (82.43)	431 (85.01)	47 (9.41)	109 (20.26)	23.8	<.001
Yes	88 (17.56)	76 (14.99)	452 (90.58)	429 (79.73)		
Online friends talked to you about HIV-related issues						
No	413 (82.43)	437 (86.19)	244 (48.89)	367 (68.22)	39.9	<.001
Yes	88 (17.57)	70 (13.81)	255 (51.11)	171 (31.78)		

^a There is no difference in HIV information distribution at baseline between comparison and intervention groups.

^b May not add to total because of missing responses.

Effects of Internet Popular Opinion Leaders on HIV Testing and Sexual Behaviors

The iPOL intervention also had partial effects on HIV-related behavior (Table 3). At the 6-month follow-up after controlling for baseline data, participants that visited the intervention website were more likely to have had HIV tests in the past 6

months (43.89% versus 22.31%, $P<.001$) and to use a condom during anal sex with online sex partners compared to the control website (34.15% vs 26.19%, $P=.004$). However, there was no difference in the number of male online anal sex partners, the number of male partners with UAI, and condom use during anal sex with male sex partners between MSMs visiting the intervention website and those from comparison website.

Table 3. Intervention effects on HIV testing and sexual behaviors within the previous 3 months among Internet-using MSM.

Outcome variables	Baseline ^a , n (%) n=1008		Follow-up, n (%) n=1037		χ^2 (df)	P value
	Intervention ^b n=501	Comparison ^b n=507	Intervention ^b n=499	Comparison ^b n=538		
Had HIV test in the past 6 months						
No	351 (70.05)	360 (71.14)	280 (56.11)	418 (77.69)	54.8 (1)	.001
Yes	150 (29.95)	146 (28.86)	219 (43.89)	120 (22.31)		
Number of male sexual partners						
0	145 (29.00)	145 (28.71)	117 (23.44)	175 (32.52)	9.9 (3)	.02
1	182 (36.40)	176 (34.85)	170 (34.06)	163 (30.29)		
2-5	145 (29.00)	155 (30.69)	176 (35.27)	172 (31.97)		
≥ 6	28 (5.60)	29 (5.74)	36 (7.21)	28 (5.20)		
Number of male online sex partners						
0	283 (56.48)	267 (52.87)	256 (51.30)	247 (45.91)	7.6 (3)	.06
1	85 (16.96)	104 (20.59)	72 (14.42)	112 (20.81)		
2-5	115 (22.95)	112 (22.17)	148 (29.69)	155 (28.81)		
≥ 6	18 (3.59)	22 (4.43)	23 (4.60)	24 (4.47)		
Number of male partners with unprotected anal sex						
0	295 (59.23)	302 (60.15)	279 (55.92)	308 (57.25)	2.3 (3)	.52
1	143 (28.71)	142 (28.28)	144 (28.85)	158 (29.36)		
2-5	54 (10.84)	52 (10.35)	66 (13.22)	67 (12.45)		
≥ 6	6 (1.20)	6 (1.19)	10 (2.01)	5 (0.93)		
Condom use during anal sex with online sex partners						
Never	154 (49.67)	160 (48.63)	92 (32.39)	133 (39.58)	13.4 (3)	.004
Sometimes	49 (15.80)	47 (14.28)	41 (14.43)	72 (21.43)		
Most of the time	39 (12.59)	37 (11.24)	54 (19.01)	43 (12.80)		
All the time	68 (21.93)	85 (25.83)	97 (34.15)	88 (26.19)		
Condom use during anal sex with male sex partners						
Never	92 (25.92)	100 (27.85)	81 (24.92)	92 (24.79)	3.0 (3)	.39
Sometimes	75 (21.12)	68 (18.94)	68 (20.92)	64 (17.25)		
Most of the time	65 (18.31)	60 (16.71)	54 (16.62)	78 (21.24)		
All the time	123 (34.65)	131 (36.49)	122 (37.54)	137 (36.91)		

^a There is no difference in HIV testing and sexual behaviors at baseline between comparison and intervention groups.

^b May not add to total because of missing responses.

Discussion

The current study extended prior HIV prevention research by adapting the C-POL model to the Internet. Our study created an iPOL platform on Facebook for dissemination of HIV prevention messages by 369 trained POLs on the Internet, and an estimated 959,088 people viewed the posts on the iPOL platform within 6 months. The findings of the current study are consistent with the results of social influence analysis of

Facebook users, in that influential people with influential friends help spread information [21]. Over 70% of the MSM recruited online in Taiwan sought sex partners online [22], indicating that the Internet is an important venue for conducting HIV prevention programs for MSM [4,22]. Social networks are a useful tool for supporting people affected by HIV infection and patients suffering from HIV disease [23]. In terms of using these social networks for disease support purposes, Facebook shows a higher usage rate than Twitter [24]. Our study demonstrates

that the use of iPOL on Facebook to disseminate HIV-related information to MSM is both promising and practical. The networking capability and participatory and interactive features of Facebook can be used to foster solidarity and deepen the involvement of Internet-using MSM in HIV prevention.

To our knowledge, this is the first study to measure the effects of applying the POL intervention model to the Internet. Our study shows the significant effects of the iPOL intervention on stimulating conversation about HIV among MSM on social networks and increasing the use of HIV testing. Consistent with a previous study in coastal Peru on the effects of a C-POL HIV/STI intervention on stigma [25], our study showed that iPOL intervention can significantly increase the dissemination of HIV-related information and stimulate conversation about HIV-related risky behaviors in online MSM communities. Multimedia social marketing campaigns have had a significant impact on HIV testing uptake [26]. Our study results support the role of iPOL intervention in disseminating HIV information online that could potentially increase rates of HIV testing, consistent with similar findings that online social network usage is associated with increasing HIV testing among homeless youth [9]. In the United States, health agencies such as the Centers for Disease Control and Prevention Twitter Chat and AIDS.gov have begun using online social networks to inform users about their STI risks and the services available to them [27]. Using influential online social networking to increase the number of conversations about the resources of HIV testing, HIV-related risks and prevention behaviors can increase awareness of HIV prevention among Internet-using MSM. Further studies are needed to develop online HIV intervention with multiple-language support, evaluate the accuracy of online HIV information, and document the gaps that exist when searching for information online.

The iPOL intervention showed limited effects in reducing HIV risky behaviors among Internet-using MSM. The iPOL intervention can increase condom usage with online sex partners, but there was no significant effect on reducing the number of online male sex partners and UAI partners or in increasing condom use with male sex partners. Our study results were consistent with those of previous studies that demonstrated that the C-POL intervention for homosexual men in US cities was effective in increasing condom use during anal intercourse [28-30], but inconsistent with the C-POL intervention in decreasing UAI [28,29]. A possible explanation for this is that

the effective interventions for reducing the number of sexually risky behaviors of MSM emphasized interpersonal skills training and incorporated several delivery methods [31], which cannot be achieved by increasing the dissemination of HIV information alone. It is possible that in addition to creating a platform to exchange HIV information, the iPOL intervention also increased the possibility of using online social networks to become acquainted with new friends [32] and seeking potential sex partners. These findings underscore the importance of disseminating HIV-related information online, as well as the challenges inherent in the efforts of iPOL to influence norm-changing approaches and reduce HIV-related risky behavior among Internet-using MSM.

Several limitations of this study should be noted. First, because it was difficult to randomize Internet users to either the intervention or the control website, this quasi-experimental study design with a nonequivalent control group for comparison was especially susceptible to the threats of cross-contamination on the effects of iPOLs. To reduce the differences in outcome variables that existed between groups exposed to the intervention, participants in the control group who reported using Facebook as their website for seeking sex partners were excluded. Second, selection bias resulting from a convenient cross-sectional design may limit the generalizability of the research findings. It is difficult to determine whether the study participants represented the MSM population as a whole or only those MSM using the Internet. Third, data on HIV testing and sexual behaviors were self-reported, which is a limitation of many behavioral studies. Although the study was conducted anonymously through the Internet, there could still be underreporting of sensitive questions, such as HIV status, UAI, or illicit substance use.

In conclusion, an iPOL platform on Facebook was built for dissemination of HIV prevention messages by 369 trained POLs, with an estimated 959,088 people viewing the posts within the 6-month period of intervention. The iPOL intervention had significant effects on the dissemination of HIV-related information and on increasing the frequency of HIV testing among Internet-using MSM. However, the iPOL intervention had a limited impact on individual risky sexual behaviors. Adaptation of the POL model to the Internet to stimulate conversation about HIV and increase HIV testing among MSM is both effective and promising.

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Conflicts of Interest

None declared.

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Abbreviations

C-POL: community popular opinion leader
HIV: human immunodeficiency virus
iPOL: Internet popular opinion leader
MSM: men who have sex with men
POL: popular opinion leader
STI: sexually transmitted infection
UAI: unprotected anal intercourse

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Original Paper

Queer as F**k: Reaching and Engaging Gay Men in Sexual Health Promotion through Social Networking Sites

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Abstract

Background: A growing number of health promotion interventions are taking advantage of the popularity and interactivity of new social media platforms to foster and engage communities for health promotion. However, few health promotion interventions using social networking sites (SNS) have been rigorously evaluated. "Queer as F**k"(QAF) began as pilot project in 2010 to deliver sexual health promotion via short "webisodes" on SNS to gay men. Now in its fifth season, QAF is among the few published examples internationally to demonstrate the sexual health promotion potential of SNS.

Objective: The objective of this evaluation is to assess reach, interactivity, and engagement generated by QAF to inform future health interventions and evaluations using SNS.

Methods: We undertook a mixed method process evaluation using an uncontrolled longitudinal study design that compared multiple measurements over time to assess changes in reach and engagement. We adapted evaluation methods from the health promotion, information systems, and creative spheres. We incorporated online usage statistics, interviews informed by user diary-scrapbooks, and user focus groups to assess intervention reach and engagement.

Results: During Series 1-3 (April 2010 to April 2011), 32 webisodes were posted on the QAF Facebook and YouTube pages. These webisodes attracted over 30,000 views; ranging from 124-3092 views per individual episode. By April 2011, the QAF Facebook page had 2929 predominantly male fans. Interview and focus group participants supported the balance of education and entertainment. They endorsed the narrative "soap opera" format as an effective way to deliver sexual health messages in an engaging, informative, and accessible manner that encouraged online peer discussion of sexual health and promoted community engagement.

Conclusions: QAF offers a successful example of exploiting the reach, interactivity, and engagement potential of SNS; findings from this process evaluation provide a model to inform the delivery and evaluation of future health promotion interventions on SNS.

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KEYWORDS

health promotion; Internet; social networking sites; sexual health; gay men

Introduction

Background

The Internet is increasingly recognized as a platform for health communication and education due to its enormous and growing reach and ability to share information unrestricted by geographical location and time [1-3]. The advent of social media and Web 2.0 applications like social networking sites (SNS), blogs, wikis, podcasts, RSS feeds, and online support groups have revolutionized Internet use and dramatically changed the nature of online engagement and the cumulative time individuals spend communicating, interacting, and accessing information. Eager to capitalize on this potential, many organizations have developed online health interventions for a variety of health issues and clinical outcomes [1,4-6], including for HIV prevention to gay men [7-9] with some reporting positive outcomes [10-12]. Yet to date, there have been very few published examples of evaluation of interventions delivered on SNS [13]; a recent review of sexual health promotion on SNS found the vast majority of activities are unreported in the scientific literature and showed limited success in practice [14]. One very recent randomized controlled study in the United States showed some promising results for SNS as a sexual health education tool [15]. This trial aimed to determine the effect of STI prevention messages delivered to youth via Facebook in reducing sexual risk behaviors compared to a control group that received news stories via Facebook. Findings showed mild effects for condom use (intervention 68% vs control 56%, $P=.04$) and proportion of sex acts protected by condoms (intervention 63% vs control 57%, $P=.03$) at 2-month follow-up; however, no lasting effects were reported at 6 months.

SNS are of particular interest for health promotion due to their enormous potential audience reach and interactive features. SNS allow individuals to create online “profiles” and connect with other users within the system [16]. SNS act as an “open communication” channel to foster social interactions, create online communities [17], and allow the sharing of user-generated content [16]. Previous studies have shown benefits of such interactive health communication capabilities to enhance learning [18]. The adaptive and interactive features of Web 2.0 applications like SNS that allow increased user-generated content have the potential to promote active and engaged learning [19], whereby users “construct their own knowledge through social interaction and exploration” [20]. By encouraging communication between users or creating “community dialogue”, SNS have the potential to encourage active learning, as well as peer-to-peer learning. These learning strategies have shown some potential in helping individuals internalize and process messages and increase knowledge and improve attitudes and skills for HIV prevention and sexual health; however, these data are largely inconclusive [21-23]. Additionally, using social networking features, interventions are able to disseminate health messages quicker through a population when compared to traditional forms of social marketing [24]. Yet to date, no study has assessed the relative effect of novel functions of SNS for

health promotion, and these dimensions present obvious challenges for both monitoring and evaluating impact. Additional dimensions to evaluate SNS-based health promotion not typically considered in traditional media approaches, such as user interactions, functions to support interaction, content quality, and credibility of content have been suggested as useful tools to help evaluate future interventions in this space [20].

In 2010, we launched “Queer as F**k” (QAF), an innovative and novel sexual health promotion intervention using SNS to target gay men in Victoria, Australia [25,26]. We have previously published implementation recommendations based on our experience in the first phase of this project targeting young people [27]; this paper reports the results of the process evaluation of QAF over the initial pilot phase (Series 1) and through the subsequent two series. The aim of this evaluation is to assess reach, interactivity, and engagement generated by QAF to inform future health interventions and evaluations using SNS.

The Queer as F**K Project

QAF originated as one arm of “The FaceSpace Project”, which tested the delivery of sexual health promotion via SNS to two key at-risk groups: young people aged 16-29 years and gay men in Victoria, Australia [27]. QAF was designed as a drama series featuring 4 fictional gay characters, with health messages delivered through short “webisodes” posted on Facebook and YouTube (see Figure 1), and in accompanying online narrative. The narratives and health messages were developed during formative evaluation workshops with members of the target audience and key stakeholders. Much like a TV drama, this online drama series was made up of sequential and individually discrete series, each containing a number of webisodes. Series 1 included 10 webisodes posted on the QAF Facebook and YouTube pages from April 12 - August 10, 2010. Series 2 contained 12 webisodes posted from October 5 - December 21, 2010, and Series 3 consisted of 12 webisodes posted from February 16 - April 18, 2011. Between episodes, project staff posted questions and content daily on the QAF Facebook page to prompt online discussion about the sexual health issues embedded in the narrative of the QAF webisodes and encourage interaction with and between QAF Facebook fans. QAF was promoted through a mix of online and offline advertising, including press advertisements (Figure 2) and editorial coverage in local gay media, Facebook advertisements, updates to fans through the QAF page, and community engagement at gay public events.

The project was a collaboration between public health researchers (Centre for Population Health, Burnet Institute), experts in user interaction with information technologies (Department of Computing & Information Systems, University of Melbourne), a creative productions company (X:Machine), and a community organization with marketing and production expertise (Victorian AIDS Council/Gay Men’s Health Centre, VAC/GMHC).

The primary aims of QAF were to: (1) explore the extent to which SNS can reach and engage gay and bisexual men and improve their knowledge and attitudes to sexual health, and (2) provide recommendations of appropriate frameworks for evaluating health promotion interventions delivered via SNS.

Following the relative success of Series 1, funding to continue QAF was secured. Over the first three series, sexual health promotion topics covered by QAF included sero-discordant relationships, unprotected sex, post-exposure prophylaxis (PEP) [28], strategic positioning [29], sexual health testing, coming out to family, casual hook-ups, HIV disclosure, sero-conversion, alcohol and recreational drugs, and surrogacy.

Figure 1. Screen shots of Facebook and YouTube.



Figure 2. Press ads in gay community magazine used for promotion of QAF project.



Methods

Overview

To monitor and evaluate QAF, we undertook a mixed method process evaluation using an uncontrolled longitudinal study design comparing multiple measures over time to assess changes in reach and engagement. We adapted and combined evaluation methods from the health promotion (eg, focus groups), information systems (eg, usage statistics), and creative spheres (eg, creative/development workshops) to create a dynamic and appropriate evaluation framework (Multimedia Appendix 1) [20]. Project reach (who we were able to recruit) was measured, as was the level of engagement and interaction (degree of fan interest and interaction) using repeat measures over time of website insight statistics, a qualitative diary, and focus groups. An iterative approach allowed QAF evaluation findings to feed

back into the project implementation and evaluation, with knowledge gained from previous phases used to improve intervention delivery. This paper describes process evaluation outcomes from Series 1-3. Evaluation periods were constructed around the three series implementation dates (Series 1 = April 1 - August 31, 2010; Series 2 = September 1 - December 30, 2010; Series 3 = January 1 - April 30, 2011), and data were compared across the three time periods.

Data Collection Methods and Analysis

Website Insight Statistics (Series 1-3)

Insight statistics were downloaded from Facebook and YouTube on a weekly basis, monitored throughout the project, and used to measure reach, engagement, and interaction. Facebook data included fan demographics (gender, age group, country where fan is based), usage data (unique page views, active users, photo

views), and total interactions (wall posts, comments, “likes” per day). Fans refer to people who “like” a Facebook page. A user was considered “active” by Facebook if they viewed or engaged with the QAF page or any content on the page. YouTube data included cumulative number of video views, demographics, and traffic sources, which described where users accessed the YouTube channel from. However, Youtube demographics data were available only for logged-in users. The number and proportion of logged-in users compared to total users was unreported and thus unknown, yet was thought to be only a small proportion [30].

Descriptive analysis of insight statistics assessed reach, delivery, and engagement for the three evaluation periods, and data are presented individually for all three series and then compared between Series 1 and Series 2-3 combined.

Diary Scrapbook Activity (Series 1 Only)

A qualitative diary scrapbook activity was chosen to collect prospective data on engagement and interaction of fans with the project page and reduce recall bias and improve data validity by providing real-time information [31-33]. The aim was to provide information surrounding the context of engagement with QAF and identify potential drivers of participant engagement for future QAF series. Recruitment occurred through an online quantitative survey, which was advertised during Series 1 to all fans of the QAF fan page by posting a link to the survey on the wall of the QAF Facebook fan page and via Facebook advertisements; only 188 (14.2%) participants completed a baseline survey. Survey data revealed very few meaningful insights to inform the project or measure impact, thus these data are not reported here. Participants who completed an online survey and agreed to participate further in evaluations were then invited via email to participate in the diary-scrapbook activity. Participants then attended a face-to-face introductory briefing, received their diary scrapbook, and signed a participant and information consent form. The diary scrapbook activity aimed to gain information about participant engagement with QAF and involved participants regularly recording their weekly activity on the QAF sites in a diary-scrapbook for 6 weeks (June 8th - July 20th, 2010). After 6 weeks, participants returned their diary scrapbook via regular mail and participated in a follow-up interview in which diary-scrapbook content was used to guide the interview. Interviews were conducted face-to-face, took between 30 and 50 minutes, and were audio recorded. Participants were reimbursed AUD\$100 in cash for participation in the diary-scrapbook activity. The diary-scrapbook follow-up interviews were thematically analyzed to assess and contextualize participant engagement with QAF. Of the 10 men who agreed to participate in the diary-scrapbook activity, 9 completed the activity and interview. Participants’ age ranged from 27 to 47 years (medium 38 years). Results for the diary-scrapbook activity interviews are presented only for Series 1 and presented together with Series 1 focus group data.

Focus Groups (Series 1-3)

To support website usage data, we conducted a series of qualitative focus groups to provide more in-depth information on engagement and interaction through Series 1-3 and explore the perceived utility of QAF and SNS more generally for sexual health promotion. Four evaluation focus groups were conducted; two at the end of Series 1 (November 2010), and one each at the end of Series 2 (January 2011) and Series 3 (May 2011). Focus group participants were recruited from the pool of online survey participants who had agreed to participate in further evaluation. Focus group schedules included themes regarding general uses of SNS, reflections on QAF (aims, content, website layout, and characters), strategies to drive interaction, and future improvements. Focus group participants were reimbursed AUD\$50 in cash for time and traveling costs. All focus group data were audio recorded and transcribed. Transcripts were analyzed thematically to assess participant engagement with QAF [34-36]. Focus group data are presented by series and then compared between Series 1 and Series 2-3 combined. Fourteen participants attended two Series 1 focus groups. Participants’ age ranged from 21 to 46 years (medium 35 years). Thirteen participants attended two Series 2 and 3 focus groups. Participants’ age ranged from 22 to 46 years (medium 34 years).

Qualitative results from both the diary scrapbook and focus groups are presented together under “Reach” and “Engagement and Interaction”, as emerging themes and findings were largely shared by both groups. However, under “Engagement and Interaction”, data are divided into three themes: 1) participant engagement and interaction with the QAF project, 2) participant engagement and interaction with the sexual health content of the QAF project, and 3) barriers to participant engagement and interaction with QAF project.

Ethics

Ethics approval for this project was obtained from the Alfred Health Human Ethics Committee.

Results

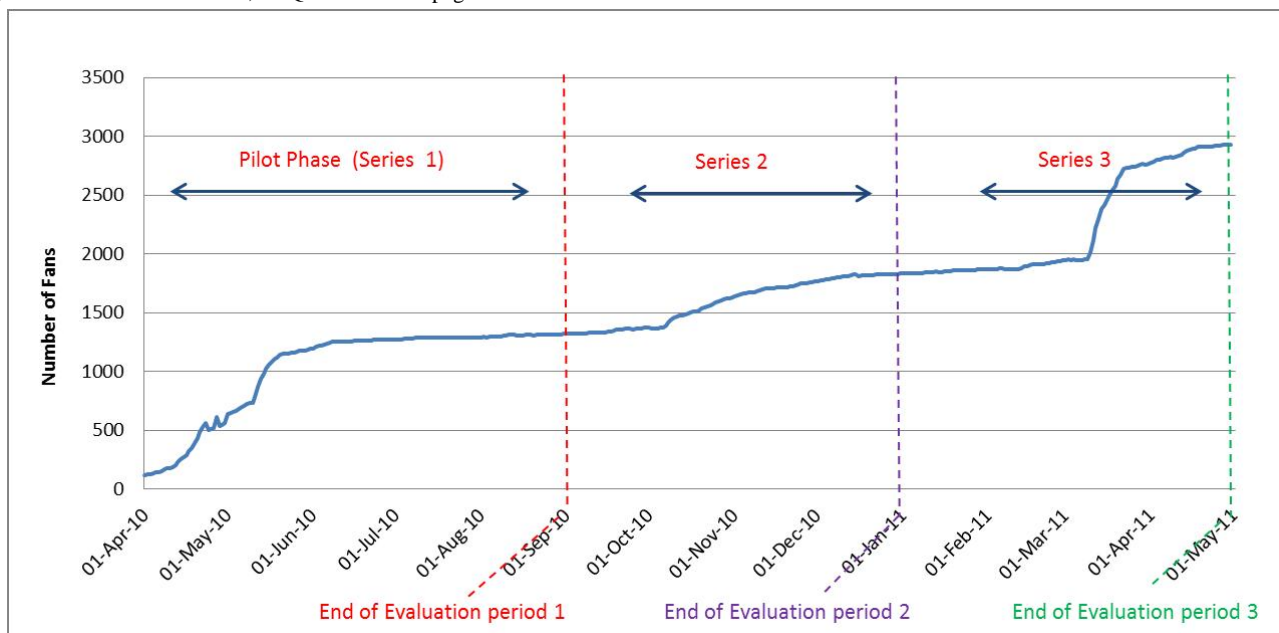
Series 1 (Pilot): Trailing the Approach

Reach

Facebook Insight Statistics

At the end of the Series 1, QAF had reached 1320 fans. The majority of fans were male (80%) and based in Australia (87%) (Table 1). Around two thirds of male fans were aged 25-44 years (Table 1). There was a rapid increase in number of fans in April-May 2010, coinciding with initial series promotion (Figure 3). The greatest increase in numbers of fans (from 782 to 1153) coincided with the use of Facebook advertisements (May 11 – 21, 2010) (Figure 3).

Figure 3. Total fans over time, on QAF Facebook page from Series 1-3.



YouTube Insight Statistics

At the end of Series 1, the QAF YouTube Channel had received 7297 video views. The majority of logged-in viewers were male (92%), located in Australia (72%), and aged 44-54 years (43%)

(Table 2). The most popular video was Episode 1, “I’ve Never...Felched”, which covered coming out and past sexual experiences, with 1672 video views. The next most viewed was Episode 2, “Lady Gaga on a Disco Stick”, which covered drug use and risky sex, with 1077 views.

Table 1. Key metrics from the QAF Facebook page usage statistics per series (source: Facebook insights statistics).

Variables	Series 1	Series 2	Series 3
Evaluation period	April – Aug. 2010	Sept. – Dec 2010	Jan. - April 2011
Reach			
Total fans at series conclusion (cumulative)	1320	1835	2929
Number of new fans reached	1199	501	1094
n (%) male	1026 (80.3)	1446 (81.5)	2424 (84.7)
Age groups, n (%)			
13-17 years	54 (2.2)	34 (2.4)	54 (2.2)
18-24 years	641 (19.1)	272 (18.8)	641 (26.4)
25-34 years	784 (33.0)	500 (34.6)	784 (32.3)
35-44 years	582 (29.8)	399 (27.6)	582 (24.0)
45-54 years	275 (11.9)	184 (12.8)	275 (11.3)
> 55 years	88 (3.9)	57 (3.9)	88 (3.6)
Top countries where fans are based, n (%)			
Australia	1115 (87.4)	1493 (85.3)	2504 (88.4)
United States	44 (3.5)	75 (4.3)	107 (3.8)
United Kingdom	41 (3.2)	76 (4.3)	91 (3.2)
Other	76 (5.9)	57 (6.1)	132 (4.6)
Engagement and Interaction			
Total page interactions	526	942	927
Likes	281	546	495
Comments	205	380	413
Wall posts	40	16	19
Unsubscribes	39	24	10
Unique page views	6105	4898	5771
Video views	2642	9608	9903

Table 2. Key metrics from the QAF YouTube page usage statistics per series (source: YouTube insights statistics).

Variables	Series 1	Series 2	Series 3
Evaluation period	April – Aug. 2010	Sept. – Dec. 2010	Jan. - April 2011
Reach			
Total video views per series	7297	9594	14466
Number of views of most popular episode	1672	831	1816
Proportion male (%) ^a	92.1	91.2	91.1
Age group of male fans (%) ^{a,b}			
13-17 years	0.0	0.0	0.8
18-24 years	6.1	7.3	4.3
25-34 years	8.6	12.6	7.9
35-44 years	21.1	22.3	25.3
45-54 years	43.0	29.4	37.5
> 55 years	13.3	19.5	15.3
Top countries where fans are based (%) ^a			
Australia	71.6	73.2	67.2
United States	13.7	8.3	9.8
United Kingdom	2.4	3.0	4.2
Saudi Arabia ^c	-	2.2	4.4
Engagement and Interaction			
New subscribers	79	61	44
Likes	36	70	75
Dislikes	1	0	3
Favorites	17	15	23
Comments	11	9	17
Sharing	0	0	5

^aThese variables are based on the number of users with a YouTube profile, which account for only a small proportion of the total sample, thus caution should be taken when interpreting these results.

^bPercentages of male fans only; so do not add up to 100%.

^cIn Series 3, Saudi Arabia took over the United Kingdom as the third country with most video views.

Diary Scrapbook Activity and Focus Groups

The majority of participants reported first finding out about QAF from Facebook advertisements. Facebook advertisements appeared to be more effective at attracting fans than any other form of promotional materials, including advisements in gay media (Figure 2); although a few people became aware of the project through their online social networks: “I came in at Episode 4, a friend shared it with me on Facebook, and then I got hooked!” (focus group participant). Some participants described barriers to project reach, which were largely focused around the limitations of the medium/platform in which the intervention was delivered, reporting that they either did not notice the QAF project’s presence on Facebook among the other traffic or did notice the QAF project but their attention was quickly directed to one of the many other activities on Facebook: “There’s so much stuff [on Facebook] that is released all the

time ... even if you design something really good, it’s released into this huge noise of material that’s released every day, every hour” (diary participant) and “With 300 odd friends on your list [on Facebook], the posts [on Facebook] go through very fast ... so you don’t always get to see it” (diary participant).

Engagement and Interaction

Facebook Insight Statistics

At the end of Series 1, the QAF page had received 6105 unique page views, 2642 individual video views, and 526 page interactions, including 281 likes, 205 comments, and 40 wall posts (Table 1). There were peaks in active users and unique pages views during the early stages of implementation, particularly during the initial promotion period (April-May 2010), then a plateau throughout the rest of the series (Figure 4). The peaks in page interactions coincided with webisode postings (Figure 5).

Figure 4. Total number of weekly and monthly active fans, on QAF Facebook page from Series 1-3.

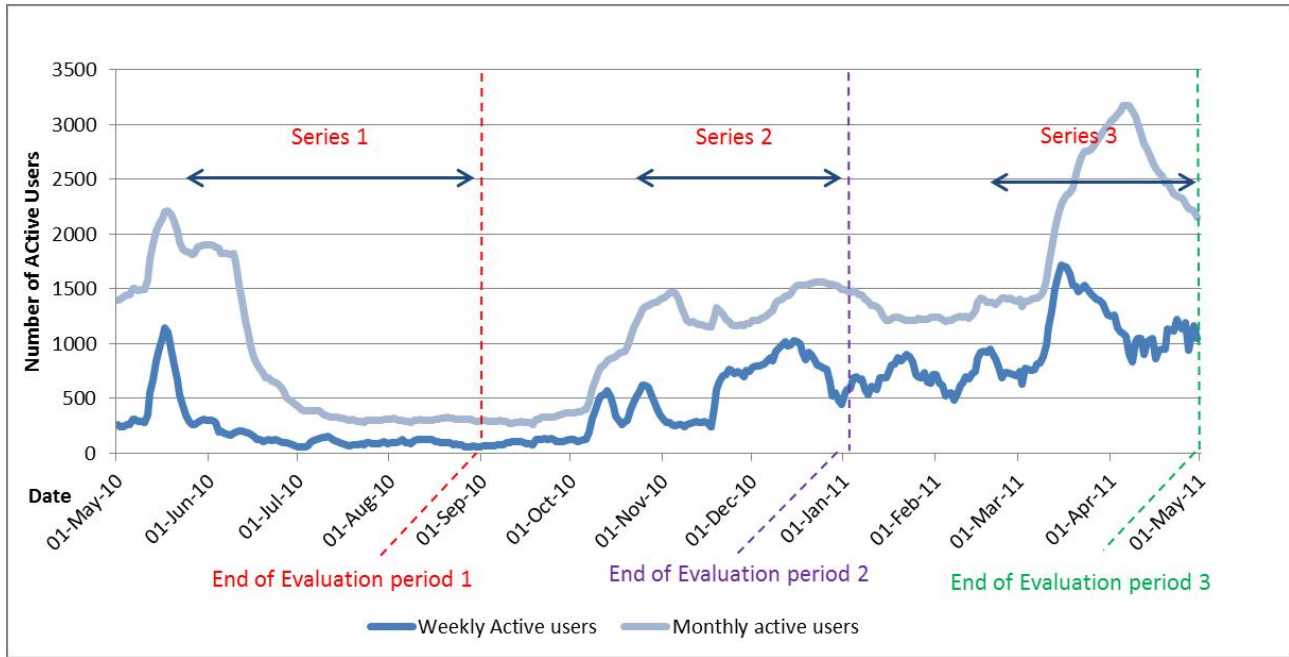
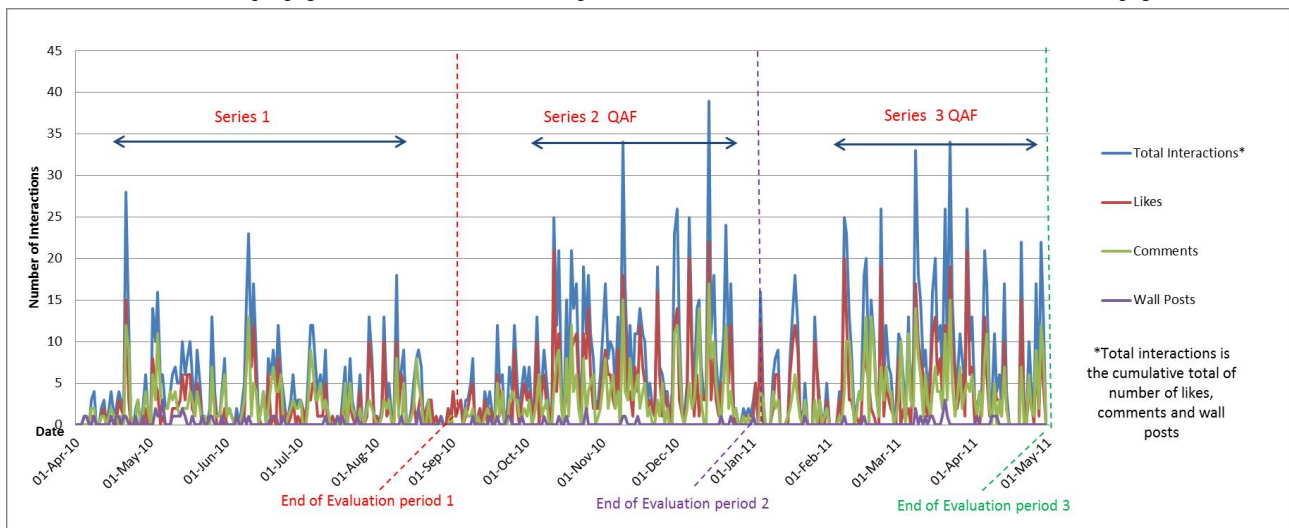


Figure 5. Total number of unique page interactions (includes wall posts, comments, and ‘likes’) over time, on QAF Facebook page from Series 1-3.



YouTube Insight Statistics

The QAF YouTube channel had received 7297 video views by the end of Series 1, which, along with the 79 subscriptions to the channel, 36 likes, and a small proportion of comments and favorites the page received, provided evidence of user engagement and interaction (Table 2). The comments from fans were largely positive and included quotes such as “Very cute! That scene would be really funny if they were all drinking VB [beer]”, “OMG! I love this parody!”, and “Very funny”.

Diary Scrapbook Activity and Focus Groups

Participant Engagement and Interaction With the QAF Project

Participants reported the main reason for visiting and interacting with the QAF page was to watch the webisodes. They described the webisodes as interesting and engaging and liked the interactive web-based soap-opera style. They also commented

positively on the quality of the content produced: “I found the videos really interesting and the videos were well produced ... that was the thing that drove me to go back [to the page] a few times” (diary participant), “I went back just to watch the videos, I found them really good” (diary participant), and:

I felt comfortable watching it, it was entertaining. I didn't get the sexual health message at first, it's quite subtle. Entertaining to watch which kept my interest.
[focus group participant]

Participant Engagement and Interaction With the Sexual Health Content of the QAF project

Participants also describe how they liked the subtlety and realism of the content of the webisodes. They also discussed how the style of the presentation of the sexual health information (via video), made them feel comfortable to engage with the project:

I mean [the episodes] are digestible, they're good. They show a true side to gay friends

getting together and talking about probably what some people would see as trivial things in our lives, but they're actually real things in our lives. [diary participant]

I like it because I'm comfortable watching it. But I'm also uncomfortable at times. There are certain episodes that break me, but I can relate to those episodes because I know people who would react like that. [focus group participant]

I respond better and like it because it's subtle, it's not rammed down your throat. I wouldn't respond well if it was rammed down my throat. [focus group participant]

Some participants also discussed how they thought QAF provided the gay community with an opportunity to discuss sexual health content on Facebook with peers, which was a positive step: "I think congratulations, it's a really useful tool for the community that allows them to interact, and talk about subjects that I don't think really exist so there's a real need for it" (diary participant).

Barriers to Participant Engagement and Interaction With the QAF Project

Although most participants expressed initial enthusiasm for the project, they described that after a few episode they tended to lose interest. There were two main reasons cited for not returning to the QAF Facebook page. First, the QAF Facebook page was not very visible in the large amount of traffic occurring on their Facebook newsfeeds. Second, the frequency of webisode posts without sufficiently engaging additional content on the QAF page was a barrier to coming back:

The long wait between episodes and the length... it's easy to forget about the project. And there was almost no reason to go back ... I probably watched two or three times and that was it ... [focus group participant]

When I first signed up to it, I probably went on two or three times in that first week and then

it was just like totally forgotten about. [focus group participant]

Participants also reported that the public nature of Facebook meant they were careful about what they commented on because it would show up in their status updates. Some participants questioned the suitability/appropriateness of Facebook as a forum for discussing sexual health: "Maybe it was a bit odd, talking about [sexual health issues] on Facebook...it's not really the right forum, like you're not in the mind space to be talking about this kind of stuff" (diary participant) and "I didn't really even necessarily have a reason to interact. I don't know why ... The way [QAF] is doesn't really seem like a social site" (diary participant).

I don't know that Facebook lends itself to sexual health promotion in some ways ... I tend to engage on Facebook as a communicative method to keep in touch with my friends. But there are interests and causes that I like pages for ... like a justice cause ... I can't see how sexual health fits into either of those. [focus group participant]

Some participants acknowledged that their usual habits or interactions on Facebook dictated the extent of their engagement with the QAF page, not necessarily the content of the project: "I tend not to comment a lot on Facebook anyway. The only times I tend to comment on people's various updates and things is if I know them particularly well" (diary participant) and "Normally I wouldn't write comments [on Facebook fan pages], I'd normally just 'like' something" (diary participant).

Series 2 and 3 – Increasing Reach and Engagement

Building on the success of the Series 1 pilot and aiming to capitalize on the existing fan base, QAF continued into further series. Several changes were made to the subsequent series based on evaluation findings from Series 1 (Table 3).

Table 3. Changes made to QAF project implementation following evaluation of Series 1 pilot.

Challenges from Series 1	Changes for subsequent series
Plateau of new fans reached by mid-season	Introduction of new characters to increase/sustain engagement
Infrequent & irregular timing of episode releases	Twelve episodes, posted every Wednesday at midday; compared to almost every 2 wks on no particular day in Series 1
Decrease in return of fans to pages	Intensified use of Facebook advertisements to target self-identified gay men
Discussions on Facebook about the webisodes or sexual health issues was minimal, communication still largely one-way	Using dramatic themes in episodes to elicit organic user-led discussion about sexual health

Reach

Facebook Insight Statistics

There was a steady increase in fans throughout Series 2 and a sharp increase mid-way through Series 3 (Figure 3). By the end of Series 2, QAF had gained 501 fans in addition to those from Series 1 (38% increase from Series 1) to total of 1835 fans. By the end of Series 3, this had reached 2929 fans (59% increase

from Series 2). Fans continued to be predominantly male. However, the proportion of younger fans increased in Series 3 (Table 1). While fans remained predominantly based in Australia, by the end of Series 3, there were QAF fans in over 18 other countries. The total number of video views increased dramatically over Series 2 and 3 compared to the first series.

YouTube Insight Statistics

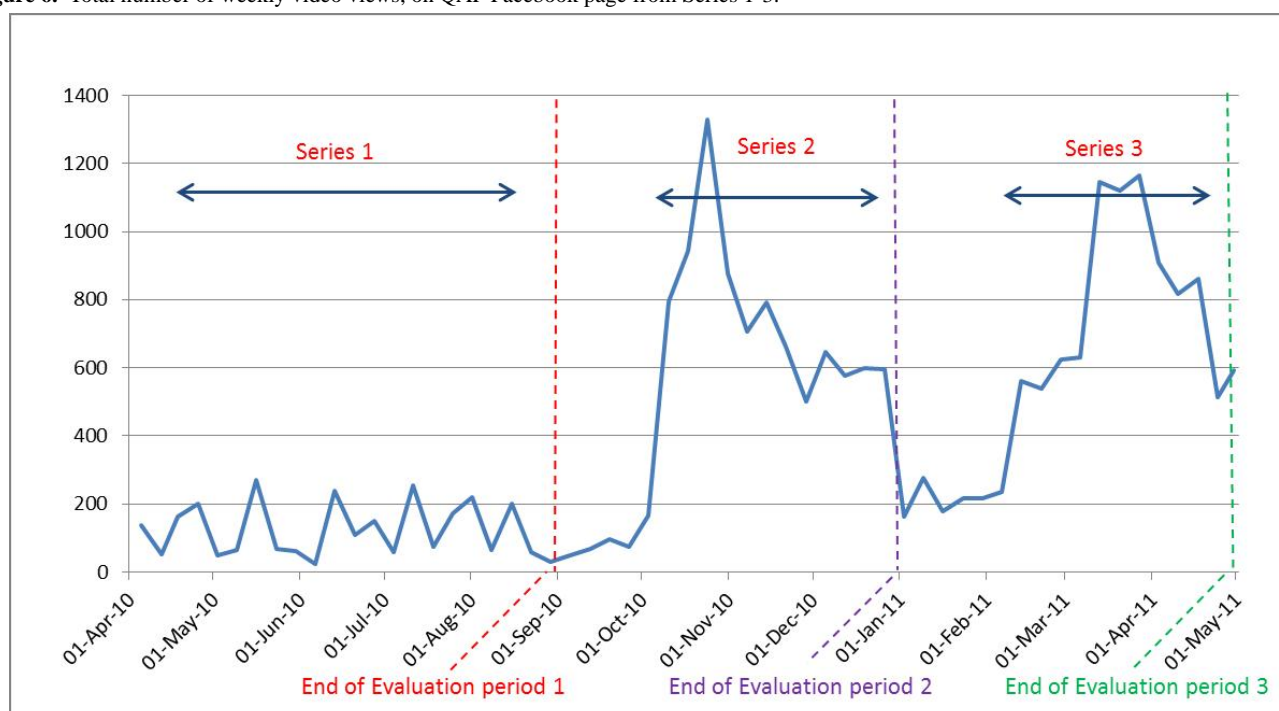
At the conclusion of Series 3, the QAF YouTube channel had received 31,357 video views. Compared to Series 1, QAF increased its video views in both series: 9594 views (31% increase) by the end of Series 2 and 14,466 views (98% increase) by the end of Series 3. YouTube viewers (logged-in viewers) remained predominantly male, resided in Australia, and were older at 35-54 years (65%) compared to Facebook fans (Table 2). The QAF YouTube channel received almost a third of their views from other countries; including the United States, United Kingdom, and Saudi Arabia (Table 2). The most popular videos were those of Series 1, with the most popular being Episode 5, "Sex text ... call Aaron for a good time", which deals with multiple sex partners and received 3092 individual video views.

Engagement and Interaction

Facebook Insight Statistics

Compared to Series 1, video views and page interactions, including wall posts, comments, and likes, increased during Series 2 and 3 and displayed a very different dynamic (Figures 5 and 6). Figure 6 clearly demonstrates the increased engagement with the videos over Series 2-3, while Figure 5 shows increased interaction with the page, evident by increases in both wall posts, comments, and likes compared to Series 1. There were similar increases in the proportion of active fans in Series 2 and 3 compared Series 1 (Figure 4). By the second half of Series 3 (Mar.-April 2011), between 50%-70% of fans were active users, interacting with the page at least monthly.

Figure 6. Total number of weekly video views, on QAF Facebook page from Series 1-3.



YouTube Insight Statistics

By the end of Series 3, the YouTube channel had received over 30,000 video views across all the three series, ranging from 124 to 3092 views per individual episode. Compared to Series 1, the page received increased numbers of fan subscriptions and numbers of likes, comments, and favorites, and by Series 3, fans had begun sharing the QAF videos with their friends, further evidence of user engagement (Table 2). Comments from fans over Series 2-3 progressively went beyond simply endorsing the videos as "funny" as seen in Series 1, and began to discuss and debate the sexual health content of the videos with other users, again evidence of user interaction with both the medium and content. Examples of these comments include: "I don't know if that's true. HIV is a big issue, and a big killer, but it's a surprisingly ineffective virus in terms of infecting people, as in, compared to the common cold etc.", "HIV isn't going to infect people at any opportunity ... still important to be safe, but chances of contracting it when practicing safe sex are very low", and:

I think the HIV+ guy should have been honest straight up, and then let the other guy decide for himself whether he was willing to take the risk. Personally I would still have safe sex with him, but I would most certainly be angered if I was put at risk without my knowledge. It's not fair on your partner to keep them in the dark about something which could result in their death.

Focus Groups

Results from the two focus groups at the end of Series 2 and 3 are presented together, as they covered similar themes. Comments were not necessarily restricted to specific series.

Participant Engagement and Interaction With the QAF Project

Similar to Series 1, participants' engagement and interaction with the QAF project were based around the webisodes. Again participants commented that the high production values and the balance between entertainment and education kept them engaged through subsequent series. Participants also reported that the

regular format of posting videos once a week on the same day and the introduction of new characters, including popular celebrities, helped keep them interested and engaged with the project: “It’s good for its entertainment value, and the episodes are short and don’t take long to watch, so don’t have to keep my interest for too long. I liked the subplot with Brendan’s mum, Denise Scott, and her coming to terms with Brendo being gay” (Series 2 focus group participant), “Yep. It gets a bit ridiculous trying to put a message into every episode. Some are just purely entertaining” (Series 2 focus group participant), and “The fact the QAF could fill out a screening at the queer film festival means it must be very engaging” (Series 3 focus group participant).

Participant Engagement and Interaction With the Sexual Health Content of the QAF Project

Participants described how they continued to engage and interact with the project throughout subsequent series due to realistic portrayal of the characters and relatable scenarios depicted in the QAF. Participants also were easily able to recall the characters and storylines from the previous series, further evidence of engagement with QAF: “My first impression was that it was an interesting but positive portrayal of gay culture. It had real people in it, people I would know.” (Series 3 focus group participant), “I’ve been in a situation exactly like that, that’s how realistic it was” (Series 2 focus group participant), and:

I think people can relate to Brendan’s vulnerability. And it’s a rational message about PEP – telling people that it needs to be taken within 72 hours, and you have to take it for 28 days. It wasn’t preachy, just realistic. [Series 3 focus group participant]

The one with the altercation on the kitchen floor, I hated that one, it clearly sticks in my mind. When he finds out the guy he’s been seeing is positive. It’s most memorable for me. [Series 3 focus group participant]

Some participants also described how QAF provided them with an opportunity to discuss sexual health issues with their peers. They also described how these discussions that occurred on the page with other fans and with the QAF project made them feel involved and “gave them a voice”: “It encourages you to talk about your sex life. I’ve spent years of not talking about my sex life with anybody” (Series 2 focus group participant) and:

I like that I can also share it with my friends, both gay and straight. It opens up communication with people who aren’t necessarily part of the target audience. It’s a good discussion point with friends, everyone has different opinions so it’s great to have a discussion about it. [Series 3 focus group participant]

I didn’t know a great deal about PEP, so that episode made me find more information about it and share that with my friends who had never even heard about it. So it provided me with new knowledge. Also that it shows that you can have HIV+ve/-ve relationships and showing these in a ‘normal’ positive light, I think it’s great education in that way. I like the way that was handled. [Series 3 focus group participant]

Barriers to Participant Engagement and Interaction With QAF Project

Similar to Series 1, some participants were still not comfortable with interacting with the page and preferred to just to view the videos or discussions, while others appear to still be engaged with the project but simply chose not to interact with others on the page:

I just watch it. I don’t read the discussions or comment. I only look when I remember, sometimes I forget about it, maybe it’s not in my face enough. [Series 3 focus group participant]

Some episodes that I’ve really enjoyed and engaged with and so I read the discussions. But I’m not at a point where I’ll write on the discussions, I don’t feel comfortable putting my view across with my name and photo there. But I do discuss heavily the big issues that come out of the episodes with friends, for example the one where he comes out about being HIV positive. [Series 2 focus group participant]

The public nature of Facebook remained a concern throughout the subsequent series and was a potential barrier for some people to engage/interact with the project:

I think it’s missing a website, there needs to be a website for those who don’t use Facebook or YouTube or who want it to be more private. A website would be easy to access and could be anonymous, that could further engage people. [Series 3 focus group participant]

Discussion

The QAF project is among the first published examples of how to develop, implement, and evaluate an online sexual health promotion intervention on SNS [14]. This process evaluation of a pilot study that developed into a sustained health promotion project demonstrates how an iterative and reflexive approach to health promotion interventions can be applied successfully to new media. While many organizations are using SNS for health promotion, the majority are not effectively exploiting SNS functions to engage their target audiences [14]. With the sustained number of fans and increasing engagement over time, QAF provides a useful model for developing health promotion interventions on SNS.

Reach

Within a relatively short period, the QAF project managed to reach almost 3000 fans and received over 30,000 videos views. While these numbers may not appear large considering the popularity of SNS [37] and the ability for “viral” spread, when considered against other sexual health promotion activities being delivered on Facebook (median of 327 fans, range 15-111,391) and other SNS [14], it is considerable.

Across the three series, the reach of QAF continued to increase. The most successful promotion tool for reaching potential fans was Facebook advertisements, which enabled targeting of fans by age, geographical location, and sexual orientation (ie, “Interested in” males or females). Mid-way through Series 3,

Facebook enhanced the targeting capabilities for their advertisements, enabling the targeting of friends of current fans. This resulted in a substantial boost in fan numbers with no additional effort required by the project team. Furthermore, although promotion efforts were focused locally, viewers from over 50 countries were reached, including a considerable number of Facebook fans and YouTube viewers from the United States, United Kingdom, and Saudi Arabia. This result highlights the huge multijurisdictional potential reach of SNS.

Engagement and Interaction

A key aim of QAF was to explore the use of SNS as a space for engaging gay men in interactive sexual health promotion. This evaluation showed ongoing and increasing participant engagement with QAF across series, as measured through a variety of methods. Fans engaged primarily with the short webisodes in which health promotional messages were embedded, highlighting the utility of video content in engaging fans but also in delivering health messages. Key reasons for fans returning to the site and continuing to engage with the project included the format (video drama series), the content (realistic, relatable, subtle), the quality (high production values), and the entertainment-education or “Edutainment” approach [38]. These results demonstrate the benefits of interactive health communication to engage users on health topics, particularly on sensitive issues such as sexual health, as evidenced by the rich qualitative data presented in this evaluation. Similar findings have been described elsewhere [18-20]. Furthermore, “Edutainment” has emerged as a popular approach [39,40] for increasing “functional” learning through content that both entertains and educates [38].

These attributes place further emphasis on the quality and credibility of content produced in these spaces, as SNS rely on users’ ability to assess the usefulness, utility, and trustworthiness of content before they choose to engage [20]. Throughout this evaluation, qualitative data highlighted how participant engagement and interaction were heavily dependent on the credibility of the video content. This evaluation provided some evidence of the importance of these attributes, as participants consistently described the high production quality of the webisodes, in combination with the realistic characters and storylines as key factors in maintaining their engagement. Participants also described how the QAF Facebook page provided both impetus and space for online discussions with peers and encouraged interactions between fans. Project staff (data not reported here) also noted that by the end of Series 3, less promoting and probing were required by project staff as fans began initiating discussions and debate around sexual health topics and ongoing user-led discussions became more routine. Given the volume of content produced on SNS, intervention designers must carefully consider the quality and credibility of content if they are to be successful in reaching and engaging their audience in a sustained manner. Other similar studies have used different methods for building community engagement through online social networks, with a US-based study choosing to pay community members rather than research project staff to engage their peers in HIV prevention efforts [15].

This evaluation exposed a number of potential barriers to fan engagement. Concerns about privacy and the public nature of Facebook inhibited some people from engaging with the project. Privacy has been identified previously [16,41] as a key barrier to engaging groups in an online environment, particularly on a SNS where there is a lack of anonymity and limited capacity to provide confidentiality for participants. One important consideration here is the different opportunity that SNS can provide for different “types of users” (ie, The Creator, The Critic, The Spectator)[42-44] to engage in a way that is comfortable to them. More in-depth evaluation designs, including more detailed content analyses of discussions that occurred on the QAF page, may offer insights to understand the characteristics and online behaviors of different types of users. Disaggregating analyses of outcome data may also help determine what effects the depth of user engagement may have on overall impact of the intervention. For example, are fans that interact at a high frequency more likely to modify behavior or have greater awareness of the health issue than other fans?

The success of SNS and other online applications to provide opportunities for online communities to form, often created through shared beliefs and values, has resulted in enthusiastic socializing and network building [44]. Exploiting the functionalities of SNS to increase engagement with interventions and excite social activity around topics such as sexual health is an important step to potentially enhance the impact of such interventions on behavioral and attitudinal change [45].

Evaluation Learnings

A number of key evaluation learnings emerged from this project. The combination of different evaluation methodologies (usage statistics, diary-scrapbook activity, focus groups) provided a rich mix of quantitative and qualitative data enabling assessment of reach, interaction, and engagement. The SNS platform enabled close monitoring of user interaction with QAF via website insight statistics, which included common website usage metrics (ie, number of fans, likes, comments, wall posts, and shares, including changes over time). As suggested by Bennet and Glasgow (2009) [3], it is vital that researchers working in this area develop a key set of metrics for the monitoring of social media and SNS. A recent report by Gordon (2011) [46] suggests a simple framework for planning and reporting social media metrics—SEE, SAY, FEEL, DO—which categorizes website usage metrics into meaningful groups to help plan and measure combination campaigns. With the focus of many publically funded health promotion interventions on impact, one important challenge for future evaluations will be to ensure that enough emphasis is placed on the importance of process evaluation. A detailed process evaluation was crucial for the success of QAF and provided detailed understanding of the key elements of the intervention and the SNS platform that drove reach and engagement with the intervention.

Limitations

There are several limitations to this evaluation. Usage data were not always complete nor provided as raw data, thus limiting further data manipulation, analysis, or comparisons across SNS platforms or across other interventions. There were only small numbers of participants in the diary-scrapbook activity and the

focus groups, and those that chose to participate may be fans more engaged with QAF. Finally, given the limited resources available to implement and evaluate QAF, a detailed qualitative content analysis of the QAF Facebook page for Series 1 to 3 was not feasible. This also limited our ability to undertake an analysis of how learnings can be passed on through people's online social networks. Such data would provide further insights regarding enhancing participant engagement and reach for such sexual health programs through SNS. However, such an evaluation is planned for subsequent series now that additional evaluation funding has been secured.

Conclusions

“Queer as F**k” is one of the first published examples of how to develop, implement, and evaluate an online intervention delivering sexual health promotion on SNS. QAF reached a substantial number of fans over a sustained period and continued to increase reach and user engagement and interaction over time. An iterative approach to project development, implementation, and evaluation allowed ongoing improvements to project delivery and expanded reach and engagement to gay men in these important social networking spaces.

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Authors' Contributions

All authors were involved in the design and implementation of the QAF project. AP led the conception, preparation, and review of this manuscript. MS, JG, and MH were involved in manuscript conception and preparation. NA, SH, SC, JA, OL, and CB reviewed the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Development and evaluation framework for the QAF Project.

[[PDF File \(Adobe PDF File\), 264KB - jmir_v15i2e25_app1.pdf](#)]

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Abbreviations

PEP: post-exposure prophylaxis

QAF: Queer as F**k

SNS: social networking sites

VAC/GMHC: Victorian AIDS Council/Gay Men's Health Center

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Original Paper

Misleading Health-Related Information Promoted Through Video-Based Social Media: Anorexia on YouTube

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Abstract

Introduction: The amount of information being uploaded onto social video platforms, such as YouTube, Vimeo, and Veoh, continues to spiral, making it increasingly difficult to discern reliable health information from misleading content. There are thousands of YouTube videos promoting misleading information about anorexia (eg, anorexia as a healthy lifestyle).

Objective: The aim of this study was to investigate anorexia-related misinformation disseminated through YouTube videos.

Methods: We retrieved YouTube videos related to anorexia using the keywords anorexia, anorexia nervosa, proana, and thinspo on October 10, 2011. Three doctors reviewed 140 videos with approximately 11 hours of video content, classifying them as informative, pro-anorexia, or others. By *informative* we mean content describing the health consequences of anorexia and advice on how to recover from it; by *pro-anorexia* we mean videos promoting anorexia as a fashion, a source of beauty, and that share tips and methods for becoming and remaining anorexic. The 40 most-viewed videos (20 informative and 20 pro-anorexia videos) were assessed to gauge viewer behavior.

Results: The interrater agreement of classification was moderate (Fleiss' kappa=0.5), with 29.3% (n=41) being rated as pro-anorexia, 55.7% (n=78) as informative, and 15.0% (n=21) as others. Pro-anorexia videos were favored 3 times more than informative videos (odds ratio [OR] 3.3, 95% CI 3.3-3.4, $P<.001$).

Conclusions: Pro-anorexia information was identified in 29.3% of anorexia-related videos. Pro-anorexia videos are less common than informative videos; however, in proportional terms, pro-anorexia content is more highly favored and rated by its viewers. Efforts should focus on raising awareness, particularly among teenagers, about the trustworthiness of online information about beauty and healthy lifestyles. Health authorities producing videos to combat anorexia should consider involving celebrities and models to reach a wider audience. More research is needed to study the characteristics of pro-anorexia videos in order to develop algorithms that will automatically detect and filter those videos before they become popular.

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KEYWORDS

Medical Informatics; Internet; Online videos; YouTube; Eating Disorder; Anorexia Nervosa; Social Network

Introduction

Social networking has emerged as a new channel for seeking information, and also for creating and exchanging user-generated content among peers [1]. An increasing amount of content is being disseminated on social video platforms, such as YouTube, Vimeo, and Veoh. For example, approximately 26% of teenagers aged 13 to 17 years create and upload videos [2], and approximately 60 hours' of content is uploaded onto the video-sharing platform YouTube each minute, with more than 4 billion page views every day [3]. YouTube is gaining popularity among American and European health care providers [4,5] not just as a video repository, but also as a social network where users interact to build trust with comments and favorites [6]. Approximately 100 million people take some form of social action on YouTube (eg, likes, shares, and comments) every week [3].

Many different stakeholders generate health-related content on social media platforms [7]. For example, health consumers publish videos about their diseases on YouTube [8-10], whereas health care professionals collaborate to increase the quality of articles published in Wikipedia [11]. Traditional health portals, such as NHS Choices, Mayo Clinic, and PubMed, use social media channels (eg, YouTube and Facebook) to distribute their content [7], whereas an increasing number of health consumers search for health information on social media channels [12]. However, finding informative and trustworthy online health information is hampered by the vast amount of information available [13-16], the quality of which is heterogeneous. This is clearly the situation faced by users of YouTube [6,17-24] where thousands of videos promote misleading information, such as disparaging vaccinations [17,23,24]. This clearly jeopardizes the safety of social media content.

Online information about anorexia provides a good example of potentially harmful online information. Anorexia is an eating disorder which has a huge impact on the health and quality of life of sufferers [25], and these people commonly engage in the creation of online content promoting anorexia as a lifestyle (see Figure 1 and Multimedia Appendix 1) [26-35]. Pro-anorexia websites have been defined as those encouraging disordered eating [26], promoting anorexia as a fashion or as a source of beauty, and sharing tips and tactics on how to become and

remain anorexic. However, for people affected by anorexia who deny the disease, pro-anorexia information can be "trustworthy" and very informative. In this paper, we consider pro-anorexia information as misleading because, as we explain subsequently, it can be detrimental to a person's health [28,32-35]. On the other hand, there are also videos that inform about the health consequences of anorexia (see Multimedia Appendix 2 for an example of an informative video).

The desire to be thin (*thinspiration*) leads adolescents, mainly females, to develop low perceptions of their own body image [34-37], together with unrealistic ideals of thinness based on models depicted on the Internet. Recent studies have identified pro-anorexia and pro-eating-disorder websites as negatively affecting females' perceptions of their body image [8,32,34]. Many pro-anorexia members share pictures and videos of extremely thin models, reflecting the current media trend toward very thin beauty canons, which is pushing many teenagers toward unhealthy eating habits [35].

Pro-anorexia content has the potential to become a public health concern. One study showed that 13% of 1575 female undergraduates reported viewing 1 or more pro-eating disorder sites, rating them higher on eating measures and body image disturbances [30]. Pro-anorexia content has been found to exacerbate eating disorders and promote anorexic lifestyles [32,34]. In a recent review, Rouleau and von Ranson [32] summarized 3 main reasons why pro-anorexia communities can be harmful: (1) they claim to provide support, (2) they promote disordered eating, and (3) they discourage people from seeking help or trying to recover.

Pro-anorexia content tends to be more popular among young people who are more susceptible to concerns about body weight [36]. Most people affected by anorexia fall within the age group in which Internet and social media are used heavily [25]. Studies suggest that pro-anorexia content is developed within online communities [27,29]. Therefore, one would expect a high presence of pro-anorexia content on social media platforms. Despite the popularity of social media, little is known about pro-anorexia content and the use of social media platforms [33], especially on multimedia platforms, such as videos (ie, YouTube) and images (ie, Flickr). To our knowledge, this study is the first to investigate pro-anorexia-related information disseminated through YouTube videos.

Figure 1. Screenshot of a pro-anorexia video promoting misinformation.

Methods

As shown in [Figure 2](#), we used the YouTube application programming interface (API) to search for videos with queries related to anorexia using the keywords anorexia, anorexia nervosa, proana, and thinspo (inspiration to become thin) on October 10, 2011. We retrieved up to 4000 results for each query and sorting criteria (relevance, uploaded, number of views, and rating). In total, 16,000 search results were retrieved containing 7583 videos uploaded by 3968 users.

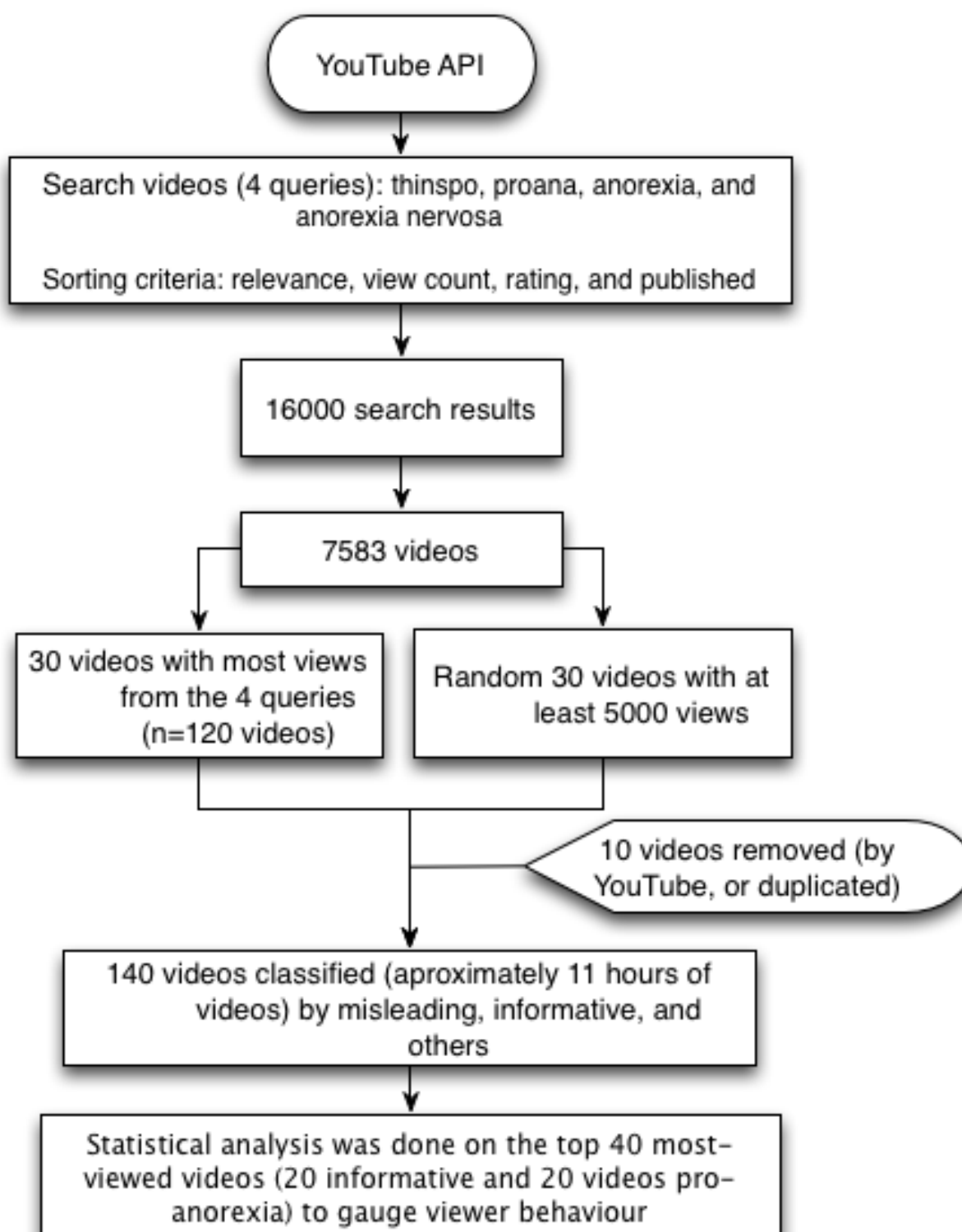
We selected the 30 most-viewed videos for the previously mentioned 4 keywords ($n=120$) and a subset of 30 random videos with at least 5000 views for classification by experts. Out of the 150 videos selected, only 140 were analyzed because 8 videos were retrieved in several of the queries and 2 videos were removed from YouTube in the middle of the reviewing process. They may have been deleted because of a copyright issue or a violation of YouTube regulations. An additional 21 videos were in a European language (Spanish, Italian, and Portuguese) and experts with knowledge of these languages were contacted for clarification. The 140 videos totaled 11 hours of video.

Three independent physicians (Y-CW, EC, and DK) reviewed the 140 videos. A predetermined classification criterion was agreed upon based on a review of the literature and group discussions among the authors. A subset of videos was used to

test the classification criterion, although these videos were not included in the study analysis. Finally, reviewers received a written description for each category. Videos describing anorexia as an eating disorder, explaining the consequences of malnutrition on health, or suggesting how to recover from this condition were rated as informative. In contrast, videos describing anorexia as a fashion, a source of beauty, a healthy lifestyle, included ways of avoiding meals, or included tips on how to become and remain anorexic were rated as pro-anorexia. Finally, videos that were not related to anorexia or eating behavior were rated as others. The interrater agreement was estimated by Fleiss' kappa. A majority consensus was not reached for 10 videos; therefore, 3 additional reviewers (LFL, SAS, and CS) reclassified these videos by consensus after watching them together.

We selected the top 40 videos (the 20 most-viewed pro-anorexia videos and the 20 most-viewed videos from the informative categories) because we were interested in the videos with the maximum number of viewers, and users normally just browse the first pages of search results. These 40 videos had a total of 61.13 million views, which is a large enough sample size to understand the characteristic features of the viewers. The statistics software SPSS v17 (SPSS Inc, Chicago, IL, USA) was used to analyze the different features of the pro-anorexia and informative videos. We also analyzed the content of videos and viewership whenever demographic information was available.

Figure 2. Study design.



Results

Of the 140 videos, 41 (29.3%) were rated as pro-anorexia, 78 (55.7%) as informative, and 21 (15.0%) as others (see [Table 1](#)). The interrater agreement of their classification was moderate

(Fleiss' kappa = 0.5) [38]. The random selection of 30 videos with at least 5,000 or more views had similar percentages: 10 (33%) were pro-anorexia videos, 17 (57%) were informative, and 3 (10%) were others. If this percentage is extrapolated to the total dataset, we can assume that YouTube contains approximately 2,222 pro-anorexia videos (29.3% of 7,583).

Table 1. Results of the classification of anorexia-related videos on YouTube according to the informative nature of the videos.

Selected YouTube videos	Total, n	Video classification, n (%)		
		Pro-anorexia	Informative	Others
Top 30 videos with most views for each query	110	32 (29.0%)	61 (55.5%)	17 (15.5%)
Random selection of videos with more than 5000 views	30	10 (33%)	17 (57%)	3 (10%)
Total reviewed videos	140	41 (29.3%)	78 (55.7%)	21 (15.0%)

Furthermore, the 40 most-viewed videos (20 pro-anorexia and 20 informative videos) with a total of 61.13 million views were assessed to understand the behavior of the viewers (see [Table 2](#)). Users normally just browse the first pages retrieved by search engines, thus making it important to study the top results. Pro-anorexia videos were favored 3 times more than informative videos. The response rate was estimated from the number of viewers who clicked on the like/dislike icon over total views. Pro-anorexia video viewers responded twice as often as those of informative videos.

In most cases, the pro-anorexia videos featured photos of extremely thin models. These videos were explicitly used to inspire people to become very thin. It was also common for some of the videos to include quotations with tips and advice for losing weight. For example, [Figure 3](#) is a screenshot of a video in Spanish with a thinspo nutritional pyramid with advice such as “Smoke as much as necessary, or eat sugar-free chewing gum, use drugs such as Xenadrine, Reductil, etc, to lose weight.” Nearly all the videos featured very thin female models ([Figure 4](#)), although we did encounter a few videos featuring very thin male models.

Although we did not study the creators of these videos as a part of this study, we observed that a wide range of users provided

the informative videos: individuals recovering from the disease, health organizations, news agencies, and students (see [Figure 5](#)). The most popular videos were produced by news agencies. Health authorities, such as the Centers for Disease Control and the National Health Service, also had videos about anorexia on YouTube.

In the others category, some videos were tagged with the keywords without any clear explanation. In other cases, the videos were from a music band called Anorexia.

To understand the demographic characteristics of the pro-anorexia community, we analyzed the demographic information available in the 15 videos from the pro-anorexia group (see [Figure 6](#)). A total of 15 pro-anorexia videos included demographic information, of which 80% (n=12) had minors (13-17 years) in a top-3 age group as viewers, with one-third (n=5) of the videos not having age restrictions. This implies that some videos were very popular among minors before being flagged as inappropriate for minors. Any registered user can flag videos as inappropriate, and then YouTube decides on the deletion or age restrictions for the videos based on flags from the community of users.

Table 2. Assessment of the 20 most-viewed anorexia-related videos on YouTube.

Variable	Video type				OR ^a (95% CI)	P value
	Pro-anorexia		Informative			
	n	%	n	%		
Total views	9.51 million	100	51.62 million	100		
Favorite	24,462	0.26	39,424	0.08	3.37 (3.32-3.43)	<.001
Total Responses ^b	15,209	0.16	45,486	0.09	1.82 (1.78-1.85)	<.001
Likes	12,560	82.58 ^c	40,332	88.67 ^c	0.61 (0.58-0.64)	<.001
Dislikes	2649	17.42 ^c	5154	11.33 ^c	1.65 (1.57-1.74)	<.001

^a OR: odds ratio (informative group is reference).

^b Response: videos were rated with like or dislike.

^cThe percentages of likes and dislikes were calculated by using total responses as denominator.

Figure 3. Screenshot of a Spanish video promoting anorexia through drugs and smoking.

pro ana pro mia anorexia y bulimia princesas de porcelana t

diegopancho696969 Subscribe 9 videos

pro ana pro mia anorexia y bulimia princesas de porcelana t

diegopancho696969 Subscribe 9 videos

Handwritten notes:

- Top: *Solo Si Te Sientes Muy Mal Puedes Comer Lo Siguiente: 100 Grs - 17 Cal 125 Grs - 15 Cal*
- Second section: *Café Con Y Sin Sacarina Laxantes*
- Third section: *Pastillas Para Adelgazar Recomendadas: Xenadrino - Reductil - Xenical - Sibutramina - Flouxetina - Mazindol*
- Bottom section: *Agua 10 A 15 Vasos Diarios Aguas Recomendadas: Next (Baja En Sodio) Sin Gas*
- Right side: *Cada Kilo Que Pierdo Es Un Sueño Logado*
- Top right: *Siempre que me nutro me destruyo*
- Left side: *Alimenta Me*

0:00 / 4:26 CC 480p

Like Add to Share 11,435

Uploaded by diegopancho696969 on Oct 8, 2009

una recopilacion de fotos de ana y mia pero con un enfoque diferente espero que les guste

33 likes, 5 dislikes

! This video has been age-restricted based on our [Community Guidelines](#)

Figure 4. Screenshot of a video promoting anorexia featuring very thin models.

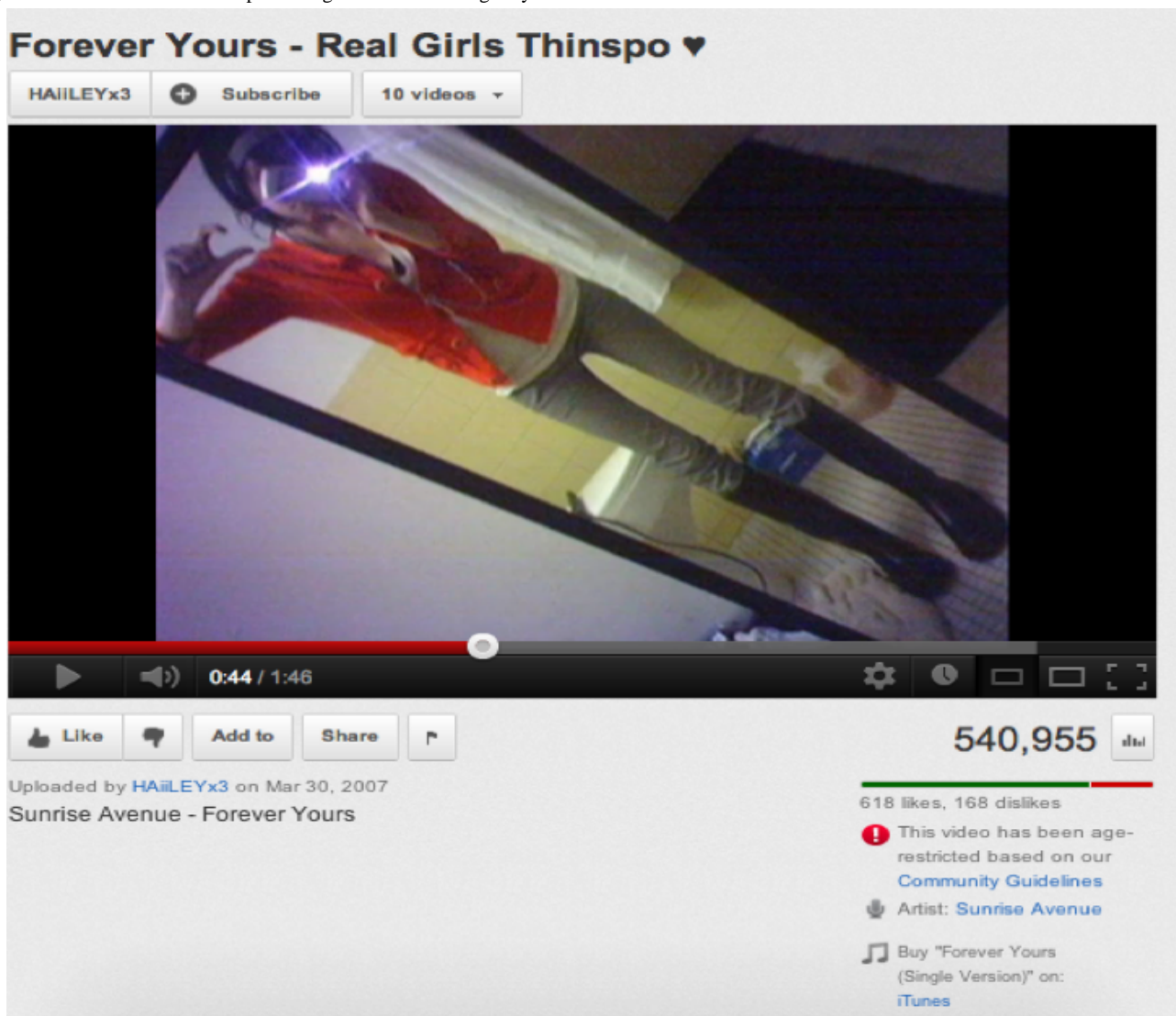


Figure 5. Screenshot of an informative video about anorexia.



Figure 6. Demographics of the pro-anorexic video “Princesas de Porcelana” (Spanish).



Discussion

Video content on YouTube has been analyzed in previous studies as a source of information about the human papillomavirus vaccine, rheumatoid arthritis, influenza A (H1N1) virus, kidney stones, and immunizations [17-24]. To our knowledge, this is the first study to categorize and quantify anorexia-related videos on YouTube. We found a high prevalence of pro-anorexia videos on YouTube; nearly one-third of all anorexia-related videos promoted anorexia as a lifestyle (see Table 1). In both subsets of videos, the 110 most-viewed and the 30 randomly selected videos, the percentage of pro-anorexia videos was approximately 30% (see Table 1). These percentages are similar to studies analyzing YouTube videos on other health-related topics, such as rheumatoid arthritis and immunization [17,24]. If we extrapolate the percentage of pro-anorexia videos from our dataset to all the anorexia videos we extracted (n=7583), we can estimate that there are more than 2222 pro-anorexia videos on YouTube.

In this study, we found that the most-viewed informative videos were produced by news agencies. This could be because news agencies, such as CBS News, have a wide viewership and therefore any video uploaded by them will get many viewers. In some cases, the informative videos from news agencies reported cases of celebrities affected by the disease. The popularity of videos created by health authorities was relatively low compared with news agencies and some personal videos. Studying why videos from health authorities were not so popular did not fall within the scope of our study. However, we did observe that certain topics triggered many views (ie, fashion and celebrities), and these topics were not normally featured in health authority videos.

When we analyzed the characteristics of the most popular videos, we found that the pro-anorexia videos were favored 3 times more by viewers than the informative videos. The response rate was estimated from the number of viewers who clicked on the like/dislike icon over total views. The number of comments for pro-anorexia videos was twice that for informative videos. A study has reported that the interaction among the pro-anorexia community is very intense [39]. One of the reasons for the lower response to informative videos could be that some health authorities opt to block comments on their videos. Greater popularity, in terms of likes and comments, will increase the visibility of the video because search and recommender algorithms within YouTube promote highly linked and commented videos [40]. We observed differences in the use of textual descriptions of the videos; for example, many pro-anorexia videos were described as having tips for weight loss that may attract a wider audience than just pro-anorexia members. We encourage health authorities to study the content dissemination strategies used by the pro-anorexia users to design their own dissemination strategies for informative content. In addition, health authorities should see YouTube as an online community and engage with it to increase their popularity. Among other things, we recommend they involve other health authorities or research institutions and engage with the viewership via comments when possible.

Approximately 82.6% of pro-anorexia video raters liked the misleading information. In contrast, 11.3% of informative video raters disliked the informative content (see Table 2). We assume this is because misleading videos are made attractive with pictures of celebrities and models and fashionable music [35], whereas informative videos are often just simple lectures that are less visually appealing. This reflects the fact that even though there are a significant number of informative videos (55%), they are less favored than the pro-anorexia ones. Therefore, more effort is required to promote the visual appeal of informative videos. Merely increasing the number of informative videos does not necessarily correlate with the number of views.

We observed characteristics through the most-viewed pro-anorexia videos congruent with the review conducted by Rouleau and von Ranson [32] on the risk of pro-anorexia webs. First, the videos provide support such as emotional reinforcements via music, photos (see Figure 4), and quotations. The reinforcement of disordered eating is also common on the videos with the sharing of pro-anorexia tips (see Figure 3) and help seeking is discouraged by denying the disease exists (see Figure 1). Videos can be heavily pro-anorexia; in a few minutes and with an appealing format, they can combine all the risks identified by Rouleau and von Ranson [32]. Harshbarger et al [31] concluded in their study that the “tips and tricks” sections of pro-anorexia websites posed the most serious medical threat because the most frequent theme was dieting and calorie restriction. This is also true of the pro-anorexia videos on YouTube. As in many pro-anorexia websites [31], some videos recommend smoking, drinking a lot of water to avoid eating, and the use of laxatives and weight loss drugs (see Figure 3). A simple search on YouTube for “water fasting” retrieves more than 8000 videos. In addition to pro-anorexia and pro-eating disorder websites, music videos featuring thin models have also been shown to be an influential form of mass media for adolescents [38]. Although viewers pay less attention to these videos, exposure to them has led to increased body dissatisfaction [38]. Similarly, this study also found that the most popular pro-anorexia videos were music videos featuring thin models.

The flagging of videos as inappropriate to minors was shown to be of limited use. In fact, minors (age 13-17 years) were found to be the top viewers. The most logical explanation for minor viewers of flagged videos is that the minors were actively watching them before they were flagged. Another problem with flagging is its reliance on the data provided by users, which can be inaccurate [41]. Pro-anorexia content on social media can be particularly dangerous for minors because they may come across pro-anorexia content while searching for related topics, such as healthy diets. Therefore, on the one hand, awareness needs to be raised among teenagers about their perception of beauty and healthy lifestyles; on the other hand, future research needs to focus on the development of search algorithms to promote informative content and prevent harmful content from being accessible.

There is a common misconception that the accuracy of online information is directly related to the number of hits or views. In other words, the more hits or incoming links, the more relevant the information is in search algorithms such as

PageRank [42]. The same applies to videos; more views mean the content is popular and, therefore, more accurate and relevant. However, this is not true. There are thousands of health-related videos promoting misleading information that garner millions of views. Studies reporting the characteristics of misleading information and the community that generates such content could be used to create more robust search engines to make it easier to find trustworthy content while filtering out misleading information. For example, Fernandez-Luque et al [6] explored the use of social network analysis to find relevant diabetes content on YouTube. In this study, we found (as shown in Table 2) that popularity favored misleading information. Therefore, a robust search engine will need to take into account other parameters, such as trust-based algorithms based on social network analysis or natural language processing (NLP) techniques, and not merely popularity. For example, NLP has demonstrated its ability to extract information and relations from texts [43]. A classification of the content according to its informative nature could be performed by analyzing the metadata of extracted videos, as proposed by Himmel et al [44] on health forums.

Study Limitations

This study was limited to the content analysis of videos retrieved on October 10, 2011, from YouTube; it was not replicated in other video platforms, such as Vimeo. Therefore, the external validity of the data is limited and may not be generalized to overall health-related videos available on the Internet. The classification performed by physicians was subjective, although definitions for each category were provided. We did not use thinspo as a separate criterion. However, during our group discussions we agreed that videos about the inspiration to become thin (thinspo) should be rated as videos promoting anorexia. In addition, referring to pro-anorexia videos as misleading is a simplification because they can be informative, but still harmful from a health point of view.

The data used for this study was from YouTube and was anonymous. For example, it is virtually impossible to be certain about the identity of those responsible for creating or uploading the videos because individual users may have (illegally) uploaded videos using false email identification. In addition, the age of users cannot be confirmed because minors can fake their age to gain access to restricted content.

We were interested in the videos with the maximum number of viewers and not the number of videos per se; therefore, we selected the top 40 videos, not all 140 videos. These 40 videos had a total of 61.13 million views, which is a large enough sample size to understand the characteristic features of the

viewers. Furthermore, search engine optimization experts suggest that 95% of search engine users do not go beyond 2 pages of search results [45]. The interrater agreement in the study was only moderate, primarily because of the complexity of classifying videos that combined music, photos, and text; in 10 cases, the text was not congruent with the photos. We conducted an additional review process to resolve discrepancies pending from the first review.

Conclusion

In this study, we found and quantified the presence of content promoting anorexia on YouTube, the most popular video site. Pro-anorexia videos are less common than informative videos; however, pro-anorexia content is highly favored and rated by users. Another problem identified in our study is the popularity of pro-anorexia videos among young viewers. Health authorities generating health videos on anorexia should be aware of the presence of the pro-anorexia communities and the strategies they use to reach a wider audience, such as featuring models and celebrities.

With the rapid development of information and communication technologies (ICT), digital information is becoming widely available on mobile devices. Social networking websites are acting as catalysts for the dissemination of information. To rephrase Alvin Toffler, the illiterate in this ICT era will not be those who cannot read and write, but those who cannot distinguish between trustworthy and misleading information available online [46]. Most viewers of videos with misleading information are minors; therefore, children need to be taught how to discern between trustworthy and misleading information at school. Health authorities should involve models and celebrities to help them promote health-related information. Researchers should not confine themselves to journals (research communities), but share their research findings on social network sites [47,48]. Laypeople prefer to search for information on the social platforms rather than in scientific journals. We recommend active participation from health institutions and individual researchers to promote informative videos. Active participation also includes flagging (or denouncing) misleading videos.

In addition, more research is required to identify misleading content automatically by using filtering algorithms based on the different characteristics of pro-anorexia and informative videos. A recent study of pictures promoting anorexia in a photo-sharing community [39] found that social and textual clues could be used to automatically identify pro-anorexia pictures. These approaches could be used to filter pro-anorexia content before it is published.

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Authors' Contributions

The authors S Syed-Abdul, L Fernandez-Luque, and Y-C Li were involved in the study design; S Syed-Abdul, L Fernandez-Luque, S Crain, Y-C Wang, K Dorjsuren, and E Chuluunbaatar participated in the data collection; W-S Jian, M-H Hsu, A Nguyen, and D-M Liou participated in the discussion and interpretation of the results; and S Syed-Abdul and L Fernandez-Luque led the manuscript drafting. All authors have read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Example of a pro-anorexia video “Thinspo (Syntax Error - Träumen im Gras)” by MelinaAnaJolie, from <http://www.youtube.com/watch?v=QD3nLj58j2Q> (<http://www.webcitation.org/6EP3xdcPt>), reproduced under Creative Commons Attribution License.

[[FLV File, 25MB - jmir_v15i2e30_app1.flv](#)]

Multimedia Appendix 2

Example of an informative video “10 Things I want Parents to Know About Anorexia” by 101daisysaisy, from <http://www.youtube.com/watch?v=j8txQmvin4> (<http://www.webcitation.org/6EP4COGC>), reproduced under Creative Commons Attribution License.

[[FLV File, 17MB - jmir_v15i2e30_app2.flv](#)]

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Abbreviations

API: application programming interface
ICT: information and communication technologies
NLP: natural language processing
OR: odds ratio

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Original Paper

Impact of Internet Use on Loneliness and Contact with Others Among Older Adults: Cross-Sectional Analysis

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Abstract

Background: Older adults are at increased risk of experiencing loneliness and depression, particularly as they move into different types of care communities. Information and communication technology (ICT) usage may help older adults to maintain contact with social ties. However, prior research is not consistent about whether ICT use increases or decreases isolation and loneliness among older adults.

Objective: The purpose of this study was to examine how Internet use affects perceived social isolation and loneliness of older adults in assisted and independent living communities. We also examined the perceptions of how Internet use affects communication and social interaction.

Methods: One wave of data from an ongoing study of ICT usage among older adults in assisted and independent living communities in Alabama was used. Regression analysis was used to determine the relationship between frequency of going online and isolation and loneliness (n=205) and perceptions of the effects of Internet use on communication and social interaction (n=60).

Results: After controlling for the number of friends and family, physical/emotional social limitations, age, and study arm, a 1-point increase in the frequency of going online was associated with a 0.147-point decrease in loneliness scores ($P=.005$). Going online was not associated with perceived social isolation ($P=.14$). Among the measures of perception of the social effects of the Internet, each 1-point increase in the frequency of going online was associated with an increase in agreement that using the Internet had: (1) made it easier to reach people ($b=0.508$, $P<.001$), (2) contributed to the ability to stay in touch ($b=0.516$, $P<.001$), (3) made it easier to meet new people ($b=0.297$, $P=.01$), (4) increased the quantity of communication with others ($b=0.306$, $P=.01$), (5) made the respondent feel less isolated ($b=0.491$, $P<.001$), (6) helped the respondent feel more connected to friends and family ($b=0.392$, $P=.001$), and (7) increased the quality of communication with others ($b=0.289$, $P=.01$).

Conclusions: Using the Internet may be beneficial for decreasing loneliness and increasing social contact among older adults in assisted and independent living communities.

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KEYWORDS

computers; Internet; loneliness; social isolation; social interaction; older adults; assisted living facilities; independent living

Introduction

As individuals age, they often lose contact with their social network members because of retirement, death of friends and family, and people moving away [1], or communication becomes difficult to maintain due to time or distance. This loss of contact is often associated with declines in socioemotional outcomes, such as feelings of social isolation and increased loneliness. Information and communication technology (ICT) use may help improve socioemotional outcomes by helping older adults overcome time and distance to create or maintain social relationships, thereby decreasing social isolation and loneliness. One particular setting in which loneliness and social isolation may become problematic is in assisted and independent living communities (AICs). Residents of AICs often leave behind social ties when they move from private homes into AICs [2]. The purpose of this study is to examine whether one type of ICT use, specifically Internet use, is related to experiences of loneliness and social isolation among people in independent and assisted living.

Background

Although aging in place (remaining in one's home and community) is often cited as the living option preferred by most older adults [3], this is often not a viable option. As people age, they often find themselves in situations where they require more monitoring or care than they can receive living in their home due to declining health or other factors, precipitating a move to an AIC [4]. This type of move often puts older adults at increased risk of feelings of loneliness and social isolation.

Loneliness and social isolation are closely related, yet distinct, concepts. Loneliness is the subjective experience [5] of negative feelings about levels of social contact [6]; otherwise stated, it is the involuntary state of social isolation or the feeling of being alone [7]. Loneliness does not stem solely from objective levels of contact, but rather results from the differences between the levels of desire for social relationships and the availability of relationships [8]. Researchers using loneliness measures typically ask respondents whether they feel lonely, whether they see enough of people, and whether they wish for more contact [6].

Social isolation is the objective experience [5] of the absence of contact with other people [9], especially the absence of contact with people who provide needed or desired social support [6]. Therefore, social isolation is the absence of meaningful social relationships [10]. Although social isolation and loneliness are closely related concepts, the socially isolated person may not report feelings of loneliness even though they lack social contact [1,11]. Conversely, the person who is not socially isolated and has abundant social contact may report feelings of loneliness if that contact is not perceived as fulfilling what the person wants from the relationship [11].

Older adults, in particular, often experience higher rates of loneliness [12,13] and social isolation [1]. This occurs for a variety of reasons, including death of social ties, relocation to different types of living and care communities, and limitations in physical and mental health. In addition, age is negatively

related to network size, closeness to network members, and number of primary group ties [14]. Social isolation is a particular problem for older African Americans [15], childless individuals, and widows [6]. Those at risk for loneliness include older adults who have recently migrated following retirement, those caring for a dependent spouse [6], the chronically ill [1], those living alone [7], females, and those living in rural communities [13]. Another risk factor for loneliness among older adults appears to be living in an assisted living facility [2]. A meta-analysis on the influences of loneliness in older adulthood confirmed some of the aforementioned risk factors, such as moving to an institution, having less contact with others, and being female [16]. Another meta-analysis on loneliness in older adulthood showed that decreased levels of physical health, occupying a lower socioeconomic status, and residing in a nursing facility were also risk factors for loneliness among this population [17]. Loneliness does not increase simply because of additional years, but because of an increase in disability and a decrease in social integration [12]. Both loneliness [18] and social isolation [9] are multidimensional concepts, which indicate the need for researchers to examine the social and contextual factors behind the presence or absence of the 2 experiences.

Each of these risk factors for social isolation and loneliness are particularly prevalent among older adults who move to different types of care communities. Older adults who move into assisted living communities are likely to experience loneliness [2]. The importance of familial relationships for such residents combined with dissatisfaction regarding the levels of contact with family members can result in a reduced quality of life for assisted living residents [2]. One possible way to counteract these effects is through Internet use to help maintain social contact with social network ties [19].

Internet Use, Contact with Others, and Loneliness Among Older Adults

Internet use enables older adults to stay in contact with others [20,21] and communicate with their social ties [22,23]. For example, email is more effective than in-person or phone communication for facilitating regular contact with family and friendship networks [24-29]. A wealth of research indicates that ICT usage may help older adults maintain contact with social ties [20-22,24,27,30-46] with relationships taking place both online and offline [38]. Internet use can also reduce the impact of geographic distance for older adults [45,47], with dispersed families increasingly using the Internet as the primary conduit through which they sustain generational bonds [48].

Older adults lag behind younger age groups in using the Internet. Approximately half of individuals aged 65 and older use the Internet, with 70% of users reporting going online on a usual day [49]. This group is still the least likely to use a computer at home [50]. Social networking site (SNS) use is one Internet application use that has grown exponentially among older adults in the past few years, with just over one-third of Internet users being active on SNSs. They often report doing so to keep in touch with family members. However, email is the primary conduit through which online communication happens for older adult users, with 86% reporting using it. Once older adults are able to cross the digital divide, going online seems to become

a usual part of their lives [49]. Unfortunately, older adults aged 75 years and older tend to remain on the wrong side of the digital divide: “Few among this oldest segment of the population are likely to start using the Internet without some assistance and encouragement” [49].

Whether Internet use increases or decreases social isolation is not clear-cut. Although much research has shown Internet use to be of benefit in reducing social isolation and loneliness, other research has found Internet use to be of little or no benefit. Various researchers have found Internet use to be associated with decreases in social isolation and loneliness or to be associated with increases in social connectivity [30,33-39,46-48,51,52]. Use of the Internet has also been shown to enrich the lives of isolated older adults [53], with some older adults reporting lower perceived life stress as a result of ICT use [54]. Likewise, positive associations have been shown between use of the Internet and perceptions of self-efficacy [35].

Other results have not been so positive. Loges and Jung [55] found no relationship between Internet connectedness and social isolation in older adults. Another study of the general population (not just older adults), demonstrated that Internet use had a relatively limited impact on social relationships [56], with still other research indicating that ICT use was associated with an initial decline in social network size and increased loneliness [57]. However, a follow-up study with this same sample done in 2002 showed that Internet users experienced positive effects on communication, social involvement, and well-being [58].

Even when Internet use helps create or maintain relationships, the effects may not fully replicate what has been lost. Nimrod [21], for example, found that relationships constructed in online senior communities are more superficial than offline or real relationships. Results are also likely to vary as a function of the type, amount, timing, and function of Internet usage [59]. If individuals use the Internet for noncommunicative purposes or they are using it in excessive amounts to the detriment of their social roles, it is likely that there will be little impact on their loneliness and social isolation, or that loneliness and social isolation will increase. However, regular usage and use for communicative purposes, such as keeping in touch with social ties and garnering social support, are likely to have positive benefits for older adults. Recent research has shown that going online twice per week was associated with lower levels of loneliness and depression for older adults [60]. As Cotten and colleagues [59] have shown, researchers must go beyond merely including simple measures of Internet usage; they must also examine the type, amount, timing, and function of use because these can influence outcomes in a variety of ways. Although there is much evidence to indicate that Internet use can be beneficial for older adults in overcoming social isolation or loneliness, more research is needed, especially among older adults in continuing care communities.

The purpose of this study was to examine whether frequency of Internet use among older adults in AICs is associated with perceptions of (1) loneliness, (2) perceived social isolation, and (3) the usefulness of the Internet in affecting quantity and quality of communication with social network ties.

Methods

Recruitment

The data for this analysis came from an ongoing randomized controlled trial intervention. Alabama, the state where the intervention was conducted, ranked among the lowest in regards to individuals living in households with Internet access [61].

In this study, older adults living in AICs were randomized into 3 groups: (1) ICT (treatment), (2) attention control (placebo), or (3) true control (no treatment or placebo). Older adults living in AICs in the treatment arm were given 8 weeks of training in using computers and the Internet to communicate with family and friends (primarily through email and Facebook) and to find information. Participants in the attention control arm were involved in 8 weeks of activities unrelated to ICTs. Participants in the true control arm did not participate in any intervention activities. Participants from all 3 arms were surveyed 5 times over the course of 1 year: before the 8 weeks (at baseline); at the end of the 8-week intervention; and at 3, 6, and 12 months after the end of the 8-week intervention. Because the purpose of this paper is to examine the relationship among Internet use and outcomes such as loneliness, perceived social isolation, and perceptions of the usefulness of the Internet for staying in touch, ICT users (participants with Internet access) from all 3 arms are included. Additionally, because data collection is not yet complete for all waves of the study, this analysis only uses time 1 (or pretest) data for a cross-sectional analysis. Baseline time 1 data were collected within 1 to 2 weeks of the beginning of any intervention activities. There were 205 participants in the entire sample, with data from 205 participants for the socioemotional analyses, and data from 60 participants for the Internet outcomes because people who responded that they never went online ($n=145$) were not asked the Internet outcome questions.

Measures

Our socioemotional outcomes include loneliness, perceived social isolation, and the quality and quantity of communication with others as a result of Internet use. Loneliness was measured with a 3-item version of the UCLA Loneliness Scale [62]. Items in the scale ($\alpha=.74$) were:

1. How often do you feel that you lack companionship?
2. How often do you feel left out?
3. How often do you feel isolated from others?

Responses were measured on a 3-point scale: 1 (hardly ever), 2 (some of the time), and 3 (often). Scores on the individual items were summed to produce the scale.

To measure perceived social isolation, a scale was used ($\alpha=.69$) in which participants were asked how much of the time they were bothered by (1) not having a close companion, (2) not having enough friends, and (3) not seeing enough of the people you feel close to. The responses were coded as 1 (never), 2 (a little of the time), 3 (some of the time), 4 (most of the time), or 5 (all the time). The mean of the 3 scores was used as the scale measure.

Participants who reported going online at least once every few months were asked a series of 7 questions regarding their perceptions of how Internet use had affected their social interactions with others. Participants were asked to what extent they agreed or disagreed with the following statements: “Using the Internet has...” (1) made it easier for me to reach people, (2) contributed to my ability to stay in touch with people I know, (3) made it easier to meet new people, (4) increased the quantity of my communication with others, (5) made me feel less isolated, (6) helped me feel more connected to friends and family, and (7) increased the quality of my communication with others. The responses were coded as 1 (strongly disagree), 2 (disagree), 3 (neither agree nor disagree), 4 (agree), or 5 (strongly agree). These items were assessed individually to better analyze the respondent’s perceptions of the usefulness of the Internet in each specific domain (eg, quality of communication versus quantity; ability to maintain relationships versus establishing new ones).

Internet use was measured simply as frequency of going online. Participants were asked how often they went online: 0 (never), 1 (once every few months), 2 (about once a month), 3 (several times a month), 4 (about once a week), or 5 (several times a week). Only participants who reported having Internet access were included in the analysis because those reporting no Internet access were not asked about their perceptions of how Internet use has affected their communications with others.

Statistical Analysis

A series of ordinary least squares (OLS) regression analyses were conducted using communications, social isolation, and loneliness as the primary outcomes, and Internet use as the primary independent variable. Analyses controlled for age, the number of social network members (friends and family to whom the participant felt close), study arm (ICT intervention group, attention control group, or true control group), assisted or

independent living status, and physical or emotional limitations that would limit social interaction, ie, how much of the time in the past month the participant experienced mental or physical health problems that limited social interaction, measured as 0 (none of the time), 1 (a little of the time), 2 (some of the time), 3 (most of the time), or 4 (all the time). Although we would normally have controlled for race/ethnicity and gender, these controls were not included because most of the sample was white and female.

Results

Sample Demographics

As noted, our sample (N=205) was predominantly white (n=194, 94.6%) and female (n=169, 82.4%), with a mean age of 82.8 years (full sample characteristics are presented in [Table 1](#)). The sample contained 79 participants who enrolled for ICT training and 126 who had not. On average, study participants had 11.2 friends or family to whom they felt close and appeared unencumbered by physical or mental health issues that might affect their social interaction. The sample was almost evenly split between assisted and independent living residents.

The mean frequency of going online was 1.30 (between once every few months and about once a month), whereas the median frequency of going online was 0.0 with an interquartile range (IQR) of 3.5. Median loneliness was 4.0 (IQR 2.0), indicating low to moderate levels of loneliness in the sample as a whole. Mean perceived social isolation was 1.96, with a median of 1.67, indicating little perception of social isolation. With the exception of “the Internet has made it easier to meet new people,” median scores on the Internet outcome measures were all 4.0, indicating that the sample tended to agree that the Internet had affected their social interactions (summaries of key measures are presented in [Table 2](#)).

Table 1. Sample characteristics (N=205).

Study variables	Participants
Sex, n (%)	
Male	36 (17.6)
Female	169 (82.4)
Age, mean (SD)	82.8 (7.7)
Race/ethnicity, n (%)	
White	194 (94.6)
Other	11 (5.4)
Study arm, n (%)	
ICT intervention	79 (38.5)
Attention control	72 (35.1)
True control	54 (26.3)
Living status, n (%)	
In independent living	103 (50.2)
In assisted living	102 (49.8)

Table 2. Summary of key measures (N=205).

Key variables	Mean (SD)	Median (IQR) ^a
Key independent variable		
Frequency of going online	1.30 (2.1)	0.0 (3.5)
Number of close family/friends	11.16 (7.29)	10.0 (8.5)
Physical/emotional limitation to social interaction	0.73 (0.99)	0.0 (1.0)
Outcomes		
Loneliness	4.24 (1.57)	4.0 (2.0)
Social isolation	1.96 (0.82)	1.7 (1.0)
The Internet has: (n=60)		
Made it easier to reach people	3.73 (1.10)	4.0 (1.0)
Contributed to my ability to stay in touch	3.87 (1.08)	4.0 (1.0)
Made it easier to meet new people	2.72 (0.98)	2.5 (1.0)
Increased the quantity of my communication	3.53 (1.03)	4.0 (2.0)
Made me feel less isolated	3.60 (0.98)	4.0 (1.0)
Helped me feel more connected to friends/family	3.73 (1.02)	4.0 (1.0)
Increased the quality of my communication	3.60 (0.96)	4.0 (1.0)

^a IQR: interquartile range

The primary independent variable (frequency of going online) was weakly and negatively correlated with loneliness (Pearson $r=-0.232$, $P=.001$) and social isolation ($r=-0.134$, $P=.06$). Frequency of going online was moderately correlated with the Internet outcome variables, with Pearson correlation coefficients

ranging from 0.304 ($P=.02$) (using the Internet has increased the quality of my communication with others) to 0.514 ($P<.001$) (using the Internet has made me feel less isolated). Full correlation results are presented in [Tables 3](#) and [4](#).

Table 3. Correlations (Pearson r) among independent variables and outcomes.

Variable	Loneliness (n=205)		Social isolation (n=205)	
	r	P	r	P
Frequency of going online	-0.232	.001	-0.134	.06
Number of close friends/family	-0.136	.05	-0.144	.04
Physical/emotional limitations	0.162	.02	0.273	<.001
Age	-0.099	.16	-0.064	.36
In ICT intervention arm	-0.025	.72	-0.065	.35
In attention control arm	0.136	.05	0.170	.02
In assisted living	0.210	.003	0.116	.10

Table 4. Correlations (Pearson *r*) among independent variables and answers to the question “Using the Internet has...” (n=60).

Key variables	Using the Internet has... ^a													
	A		B		C		D		E		F		G	
	<i>r</i>	<i>P</i>	<i>r</i>	<i>P</i>	<i>r</i>	<i>P</i>	<i>r</i>	<i>P</i>	<i>r</i>	<i>P</i>	<i>r</i>	<i>P</i>	<i>r</i>	<i>P</i>
Frequency of going online	0.477	<.001	0.494	<.001	0.314	.01	0.308	.02	0.514	<.001	0.411	.001	0.304	.02
Number of close friends/family	0.065	.62	0.089	.50	0.191	.14	0.144	.27	0.061	.64	0.215	.10	0.186	.15
Physical/emotional limitations	0.126	.34	0.128	.33	0.013	.92	0.227	.08	0.108	.41	-0.048	.72	0.164	.21
Age	-0.088	.50	-0.056	.67	-0.052	.69	-0.081	.54	-0.154	.24	0.111	.40	-0.114	.39
In ICT intervention arm	0.027	.84	-0.034	.79	0.187	.15	-0.126	.34	0.064	.63	0.166	.21	0.065	.62
In attention control arm	-0.163	.21	-0.101	.44	-0.252	.05	-0.204	.12	0.054	.68	-0.287	.03	-0.182	.16
In assisted living	0.018	.89	-0.060	.65	0.031	.81	-0.039	.77	-0.122	.35	-0.017	.90	0.070	.60

^a A: made it easier to reach people; B: contributed to my ability to stay in touch; C: made it easier to reach new people; D: increased the quantity of my communication with others; E: made me feel less isolated; F: helped me feel more connected to friends and family; and G: increased the quality of my communication with others.

Frequency of Going Online and Outcomes

Results of OLS regression analyses showed a relationship between the frequency of going online and socioemotional outcomes (see Table 5) and between frequency of going online and selected Internet-usefulness outcomes (see Table 6). Among the socioemotional outcomes, a 1-point increase in the frequency

of going online was associated with a 0.172-point decrease in loneliness scores ($P=.001$) (full results presented in Table 5). After controlling for the number of friends and family, physical/emotional social limitations, age, and study arm, the association remained with a 1-point increase in the frequency of going online being associated with a 0.147-point decrease in loneliness scores ($P=.005$).

Table 5. Ordinary least squares (OLS) regressions^{a,b} of socioemotional outcomes (N=205).

Independent variables	Loneliness (score range: 3-9)				Social isolation (score range: 1-5)			
	Model 1		Model 2		Model 1		Model 2	
	<i>b</i>	<i>P</i>	<i>b</i>	<i>P</i>	<i>b</i>	<i>P</i>	<i>b</i>	<i>P</i>
Constant	4.463	<.001	6.537	<.001	2.028	<.001	2.451	<.001
Frequency of going online	-0.172	.001	-0.147	.005	-0.051	.06	-0.040	.14
Number of family/friends			-0.027	.06			-0.014	.06
Physical/emotional social limitation			0.178	.10			0.200	<.001
Age			-0.028	.05			-0.007	.37
In ICT intervention arm			0.123	.65			0.027	.85
In attention control arm			0.304	.27			0.223	.12
In assisted living			0.408	.07			0.058	.61
<i>F</i> statistic (df) ^c	11.55 (1, 203)	.001	4.34 (7, 197)	<.001	3.69 (1, 203)	.06	4.17 (7, 197)	<.001
Adjusted R^2	0.05		0.13		0.01		0.10	

^a Unstandardized coefficients presented.

^b Model 1 uses the key independent variable only. Model 2 adds control variables.

^c Degrees of freedom.

Likewise, going online more often was associated with a decrease in the perception of social isolation. A 1-point increase in online frequency was associated with a 0.051-point decrease

in respondents’ perceived social isolation ($P=.06$). This relationship, however, failed to hold up in the presence of the controls with a 1-point increase in frequency of going online

being associated with a statistically nonsignificant 0.040-point decrease in perceived social isolation ($P=.14$).

Among the measures of perception of the social effects of the Internet (see Tables 6-9), all outcomes showed a statistically significant relationship with frequency of going online. Each 1-point increase in the frequency of going online was associated with a 0.508-point increase in agreement that using the Internet had made it easier to reach people ($P<.001$); a 0.516-point increase in agreement that using the Internet had contributed to the respondents' ability to stay in touch ($P<.001$); a 0.297-point increase in agreement that using the Internet had made it easier

to meet new people ($P=.01$); a 0.306-point increase in agreement that using the Internet had increased the quantity of respondents' communication with others ($P=.01$); a 0.491-point increase in agreement that using the Internet had made the respondent feel less isolated ($P<.001$); a 0.392-point increase in agreement that using the Internet helped the respondent feel more connected to friends and family ($P=.001$); and a 0.289-point increase in agreement that using the Internet had increased the quality of respondents' communication with others ($P=.01$).

There were no consistent patterns of association between the control variables and the outcomes.

Table 6. Ordinary least squares (OLS) regressions^{a, b} for using the Internet has made it easier to reach people and contributed to my ability to stay in touch (n=60).

Independent variables	Made it easier to reach people				Contributed to ability to stay in touch			
	Model 1		Model 2		Model 1		Model 2	
	<i>b</i>	<i>P</i>	<i>b</i>	<i>P</i>	<i>b</i>	<i>P</i>	<i>b</i>	<i>P</i>
Constant	1.661	.002	3.240	.03	1.763	.001	2.492	.09
Frequency of going online	0.467	<.001	0.508	<.001	0.475	<.001	0.516	<.001
Number of family/friends			0.021	.35			0.023	.31
Physical/emotional social limitation			0.015	.91			0.039	.77
Age			-0.024	.18			-0.013	.45
In ICT intervention arm			-0.196	.54			-0.300	.34
In attention control arm			-0.370	.28			-0.214	.52
In assisted living			0.288	.35			0.074	.81
<i>F</i> statistic (df) ^c	17.094	<.001	3.136	.01	18.737	<.001	3.175	.007
	(1, 58)		(7, 52)		(1, 58)		(7, 52)	
Adjusted R^2	0.21		0.20		0.23		0.21	

^a Unstandardized coefficients presented.

^b Model 1 uses the key independent variable only. Model 2 adds control variables.

^c Degrees of freedom.

Table 7. Ordinary least squares (OLS) regressions^{a,b} for using the Internet has made it easier to meet new people and increased the quantity of my communication with others (n=60).

Independent variables	Made it easier to meet new people				Increased quantity of communication with others			
	Model 1		Model 2		Model 1		Model 2	
	<i>b</i>	<i>P</i>	<i>b</i>	<i>P</i>	<i>b</i>	<i>P</i>	<i>b</i>	<i>P</i>
Constant	1.508	.003	2.690	.06	2.280	<.001	2.673	.07
Frequency of going online	0.273	.01	0.297	.01	0.283	.02	0.306	.01
Number of family/friends			0.040	.06			0.024	.28
Physical/emotional social limitation			-0.052	.69			0.170	.21
Age			-0.022	.17			-0.007	.70
In ICT intervention arm			0.249	.40			-0.603	.06
In attention control arm			-0.333	.29			-0.632	.06
In assisted living			0.322	.26			0.149	.62
<i>F</i> statistic (df) ^c	6.358	.01	2.237	.05	6.086	.02	2.526	.03
	(1, 58)		(7, 52)		(1, 58)		(7, 52)	
Adjusted <i>R</i> ²	0.08		0.13		0.08		0.15	

^a Unstandardized coefficients presented.

^b Model 1 uses the key independent variable only. Model 2 adds control variables.

^c Degrees of freedom.

Table 8. Ordinary least squares (OLS) regressions^{a,b} for using the Internet has made me feel less isolated and helped me feel more connected to friends and family (n=60).

Independent variables	Made me feel less isolated				Helped me feel more connected to friends and family			
	Model 1		Model 2		Model 1		Model 2	
	<i>b</i>	<i>P</i>	<i>b</i>	<i>P</i>	<i>b</i>	<i>P</i>	<i>b</i>	<i>P</i>
Constant	1.619	.001	3.211	.01	2.076	<.001	1.685	.23
Frequency of going online	0.447	<.001	0.491	<.001	0.374	.001	0.392	.001
Number of family/friends			0.022	.25			0.042	.05
Physical/emotional social limitation			0.009	.94			-0.091	.48
Age			-0.027	.07			-0.001	.96
In ICT intervention arm			0.266	.33			0.035	.91
In attention control arm			0.383	.18			-0.444	.16
In assisted living			-0.096	.71			0.189	.51
<i>F</i> statistic (df) ^c	20.876	<.001	4.171	.001	11.806	.001	3.090	.008
	(1, 58)		(7, 52)		(1, 58)		(7, 52)	
Adjusted <i>R</i> ²	0.25		0.27		0.16		0.20	

^a Unstandardized coefficients presented.

^b Model 1 uses the key independent variable only. Model 2 adds control variables.

^c Degrees of freedom.

Table 9. Ordinary least squares (OLS) regressions^{a,b} for using the Internet has increased the quality of my communication (n=60).

Independent variables	Increased the quality of my communication			
	Model 1		Model 2	
	<i>b</i>	<i>P</i>	<i>b</i>	<i>P</i>
Constant	2.449	<.001	3.482	.01
Frequency of going online	0.260	.02	0.289	.01
Number of family/friends			0.042	.05
Physical/emotional social limitation			0.094	.46
Age			-0.022	.17
In ICT intervention arm			0.031	.92
In attention control arm			-0.269	.39
In assisted living			0.427	.13
<i>F</i> statistic (df) ^c	5.917 (1, 58)	.02	2.213 (7, 52)	.05
Adjusted <i>R</i> ²	0.08		0.13	

^a Unstandardized coefficients presented.

^b Model 1 uses the key independent variable only. Model 2 adds control variables.

^c Degrees of freedom.

Discussion

Key Results

Our findings indicate that Internet use was associated with lower levels of loneliness among residents of AICs. Given recent research showing that loneliness among the older adult population is associated with a higher chance of fulfilling the criteria for metabolic syndrome [63] and an increased risk of death [64], the maintenance of personal relationships through the Internet could be critical to well-being for this segment of the population. Moreover, among the general population, using the Internet to maintain communication with family and friends has been associated with well-being [65], further providing support for the idea that going online could be beneficial for older adults.

Our results, however, suggest that the frequency of going online impacts loneliness, but not perceptions of social isolation, with higher frequency associated with lower levels of loneliness but not with lower levels of perceived social isolation. It may be that perceptions of social isolation are related more to face-to-face contact than online contact with network ties; thus, frequency of going online is not related to perceived isolation. Unfortunately, our data do not allow us to further explore this relationship. Although mixed, these results support prior research showing that Internet use positively impacts quality of life among older adults [19-21,33-37,39,44-45,53,66,67].

Perhaps unsurprising among a group of self-motivated Internet users, participants tended to agree that using the Internet had a positive effect on their social relationships, making it easier to reach people, stay in touch, meet new people, feel less isolated, and feel more connected to friends and family. It is interesting that frequency of going online was not associated with our social isolation scale; however, frequency of going online was

associated with participants agreeing that using the Internet made them feel less isolated. Although they may perceive that the Internet is useful in this particular way, simply measuring frequency of going online is not sufficient to impact social isolation. Participants also tended to agree that using the Internet had increased both the quantity and quality of their communication with others. Unfortunately, our measure does not allow us to speak to the degree of this change, only to the degree of agreement that each one has increased.

Of note is that the strength of these various relationships varies greatly. For example, the relationship between frequency of going online and agreement that the Internet had made it easier to reach people, contributed to my ability to stay in touch, made me feel less isolated, and helped me feel more connected to friends and family were all comparatively strong, with coefficients ranging from 0.392 to 0.516. Much weaker were the associations between frequency of going online and agreement that the Internet had made it easier to meet new people, increased the quantity of communication with others, and increased the quality of my communication with others, with coefficients ranging from 0.289 to 0.306. Taken together, these results suggest the perception that the Internet is comparatively better at facilitating established communications, even perhaps replacing older communications methods. The Internet is comparatively worse at affecting either the quantity or quality of communications or helping to establish new relationships.

Although other studies have found that older adults report the quality of social contact being more important than the quantity of social contact [68], our results suggest that the more important contrast is between the ability of the Internet to help simply maintain relationships and the ability (or lack thereof) of the Internet to help deepen relationships or create new ones, at least

among older adults. This may be related to the previous finding that online relationships may be perceived as more superficial than other relationships [21]. Thus, in terms of using the Internet to help alleviate the effects of loneliness or social isolation, it may be enough to use the Internet to simply stay in touch or feel like one is a part of what is going on in the world, as opposed to attempting to use the Internet to create and/or maintain deep, personal relationships.

Although recent data have shown communication with others to be a primary reason why older adults go online [49], some might still be reluctant to adopt the Internet as a way of connecting with others, thereby placing them at further risk of loneliness and social isolation. Regardless of older adults' level of motivation and reasons for going online, ICT training and interventions could enable them to cross the digital divide [22,68-70] and employ ICTs as a way to alleviate loneliness.

Limitations

Limitations of the current study include the small sample size, the lack of diversity in terms of gender and race/ethnicity, and lack of measures of disability, caregiving, migration, chronic health conditions and pre-AIC levels of social integration, and that the study was only conducted in AICs in Alabama. Another limitation of the present study is that it did not measure participants' expectations about how going online might impact levels of loneliness and social isolation. As reported elsewhere, computer acceptance is motivated by older adults' expectations of how computer usage will help them achieve what they deem

valuable [71]. An important variable to include in analyses such as the ones presented here, for example, could be whether participants were going online with the intention of connecting with others. Similarly, additional measures assessing the type, timing, amount, and function of Internet use could provide further insights into these relationships [59]. Also, further research is needed on how technology usage may impact older adults not living in AICs and how these processes may vary as a function of gender, race/ethnicity, severity of health impairment, and region of the country. Given that only cross-sectional data were used, the results of this study indicate associations between key measures but should not be seen as reflective of causal relationships.

Conclusions

In sum, this research contributes to the work in this area by showing that Internet usage has positive benefits for older adults living in AICs. Given that this population experiences high rates of loneliness and depression, with psychosocial resources providing a buffer for depression [72] and personal social networks enhancing well-being [73], encouraging older adults to begin using the Internet to communicate with others could help to enhance social contact and decrease loneliness. As formal care homes are able to encourage social engagement between residents [74], continuing existing ICT programs and beginning new ones in communities without programs could be beneficial for fostering relationships among residents as well as with others in their social networks.

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Conflicts of Interest

None declared.

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Abbreviations

- AIC:** assisted and independent living community
- ICT:** information and communication technology
- IQR:** interquartile range
- OLS:** ordinary least squares
- SNS:** social networking site

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Original Paper

Web 2.0 Chronic Disease Self-Management for Older Adults: A Systematic Review

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Abstract

Background: Participatory Web 2.0 interventions promote collaboration to support chronic disease self-management. Growth in Web 2.0 interventions has led to the emergence of e-patient communication tools that enable older adults to (1) locate and share disease management information and (2) receive interactive healthcare advice. The evolution of older e-patients contributing to Web 2.0 health and medical forums has led to greater opportunities for achieving better chronic disease outcomes. To date, there are no review articles investigating the planning, implementation, and evaluation of Web 2.0 chronic disease self-management interventions for older adults.

Objective: To review the planning, implementation, and overall effectiveness of Web 2.0 self-management interventions for older adults (mean age ≥ 50) with one or more chronic disease(s).

Methods: A systematic literature search was conducted using six popular health science databases. The RE-AIM (Reach, Efficacy, Adoption, Implementation and Maintenance) model was used to organize findings and compute a study quality score (SQS) for 15 reviewed articles.

Results: Most interventions were adopted for delivery by multidisciplinary healthcare teams and tested among small samples of white females with diabetes. Studies indicated that Web 2.0 participants felt greater self-efficacy for managing their disease(s) and benefitted from communicating with health care providers and/or website moderators to receive feedback and social support. Participants noted asynchronous communication tools (eg, email, discussion boards) and progress tracking features (eg, graphical displays of uploaded personal data) as being particularly useful for self-management support. Despite high attrition being noted as problematic, this review suggests that greater Web 2.0 engagement may be associated with improvements in health behaviors (eg, physical activity) and health status (eg, HRQoL). However, few studies indicated statistically significant improvements in medication adherence, biological outcomes, or health care utilization. Mean SQS scores were notably low (mean=63%, SD 18%). Studies were judged to be weakest on the Maintenance dimension of RE-AIM; 13 reviewed studies (87%) did not describe any measures taken to sustain Web 2.0 effects past designated study time periods. Detailed process and impact evaluation frameworks were also missing in almost half (n=7) of the reviewed interventions.

Conclusions: There is need for a greater understanding of the costs and benefits associated with using patient-centered Web 2.0 technologies for chronic disease self-management. More research is needed to determine whether the long-term effectiveness of these programs is sustainable among larger, more diverse samples of chronically ill patients. The effective translation of new

knowledge, social technologies, and engagement techniques will likely result in novel approaches for empowering, engaging, and educating older adults with chronic disease.

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KEYWORDS

chronic disease; self-care; internet; social media

Introduction

Background

According to the Centers for Disease Control and Prevention, nearly half of all adults in the United States are living with at least one chronic health condition [1]. Globally, chronic diseases such as heart disease, chronic respiratory illness, and diabetes are by far the leading cause of death, topping most all-cause morbidity lists [2]. As a result, chronic disease care accounts for eighty cents of every health care dollar spent (80%) of total health care expenditures [1]. By 2015, it is estimated that 7 of every 10 (70%) adults aged 50-64 will have been diagnosed with at least one chronic condition, with nearly half living with two or more chronic conditions [3].

Among individuals with chronic disease, the use of the Internet as a “first stop” for health information has increased steadily [4]. Even after controlling for various demographic factors such as age and education, Internet users living with chronic disease are slightly more likely than other Internet users to access health information online and more likely to share acquired health information with others [5]. Considering that more than 2 of every 4 (50%) adults aged 65 and older are now using the Internet or email [6], and 7 in 10 (70%) Internet users 65 and older go online daily [6], Internet-mediated chronic disease self-management and self-monitoring interventions may exhibit great potential to reach a broad population of chronically ill older patients [7-9].

Chronic Disease Patients and Social Networking

Older adults remain strongly connected to offline sources of medical assistance and advice [5]. This is especially true for Americans 65 and older, of whom only 53% used the Internet and only 34% used any social networking site as of spring 2012 [10]. An earlier report in 2011, however, showed Internet use to be significantly more common among adults 50-64 years old, with 78% online, 58% seeking health information on the Web, and 47% using social networking sites [11]. Research shows that the most common explanation offered by those who do not use the Internet is the perception that the Internet is irrelevant to them; they can meet information and communication needs in other ways and see no point in going online [12]. Among older adults, another major reason for less frequent use of the Web, including social media, is lack of access to high-speed Internet connections. While 60% of adults aged 50-64 have broadband access at home, the figure falls to 30% for those 65 and older [12]. Blogging and online health discussion forums are the two most popular social networking activities for people living with chronic disease, primarily because these activities allow an Internet user to dive deeply into a health topic without the need for advanced technical knowledge sometimes

associated with using social media/networking applications such as Twitter or Facebook [5].

Nonetheless, use of social networking among older adults is growing [6]. Approximately 1 in 3 (34%) older Internet users access social networking sites like Facebook and LinkedIn, and approximately 1 in 5 (20%) of these users contributes to these sites regularly by tagging, categorizing, or commenting on online health/medical content [5,6]. Patients increasingly have begun to use the Web as a communication tool, instead of simply an information vending machine [13]. Older adults, in particular, are willing to share self-care information within selected social networks for the purpose of giving and receiving disease-specific self-management information [14]. The evolution of e-patient communities has led to greater opportunities for knowledge acquisition and social support, leading to improved health-related quality of life (HRQoL) [7-9,15,16].

Transitioning from Web 1.0 to Web 2.0 in Chronic Disease Management

Traditionally, public health experts have provided chronic disease information in static form through Web 1.0 interventions, which primarily make written and audio materials available online [17-19]. The use of these eHealth interventions has shown potential to improve health outcomes cost-effectively [15,20-23]. The rapid growth in adoption of Web 2.0 technologies, as documented above, suggests that participatory Internet interventions can help older individuals with chronic diseases become actively engaged in their own health care [15,20,21]. Controlling for age, education, and type of Internet access, living with chronic disease increases the likelihood of contributing to or consuming user-generated health content such as blog posts, hospital or doctor reviews, and podcasts [5,24]. Moreover, online discussion boards provide an open-access space for chronic disease patients to exchange information and learn about how to control disease exacerbations [25-28]. Additionally, available evidence shows that online self-help groups can enhance social capital in ways that do not undermine, and might in some cases strengthen, hyperpersonal connections between patients and providers [29-31].

Multimedia-sharing software enables chronic disease patients to share disease management videos, wikis, and podcasts without the need for advanced technical knowledge. Teleconferencing tools such as Skype provide intimate, two-way communication channels for patients and providers to share information, provide emotional support, and offer practical disease management advice from a distance [32]. These types of social software promote collaboration between patients, caregivers, and practitioners, leading to marked shifts in how patient education for chronic disease management [33].

Current Investigation

Given that older adults suffering from chronic disease are becoming more likely participate in Web 2.0 e-patient communication, it is surprising to note the paucity of formal evaluations examining use of Internet-mediated information and communication technologies (ICTs) among older adults. Specifically, there are no review articles that investigate the planning, implementation, and/or effectiveness of Web 2.0 self-management interventions among older adults with various chronic diseases. Consequently, few evidence-based recommendations exist regarding the development of Web 2.0 interventions for this vulnerable population [34]. A synthesis of the empirical evidence regarding the benefits and limitations of Web 2.0 interventions can enhance the transferability and translational potential of participatory technologies designed for healthy aging. Because of this emergent need, the primary objective of this study was to systematically review the planning, implementation, and overall effectiveness of Web 2.0 chronic disease self-management interventions delivered to older adults living with chronic disease.

Methods

Overview

First, it is important to operationalize several terms that informed our literature screening process. *Web 2.0* was defined as the technical, aesthetic, and functional criteria established to enable collaboration and sharing of information between users on the Internet [35]. A *chronic disease* was defined as a prolonged illness not resolving spontaneously or becoming cured completely, causing nonreversible pathological alteration and residual disability [1]. We specifically searched for studies examining selected chronic diseases (eg, heart disease, chronic obstructive pulmonary disease (COPD), arthritis, hypertension and diabetes) known to be pervasive worldwide [2]; however, studies of individuals with other chronic diseases were included if they met other search criteria. A *chronic disease self-management intervention* was defined as a program specifically designed to train patients to live with their chronic condition by teaching them behaviors to promote self-care and/or foster self-confidence in long-term self-management capability [36,37].

Search Procedures

Because Web 2.0 formally emerged in the research literature in 2004 [38], only manuscripts published in English from January 2004 to October 2012 were considered. The searched databases included: ERIC, PsychINFO, PubMed, Academic Search Premiere, CINAHL Plus, and Applied Social Sciences Index and Abstracts. Search methodology included entering various combinations of key search terms into each database, using controlled vocabulary with the Boolean operators AND and OR. The search terms included: *chronic disease, chronic illness, heart disease, diabetes, arthritis, hypertension, COPD, self-care, self-management, outcome, internet, and website*. The terms “older adult” or “elderly” were not included as search terms to prevent unintentional exclusion of studies examining adults aged 50 and older, the age cutoff previously used by international health organizations [39]. Following the literature

search, reference lists for each eligible study were reviewed for additional articles.

Selection Criteria

The experimental unit of analysis in this review was studies of Web 2.0 interventions administered to adults 50 and older (mean age ≥ 50), living with one or more chronic disease(s). Articles had to describe the planning, implementation, and impact of the intervention by measuring either process (eg, attitudes, self-efficacy, social support), functional (eg, health behavior, participants’ subjective experience of functioning), and/or clinical (eg, morbidity, mortality, HRQoL) outcomes. To minimize the risk of assessment bias, 2 trained researchers documented the literature search at each step of the screening process by tracking results generated within each database search. Titles and abstracts of each study were assessed independently by 1 reviewer and checked by the second. Disagreements between reviewers were discussed and resolved by consensus after referring to the search protocol. A third qualified reviewer in eHealth communication was consulted to resolve any discrepancies before data were extracted.

Study Quality Score

We also assessed the extent to which each study minimized bias and maximized internal and external validity to obtain an indicator of study quality using the RE-AIM evaluation framework [40]. The extracted data from the retained studies were evaluated according to the five dimensions of RE-AIM: Reach, Efficacy, Adoption, Implementation, and Maintenance [40]. *Reach* refers to the percentage and risk characteristics of individuals who participate in an intervention and how representative they are of the population being considered. *Effectiveness* concerns both the intended or positive outcomes of an intervention on targeted outcomes (eg, process, functional, and clinical) and the possible negative or unintended consequences on quality of life and nontargeted outcomes. *Adoption* is characterized as the participation rate and representativeness of both the settings in which an intervention is conducted (eg, doctor’s offices, communities) and the intervention staff who deliver the intervention (eg, physicians, health educators). *Implementation* refers to the extent to which an intervention is delivered consistently across different components of staff over time. *Maintenance*, at the individual level, describes the long-term results of an intervention (≥ 6 months following intervention contact) among participants; at the setting level, it refers to either the short-term continuation or long-term institutionalization of an intervention once the research project and its supports are withdrawn [41].

RE-AIM can help media developers create practical products that are more likely to be widely adopted, feasible in medical practice, and able to produce public health impact. The framework has been successfully applied to evaluate the impact of interactive technology approaches [42]. For example, a focus on the reach of individuals who engage with technology and the robustness of intervention effects is crucial to designing self-management support systems that use appropriate multimedia aids to help all patients, particularly those from low-literate populations. In addition, self-management support is enhanced by focusing on factors such as adoption,

implementation, and sustainability to provide actionable information [42].

To develop a unique assessment instrument for this evaluation task, we assembled quality items from a number of systematic review guides [43–46]. Reach was assessed by analyzing the representativeness of our sample by evaluating the sampling frame, screening criteria, and response rate using items from the *Guide to Community Preventive Services: Systematic Reviews and Evidence-Based Recommendations* [43] and the Effective Public Health Practice Project [44]. To assess efficacy, we used a variety of validated items [43–46] to assess the suitability of study design, credibility of data collection, program evaluation, and statistical analyses. We also created two new items to evaluate how missing data were handled as well as whether *P* values and effect sizes were reported.

Adoption was assessed at both the setting and staff levels. At the setting level, we assessed the short-term feasibility of delivering the program and whether the Web 2.0 intervention was incorporated into the existing structure of the sponsoring institution or organization. At the staff level, we assessed if the project manager possessed adequate expertise and whether stakeholder feedback was collected among program staff members. Implementation was assessed by evaluating Web 2.0 uptake to determine web accessibility, participation adherence [44], and duration (dosage) and intensity of participant exposure to the Web 2.0 intervention. In addition, to assess intervention development and program integration, we administered items from the Intervention Development and Implementation subscales of the Preffi 2.0 health promotion quality assessment package [46], along with one item we created for evaluating use of incentives (eg, gift cards) for participation. Maintenance was assessed at the setting and participant levels. At the setting level, we assessed the contextual conditions and long-term feasibility of each reviewed study using the Contextual Conditions and Feasibility subscale of the Preffi 2.0 package [46]; we added one item to determine whether policies were developed to institutionalize Web 2.0 in practice. At the participant level, we created new items based on RE-AIM evaluation criteria [41] to assess whether positive intervention effects were observed at ≥ 6 months or ≥ 1 year. We also assessed whether long-term attrition remained at or below 30% at follow-up.

Multimedia Appendix 1 lists of all quality criteria measures (with scale origins and ranges) that were used to evaluate each study, and **Multimedia Appendix 2** lists the actual items (with response options and codes) organized by RE-AIM dimensions. Overall, there were 38 total items programmed into an online data extraction rubric that was built to input data from this quality assessment. This tool was pilot tested by the research team on one manuscript that was not included in the final group of reviewed studies. Following the pilot test, minor modifications were made to the format and wording to improve clarity and accuracy. Scores on these items were summed to compute a raw study quality score (SQS) (range = 1 to 61) for each retained study. To interpret this aggregated total score, each raw score was transformed by dividing it into the total possible score (61) and then multiplying it by 100 to obtain a percentage score for each study that ranged from 0% to 100%.

Higher percentage scores on the SQS were indicative of higher quality study design.

The research team also classified Web 2.0 implementation characteristics including design (ie, technical, information architecture, aesthetic, and functional), interactivity (ie, synchronous or asynchronous communication), and content (ie, disease management information, web content) described within each reviewed study. We then analyzed which Web 2.0 intervention qualities were associated with targeted outcomes (eg, process, functional, and clinical) and possible negative or unintended consequences of the intervention on HRQoL and nontargeted outcomes.

Results

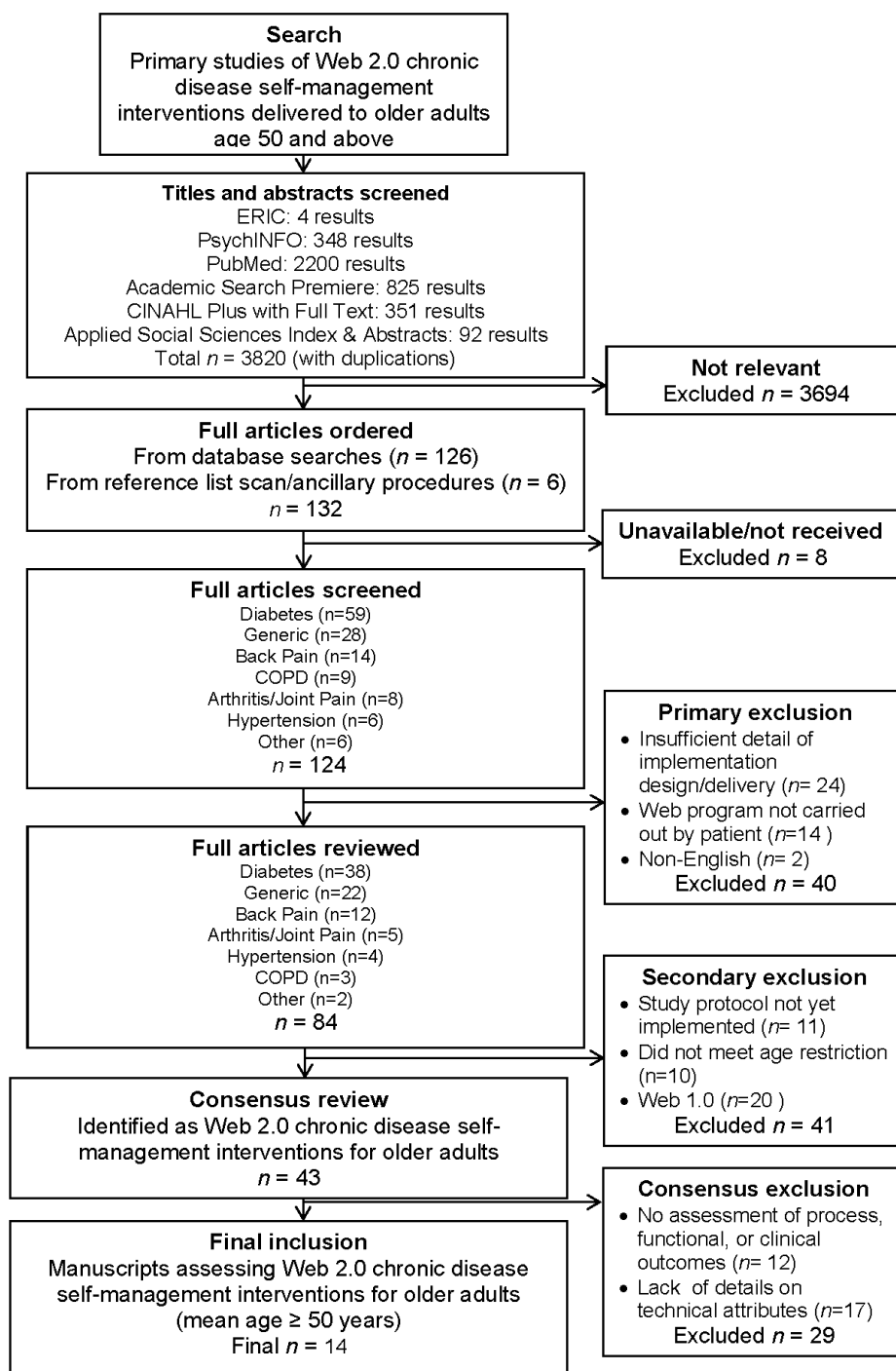
Study Characteristics

Figure 1 illustrates the three-round process used to select articles from the initial pool of 3820 articles identified. Eliminating manuscripts that were not relevant ($n=3694$) left 126 articles with another 6 identified through reference list scans. Eight articles were unavailable through the institutional e-library database leaving 124 to screen. During the initial review, articles were excluded for these reasons: insufficient details on research design and delivery ($n=24$); web program not being used by a chronic disease patient ($n=14$); or manuscripts written in a language other than English ($n=2$). The secondary wave of exclusion was completed following a full-text review of the remaining 84 articles. Forty-one of these articles were deemed ineligible due to reporting incomplete research protocols ($n=11$), participants not meeting the pre-specified age range ($n=10$), or because they involved only a noninteractive Web 1.0 interface ($n=20$). The secondary exclusion left 43 articles for final review. The final wave of exclusion resulted in 28 additional articles being excluded because they lacked any process, functional or clinical outcome assessments ($n=11$), or because they provided little detail on Web 2.0 components included within the intervention ($n=17$). These procedures produced 15 articles that met our inclusion criteria.

The final sample of studies were published in a variety of peer-reviewed journals, including the Journal of Medical Internet Research [47–51], CIN: Computers, Informatics, Nursing [52], Telemedicine and e-Health [53,54], Diabetes Care [55,56], The Diabetes Educator [57], Patient Education and Counseling [58], Arthritis & Rheumatism [59], Health Education and Behavior [60], and Journal of Pain and Symptom Management [61]. Included articles had been published between 2005 and 2012, with the majority ($n=10$ or 67%), published in 2010 or later.

Multimedia Appendix 3 describes the primary characteristics of interest (authorship, study purpose, sample size, and RE-AIM attributes) in each retained study. **Multimedia Appendix 4** reports the SQSs for each reviewed study on each RE-AIM dimension and subdimension. On a scale from 1 to 61, the raw SQSs for all reviewed studies ranged from 16 (26%) to 52 (85%). The mean raw SQS score of all reviewed studies was 38.33 (SD 10.43), which corresponded to a mean SQS score of 63% (SD 18%), which was notably low. Only four studies [51,56,58,59] scored 80% or above on the SQS scale.

Figure 1. Stem-tree illustrating manuscript selection process using various search databases and combinations of controlled vocabulary.



In the following, we report on results from the reviewed studies with respect to each aspect of the RE-AIM framework.

Reach Characteristics

Representativeness

Eight studies examined individuals with diabetes [48-51,55-58], with four (n=4) studies specifically targeting type 2 diabetes

[49,51,56,58]. Two studies examined individuals with COPD [47,61], and two investigated patients with arthritis or related musculoskeletal disorders [54,59]. Three (n=3) other studies were designed for individuals suffering from one or more chronic condition(s) [52,53,60]. The mean SQS score on the Reach dimension was 2.33 (SD 0.62) on a scale from 0 to 3.

Participation Rate and Country

Sample sizes ranged from n=18 participants in a qualitative feasibility study [53] to n=855 participants in one randomized controlled trial (RCT) [59]. Eight studies had more than 250 participants, while six studies reported n≤100. Eleven of the reviewed studies enrolled primarily White participants, ranging from 67% (181 of 270 participants) to 97% (38 of 39 participants) of total sample sizes. A little more than half of the reviewed studies (n=8) consisted of mainly White females [48,50,52,53,56,57,59,60]. Across all reviewed studies, the mean age of participants ranged from 52 to 69 years. Studies took place in several countries; twelve in the United States, and one each in Canada, Australia, and the Netherlands.

Empirical Effectiveness

Theoretical Framework and Research Design

Eleven (n=11) studies were RCTs [47-50,52,55-58,60,61], while five adopted a randomized cluster [54], quasi-experimental [60], cross-sectional [51], or qualitative [53] design. Constructs from the social cognitive theory (eg, self-efficacy) were used in eight studies [47,50,54,56,57,59-61], while the social ecological theory and the 5 As (assess, advise, agree, assist, and arrange) self-management model were used in two studies [49,58]. Four reviewed studies did not specify a theoretical framework [48,52,53,55]. The reviewed studies had relatively stronger mean SQS scores on suitability of study design (mean=5.47, SD 1.64 on a scale from 1 to 7) versus overall program evaluation (mean=7.2, SD 2.98 on a scale from 0 to 12).

Process Outcomes

A variety of process outcomes were measured in the reviewed studies, providing evidence that Web 2.0 improved confidence in several aspects of self-management. In five studies, use of Web 2.0 interventions was associated with statistically significant improvements in self-management self-efficacy [47,56,57,59,60], with one study noting positive trends falling just short of statistical significance ($P=.06$) [56]. Four studies reported positive responses towards using Web 2.0 for communicating with health care providers (ie, nurses, care managers) [51-54], and five reviewed studies showed improvement in perceived social support [48,50,56,57,61].

Chronic disease patients' utilization of Web 2.0 self-management features was also widely examined in 14 of the 15 studies. To determine which Web 2.0 features were accessed most/least often, web log activity was mined in 13 studies [47-52,54-56,58-61]. Three studies [49,51,58] explicitly noted that individuals enrolled in Web 2.0 interventions at baseline did not participate after the first few weeks. For example, in a 4-month study of individuals with diabetes [49], weekly web usage decreased from 189 of 270 (70%) participants

logging on during the first 6 weeks to 127 of 270 (47%) participants logging on during weeks 7-16.

Despite short-term attrition being noted as problematic, greater website engagement was generally associated with better behavioral and clinical outcomes. For example, more actively engaged individuals with diabetes showed greater evidence of disease management activity. McMahon and colleagues [55] noted that a larger number of website data uploads was associated with a larger decline in A1C ($P=.019$), while Nijland and colleagues [51] noted that highly active Web 2.0 users consumed medication more often than low/inactive users ($P=.005$) [51]. Richardson and colleagues [50] noted that online walking community participants who viewed more pages, or posted to the website more often, demonstrated larger increases in walking step counts ($P<.001$; $P=.03$). However, two RCTs studying individuals with type 2 diabetes suggested that self-monitoring using Web 2.0 did not improve medication adherence [49,58].

Functional Outcomes

Findings related to physical activity and nutrition outcomes were mixed. Three studies by Lorig and colleagues [56,59,60] reported conflicting results regarding the effect of Web 2.0 participation on physical activity. In RCTs of patients with musculoskeletal disorders [59] and type 2 diabetes [56], there were no improvements noted in self-reported aerobic, stretching, and strengthening exercise; whereas, a quasi-experimental study of Australians with one or more chronic conditions [60] noted improvements on weekly minutes of exercise and behavioral adherence. In other studies of individuals with diabetes [49,58], self-monitoring of physical activity behaviors improved with concomitant reductions in dietary fat intake.

Clinical Outcomes

For the most part, the Web 2.0 interventions tested did not meaningfully impact short-term clinical outcomes, although only 6 reviewed studies [47,49,55,57,58,61] measured the near-term effectiveness of biological and clinical outcomes. For example, over a 4-month study period, website engagement among individuals with diabetes was not associated with any improvements in biological or clinical outcomes [49].

Adoption: Setting and Staff

At the setting level, five of the Web 2.0 interventions were operated by academic research centers [47,52,54,55,57], while four were administered by various health care foundations and clinics [49,51,53,58]. Only three reviewed studies [48,50,60] did not address issues of adoption at the setting level. Thirteen of the 15 reviewed studies (87%) discussed staff level characteristics associated with intervention adoption. Multidisciplinary teams of researchers and practitioners were actively involved in adopting the delivery of Web 2.0 interventions for individuals with chronic disease. Several studies of individuals with diabetes described team science initiatives and collaborations [49,51,55,57,58]. These Web 2.0 interventions were staffed by a variety of health professionals including (but not limited to): diabetes care managers [49,55,58], nutritionists [49,55,58], nurses [51,55,57], behavioral scientists [51], primary care physicians [51,58], pharmacists [55],

psychologists [57], diabetes educators [55], and social workers [57]. In each of these studies, one health professional generally acted as the intervention gatekeeper by conducting an initial consultation with the participant. Following this preliminary consultation, routine online follow-up contacts were coordinated by a multidisciplinary set of providers. Often, these follow-up sessions or meetings specifically addressed the variety of concerns that a patient with diabetes is likely to encounter (eg, medication changes, depression, burnout, coping, healthy eating).

Other reviewed studies (not restricted to diabetes) also described how multidisciplinary researcher and practitioner teams came together to staff Web 2.0 chronic disease self-management interventions [47,52-54]. These research teams were responsible for developing and delivering online instructional units and managing program content and communications. In three of these studies [47,53,61], nurses took leading roles to execute patient-centered consultations, host weekly chat sessions and videoconferences, as well as schedule and coordinate follow-up sessions. Studies conducted by Lorig et al [56,59,60] reported the use of peer moderators (ie, individuals also living with a chronic condition who are trained to lead self-management training programs on the Internet) to staff online workshops and facilitate scheduled Web 2.0 intervention learning activities. On scales ranging from 0 to 4, the setting (mean=2.2, SD 1.26) and staff (mean=2.27, SD 1.58) level SQS scores were quite similar.

Implementation: Program Delivery

Almost half (n=7) of the 15 reviewed studies did not provide a detailed evaluation of program costs (money, time, human resources expended), adaptations made to Web 2.0 interventions over time, or fidelity to the intervention protocol. The costs of intervention implementation (ie, money, time, human resource management) were addressed in only six (40%) of the reviewed studies [47,49,51,52,54,55]. Cost considerations included time spent training study staff [55], administration time operating the Web 2.0 intervention [49,54], and developmental costs creating web-based instructional materials [52]. Most studies discussing costs noted that Web 2.0 development and operation costs were high [47,52,54,55]; however, one reviewed study noted minimal financial and human resource burdens [51]. Adaptations were made to Web 2.0 interventions in only four reviewed studies [47,50,54,60]. Changes were necessary due to technical difficulties [47,60], increased staff needs [50], and requests for more scheduled web events to stimulate participant involvement and interaction [54]. Three of the reviewed studies [48,56,58] reported technical, usability, and integration challenges that even caused one study to stop early [58]. Less than half (n=6) of the reviewed studies [47,49,51,52,54,55] described formal process evaluations to assess program fidelity. Mean SQS scores on the Implementation subdimensions (ie, Web 2.0 uptake, intervention development, program integration) were not judged to be noteworthy (see [Multimedia Appendix 4](#)).

[Multimedia Appendix 5](#) describes the Web 2.0 implementation characteristics for each retained study. The web design and user interface of all reviewed studies supported two main web

architectures: (1) online discussion groups, forums, boards, and communities, and/or (2) individualized entry and upload of personal health data (eg, medication, blood glucose, weight, exercise frequency). Seven of the 15 reviewed studies (47%) described how patients uploaded their personal data to a web platform for review by a clinician or peer moderator [48,49,56,57,59-61]. Graphic displays of user performance meeting personal goals were tracked in five of these studies [49-51,58,61]. Asynchronous communication (ie, participants do not communicate concurrently with one another, sending/posting messages at different times) was used most often through email or an internal messaging system [47,49,51,55,56,58,61]. Several Web 2.0 interventions implemented a combination of asynchronous and synchronous (ie, direct communication where parties are present at the same time) communication features [47,48,51,54,55,61]. Participants reported discussion boards [52], resource pages [52,59], asynchronous electronic messaging [54], personal action plans [49], and individual progress reports [49] as being especially useful for interactive health communication.

Lorig et al [56,59,60] enabled participants to “self-tailor” their interactive learning experiences while participating in interventions. This empowering approach represents an innovative implementation strategy for Web 2.0 self-management [60]. Using this strategy, participants devise a periodic action plan for themselves according to what particular self-management activities (eg, use of cognitive symptom management techniques, drawing up fitness/exercise regimens, planning meals) they want to engage in over a set period of time. Then, they are asked to rate their self-efficacy for accomplishing these planned activities before participating in the tasks. This reflection encourages patients to think about doing what is “real” as opposed to what is “ideal” [60]. Self-tailoring operates under principles of self-efficacy theory [62] by supporting the participant to pursue mastery experiences over time to build self-confidence. Six other studies also alluded to implementing principles of self-tailoring by helping participants develop: (1) action plans, (2) “To Do” lists for attaining weekly goals, (3) symptom self-monitoring diaries, and (4) tailored reasons/strategies for goal attainment [49-51,54,56,58].

Maintenance: Individual and Setting

At the individual level, there were mixed results on the effect of technical mishaps on patient exposure to Web 2.0 chronic disease self-management. In several studies [47,48,51], technical difficulties were associated with (1) decreased participant engagement, (2) lower intervention enrollment, and (3) increased nonusage attrition. Problems included lack of Internet access, unreliable wireless coverage, slowed performance due to proprietary security software, poor navigation structures, and overall trouble with log-ins. Several other studies did not report these types of long-term technical problems, however, and instead reported highly active participation for up to 1 year among participants [51,54,59-61]. Even comfort with using computers and the Internet improved among participants [52-54].

While only moderate 12-month improvements were noted in biological outcomes and self-reported health care utilization [56,59,60], there were other several notable long-term effects maintained at the individual level. Glasgow et al [58] and Lorig et al [60] found statistically significant improvements in health behaviors and health status. Several RCTs of individuals with diabetes reported that Web 2.0 participation was associated with improved generic health-related quality of life and a reduction in depressive symptoms [57], greater declines in A1C [55,56], and reductions in blood pressure [55,58].

At the setting level, 13 of the 15 reviewed studies (87%) did not describe any substantive measures taken to sustain Web 2.0 interventions past designated study time periods. The mean SQS scores on both the setting (mean=3.13, SD 2.26 on a scale from 0 to 7) and individual (mean=1.53, SD 1.25 on a scale from 0 to 3) levels of the Maintenance dimension were judged to be the lowest of all RE-AIM dimensions that were evaluated.

Discussion

This review provides a synthesis of research studies that describe Web 2.0 chronic disease self-management interventions for older adults. *Healthy Aging 2.0* argues that the evolution of older e-patients using participatory Web 2.0 technologies (eg, social networking, telemedicine, mHealth applications) requires new methods for transforming current health care communications [63]. Several overarching recommendations gleaned from this literature review will be discussed in the context of RE-AIM to guide the planning, implementation, and evaluation of future chronic disease self-management Web 2.0 interventions.

Reach

Some researchers have proposed that the “digital divide” in health promotion and disease management may be shrinking [24,64]. This systematic review indicated that the majority of reviewed interventions targeted only older adults with diabetes, and most involved small samples primarily consisting of white females in the United States. Additional research is needed among older adults with other types of chronic conditions (eg, arthritis, hypertension, COPD) to determine actual usage as well as disease-specific reasons for use and nonuse of Web 2.0 technologies. Understanding disease-specific factors is important, because the effects of Web 2.0 engagement will likely be stronger if health care practitioners determine the type of patients more likely to log in regularly as opposed to sporadically. Strengthening the breadth of Web 2.0 interventions to include multiple chronic conditions will likely have an adverse impact on reach however [58]. Therefore, we need to cost-effectively reach diverse samples of older adults who are managing a variety of comorbid conditions. More sufficiently powered studies should attempt to include underrepresented, medically underserved chronic disease patients to determine how these populations may benefit from Web 2.0 self-management support programs.

Effectiveness

To date, researchers have insisted that too few high-quality Web-based interventions have been conducted to sufficiently test the effectiveness of different types of Internet-mediated

interventions [20,65]. The majority of studies in this review (n=9), however, were theoretically based RCTs that provided a relatively high level of evidence. Older adults felt greater self-efficacy for managing their disease(s) and benefitted from interacting with health care providers and/or website moderators to receive feedback and support. When familiarity with Web 2.0 improves, older participants (especially those with low self-efficacy and social support) may gain knowledge, skills, and mastery experiences to reinforce recommended self-management strategies. Evidence suggests that greater Web 2.0 engagement may also be associated with more positive behavioral (ie, physical activity) and clinical (ie, HRQoL) outcomes; however, this review indicates that Web 2.0 self-management interventions have yet to meaningfully impact medication adherence, biological outcomes, and health care utilization among older adults.

In order for Web 2.0 self-management interventions to become core components of chronic disease management programs, more evidence is needed to support that Internet-mediated health ICTs are associated with improvements in health outcomes. For many of the reviewed studies, it was not clear which aspect or component of each intervention was most effective even though web log activity was monitored in almost all (93%) of the reviewed studies. As was indicated in our SQS quality assessment, impact evaluations assessing Web 2.0 engagement were generally lacking. This diminished the researchers' ability to determine patient satisfaction with different ICT exposures and limited further insights into the primary usability problems leading to low usage. Future Web 2.0 studies should use impact evaluation frameworks to reveal the active components of multicomponent Web 2.0 interventions so that we may determine the contexts in which treatments are most effective [66] and also distinguish the right combination of human and computerized support necessary to facilitate sustained participation [58].

Adoption

Among the studies that addressed adoption at the setting level, most described team science approaches to adopting Web 2.0 for chronic disease self-management support. Multidisciplinary groups of health care and ICT professionals built upon shared skills and experiences to develop chronic disease self-management interventions, primarily for individuals with diabetes. Given the increased emphasis on the coordination of chronic care teams [3], it is interesting to note the omnipresence of provider teams participating in the development of Web 2.0 interventions. The minimum administrative time burden associated with operating an interactive chronic disease self-management website may be quite high; thus, team-based approaches may reduce the administrative burden placed on individual health care units to operate Web 2.0 self-management support programs. Future studies should conduct more detailed setting and staff level analyses to determine whether operating Web 2.0 self-management interventions is feasible within existing public health and health care administration units.

Implementation

Even though participants viewed Web 2.0 favorably, program implementation was not seamless. Most studies noted that Web

2.0 development and operation costs were high, and the majority of studies did not sufficiently evaluate implementation quality [67]. Less than half of the reviewed studies described formal process evaluations to assess program fidelity. Process evaluations are important to: (1) identify best-practice strategies for future programs, (2) reduce potential for technical difficulties, (3) determine the amount of time patients are willing to spend using Web 2.0 for self-management support, and (4) estimate the amount of human and financial resources necessary for high-quality delivery. Implementation costs include trained facilitators, online data collection/analysis, Web system testing and hosting, as well as back up services for technical anomalies [54]. Cost projections encourage program developers to consider issues of dosage, staff training/supervision procedures, and revising administrative and practice responsibilities of health care personnel. Different Web 2.0 models need to be evaluated economically before these resource-intensive interventions are disseminated to chronically ill older adults at the population level [47].

Asynchronous communication tools (ie, email, internal messaging systems, discussion boards) and personal tracking features (ie, graphical displays of uploaded data) were noted as some of the more useful interactive Web 2.0 components. Promising findings from multiple studies suggested that “self-tailored” Web 2.0 approaches may reduce health distress and activity limitation, improve health status, and foster patient engagement more so than less patient-centered Web 2.0 approaches. While these tools and strategies have shown promise in promoting interaction, it remains unclear how best to define and measure web engagement/participation among older participants [68]. Post hoc patient interviews in this population may be important for better understanding the engagement construct, especially since individual psychosocial characteristics may be highly associated with level of Internet use [49,58]. Some researchers have recommended that scatter plot displays of the relationship between engagement and outcomes be analyzed, along with logistic regression analyses that determine whether unique patient characteristics predict dichotomous threshold use indices for different Web 2.0 components [49,58]. Future research should determine engagement metrics that are important to evaluate during Web 2.0 chronic disease self-management interventions.

Integrating Web 2.0 self-management interventions into primary care settings seems like a logical next venue for implementation [58]. Patient-centered health care organizations can employ virtual communities to direct and support chronic disease patients [69]. Some research has shown that e-patients with chronic diseases want easy access to multiple interactive tools they can control and customize [70]. Other research indicates that patients prefer fewer system components that can be used repeatedly [71]. Flexible tools that give users greater control and choice may be more convenient and customizable, and thus result in greater patient satisfaction, sustained engagement, and more positive health outcomes. Forward-thinking implementation strategies should recognize patients as experts in their own disease process and management [54]. These types of progressive approaches are likely to generate on-line contexts

that deliver more personalized self-management training experiences.

Maintenance

Managing illness is a lifelong responsibility for chronically ill older adults, who often have to deal with physical limitations and increasingly difficult living conditions over time [72]. Regrettably, the reviewed studies were judged to be weakest on the Maintenance dimension of the RE-AIM evaluation framework. At 12 months, only moderate overall gains were observed in biological outcomes and health care utilization. There were, however, some long-term improvements to report in health behavior, health status, and even with respect to a few clinical markers [55,58-60]. Future studies should be designed to have longer follow-up periods to test whether positive 1-year intervention effects can be sustained among larger, more diverse samples of chronically ill patients over longer periods of time in spite of low-usage attrition or dropout [22].

Maintaining and expanding Web 2.0 for chronic disease self-management requires a better understanding of the barriers that prevent continuous access to the Internet. We do not yet fully understand which factors influence long-term use/nonuse of Web 2.0 because user attrition in older adult chronic disease populations is rarely examined in depth. Health care policy makers would be best served by accounting for the way older adults are using Web 2.0 technologies to research personal health choices and interact with health care experts [73]. Elements crucial to the maintenance of future interventions may include: (1) establishing multidisciplinary teams, (2) allowing adequate time for research and development, (3) securing sufficient resources for building and maintaining an online presence, and (4) developing an integrated process and impact evaluation framework [74]. Future interventions should continuously evaluate individual needs and system requirements to understand which intervention strategies are best suited for Web 2.0 [51].

It was interesting to note that as program exposure increased among participants, so too did comfort with using computers and the Internet. Future interventions should consider installing feedback mechanisms and triggers (eg, email reminders) that provide automated messages to motivate and inspire users to participate in interactive self-management experiences on the Internet. So-called “push factors” may influence persistent engagement and support longer-term use [75]. Currently, it is unclear which types of automated supports (eg, email alerts, text message reminders, inspiring testimonials) encourage more active involvement in Web 2.0 chronic disease self-management. Additional research should determine whether personalized feedback from a real person is more persuasive than computerized tailored feedback and how to achieve the most effective and cost-effective balance between automated and nonautomated correspondence when using Web 2.0 [51,58].

Limitations

This study had several limitations. Although the search was comprehensive and systematic, using a rigorous method of searching and reviewing articles, some studies may have been overlooked due to lack of indexing in searched databases.

Moreover, variable terminology used to describe web-based chronic disease self-management programs on the Internet could have led to missing certain eligible studies. As a result, the final sample of articles included in the study (n=15) may have been limited. In addition, several articles had relatively small sample sizes, which may have not been representative of the patient populations from which they were drawn. Consequently, our ability to generalize is limited. Diversity in the samples was also lacking. The samples in the reviewed studies consisted primarily of highly educated, white patients. Lower socioeconomic status populations, with low-literacy levels, were underrepresented in the reviewed studies.

The combination of dropouts and limited adherence to program activities may also have led to a misrepresentation of intervention effects. Participants who did participate in these interventions may have unintentionally (or intentionally) contributed dubious or outright false health information that may have negatively impacted other intervention participants. The lack of regulation when delivering self-management training opportunities via Web 2.0 may prompt false senses of empowerment to the extent that patients may even contest treatment options and decisions handed down from their health care providers.

Conclusions

We can expect many specialized, patient-centered websites to arise in response to specific chronic disease information needs [76]. While Web 2.0 may help train chronically ill patients to make informed decisions and solve daily self-management problems [22,48], the effectiveness of Web 2.0 interventions

for patients with chronic diseases remains a significant challenge [77]. There is concern that Web 2.0 tools are made available regardless of usability, acceptability, and/or associated outcomes [78]. To extend the reach of chronic disease self-management and promote more widespread Web 2.0 adoption across different health care settings and among multidisciplinary teams of health care providers, future research should attempt to determine how to create personally customizable content-sharing websites regarding healthy lifestyles, treatment options, and locating available health services. Given that older adults are the fastest growing group of novice computer users [79] and that the opportunity to reach these individuals will increase as older adults become “wired” for Internet access [6], researchers must actively explore how to improve the quality of these interventions for older populations.

A patient-centered, evidence-based framework is needed to design and deliver Web 2.0 technologies to older adults who may require specialized tools because of functional and cognitive impairments associated with aging [80]. Using results from this review in concert with the RE-AIM model may provide guidance for creating more patient-centered chronic disease self-management models that consider Web 2.0 user interfaces (technical, information architecture, aesthetic, and functional), communication features (synchronous or asynchronous), and learning modalities (low-literate instructional design). The effective translation of these strategies using Web 2.0 applications will likely result in new approaches for empowering, engaging, and educating older adults with chronic disease.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

SQS measurement criteria.

[PDF File (Adobe PDF File), 217KB - [jmir_v15i2e35_app1.pdf](#)]

Multimedia Appendix 2

SQS measurement items.

[PDF File (Adobe PDF File), 181KB - [jmir_v15i2e35_app2.pdf](#)]

Multimedia Appendix 3

RE-AIM Attributes of Reviewed Studies.

[PDF File (Adobe PDF File), 164KB - [jmir_v15i2e35_app3.pdf](#)]

Multimedia Appendix 4

SQS scores for articles.

[PDF File (Adobe PDF File), 164KB - [jmir_v15i2e35_app4.pdf](#)]

Multimedia Appendix 5

Web 2.0 Implementation Characteristics.

[[PDF File \(Adobe PDF File\), 109KB - jmir_v15i2e35_app5.pdf](#)]

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Abbreviations

COPD: chronic obstructive pulmonary disease

HRQoL: health-related quality of life

ICT: information and communication technology

RCT: randomized controlled trial

RE-AIM: Reach, Efficacy, Adoption, Implementation, and Maintenance

SQS: study quality score

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Original Paper

Internet-Based Recruitment to a Depression Prevention Intervention: Lessons From the Mood Memos Study

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Abstract

Background: Recruiting participants to randomized controlled trials of health interventions can be very difficult. Internet-based recruitment is becoming an increasingly important mode of recruitment, yet there are few detailed accounts of experiences recruiting participants to mental health interventions.

Objective: To report on our experience with Internet-based recruitment to an online depression prevention intervention and pass on lessons we learned.

Methods: Participants were recruited to the Mood Memos study, an online preventive depression intervention, purely through Internet-based sources. The study was targeted to adults with subthreshold depression symptoms from several English-speaking countries. A variety of online recruitment sources were trialed, including search engine advertising (Google, Yahoo!, Bing), Facebook advertising, posts in forums and online noticeboards, and promotion through relevant websites and email newsletters of mental health organizations.

Results: The study website received visits from 94,808 individuals over the 14-month recruitment period. The recruitment target was reached with 1699 individuals signing up to the randomized controlled trial and 1326 fully enrolling. Most visitors arrived via Google advertising, which promoted a depression-screening questionnaire. Google advertising accounted for nearly half of the total participants who signed up to the study, at an average cost of AUD \$12 per participant. Promoting the study through trustworthy organizations and websites known to participants was also effective. Recruitment techniques that were less effective were contacting forums, email groups, and community noticeboards.

Conclusions: Several techniques, including Google advertising, were successful in recruiting participants to a trial evaluating an online depression intervention. Results suggest that Internet-based recruitment to mental health interventions is feasible and can be relatively affordable.

Trial Registration: ACTRN12609000925246

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KEYWORDS

Internet; research subject recruitment; depressive disorder; preventive psychiatry; randomized controlled trial

Introduction

It can be very difficult to meet recruitment goals in health research, particularly trials of interventions. Many studies fail

to recruit the targeted number of participants or experience delays in participant recruitment [1]. A number of strategies have been proposed to improve recruitment rates [2]. Among these, Internet-based recruitment is growing in popularity,

particularly in health survey research [3] and in interventions to improve physical health, such as smoking cessation interventions [4,5]. This is increasingly feasible given the high levels of access to the Internet in developed countries [6]. Internet-based recruitment has several advantages, such as the ease of reaching people from a wide geographic area including locations remote from researchers. Anonymous participation is possible, which is useful for highly sensitive topics such as illicit drug use [3] and sexuality [7]. It can also be easier to recruit large samples cost-effectively [4].

Most research on the cost of Internet-based recruitment has been published in the area of substance use and smoking cessation [4,5,8-11]. Costs per completed survey or enrolled participant have varied across (and within) these studies for a variety of reasons, such as different online advertising types (eg, Facebook, Google search, and banner advertising), the percentage of eligible participants who clicked on the ad, and the use of incentives to participate. Ramo et al [5] evaluated the cost of recruiting young adult smokers in the United States to complete an online survey about substance use through text advertisements and banner advertisements on social networking and lifestyle websites, as well as a separate study using Facebook advertising [11]. Text and banner advertisements cost an average of US \$43 per completed survey, but Facebook advertising (targeted to sociodemographic characteristics and substance keywords in user profiles) cost an average of US \$4.28 per completed survey. Recruitment through Google advertising was also cost-effective for several smoking cessation interventions, including 2 randomized controlled trials [4,8,9]. Google Search advertisements cost on average US \$5 to \$8 per registrant to QuitNet [4]. This was far less expensive than banner advertising on popular websites with broad reach, which cost up to US \$476 per participant and had fewer registrants to the program. Similarly, Gordon et al [9] found an average cost per participant of US \$6.70 through Google advertising, which was much less expensive than a media campaign (US \$92) and newspaper advertising (US \$115). Buller et al [8] found a higher average cost per participant from Google advertising (US \$41), but it was the least expensive advertising type in their study, comparing favorably with US \$56 for distribution of printed promotional material and US \$134 for Quit-Line phone screening.

Despite the growth in Internet-based interventions for mental health problems, such as computerized cognitive behavior therapy [12], Internet-based recruitment to mental health studies is uncommon [13,14]. Evaluations of these interventions have often used traditional offline recruitment methods, such as flyers, newspaper advertising, and sourcing participants from users of health services. Recruitment problems are amplified in preventive medicine where it can be especially difficult to recruit participants to preventive trials targeting individuals at risk rather than those with a diagnosed condition (who may already be in contact with health professionals). In addition, these studies typically require large sample sizes. Trials that do not recruit participants from a health service often use media releases to advertise the study or screen members of the public through mail surveys to determine whether they meet study eligibility criteria [15].

More than a quarter of Internet users search online for information about depression, anxiety, stress, or mental health issues [16]; antidepressants are the second most searched-for treatment on WebMD [17]. Therefore, targeting individuals who use the Internet to seek information or support for mental health problems could be a useful method of recruiting participants to Internet-based mental health interventions. However, there are few detailed accounts of recruitment experiences to guide mental health researchers. Such information is critical to trial planning because recruitment success will determine the feasibility of a study, and both traditional and Internet recruitment methods can consume a substantial part of trial budgets.

We recently developed an Internet-based intervention (Mood Memos) to improve depressive symptoms in adults. The initial Mood Memos trial targeted people with mild symptoms who were at risk for depressive disorders. Thus, we did not have a geographically or service-defined population from which to sample (eg, a mental health clinic). Therefore, we decided to investigate the potential of recruiting participants solely through Internet sources. Internet-based recruitment was feasible because the intervention was completely Web-based and automated, with Web-based questionnaires used to assess eligibility. This meant that individuals who had turned to the Web for information or support about depression could seamlessly sign up to the study and start receiving the intervention immediately. Furthermore, Internet-based recruitment enabled access to a larger pool of potential participants than was possible if recruitment was restricted to our geographic location (Melbourne, Australia). This was important because the study required a large sample size to detect the predicted small effect size associated with a low-intensity preventive intervention. We explored a variety of Internet-based recruitment techniques. In this paper, we document our experience with Internet-based recruitment to a mental health intervention and the lessons we learned.

Method

The Mood Memos study was a randomized controlled trial (ACTRN12609000925246) testing whether self-help behaviors for depression could be improved by promotional messages sent by email [18,19]. Participants received a series of automated Mood Memo emails over a 6-week period, which encouraged the use of effective self-help strategies endorsed by experts. These emails were found to reduce depression symptoms and psychological distress relative to control emails that provided information only [18]. The study was an indicated prevention trial, with a minimum of 800 participants required to have adequate power to detect the predicted small effect size. Allowing for dropouts, we set a target recruitment size of 1200 participants.

The study was open for recruitment between February 2010 and March 2011. Participants joined the study by visiting the Mood Memos website [20], and undergoing screening for subthreshold depression. There were no incentives given to participate. The website was established for the express purpose of recruiting to the study and included only the screening questionnaire,

information about the study, and links for immediate help from other sources. The Patient Health Questionnaire depression scale (PHQ-9) [21] was used to screen for depression. It can be scored as a continuous measure of depression severity or by using a diagnostic algorithm to make a probable diagnosis of major depression. The frequency over the past 2 weeks of each of the 9 criterion A symptoms of a major depressive episode as defined by the *Diagnostic and Statistical Manual of Mental Disorders*, 4th Edition (DSM-IV) was assessed on a 4-point Likert scale (0=not at all; 3=nearly every day). Total scores range from 0 to 27, with cutpoints of 5, 10, 15, and 20 representing mild, moderate, moderately severe, and severe levels of depressive symptoms, respectively [22]. Because we targeted participants with subthreshold depression symptoms (clinically relevant depressive symptoms at levels that did not meet the criteria for major depression), rather than use a cut-off score, we included participants with 2 to 4 symptoms of depression [23] experienced most of the time for 2 or more weeks, which had affected work, home, or social functioning. Other inclusion criteria were aged 18 years or over; not receiving treatment for depression from a health professional (not including maintenance antidepressant medication for 6 months or more); a resident of Australia, New Zealand, the United Kingdom, Ireland, Canada, or the United States; and had access to the Internet at least weekly. Once participants were screened and found to be eligible, they provided a name and email address. A hyperlink to the baseline questionnaire package was then sent to this email address. Once the baseline assessment was complete, participants were randomized to condition and immediately sent the first of 12 Mood Memo emails. The trial was approved by the University of Melbourne Human Research Ethics Committee (HREC 0931313).

Our intention was to recruit participants from a variety of online sources, and although we initially specified some recruitment sources, we were flexible in exploring new online recruitment opportunities. We trialed a range of recruitment techniques, including search engine advertising, Facebook advertising, emails to personal and professional networks, posts in forums

and online noticeboards, submitting the website to website directories, distributing an online press release, and promotion through relevant websites. Advertising costs are reported in Australian dollars (AUD); during the advertising period, AUD \$1 ranged between US \$0.98 and \$1.02 [24].

Results

Overview

According to Google Analytics reports, there were 101,113 visits to the Mood Memos website from 94,808 unique visitors, accessed from 703 sources (eg, websites or direct uniform resource locator [URL] entry) over the 14-month recruitment period. The website was accessed from 118 countries, with most visiting from the United Kingdom (55.8%), Canada (15.0%), Australia (14.7%), and the United States (6.6%). The depression questionnaire screened 80,105 people; 1699 signed up to the study and 1326 completed all baseline assessments and were fully enrolled. The vast majority of website visitors came from Google advertising, which sent more than 87,000 visitors to the website. Nonpaid visitors from search engines such as Google, Bing, and Yahoo! (ie, organic search traffic) accounted for 936 visits. There were 5236 visits from other nonpaid websites, with most referrals from Psychological Research on the Net [25], Mood Disorders Society of Canada [26], StumbleUpon [27], eHealth Forum [28], and Balance NZ [29]. Direct traffic (eg, entering the website URL) accounted for 7415 visits. The results from selected attempts to promote the study online are described in more detail subsequently, and an overview of their advantages and disadvantages is shown in Table 1. Due to a technical oversight, it is not possible to provide data on the recruitment source of every participant; participants recruited through links from within emails (eg, an email newsletter) were recorded as direct visitors. Future recruitment campaigns can avoid this limitation by using Google's URL Builder tool, which allows details about a marketing campaign to be added to the URL and then tracked by Google Analytics. Nevertheless, we can give an overview of the success of each recruitment technique and our solutions to the challenges we experienced.

Table 1. Overview of advantages and disadvantages of recruitment sources in the Mood Memos study.

Attributes	Recruitment source						
	Google advertising	Facebook advertising	Forums	Links on other websites	Online noticeboards ^a	Google or Yahoo groups	Emails from relevant organizations
Advantages							
Broad reach	✓	✓					
Targeting	✓	✓	✓			✓	
Low ongoing effort	✓	✓					
No cost			✓	✓	✓	✓	✓
High conversion rate							✓
Implicit endorsement				✓			✓
Disadvantages							
Narrow reach						✓	✓
High learning curve	✓	✓					
High cost	✓	✓					
Low conversion rate	✓						
Time-consuming			✓			✓	
Difficulty acquiring permission			✓	✓	✓	✓	✓

^a For example, Craigslist and Gumtree.

Google Advertising

Search engine advertising was trialed with Google, Yahoo!, and Bing between October 2010 and March 2011 (Bing and Yahoo! merged their advertising services during the trial). Resources were directed toward Google advertising because it proved more effective than either Yahoo! or Bing. Search engine advertising services display a short advertisement when a user searches for certain keywords, which are preselected by the advertiser. Advertisers competitively bid on specific keywords to get their ads shown. The number of times an ad is displayed is dependent on the budget of the advertiser, competition from other advertisers for the chosen keywords, and the quality of the ad. Google provides advice on how to improve ad quality, and there are numerous books and websites that offer similar advice.

Advertisers can choose to pay each time an ad is displayed or each time it is clicked on (pay-per-click). We chose pay-per-click because this is more cost-effective for ads whose primary purpose is to direct a viewer to a website rather than promote a brand. There are a variety of advertising settings that can be adjusted and experimented with, including daily budget, targeted locations, ad scheduling for time of day or day of the week, and keyword search term precision. We experimented with a number of different keywords and ads, and found that the most successful combination were ads that targeted individuals seeking a depression test or information about symptoms because they thought they might have depression

(see [Figure 1](#) for examples of Google advertisements used in the study). The depression test ad and keyword combination attracted a large number of searches, a reasonable percentage of clicks per display of the ad (an average click-through rate of 6.0%) [30], but was still affordable (AUD \$0.08 per click). The average cost per participant sign-up using this keyword was AUD \$9.86. Although each click on this ad was inexpensive, less than 1% of clicks led to a participant signing up to our study. This low conversion rate was not unexpected, given that participation was restricted to those with a narrow range of depressive symptoms, and because Google users did not necessarily visit the Mood Memos website to sign up to the study, but rather to find out if they were depressed. In fact, most individuals who visited the website through Google advertising returned a screening result of probable major depression (5 or more depressive symptoms) rather than subthreshold depression (63.7% versus 20.7%, respectively). [Figure 2](#) shows the distribution of scores on the PHQ-9 from those who were screened via Google advertising. Other recruitment sources returned a lower rate of probable major depression (49.4%) than Google advertising.

Keywords and ads related to self-help or coping with depression were also used (eg, coping with depression, depression self-help, and how to deal with depression). However, although they were more specific to the study, they attracted fewer searches, a lower click-through rate, and consequently fewer participants. Either

we did not hit upon appropriate keywords or our ads were not attractive to users searching with these keywords.

Keyword bids were more expensive initially, but reduced in price as more people clicked on our ads and our quality score improved. The quality score is an index calculated by Google based on an estimate of the relevancy and usefulness of the ad and Web page to which it leads [31]. In our case, the “depression test” keyword cost AUD \$2.74 per click initially, but within 10 days had reduced to AUD \$0.14. The cost per click will vary with the targeted geographic location because it depends on how many other advertisers are also targeting particular keywords in that location. Although we targeted all 6 countries equally, our ads were displayed less frequently in the United States and more often in the United Kingdom. This was because we chose automatic bidding for keywords, which meant that because of greater competition in the United States for our keywords, sometimes we were outbid by other advertisers or our ads were not ranked highly enough to be displayed in the first page of search results.

Overall, our ads were shown 1,251,262 times and received 75,225 clicks from Google keyword search. The average click-through rate was 6.01%, the average cost per click was AUD \$0.09, and the average sign-up rate from those who clicked on the ads was 0.80%. This led to 602 people signing up to the study, at an average cost of \$10.75 per person.

Display network advertising on Google was also utilized. This shows advertisements (text and other media) on websites that have been contracted to display advertising from Google. Specific websites can be targeted or Google can select appropriate websites based on the keywords chosen by the advertiser. Google display network advertising was chosen as an alternative to banner advertising on popular websites, which is prohibitively expensive. Our ads were displayed 4,759,393 times and received 16,883 clicks. The majority of clicks were produced from About.com Depression [32] and NetDoctor [33]. Our click-through rate was lower than for keyword search advertising (0.35%), as found by other researchers [3]. It was also slightly more expensive than search engine advertising, costing an average of AUD \$0.13 per click over the life of the campaign, but it had a slightly higher participant sign-up rate (0.91%) compared to search engine advertising (0.80%). Display network advertising led to 153 people signing up to the study at an average cost of AUD \$14.71 per sign-up.

Overall, advertising on Google was an effective recruitment source. Of 1699 participants who initially signed up to the study, 755 (44.44%) were recruited through Google advertising. These participants were recruited over a 6-month period at an average cost of AUD \$11.55 per participant.

Figure 1. Examples of paid advertisements in the Mood Memos study. CTR=click-through rate (percentage of clicks per impressions); CPC=cost per click; Conv rate=conversion rate (percentage of sign-ups per clicks); CPS=cost per sign-up; N/A=not applicable.

a) Successful Google ads

[Depression test](#)
 Take our quick, easy, and anonymous test to see if you have depression
www.moodmemos.com

Display network

Impressions: 4,739,517
 CTR: 0.35%
 Average CPC: \$0.13
 Conv. rate = 0.90%
 CPS = \$14.81

Keyword search

Impressions: 1,248,583
 CTR: 6.02%
 Average CPC: \$0.09
 Conv. rate = 0.80%
 CPS = \$10.73
 Example keywords:
 depression test
 depression symptoms
 am I depressed

b) Less successful Google ads

[Self help for depression](#)
 Feeling depressed and want to help yourself? Join the Mood Memos study
www.MoodMemos.com

Impressions: 83,998
 CTR: 0.13%
 Average CPC: \$0.25
 Conv. rate = 0%
 CPS = N/A

Impressions: 954
 CTR: 0.84%
 Average CPC: \$0.28
 Conv. rate = 0%
 CPS = N/A
 Example keywords:
 depression self help
 self help for depression

[Feeling down or low?](#)
 Want to improve your mental health? Join the free Mood Memos study
www.MoodMemos.com

Impressions: 12,171
 CTR: 0.07%
 Average CPC: \$1.96
 Conv. rate = 0%
 CPS = N/A


Impressions: 947
 CTR: 0.84%
 Average CPC: \$1.11
 Conv. rate = 0%
 CPS = N/A
 Example keywords:
 depression help
 help for depression



Impressions: 13,622
 CTR: 0.44%
 Average CPC: \$0.18
 Conv. rate = 1.67%
 CPS = \$10.65

c) Facebook ads


Feeling blue?
 moodmemos.com



Want to help yourself feel better? Join the Mood Memos online study and you'll receive info and advice about depression by email.

Impressions: 340,406
 CTR: 0.026%
 Average CPC: \$0.69

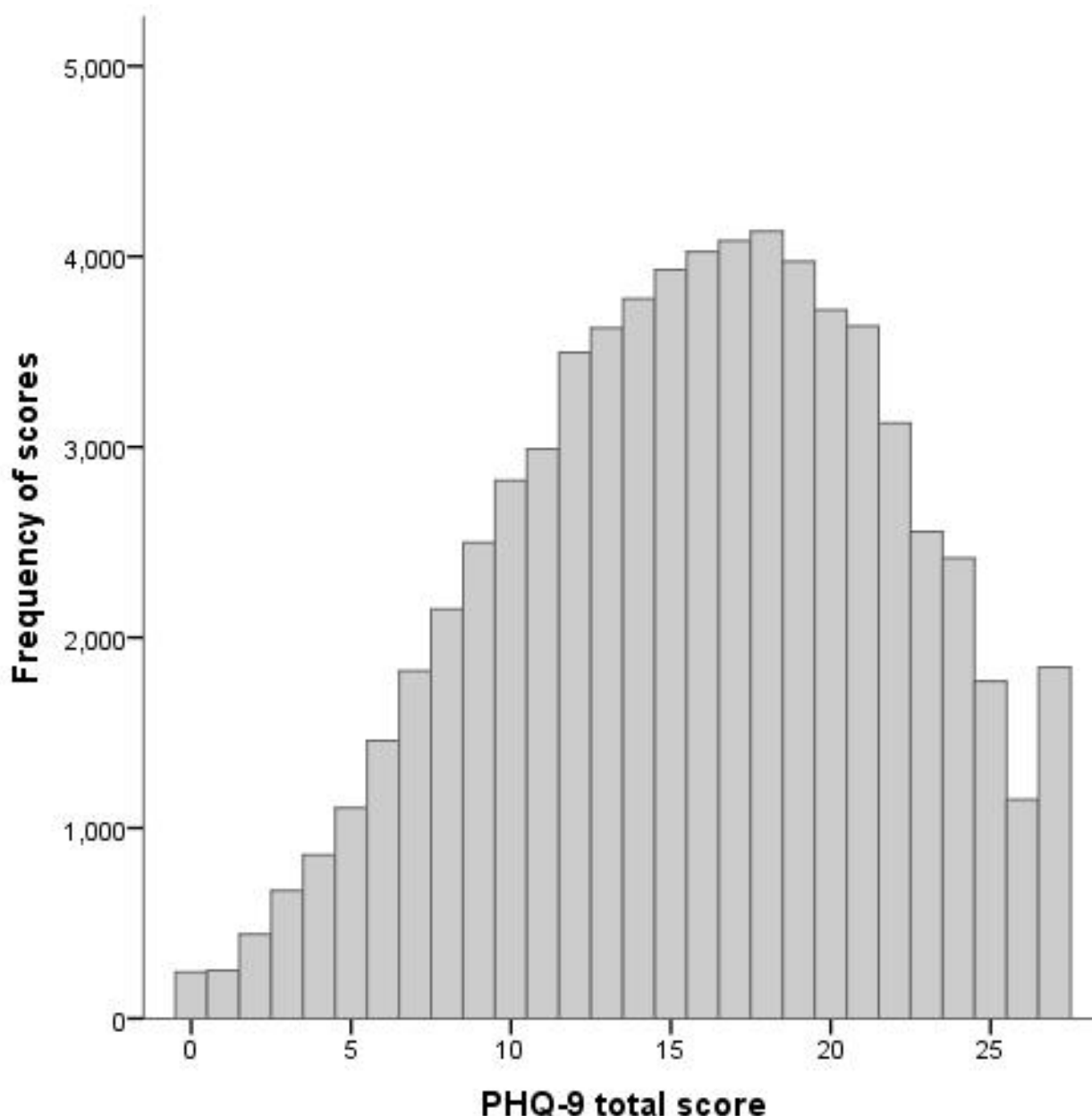
Depression test
 moodmemos.com



Take our quick and anonymous test to see if you have depression. Then sign up to the Mood Memos study for free help with depression.

Impressions: 1,507,235
 CTR: 0.065%
 Average CPC: \$0.60

Figure 2. Distribution of scores on the Patient Health Questionnaire (PHQ-9) from those participants screened through Google advertising. Subthreshold depression scores for participants eligible for inclusion in the Mood Memos study ranged from 3 to 17 on the PHQ-9.



Facebook

We tested advertising on Facebook, but found it was less cost-effective than advertising on Google, so we did not persist with it. Advertising on Facebook works differently than search engine advertising because ads are targeted to specified demographics (eg, age, gender, location, relationship status, and education) and user interests rather than search keywords. This was less useful for the Mood Memos study, which was not targeting narrowly defined demographic subgroups, other than adults 18 years or over from the 6 eligible countries (Australia, New Zealand, the United Kingdom, Ireland, Canada, or the United States). However, we experimented by targeting our ads to people whose demographics or likes/interests indicated they were at higher risk of depression (eg, females, “depressed,” “lonely,” and “unemployed”). Our ads were displayed 2,051,216

times, received 1115 clicks (click-through rate 0.05%), and cost an average of AUD \$0.62 per click. Facebook advertising recruited 35 participants, averaging \$19.89 per participant. [Figure 1](#) shows examples of the Facebook advertisements used in the study. Other studies with focused participant demographics have had more success in recruiting participants through Facebook [34].

Forums

Online depression forums (or Internet support groups) are very common and many have tens of thousands of members [35]. We thought mental health forums would be a good recruitment source of people experiencing depression symptoms who would be interested in participating in the study. Some forums also have sections dedicated to research studies seeking participants. We performed searches on Google and Bing to identify forums

in which to post, as well as following links from other websites. However, this recruitment source was much less useful than expected. We approached 58 forums related to depression and other related problems, but only 25 responded with permission to post about the study. Many of the larger forums had policies that outright denied permission to post about research studies. Although some smaller forums gave permission to post, this was usually a time-consuming process involving signing up to the forum and creating a user account, then identifying the forum moderator or administrator and contacting them for permission to post, and then finally submitting the post and monitoring responses. We found recruitment through online forums of limited use, possibly because many of the users of these forums were not eligible to participate because they were already too depressed or were receiving treatment from a professional. Furthermore, other studies that have had success recruiting through online forums have been for cross-sectional questionnaires rather than longitudinal interventions [36]. Perhaps the lack of response to our forum recruitment drive may have been partly because of the additional obligations required for participation in a longitudinal trial.

Links From Websites

A variety of mental health websites were contacted, informed about the Mood Memos study, and asked to promote it on their website or via email newsletters. Many websites would only agree if there was a reciprocal link on the Mood Memos website. A new page of supporters was created to accommodate this requirement. This page thanked each organization or website that had helped promote the study to participants. Some websites were generous and included a link and blurb on their home page; others listed the website within a section of their site that contained links to other interesting websites. The Mood Memos website was also listed on several websites that promote participation in research in general or psychology in particular. The advantage of promoting the study through other mental health websites was the broad exposure to the Mood Memos website offered by these credible, well-established websites that had hundreds or thousands of daily visitors.

Online Community Noticeboards

We explored the effectiveness of posting an invitation to participate in the study on websites that function as online community noticeboards (eg, Craigslist [37] and Gumtree [38]). It is free to post a classified ad on these websites, and other survey-based studies have found them an effective recruitment source [5]. However, although free, these websites are designed to offer products and services to local residents only. Posting in multiple categories or locations concurrently (eg, Melbourne and Sydney) is not allowed, and the American and Canadian Craigslist websites required a local mobile phone number to confirm the advertisement, preventing advertisements by foreigners. On Craigslist, we posted a study announcement in 4 cities (Melbourne, Sydney, London, and Birmingham) in various categories (volunteers and therapeutic services), but had only 29 visits, with 3 participants signing up to the study. Similarly, we posted information about the study in 4 cities with Gumtree Australia, United Kingdom, United States, and Ireland, but had only 1 participant sign up via these ads. We had more

success posting a notice in the online student noticeboard at the University of Melbourne (where the study researchers were based). This website is a portal of official services (eg, subject timetables) for students at the University of Melbourne, but also allows moderated notices to be posted that may be of interest to students. We posted the study notice 4 times over the recruitment period, and observed a noticeable increase in visits and enrollments coinciding with each posting. This success may be because the notice was targeted at a group at high risk for depression (ie, university students [39]) and because students may have trusted the study because it was conducted by staff members of their university.

Email Groups or Lists

We also tried contacting members of various email groups or lists. Yahoo! and Google provide a free service in which individuals with shared interests can join an online group and share messages and information. These messages are sent to email accounts or can be viewed in a Web browser. There are hundreds of groups related to mental health conditions or risk factors, but many of these have few members or have been overtaken by spam messages. We contacted 103 relevant groups with a reasonable number of members to advertise the study and 32 gave their permission. Again, this was a time-consuming process because groups often had to be joined before the owner of the group could be contacted for permission to post to the rest of the group. Other email lists that were more successful in recruiting participants were not Yahoo! or Google groups, but rather the email lists of mental health organizations, such as beyondblue (the Australian national depression initiative) [40] and Mental Health First Aid (MHFA) [41]. Promotion through the networks of these organizations led to a significant spike in visitors to the Mood Memos website and enrollments in the study.

Discussion

The Mood Memos study demonstrated that it is possible to recruit a large sample to a randomized controlled trial of a mental health intervention purely through Internet-based sources. We were able to meet our ambitious recruitment target over a period that was only marginally longer than planned. Participants were recruited largely through a combination of Google advertising and promotion via the online networks of mental health organizations and websites. Recruiting participants to randomized controlled trials can be very difficult, and many trials do not reach their target sample size [2]. Online recruitment can potentially reach a wider pool of potential participants more cost-effectively than traditional techniques, such as media advertising. However, promoting the study online was not without difficulty. Google advertising involved a steep learning curve and much trial and error in working out the optimal combination of ads and keywords that competed well against other advertisers, were affordable, and were searched for frequently enough to be worthwhile. Researchers using Google should be aware that establishing a campaign is not sufficient for success, and that monitoring performance during the recruitment period is critical. Changes and refinements will almost certainly be needed in the course of a recruitment

campaign. In comparison to Google, many other recruitment techniques, although free, were time-consuming and less effective.

Despite recruiting a large sample, recruitment was constrained by a number of factors, including the nature of the intervention, trial design, and eligibility criteria. For example, some recommended techniques in website promotion, such as search engine optimization, had limited application for the Mood Memos website. Search engine optimization involves designing websites so that users can find them easily through search engines such as Google. Google often updates its algorithms that determine website rankings in search results. Current recommendations by experts in the field are to provide quality content, rather than rely on many incoming links from other websites [42]. Because the Mood Memos website was designed to have minimal content (just the depression-screening questionnaire, information about the study, and links to resources for more help), other techniques to reach Internet users were essential. The choice of control intervention may also have increased the difficulty of recruiting participants to the study. To keep participants blind to which condition was the control, the promotion of the study could not solely focus on self-help or coping with depression, although this would probably have generated more interest from potential participants. Using a wait-list control may have made recruitment easier because the study could have been promoted as a way of learning techniques to cope with depressive symptoms. Instead, the study was promoted in general terms as a way of receiving expert information and advice about depression. Furthermore, targeting people at risk of major depression was difficult. Experience in the Netherlands has shown that there is minimal uptake of indicated preventive interventions, even when they are available at little or no cost [43]. Part of the reason for this may be that individuals may lack self-awareness or have insufficient mental health literacy to understand that their distress could be an early sign of depression. Much of the delay in seeking professional help for depression is due to a lack of problem recognition [44]. The difficulty of recruiting participants to the Mood Memos study from websites, forums, and email groups dedicated to mental health problems may have been because users of these had identified that they had depression, but their symptoms were too severe to meet admission criteria. This may have been why Google advertising targeting people who thought they might be depressed was a superior method of recruiting participants to the study. Unfortunately, Google advertising is not free, but an advantage is that it can occur in the background; it needs minimal attention once properly established.

Our experience also highlighted the importance of undertaking formal usability tests of the website sign-up process. Although we tested it informally, after launching the website we discovered that some participants could not find the sign-up button because it was below the plain language statement. Our experience indicates that there may be tension between best practice for Web usability and the current practice of obtaining informed consent by providing a long and detailed text-based

information sheet to participants. Over the years, printed information sheets have increased in length, becoming more comprehensive to meet ethics requirements. Yet this increase in completeness sacrifices comprehension because longer forms are less likely to be read and understood [45]. These issues are compounded when information sheets are presented online because less text is read online compared to print, and users may miss information or instructions on how to participate if they have to scroll down to view it [46]. These issues are worth considering to avoid wasting effort attracting visitors to your website only to lose them during the sign-up process.

Internet-based recruitment does have limitations. It was particularly suitable for our study because we did not require any face-to-face assessments of participants during the study. This may not be feasible for many evaluations of mental health interventions, even when Internet-based, because diagnostic psychiatric interviews are usually preferred to self-report assessments. However, other researchers have combined Internet-based recruitment with face-to-face assessments in their research [34]. Internet-based recruitment may also lead to low rates of participation from groups that are less likely to use the Internet, such as older adults, the less educated, and those with low incomes [47]. However, this does not necessarily need to be the case because reaching samples that are more representative is possible through demographic targeting with Facebook [34]. In addition, certain kinds of Internet advertising may lead to greater participation from groups less likely to participate through traditional recruitment techniques (eg, men and ethnic minorities) [4].

Combining Internet-based recruitment with Internet-based assessment poses challenges to research integrity, including the potential for multiple, fraudulent enrollments. This can be problematic if there are incentives to participate [48]. Although we found Internet-based recruitment effective in reaching individuals with subthreshold depression who wanted to improve their mental health, others have found it failed to fulfill its promise [49] and is often more challenging than first anticipated [7,50]. There is limited knowledge about which factors contribute to successful Internet-based recruitment, but it may be important to use techniques that build rapport and gain the trust of potential participants, and to balance broad exposure with appropriate targeting and tailoring of recruitment messages [3]. If direct rapport is not feasible, then derived rapport may be sufficient. This can be achieved by recruiting participants through trusted people or organizations that have an existing link with potential participants. In our study, the effectiveness of recruitment through the University of Melbourne, beyondblue, and MHFA may indicate the importance of this factor.

Internet-based recruitment is becoming an increasingly important mode of recruitment; however, there are limited data available to guide researchers on the best recruitment strategies. Our study showed that several techniques, including Google advertising, were successful in recruiting participants to an online depression intervention. Our results suggest that Internet-based recruitment to mental health interventions is feasible and can be relatively affordable.

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Conflicts of Interest

AJ Morgan is the author and developer of the Mood Memos website, but derives no personal or financial benefit from its operation.

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Abbreviations

AUD: Australian dollars

MHFA: Mental Health First Aid

NHMRC: National Health and Medical Research Council

PHQ-9: Patient Health Questionnaire depression scale

URL: uniform resource locator

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Tutorial

Single-Case Experimental Designs to Evaluate Novel Technology-Based Health Interventions

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Abstract

Technology-based interventions to promote health are expanding rapidly. Assessing the preliminary efficacy of these interventions can be achieved by employing single-case experiments (sometimes referred to as n-of-1 studies). Although single-case experiments are often misunderstood, they offer excellent solutions to address the challenges associated with testing new technology-based interventions. This paper provides an introduction to single-case techniques and highlights advances in developing and evaluating single-case experiments, which help ensure that treatment outcomes are reliable, replicable, and generalizable. These advances include quality control standards, heuristics to guide visual analysis of time-series data, effect size calculations, and statistical analyses. They also include experimental designs to isolate the active elements in a treatment package and to assess the mechanisms of behavior change. The paper concludes with a discussion of issues related to the generality of findings derived from single-case research and how generality can be established through replication and through analysis of behavioral mechanisms.

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KEYWORDS

Research design; technology; mHealth; single-case design; preliminary efficacy

Introduction

The field of technology-based behavioral health interventions is expanding rapidly. New technologies are enabling access to, and assessment of, individuals and their health-related behavior [1-3]. Even “old” technology, such as the Internet and mobile phones, is being harnessed in new ways, delivering state-of-the-art behavior therapy across diverse settings [4-7]. The fields of eHealth, mHealth, and the promise of emerging technologies have the potential to transform many systems of health care and improve public health by increasing access to cost-effective interventions. With these opportunities comes the need to evaluate rigorously the potential efficacy of new treatments. In this paper, we describe some challenges and methodological solutions associated with testing preliminary efficacy. In particular, we focus on the solutions offered by single-case experiments, which fill a unique and vital niche in

the ecology of research designs. We also highlight advances in developing and evaluating single-case experiments, which help ensure that treatment outcomes are reliable, replicable, and generalizable. Finally, we describe experimental designs that allow researchers to isolate the active elements in a treatment package and to assess the mechanisms of behavior change. Our goal is to introduce a range of techniques that will be relevant to behavioral scientists that are unfamiliar with single-case research and that are particularly well suited for the research and development of new technology-based interventions. We hope to supply enough detail to achieve a basic understanding of the mechanics, utility, and versatility of single-case research and enough resources to propel further inquiry.

Broadly, single-case designs include a family of methods in which each participant serves as his or her own control. In a typical study, some behavior or self-reported symptom is measured repeatedly during all conditions for all participants.

The experimenter systematically introduces and withdraws control and intervention conditions and then assesses effects of the intervention on behavior across replications of these conditions within and across participants. Thus, the telltale traits of these studies include repeated and frequent assessment of behavior, experimental manipulation of the independent variable, and replication of effects within and across participants. Although some forms of replication are readily apparent, such as replications of effects within and between subjects, other forms may be more subtle. For example, replication within subjects also occurs by simply measuring behavior repeatedly within a condition. Assuming some degree of stability of the dependent variable within a condition, there will be many replications of the effects of a treatment on behavior.

A recent study illustrates the efficiency and rigor of a single-case design to assess a novel technology-based treatment [8]. Raiff and Dallery assessed whether an Internet-based incentive program could increase adherence to blood glucose testing for 4 teenagers diagnosed with Type 1 diabetes. Teens monitored glucose levels with a glucose meter during a 5-day baseline (control) condition. During a 5-day treatment condition, participants earned vouchers (statements of earnings exchangeable for goods and services) for adhering to blood glucose testing recommendations (ie, 4 tests per day). After the treatment condition, participants monitored blood glucose just as they did during the first baseline condition for 5 days, without the possibility of earning incentives. Participants submitted a mean of 1.7 and 3.1 blood glucose tests per day, respectively, during the baseline and return-to-baseline conditions, compared to 5.7 tests per day during the treatment condition. Because adherence increased only when the treatment was implemented for all 4 participants and because behavior within each condition was stable (ie, five replications of treatment effects per participant and ten replications of control levels per participant), this experiment suggested that an Internet-based incentive program can reliably increase adherence to self-monitoring of blood glucose.

A Symbiosis Between Single-Case Designs and Technology-Based Data Capture

We believe that a symbiosis exists between single-case experiments and technology-based interventions. Single-case designs can capitalize on the ability of technology to easily, unobtrusively, and repeatedly assess health-related behavior [7,9]. Single-case research requires frequent contact with the participant's behavior, which can be challenging in some research contexts but is more straightforward with technology. For example, researchers have used technology-based measures of activity in the form of daily step counts [10], twice-daily measurements of exhaled carbon monoxide as an indicator of smoking status [11], and medication adherence on a daily basis [12]. Assessment may become even easier as unobtrusive biometric sensors "weave themselves into the fabric of everyday life until they are indistinguishable from it" [13] [2,14]. Such repeated assessment, whether through existing or new technology, provides excellent opportunities to analyze the

effects of treatment variables using single-case experiments. In addition, many technology-delivered behavioral health interventions permit automated treatment delivery [15]. This means that treatment can be delivered with high fidelity, which can minimize between-subject variability in treatment dose and quality. Because detecting treatment effects in single-case designs requires replications across subjects, ensuring equivalent treatment fidelity and quality across participants enhances the internal validity of the study.

There are two additional advantages of single-case research, and these advantages exist whether patient improvement is measured with technology-based or alternative methods. First, because "health" is a property of an individual (and not a group of individuals), assessing change over time in an individual patient's behavior is an empirical and conceptual necessity. Single-case research requires a fine-grained view of health-related behavior over time, and technology-based data capture can enable this view. Second, single-case research is also well suited to demonstrate preliminary efficacy, which can be defined as "clinically significant patient improvement over the course of treatment" [16]. Patient improvement can be revealed by changes in health-related behavior from baseline to treatment, and the cause of these changes can be verified via replications within and across participants. Experimental designs, such as group designs (cf. [17]) that take only a "snapshot" of behavior, fail to resolve this temporally dynamic feature of behavior. As noted by Morgan and Morgan [18], this failure is "equivalent to underusing the resolving power of a microscope."

In addition to the fit between the logic of single-case designs and the data capture capabilities of technology, single-case designs may obviate some logistical issues in using between group designs to conduct initial efficacy testing. For example, prototypes of a new technology may be expensive and time consuming to produce [1]. Similarly, troubleshooting and refining the hardware and software may entail long delays. For these reasons, enrolling a large sample for a group design may be prohibitive. Also, during development of a new technology-based treatment, a researcher may be interested in which components of treatment are necessary. For example, a mobile-phone based treatment may involve self-monitoring, prompts, and feedback. Assessing these components using a group design may be cumbersome. Single-case designs can be used to perform efficient, systematic component analyses [19]. Although some logistical issues may be mitigated by using single-case designs, they do not represent easy alternatives to traditional group designs. They require a considerable amount of data per participant (as opposed to a large number of individuals in a group), enough participants to reliably demonstrate experimental effects, and systematic manipulation of variables over a long duration. Nevertheless, in many cases, single-case designs can reduce the resource and time burdens associated with between group designs.

Addressing Common Misconceptions

There are several common misconceptions about single-case designs [20,21]. First, single-case does not mean "n of 1". The

number of participants in a typical study is always more than 1, usually around 6 but sometimes as many as 20, 40, or more participants [11,22]. Also, the unit of analysis, or “case”, could be individual participants, clinics, group homes, hospitals, or health care agencies. Given that the unit of analysis is each case, a single study could be conceptualized as a series of single-case experiments. Second, single-case designs are not limited to interventions that produce large immediate changes in behavior. They can be used to detect small but meaningful changes in behavior and to assess behaviors that may change slowly over time (eg, learning a new skill) [23]. Third, findings from single-case research do not inherently lack external validity or generality. This misconception is perhaps the most prejudicial, and addressing it requires some background in the logic and mechanics of single-case design. Thus, we shall save our discussion of this misconception to the end of this paper.

Structures and Functions of Single-Case Designs

The most common single-case designs—and those that are most relevant to technology-based interventions—are presented in Table 1. The table also presents some procedural information, as well as advantages and disadvantages for each design. All of these designs permit inferences about causal relations between independent and dependent variables (observations of behavior, self-reports of symptoms, etc). Procedural controls must be in place to make these inferences such as clear, operational definitions of the dependent variables, and reliable and valid techniques to assess the behavior. The experimental design must be sufficient to rule out alternative hypotheses for the behavior change. Table 2 presents a summary of the main methodological and assessment elements that must be present to permit conclusions about treatment effects [24]. The majority of the criteria in Table 2 have been validated to evaluate the quality of single-case research [25]. As such, the items listed in the table represent quality control standards for single-case research.

We have added one criterion to Table 2, that is, researchers should authenticate the participant who generated the dependent variable or use validation methods to assess whether the participant (and not some other person) was the source of the data. Authentication or validation is important when data capture occurs remotely with technology. The difficulty in ensuring that remote sensors are collecting data about a specific individual is referred to as the “one body authentication problem” [26]. To solve this problem, for example, a web-based video [7] or new methods in biometric fingerprinting could authenticate the end-user [26,27]. As an alternative, or as a complement, validation measures can be collected. For example, in-person viral load assessments could be measured at various points during a study to increase antiretroviral medication adherence [12], or body mass and physiological measures could be measured during an exercise or activity-based intervention.

There are two additional assessment-related items in Table 2 that warrant discussion in the context of novel technology-based interventions. The first is assessing the fidelity of technology-based treatments [28]. Carroll and colleagues [29] defined fidelity “as the degree to which the intervention implementation process is an effective realization of the intervention as planned” (p. 1). This definition entails measurement of the delivery and receipt of the intervention, which are related but not necessarily synonymous. What is delivered via technology may not be what is received by the end-user. Dabbs and associates [28] provide a list of questionnaire items that could be easily adapted to assess the fidelity of technology-based interventions. These items are based on the Technology Acceptance Model [30]. The second is assessing whether the methods and results are socially valid [31,32]; see Foster and Mash [33] for methods to assess social validity. Social validity refers to the extent to which the goals, procedures, and results of an intervention are socially acceptable to the client, the clinician or health care practitioner, and society [33-37]. During initial efficacy testing, social validity from the perspective of the client should be assessed. Indeed, technology may engender risks to privacy and confidentiality, and even an effective intervention may be perceived as too intrusive.

Table 1. Common single-case designs, including general procedures, advantages, and disadvantages.

Design	Procedure	Advantages	Disadvantages
Reversal	Baseline conducted, treatment is implemented, and then treatment is removed	Within-subject replication; clear demonstration of an intervention effect in one subject	Not applicable if behavior is irreversible, or when removing treatment is undesirable
Multiple-Baseline	Baseline is conducted for varying durations across participants; then treatment is introduced in a staggered fashion	Treatment does not have to be withdrawn	No within-subject replication; potentially more subjects needed to demonstrate intervention effects than when using reversal design
Alternating Treatment	Baseline and multiple different treatments are quickly alternated (often within the same day)	Within-subject replication; rapid demonstration of differences between several treatments	Sequence effects (ie, treatment interaction) can occur; phases may be difficult to discriminate if changed too rapidly
Changing Criterion	Following a baseline phase, treatment goals are implemented; goals become progressively more challenging as they are met	Demonstrates within-subject control by levels of the independent variable without removing treatment; useful when gradual change in behavior is desirable	Not applicable for binary outcome measures; must have continuous outcomes
Combined	Elements of any treatment can be combined.	Allows for more flexible, individually tailored designs	If different designs are used across participants in a single study, comparisons across subjects can be difficult

Table 2. Quality indicators for single-case research.

Dependent variable	<p>Dependent variables are described with operational and replicable precision</p> <p>Each dependent variable is measured with a procedure that generates a quantifiable index</p> <p>Dependent variables are measured repeatedly over time</p> <p>In the case of remote data capture, the identity of the source of the dependent variable should be authenticated or validated</p>
Independent variable	<p>Independent variable is described with replicable precision</p> <p>Independent variable is systematically manipulated and under the control of the experimenter</p> <p>Overt measurement of the fidelity of implementation of the independent variable is highly desirable</p>
Baseline	<p>The majority of single-case research will include a baseline phase that provides repeated measurement of a dependent variable and establishes a pattern of responding that can be used to predict/compared against the pattern of future performance, if introduction or manipulation of the independent variable did not occur.</p> <p>Baseline conditions are described with replicable precision.</p>
Experimental Control/Internal Validity	<p>The design provides at least three demonstrations of experimental effect at three different points in time.</p> <p>The design controls for common threats to internal validity (eg, permits elimination of rival hypotheses).</p> <p>There are a sufficient number of data points for each phase (eg, minimum of five) for each participant.</p> <p>The results document a pattern that demonstrates experimental control.</p>
Social Validity	<p>The dependent variable is socially important.</p> <p>The magnitude of change in the dependent variable resulting from the intervention is socially important.</p> <p>The methods are acceptable to the participant.</p>

General Characteristics of Single-Case Designs

Of the designs listed in [Table 1](#), the reversal, multiple-baseline, and changing criterion designs may be most applicable for initial efficacy testing of technology-based interventions. All of these

designs entail a baseline period of observation. During this period, the dependent variable is measured repeatedly under control conditions, for example for several days. Ideally, the control conditions should include all treatment elements (eg, access to the Internet, the use of a mobile phone, or

technology-based self-monitoring) except for the active treatment ingredients [38]. For instance, Dallery and colleagues used a reversal design to assess effects of Internet-based incentive program to promote smoking cessation, and the baseline phase included self-monitoring, video-based carbon monoxide confirmation via a web camera, and monetary incentives [11]. The active ingredient in the intervention, incentives contingent on objectively verified smoking abstinence (via video), was not introduced until the treatment phase. An additional consideration in the context of technology is the time needed to simply learn how to operate the device, website, or software. Baseline control conditions may need to take this learning into account before the active ingredients of the intervention are introduced. The baseline condition in the study by Dallery et al, for example, provided ample time for the participants to learn how to upload videos and navigate the study website.

The duration of the baseline should be sufficient to predict future behavior. That is, the level of the dependent variable should be stable enough to predict its direction if the treatment were not introduced. If there is a trend in the direction of the anticipated treatment effect during baseline, the ability to detect a treatment effect will be limited. Thus, stability, or trend in the direction opposite the predicted treatment effect, is desirable. The decision to change conditions is an experimenter decision, which can be supplemented with a priori stability criteria [39-41]. For example, a decision to change conditions could be made if the first two and last two data points in a five-session block are within 15% of each other, and there are no visual trends in the direction of the treatment effect as determined by two independent experimenters or by a regression coefficient above or below a certain threshold. There are no universal rules about specific criteria; they must be developed in consideration of the behavior and intervention being studied.

Reversal Designs

In a reversal design, the treatment is introduced after the baseline period. The number of data points in the treatment condition must again be sufficient to predict behavior if treatment were to continue (eg, stable performance and no trends toward baseline levels of the dependent variable). Following the treatment period, the baseline period is re-introduced, hence the “reversal” in this design. The minimum number of alternations to document experimental control in a reversal design is three alternations. Using only two conditions, such as a pre-post design, is not considered sufficient to demonstrate experimental control because other sources of influence over behavior cannot be ruled out [42]. For example, a smoking cessation intervention could coincide with a price increase in cigarettes. By returning to baseline conditions, we could assess and possibly rule out the influence of the price increase on smoking. Researchers also often employ a “reversal” to the treatment condition. Thus, the experiment ends during a treatment period. Not only is this desirable from the participant’s perspective, it provides a replication of the main variable of interest, ie, the treatment [39,43].

Figure 1 displays an idealized, four-condition reversal design, and each panel shows data from a different participant. For the

purposes of illustration, let us assume that the treatment is a text-message system delivered via mobile phone to decrease smoking (labeled “B” in the Figure). The baseline control conditions (labeled “A” in the Figure) include neutral text messages (ie, texts that are not smoking-related). Let us also assume that the dependent variable is number of cigarettes smoked per day. Although all participants were exposed to the same four conditions, the duration of the conditions differed because of trends in the conditions. For example, for Participant 1 the beginning of the first baseline condition displays a consistent downward trend (in the same direction as the expected text-message treatment effects). If we were to introduce the smoking cessation-related texts after only 5 or 6 baseline sessions, it would be unclear if the decrease in smoking was a function of the independent variable. Therefore, continuing the baseline condition until there is no visible trend helps build our confidence about the causal role of the treatment when it is introduced. The immediate decrease in the level of smoking for Participant 1 when the treatment is introduced also implicates the treatment. We can also detect, however, an increasing trend in the early portion of the treatment condition. Thus, we need to continue the treatment condition until there is no undesirable trend before returning to the baseline condition. Similar patterns, which also illustrate differences in the magnitude and variability of the effects, can be seen for Participants 2-4.

Multiple-Baseline Design

In a multiple-baseline design, the durations of the baselines vary systematically for each participant in a so-called “staggered” fashion. For example, 1 participant may start treatment after 5 baseline days, another after 7 baseline days, then 9, and so on. After baseline, treatment is introduced and it remains until the end of the experiment (ie, there are no reversals). These designs are also referred to as “interrupted time-series” designs [44]. The power of these designs is derived from demonstrating that change occurs when, and only when, the intervention is directed at a particular participant (or whatever the unit of analysis happens to be [45]). The influence of other factors, such as idiosyncratic experiences of the individual or self-monitoring (eg, reactivity), can be ruled out by replicating the effect across multiple individuals. As replications are observed across individuals and behavior changes when, and only when, treatment is introduced, confidence that behavior change was caused by the treatment increases. These designs are also useful for technology-based interventions that teach new skills, where behavior would not be expected to “reverse” to baseline levels. Multiple-baseline designs also obviate the ethical concern that control participants in a between group design are not exposed to the active treatment, as all participants are exposed to the (potentially) active treatment with multiple-baseline designs. Although all participants in a reversal design also receive the treatment, the treatment must be withdrawn to assess treatment effects. Figure 2 illustrates a simple, two-condition multiple-baseline design replicated across 4 participants. Similar to the reversal design, treatment should be introduced only when the data appear stable. The durations of the baseline conditions are staggered for each participant, and the dependent variable increases when, and only when, the independent variable is introduced for all participants. Figure 2 suggests reliable

increases in behavior and that the treatment was responsible for these changes.

The multiple-baseline is an advance over pre-post designs, which also involve a baseline (or pre-intervention) period followed by a treatment period [42]. Although pre-post designs have been used to establish the feasibility of technology-based interventions [46], one advantage of using a multiple-baseline design is that in addition to establishing feasibility, it can establish preliminary efficacy [47]. For example, Cushing, Jensen, and Steele [48] investigated the ability of a mobile device, used to measure adherence to a self-monitoring intervention, to improve weight management with a

multiple-baseline design. Overweight adolescents (n=3) were given weekly self-monitoring goals based on recording their meals and activity levels. During baseline, self-monitoring was completed with a traditional pencil-and-paper method, and goal attainment was measured for 4, 5, and 9 weeks for each successive participant. Following baseline, participants were instructed to use mobile devices with automated software to input their daily health information. Goal attainment increased dramatically when the mobile device was used, and the staggered presentation of the independent variable convincingly demonstrated that the mobile device increased self-monitoring of food intake and activity levels, as opposed to some other variable.

Figure 1. Example of a reversal design showing experimental control and replications within and between subjects (each panel represents a different participant, each of whom experienced two baseline and two treatment conditions).

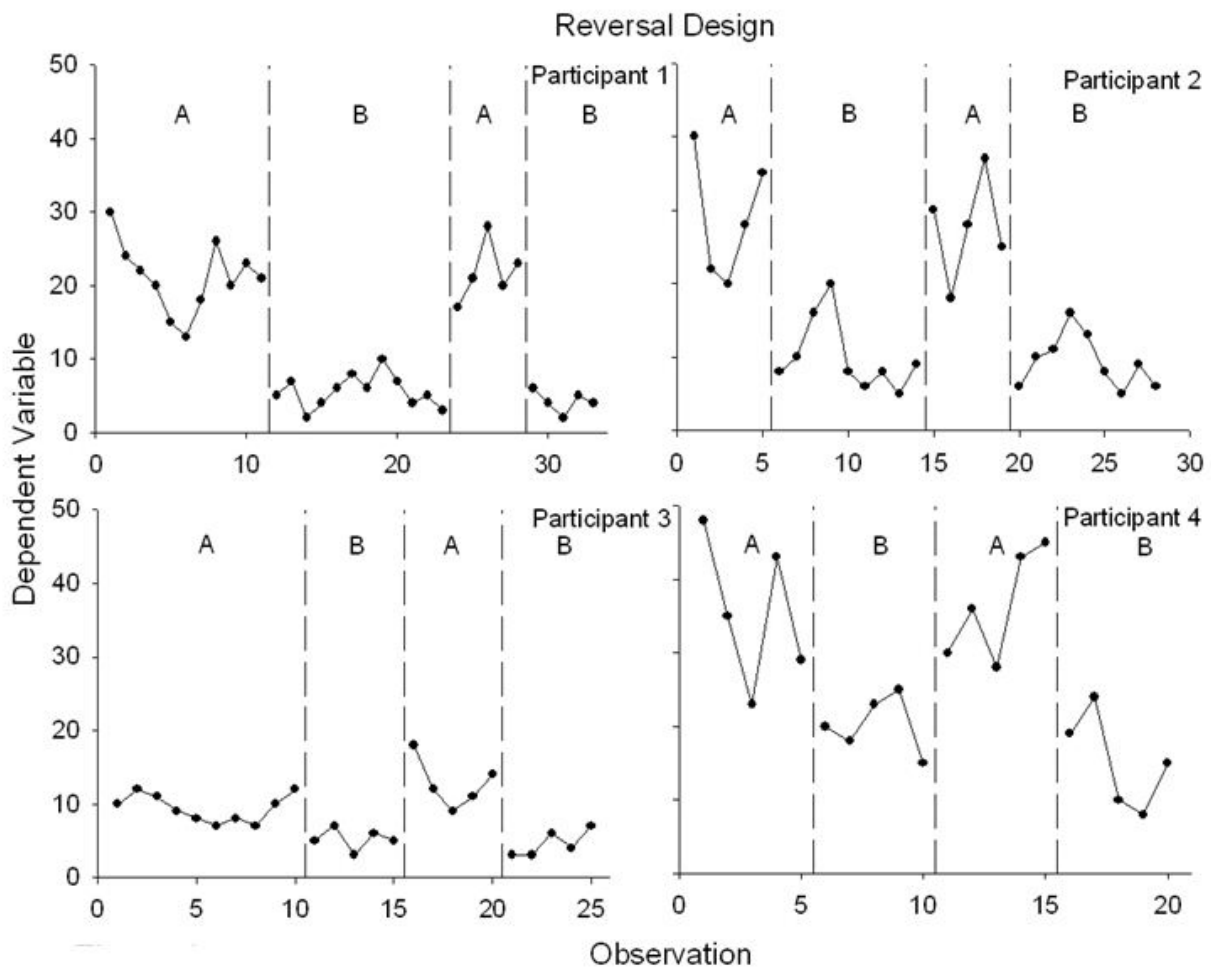
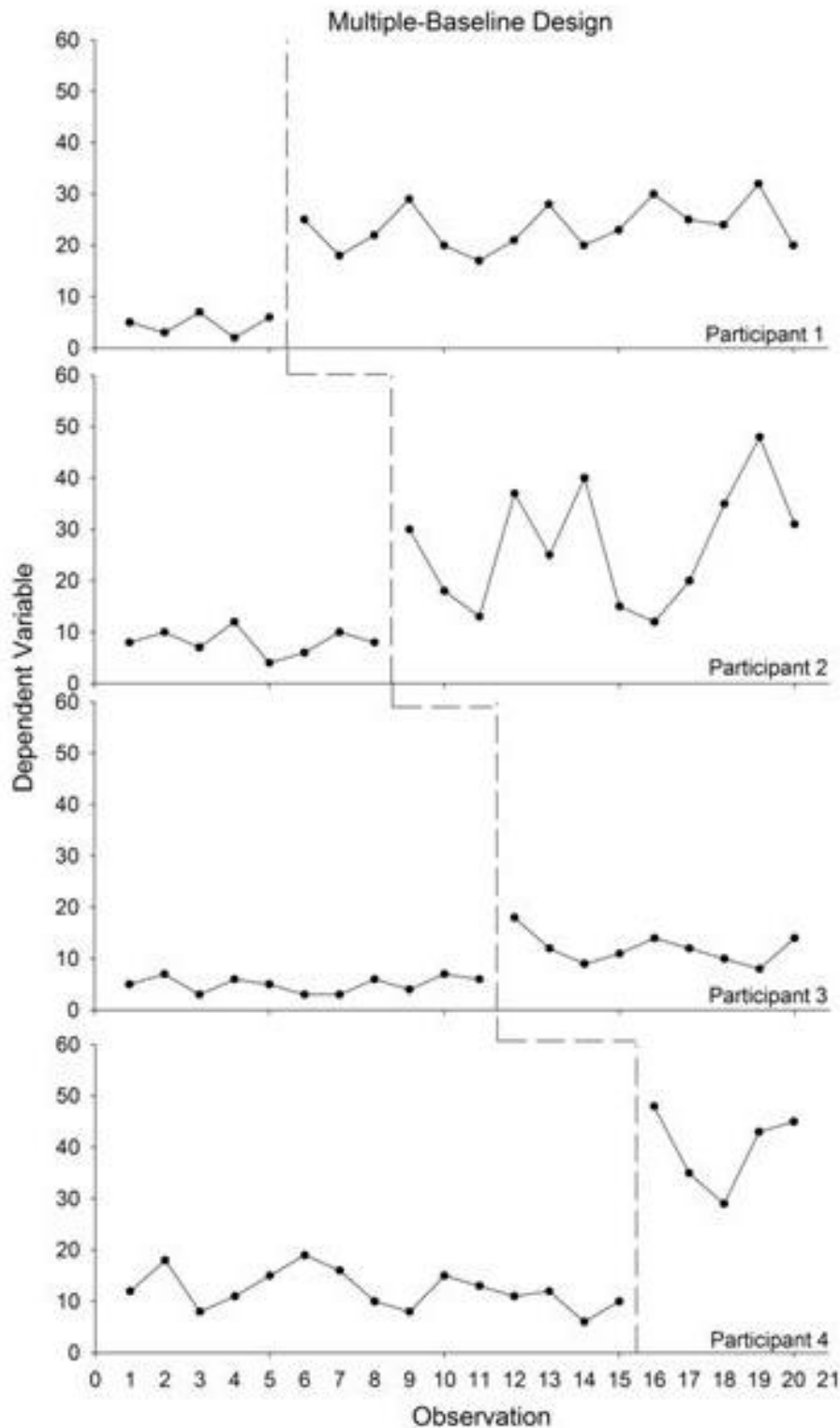


Figure 2. Example of a multiple baseline design showing experimental control and replications between subjects (each row represents a different participant, each of whom experienced a baseline and treatment; the baseline durations differed across participants).



Changing Criterion Design

The changing criterion design is also relevant to testing technology-based interventions. In a changing criterion design,

a baseline is conducted until stability is attained. Then a treatment goal is introduced, and goals are made progressively more difficult. Behavior should track the introduction of each goal, thus demonstrating control by the level of the independent

variable [39,45]. For example, Kurti and Dallery [10] used a changing criterion design to increase activity in 6 sedentary adults using an Internet-based contingency management program to promote walking. Weekly step count goals were gradually increased across 5-day blocks. The step counts for all 6 participants increased reliably with each increase in the goals, thereby demonstrating experimental control of the intervention.

Analytic Techniques to Isolate Treatment Effects

The first and most important analysis of whether a technology-based intervention affected a health-related behavior is visual analysis of the time-series data. Clinically significant change in patient behavior should be visible. Even a change in a slowly developing skill should be visible in the graphical display of the data. Visual analysis prioritizes *clinically* significant change in health-related behavior as opposed to *statistically* significant change in group behavior [16]. A statistically significant effect may be clinically meaningless [49]. These observations are not new—they echo repeated calls to reform analytic strategies in psychological science [49-51]. These calls have also emphasized graphical design and visual analysis as vital elements of data analysis. Decisions about whether the magnitude of change is clinically relevant should not be automated; they should be based on visual analysis, experience with the subject matter, and scientific judgment. For example, the data in Figure 1 may suggest a reliable change in cigarettes smoked per day. Whether such reductions are meaningful, however, is another issue that can be informed by previous research on the extent to which reductions in smoking result in reductions in health risks or future smoking cessation [52].

Parsonson and Baer described several heuristics for evaluating changes in the time-series of behavioral data [53]. Several features of the data paths under each condition must be evaluated. Single-case designs use “steady-state” design logic, which at a minimum entails a stable baseline. Ensuring a sufficiently long and stable baseline permits prediction of behavior if an intervention is not introduced (see Table 2). Although the precision duration is determined by the experimenter in consideration of the dynamics of the behavior being studied, the presence of reactivity, and so on, a rule of thumb is a minimum of five data points to detect stability or trends in the data [24]. When the intervention is introduced, a large change in level (change in behavior from the last data point in baseline to the subsequent data point in treatment) and a large change in the mean (average levels in both conditions) increases confidence that experimental control was achieved. We also consider the overall pattern in the results, the amount of variability within and between phases, and the number of replications of effects both within (if the design permits it) and across participants. These heuristics highlight the power of visual analysis to simultaneously assess a number of data attributes, such as the immediacy of treatment effects, variability within and across conditions, trends, and whether the whole data series corresponds to the effects predicted by the

intervention and study design [54]. To our knowledge, no other analytic technique can accomplish these tasks simultaneously.

New aids have been developed to assist in the visual analysis of time-series data [23]. One particularly powerful aid, called the conservative dual-criteria (CDC) method, helps the analyst judge whether a treatment effect is present relative to a baseline condition [55]. Essentially, the CDC method entails extending regression lines based on baseline performance into the treatment phase. The regression lines represent predictions of the data path if the intervention had not been introduced. The number of data points above (or below, depending on the predicted treatment effect) the lines are counted, and the binomial formula is used to assess whether this number exceeds what would be expected by chance. Monte Carlo simulations showed that the CDC method had acceptable rates of Type I error even with small datasets [55]. Furthermore, the method had greater power than other common aids to visual analysis, such as the split-middle method, and outperformed two common statistical methods to analyze time-series data (interrupted time series, general linear model), even with the presence of autocorrelation [55].

Before statistical tests are applied, the presence of autocorrelation in the time-series data must be considered. Autocorrelation means that many traditional parametric and nonparametric tests may not be appropriate to analyze treatment effects (eg, t , F , chi square, etc). Autocorrelation is when successive data points are correlated, for example, mood on day 1 is correlated with mood on day 2, and so on. The presence of autocorrelation can be assessed by calculating an autocorrelation coefficient. There is disagreement about how much autocorrelation occurs in single-case time-series data and the extent to which it inflates Type I error rate [53,55]. At a minimum, the issue of autocorrelation must be considered when deciding which statistical test is appropriate. Bockhardt and colleagues [56] framed the issue nicely:

Though it is a statistical nuisance, by its nature serial dependence reflects the momentum and gradualism of physiological, behavioral, and emotional repair. Because it is an index of serial dependence, autocorrelation can reveal something about the ebb and flow of behavioral change over time. For this reason, autocorrelation is the natural subject matter of a behavioral science. Whatever inferential statistic is applied to single-case time-series data, we believe it should approach autocorrelation not as noise that obscures change, but as music that accompanies it. Put differently, the preferred statistic gauges the occurrence of change, while preserving its structure.

There are a number of statistical techniques that can control for the presence of autocorrelation when assessing treatment effects. Although a complete discussion of these techniques is beyond the scope of this paper, several regression-based approaches are available, such as autoregressive models, robust regression, and hierarchical linear modeling (HLM) [57,58]. One limitation of some of these approaches is that they require long data streams (eg, 30 data points per condition). At least one study, however, suggests that HLM may be used with the shorter data streams

seen in typical single-case studies [59] and that are consistent with the standards presented in Table 2 (ie, a minimum of five data points per condition with no undesirable trends). HLM has also been used to assess data streams collected with technology-based methods. For example, Ben-Zeev and colleagues [60] used handheld personal digital assistants to collect data about persecutory ideation in individuals diagnosed with schizophrenia and HLM to assess relations between negative affect and persecutory ideation.

Methods for computing effect sizes in single-case research have also proliferated. These methods are a welcome advance, particularly in consideration of efforts to reform traditional null hypothesis significance testing and replace *P* values with more informative effect size estimates and confidence intervals [49,61]. Parker and Hagan-Burke [62] note that effect sizes in single-case research provide: (1) an objective measure of intervention strength (assuming a strong, internally valid design), (2) a continuously scaled index to support incremental treatment decisions, (3) improved measurement precision when results are not large and obvious, (4) an objective summary when visual judgments do not agree, (5) a method for comparing relative intervention success across single-case studies, both at the local level and within broader meta-analyses, (6) improved credibility for single-case studies in the eyes of other research traditions, and (7) an efficient method of documenting results.

One family of effect size measures is called nonoverlap techniques. In nonoverlap calculations, the degree of nonoverlap in the data between phases (ie, between two distributions) is compared. For example, consider the bottom right panel of Figure 1, which is re-drawn as Figure 3. One basic technique is to draw a horizontal line at the lowest baseline data point because the intervention sought to decrease behavior [63]. Then, the proportion of data points below this line is calculated for the following “B” phase (eg, 3/5 or 60%). Because treatment effects were replicated, the numbers are summed from the two conditions (eg, (3 of 5) + (4 of 5), or 7 of 10 = 70%). Nonoverlap methods accord nicely with visual analysis, as one key task in visual analysis is detecting the degree of difference (nonoverlap) in the data points across successive conditions. Further, nonoverlap methods provide meaningful information about treatment effects. Nonoverlap scores above 90% are very effective, 70-90% are effective, 50-70% are questionable, and below 50% suggests the treatment was ineffective [63]. The summary measures derived from nonoverlap techniques can be used to compare different treatments for the same problem in meta-analyses.

There are other effect size calculation techniques in addition to nonoverlap methods. Manalov and colleagues [54] compared the performance of four techniques using Monte Carlo

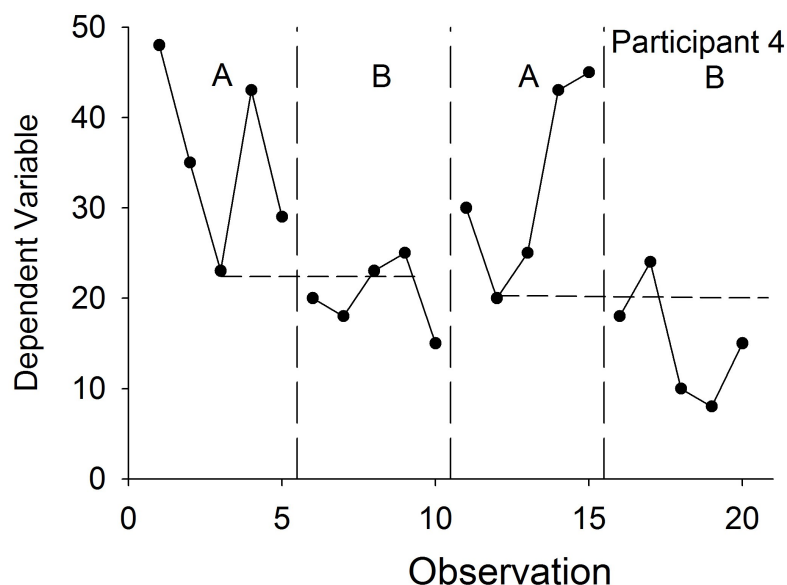
simulations. Potential confounding variables were also introduced such as autocorrelation, linear and curvilinear trends, and heteroscedasticity between conditions. Although they found that the different techniques performed better or worse depending on the nature of the data, one overlap technique called nonoverlap of all pairs performed adequately across all conditions. The authors presented a simple flowchart for decision making to select an effect size technique based on the properties of the data (eg, the presence of linear trend).

Due in part to the recent advances in statistical and effect size calculations, meta-analysis of single-case studies have started to appear in the literature. Several meta-analyses have used a variant of the nonoverlap technique described above as a measure of effect size (see [64] for details about this technique) [65-67]. Other researchers have used HLM to perform meta-analysis [68]. Jenson and colleagues [59] conducted Monte Carlo simulations of reversal designs using HLM with different amounts of autocorrelation, data points, and effect sizes and found that HLM performed well (eg, Type I error rates were acceptable). Also, under the vast majority of conditions HLM produced power greater than 0.9. In only 8 out of the 30 conditions did power drop below this number, and these conditions included small numbers of data points in baseline and treatment conditions combined with high amounts of autocorrelation (>0.8, indicating a strong trend). In light of the quality control criteria presented in Table 2, these conditions should be rare in published single-case studies.

To our knowledge, with the exception of HLM, many of the techniques described above have not been applied to assess effects of technology-based interventions. This is not surprising, as both the statistical methods and technology-based interventions are relatively new. With respect to statistical analyses of time-series data, the number of techniques have proliferated in recent years; some authors estimate that the number has tripled since the 1980s (Parker et al, 2005). One potential negative side effect of such proliferation is the lack of standards or rules to guide decision making about appropriate statistical tests. Thus, we recommend Kazdin’s [23] or Barlow and colleague’s [45] textbooks as useful resources regarding statistical analysis of time-series data. But, we hasten to note that statistical analysis should be viewed as a complement to visual analysis, not a replacement. As noted by Kazdin [23]:

We would like simple rules to guide us and to teach our students. We have a couple, perhaps: (1) consider more than one means of evaluating the data, and (2) in relation to visual inspection and statistical analysis, do not take an “either/or” position. Either/or may work well in philosophy (Kierkegaard, 1843), but may not be wise in science.

Figure 3. A visual example of how to calculate the percentage of nonoverlapping data (see text for calculations).



Some Threats to Inferences Based on Single-Case Designs

There are several potential threats to internal validity when using single-case designs. First, behavioral reactivity to the mere act of measuring behavior may be present during initial observations. Continued or unobtrusive observation can remedy this problem [45]. Given the remote data capture inherent in many technology-based interventions (eg, telemetric monitoring; [9]), reactivity may be minimized. Second, carryover effects from condition to condition may occur when using a reversal design or an alternating treatment design (in which conditions alternate more rapidly than in a reversal design; see Table 1). One solution is to specifically assess order effects by manipulating the order of sequences across participants. Another is to increase the duration of conditions: carryover effects are typically transient and will generally decrease with extended contact with the new condition. Several researchers have even recommended randomization to treatment order [69], which also permits the use of some statistical tests (eg, randomization tests). Third, experimenter bias may occur when deciding whether conditions should be changed. As described above, the experimenter decides when to change conditions based on properties of the data path (eg, stability, sufficient number of data points). Some have suggested that the durations of conditions should be decided on an a priori basis [69]. This is certainly a possibility, but it means that the timing of a treatment condition may be inappropriate if the data are trending in the direction of the predicted treatment effect. Thus, the trade-off may not be desirable between reducing potential bias and decreasing the possibility of demonstrating experimental control through careful observation and decision making.

Another potential threat is the problem of small changes in the dependent variable as a result of an intervention. The threat concerns the conclusions the researcher may draw, or fail to draw, about the intervention. For example, a technology-based intervention may produce a small change in an outcome measure for only a fraction of participants. Relying on a stringent criterion, such as large visually detectable changes in graphically displayed data for all participants, to conclude that a treatment effect is present may result in a Type II error, or a false-negative. This may be especially problematic under two conditions [23]. First, if the intervention can be applied in a cost-effective way to a large number of individuals, a small behavior change may have considerable public health impact. Consider a simple, text-based motivational or cognitive-behavioral intervention for depression. If the intervention reduces symptoms in 2 of 6 participants in a single study, this may still be meaningful. This is because the intervention could be delivered to a large number of sufferers via mobile phones, so a 33% success rate in reducing symptoms may be important. (Of course, one single-case study showing such results would require replication(s) prior to larger-scale testing and dissemination). Second, if the outcome variable being measured is highly socially significant, a small reduction in behavior may also be meaningful. Consider a community-based intervention delivered via text to reduce suicide, domestic violence, or drinking and driving. Even a small reduction in any one of these outcomes would be important. Thus, if the scalability and/or social significance of the intervention are high, then the criterion to judge the clinical meaningfulness of the results will require special consideration.

Detecting small but meaningful changes in behavior can be accomplished using single-case designs. In addition to special consideration to criteria to judge treatment effects, special

consideration must be given to the particulars of the research design. The researcher must choose designs (eg, multiple-baseline vs. reversal) and design parameters (eg, sufficiently long baseline and treatment conditions, sufficient number of participants to include in the study) to make detection of small but meaningful treatment effects more likely. In addition, detecting small but meaningful changes may be aided by statistical analysis [23,62].

Dissecting Effects: Component Analysis of Technology-Based Interventions

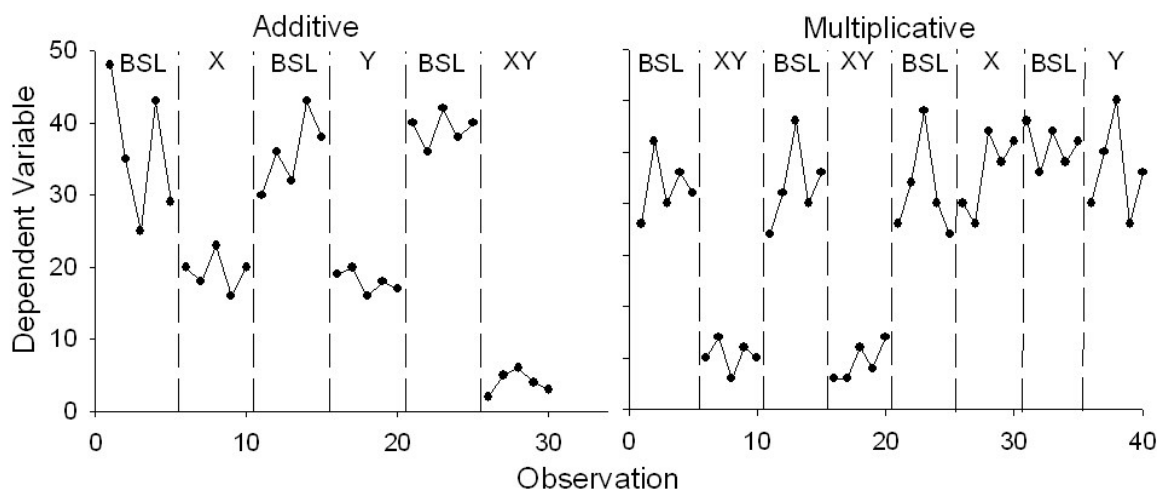
A component analysis is “any experiment designed to identify the active elements of a treatment condition, the relative contributions of different variables in a treatment package, and/or the necessary and sufficient components of an intervention” [19]. Technology-based health interventions often entail more than one active treatment element. Determining the active elements may be important to increase dissemination potential and decrease cost. For example, a mobile health intervention to promote smoking cessation might entail two potentially active components: self-monitoring of progress plus access to on-demand therapeutic support from a counselor. Whether therapeutic support is necessary will have obvious dissemination and cost implications. Single-case research designs, in particular reversal and multiple-baseline designs, may be used to perform a component analysis. The essential experimental ingredients, regardless of the method, are that the independent variable(s) is systematically introduced and/or withdrawn, combined with replication of effects within and/or between subjects.

There are two main variants of component analyses: the dropout and add-in analyses. In a dropout analysis, the full treatment package is presented following a baseline phase, and then components are systematically withdrawn from the package. A limitation of dropout analyses is when components produce irreversible behavior change (ie, learning a new skill). Given that many technology-based interventions seek to produce sustained changes in health-related behavior, dropout analyses may have limited applicability. Instead, in add-in analyses, components can be assessed individually and/or in combination before the full treatment package is assessed. Add-in reversal or alternating designs “provide the most powerful and complete analysis of the active components of a treatment package because they reduce potential confounding from the effects of component combinations” [19]. Of course, the possibility of sequence effects should be considered, and researchers could address such effects through counterbalancing, brief “washout” periods, or explicit investigation of these effects [41].

Several conclusions can be drawn about the effects of the various technology-based components in changing behavior. The data should first be evaluated to determine the extent to which the effects of individual components are independent of one another. If they are, then the effects of the components are additive. If they are not, then the effects are multiplicative, or the effects of one component depend on the presence of another component. Figure 4 presents simplified examples of these two possibilities using a reversal design and short data streams (adapted from [19]). The panel on the left shows additive effects, and the panel on the right shows multiplicative effects. The data can also be analyzed to determine whether each component is necessary and sufficient to produce behavior change. For instance, using the example above, the panel on the right shows that neither the self-monitoring nor the counseling component is sufficient to promote cessation, and both components are necessary. If two components produce equal changes in behavior, and the same amount of change when both are combined, then either component is sufficient but neither is necessary.

The logic of the component analyses described here resembles new methodologies derived from an engineering framework [70,71]. During the initial stages of intervention development, these engineering-based methodologies use factorial designs to allocate participants to different combinations of treatment components. These designs, called fractional factorials because not all combinations of components are tested, represent excellent ways to screen promising components of novel technology-based treatment packages using randomized group designs. The components tested may be derived from theory or working assumptions about which components and combinations will be of interest. Collins and colleagues [70,71] note that such factorial designs may be more feasible in the field of technology-based health interventions relative to traditional in-person methods. The reason is that the costs of such interventions may be limited, for example when the costs are derived from the computer programming necessary to administer different treatment conditions. Once the programming is complete, delivering the appropriate version of the intervention across groups may be straightforward. Although this may be true in some cases, the costs (and other logistical issues—see above) associated with technology-based interventions are still formidable. Even a relatively small 16 condition fractional factorial may not be feasible [70]. Just as engineering methods seek to isolate active treatment components of novel interventions, so too do single-case methods. As such, they represent a viable alternative to isolate active components of technology-based interventions.

Figure 4. Two examples of possible results from a component analysis (BSL=baseline, X=first component, Y=second component).



Mechanisms of Behavior Change

During the past two decades, advances in statistical mediation analyses have allowed researchers to assess potential mechanisms of behavior change [72,73]. A mechanism refers to processes by which an intervention (or other independent variable) affects behavior. A drug might produce a behavioral effect via the mechanism of agonism or antagonism of particular receptors, and a technology-based behavioral health intervention might produce behavior change via specific mechanisms such as reinforcement, problem solving, or self-control. For example, a computer-based cognitive-behavioral treatment may produce drug abstinence via the mechanism of improved coping skills [74]. Although statistical mediation analyses provide evidence for the necessity of potential mechanisms of change, they do not provide evidence for the sufficiency of the relation between a potential mechanism and behavior change. As noted by Nock (2007), “just as correlation does not imply causation, mediation does not imply mechanism” (p. 5S [75]). Statistical mediation, therefore, is one step along the path of elucidating the necessity and sufficiency of a mechanism of behavior change. To our knowledge, statistical mediation approaches in single-case designs do not exist. Single-case experimental procedures, however, can be employed to isolate behavioral mechanisms. Therefore, single-case designs can help develop evidence on the necessity and sufficiency of a mechanism of technology-induced behavior change.

Several experimental criteria must be met to build a case for a mechanism of behavior change [75,76]. These criteria include gradient, temporal relation, and experiment. Gradient goes beyond showing an association (which can be accomplished using statistical mediation approaches) to showing that more of the treatment results in more of the mechanism and also more change in the outcome measure. Essentially, this is a parametric dose-response analysis, with the addition of measurement of potential mechanisms at each dose. For example, more exposure to a computer-based cognitive behavioral treatment [74] should result in more coping skills and therefore more drug abstinence.

To achieve a temporal relation, an experiment must show that the change in the independent variable preceded a change in the mechanism, and the change in mechanism preceded the change in the outcome measure. This is where single-case procedures using technology are particularly well adapted: showing a temporal relation requires repeated, frequent assessment of the mechanism and outcome. The assessment can be enabled by technology-based approaches afforded by mobile phones, biometric sensors, or accessing a website. For example, mobile phones could be used to frequently probe changes in coping skills, and changes in skills should precede changes in drug abstinence. Finally, experiment means that researchers must use an experimental design that entails systematic manipulation of the independent variable (treatment). The mechanism should change only when the treatment is instituted and be temporally associated with changes in the outcome. Reversal designs or multiple-baseline designs, for example, can be used to meet the criterion of experiment.

Examining mechanisms of behavior change is crucial for understanding how technology-based interventions impact health outcomes (eg, increased activity, better dietary choices, sustained smoking abstinence, etc.). Isolating the key mechanisms can help ensure that these mechanisms are present when the interventions are scaled up and disseminated. This process may also increase the efficiency of an intervention by harnessing the active ingredients and discarding the inactive ingredients. Furthermore, isolating mechanisms can help bring parsimony to the field [75]. The number of technology-based interventions is multiplying, but a parsimonious assumption is that the number of mechanisms underlying these interventions is not keeping pace. Finally, because of technology’s unique ability to penetrate the daily life of the end-user, new mechanisms may be discovered and assessed. For example, technology-based therapeutic tools may be used in real-time, enabling “experiential learning”, which is an effective learning strategy that uses real-world interactions [77,78]. Overall, the symbiosis between technology-based assessment and the rigor

of single-case designs suggests that we have an excellent opportunity to assess mechanisms of behavior change.

Replication, Reproducibility, and Generality

Perhaps the most common concern with single-case research is its purported limited external validity or generality. Implicit in this concern is the premise that group designs deal with generality more effectively. Group designs, however, rarely include a random, representative sample of the relevant population and thus do not logically possess generality [21,79]. The problem of limited generality is even more likely in the context of initial efficacy testing, where groups may be based on convenience. Although some might assume that the issue of generality can be accommodated by inferential statistical testing, this is also a dubious assumption [80]:

A major limitation of statistical significance, therefore, is that it does not provide direct information about the reliability of research findings. Without knowledge about reliability there can be no examination of generality because repeatability is the most basic test of generality. Notwithstanding that limitation, however, significance testing based on group means may be seen, incorrectly, to have implications for generality of findings across subjects. Adherence to this view unfortunately gains strength as sample size increases. In fact, however, regardless of sample size, no information about intersubject generality can be extracted from a significance statement because no knowledge is afforded concerning the number of subjects for whom the effect actually occurred.

In a seminal article on null-hypothesis significance testing, similar considerations led Cohen to say, “For generalization, psychologists must finally rely, as has been done in all the older sciences, on replication” [49].

In the context of single-case research, generality can be demonstrated experimentally in several ways. The most basic way is via direct replication. Direct replication means conducting the same experiment on the same behavioral problem across several individuals (ie, a single-case experiment). For example, Raiff and Dallery [8] achieved a direct replication of the effects of Internet-based CM on adherence to glucose testing in 4 teens (as described earlier). One goal of the study was to establish experimental control by the intervention and to minimize as many extraneous factors as possible. Overall, direct replication can help establish generality across participants. It cannot answer questions about generality across settings, populations, or target behaviors. Instead, systematic replication can answer these questions. In a systematic replication, the findings from previous direct replication studies are extended to a new setting, population, or target behavior. The Raiff and Dallery study, therefore, was also a systematic replication of effects of Internet-based CM to promote smoking cessation to a new problem and to a new population because the procedure had originally been tested with adult smokers [11]. Effects of Internet-based CM for smoking cessation were also

systematically replicated in an application to adolescent smokers using a single-case design [81].

By carefully choosing the characteristics of the individuals, settings, or other relevant variables in a systematic replication, the researcher can help identify the conditions under which a treatment works. To be sure, as with any new treatment, failures will occur. However, the failure does not detract from the prior successes: “...a procedure can be quite valuable even though it is effective under a narrow range of conditions, as long as we know what those conditions are” [82]. Such information is important for treatment recommendations in a clinical setting, and scientifically it means that the conditions themselves may become the subject of experimental analysis. This discussion leads to a type of generality called scientific generality [80], which is at the heart of a scientific understanding of technology-based interventions (or any intervention for that matter). As described by Branch and Pennypacker [80], scientific generality is characterized by knowledgeable reproducibility, or knowledge of the factors that are required for a phenomenon to occur. It can be attained through systematic replication and through analysis of behavioral mechanisms. Moreover, the data intimacy afforded by single-case designs can help achieve scientific generality about technology-based health interventions. That is, the fine-grained, replicated assessments of the ebb and flow of behavior can help us discover the mechanisms by which technology-based interventions affect health. Indeed, we know very little about theory-derived mechanisms by which these interventions affect health-related behavior [83]. Once we come to understand these mechanisms and the conditions under which they may be operative, they can be harnessed and tested in further studies and eventually be integrated into community-based interventions [44].

Evolving Beyond Preliminary Efficacy

Although we focused on single-case experiments to establish preliminary efficacy in this paper, these designs can be used at all stages of technology-based treatment development [16]. For example, a series of single-case systematic replications can provide information about the efficacy and generality of an intervention [45], and recent methodological advances have promoted the use of single-case strategies for field-testing of interventions in naturalistic settings (ie, effectiveness research) [45,84]. Indeed, single-case experiments have generated a broad range of evidence-based practices in health care and related disciplines. These fields include clinical psychology [85], substance abuse [22,86], education [24], medicine [87], neuropsychology [25], developmental disabilities [23], and occupational therapy [88].

Single-case designs have similar promise to identify evidence-based practices in the field of technology-based health interventions. Because of their rigor and success rate in identifying evidence-based practices, some researchers have argued that highly controlled single-case designs should be considered on par with group designs (eg, randomized controlled trials) [87,89]. Rather than rank methods, we think it is more relevant for the researcher to have a diverse array of methodologies to choose from. Choosing the right method can

be guided by several factors including logistics, experimental control, theory, and the previous education of the researcher [23]. We hope we have enhanced the last factor, and added some diversity to the ecology of research designs to test technology-based health interventions.

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Conflicts of Interest

None declared.

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Original Paper

Dental Fear and Anxiety in Children and Adolescents: Qualitative Study Using YouTube

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Abstract

Background: Dental fear and anxiety (DFA) refers to the fear of and anxiety towards going to the dentist. It exists in a considerable proportion of children and adolescents and is a major dilemma in pediatric dental practice. As an Internet social medium with increasing popularity, the video-sharing website YouTube offers a useful data source for understanding health behaviors and perceptions of the public.

Objective: Using YouTube as a platform, this qualitative study aimed to examine the manifestations, impacts, and origins of DFA in children and adolescents from the public's perspective.

Methods: To retrieve relevant information, we searched YouTube using the keywords "dental fear", "dental anxiety", and "dental phobia". Videos in English expressing a layperson's views or experience on children's or adolescent's DFA were selected for this study. A video was excluded if it had poor audiovisual quality, was irrelevant, was pure advertisement or entertainment, or contained only the views of professionals. After the screen, we transcribed 27 videos involving 32 children and adolescents, which were reviewed by a panel of 3 investigators, including a layperson with no formal dental training. Inductive thematic analysis was applied for coding and interpreting the data.

Results: The videos revealed multiple manifestations and impacts of DFA, including immediate physical reactions (eg, crying, screaming, and shivering), psychological responses (eg, worry, upset, panic, helplessness, insecurity, resentment, and hatred), and uncooperativeness in dental treatment. Testimonials from children, adolescents, and their parents suggested diverse origins of DFA, namely personal experience (eg, irregular dental visits and influence of parents or peers), dentists and dental auxiliaries (eg, bad manner, lack of clinical skills, and improper work ethic), dental settings (eg, dental chair and sounds), and dental procedures (eg, injections, pain, discomfort, and aesthetic concerns).

Conclusions: This qualitative study suggests that DFA in children and adolescents has multifaceted manifestations, impacts, and origins, some of which only became apparent when using Internet social media. Our findings support the value of infodemiological studies using Internet social media to gain a better understanding of health issues.

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KEYWORDS

dental fear; dental anxiety; children; adolescents; qualitative research; Internet social media

Introduction

Fear of and anxiety towards going to dentists (ie, dental fear and anxiety, DFA) are major problems for a sizeable proportion of children and adolescents. The prevalence of DFA in children and adolescents ranges from 5-20% in various countries, with some cases being considered to be dental phobia (severe DFA) [1-3]. Children and adolescents with DFA are often uncooperative during dental visits, thus rendering treatment difficult or impossible [3]. Such behavior compromises the treatment outcome, creates occupational stress among dental staff, and is often a cause of discord between dental professionals and patients or their parents [4]. Fearful children and adolescents may try every possible means to avoid or delay treatment, resulting in deterioration of their oral health [4-6]. Beyond its impacts on dental care, DFA may also cause sleep disorders, affect one's daily life [7] and have a negative impact on one's psychosocial functioning [8]. DFA acquired in childhood may persist to adulthood and is a significant predictor for avoidance of dental visits in adulthood [9,10]. This pinpoints childhood as a critical stage for preventing and intercepting DFA, thereby assisting people to protect their oral health in the long term.

Previous studies into DFA draw predominantly upon quantitative instruments such as questionnaires and psychometric scales [3]. The development of these instruments, however, is largely based on professionals' presumptions and thus may not capture the whole spectrum of respondents' perceptions and views. Moreover, quantitative methods that focus on generating statistics and testing hypotheses may not be able to uncover complex mechanisms [11]. Qualitative research approach is therefore considered an important complement to quantitative methods, especially for gathering in-depth information on human behavior and reasons for such behavior [11]. Although qualitative studies do not aim to provide data that are statistically extrapolatable to a wide population, they can delineate a wide range of views and experiences in peoples' own words and a rich context [11].

Currently, there is a paucity of research employing qualitative methodologies for understanding DFA, although a few qualitative studies have produced some enlightening findings [12-14]. Abrahamsson and coworkers, through thematized in-depth interviews with 18 patients, showed that individual vulnerability and traumatic dental care experiences caused dental fear in adult patients, who were often caught in a vicious cycle of fear and negative expectations about treatment [12]. They also found that several psychological and social factors such as self-respect, well-being, avoidance, readiness to act, and ambivalence in coping, determined how adult patients coped with their fear and how dental fear affects their daily lives [13]. Through semi-structured interviews with mothers of 14 children who were uncooperative during dental treatment, 3 themes explaining children's refusal to submit to dental treatment were identified. These included the origins of child behavior, caregivers' attitudes, and the culture of resistance [14]. The findings of these studies suggest that qualitative analysis is a useful method to further our understanding of DFA.

On the other hand, recent medical studies have illustrated the potential of utilizing public uploads on Internet social media, such as YouTube, as a valuable source of qualitative data to understand health behaviors and perceptions [15-18]. For instance, through an analysis of 35 YouTube videos, a study has reported the personal narratives of cancer survivors and enriched our understandings on the psychological impact of cancer diagnosis on patients' personal and family lives [17]. The findings help professionals communicate with patients and their families more effectively and provide better care to cancer patients. The potential of Internet social media in dental research is however, hardly explored. Recently, Knösel and coworkers reported an interesting work, where they systematically assessed educational videos on YouTube related to dentistry [19]. Their analysis suggested the potential value of YouTube in dental education and its role in shaping public opinion about the dental profession.

YouTube is an online video-sharing website founded in 2005. It records more than 3 billion views a day and 800 million users each month [20]. YouTube offers an unrestricted environment for the public to share their stories and express their feelings instantaneously and freely. It helps individuals to discuss sensitive issues easily or to venture opinions without fear of embarrassment or negative judgement, which is often a concern in face-to-face interviews [21]. Theoretically, the candid in-depth testimonials and reports on YouTube could be useful data sources for investigating DFA. The personal narratives and original sharing uploaded spontaneously by patients and the public to YouTube provide a rich context to our existing knowledge on DFA. In addition, some novel or relatively neglected themes may emerge and thus deepen our understanding of DFA. This study aimed to profile the manifestations, impacts, and origins of DFA in children and adolescents from the public's perspective using a qualitative research approach and YouTube as a platform.

Methods

Video Search and Screening

YouTube videos were searched using the 3 keywords "dental fear", "dental anxiety", and "dental phobia". Since uploads to Internet social media turnover frequently, we chose 3 consecutive days in August 2010 and finished the search in this fixed period.

All of the identified videos were screened for eligibility for this study. A video was included in the study if it was in English and expressed views or experiences of a layperson with no formal dental training on any aspect of DFA. A video was excluded if: (1) it was not related to DFA, (2) it was purely an advertisement, (3) it was purely for entertainment (eg, comedy), (4) it contained only the views of dental professionals, (5) it was in a language other than English, or (6) its production quality was unacceptably poor such that the meaning of the speech or conversation could not be discerned. The screening was performed by one of the authors (HSH). When there was any doubt or ambiguity, discussions took place among authors until a consensus was reached.

Only videos concerning DFA in children and adolescents were included in this study. A further screen on the videos was made based on the age of the person experiencing DFA, not the age of the informant (eg, a video in which a mother talked about her young daughter's DFA was classified as a video on children's DFA). In 5 videos, the age of the children or adolescents was disclosed by themselves or their parents during the conversation, or by the video authors in their video descriptions. In other videos where age was not explicitly disclosed, since it was impossible to identify the exact age of the subjects, the judgement of age was mainly based on visual and verbal clues (ie, appearance, behaviors, and level of speech development) [15].

Transcription and Content Analysis

The selected videos were transcribed verbatim. Non-verbal expressions such as facial expressions and body postures were also described. A panel of 3 members consisting of a pediatric dentist, a behavioral scientist/public health practitioner, and a layperson with no dental background, read through the transcripts and watched each video carefully to ensure that the context was precisely understood and documented.

Thematic content analysis [11] was applied. Transcripts were analyzed by means of line-by-line coding manually. No data analysis software was used. Themes were developed mainly through an inductive method (ie, as they emerged from the data). The key elements that were relevant to the area of inquiry were identified and labelled concretely by using either the informant's words (in vivo codes) or the words and concepts of the researchers' disciplines (in vitro codes). This process of open coding led to a clustering of substantive codes with similar content into themes, which were subsequently grouped and organized under analytical categories [14].

All analysis was done through discussions among the 3 review panel members. The members strived to avoid being governed by their own pre-structured understanding and to maintain a self-reflective attitude to ways in which the review process could

be influenced. To ensure reflexivity, competing explanations and alternative interpretations were taken into consideration throughout the analysis. During theme development and coding, any ideas, preliminary assumptions, and theoretical reflections were noted and considered in the analysis. A certain degree of disagreement existed among panel members in coding of approximately 6% of the total contents. Discussions took place whenever there were disagreements until consensus was reached.

To characterize the key elements of each thematic category, the overall descriptions of all the videos involved were presented. Original quotes, verbatim excerpts, or illustrative examples drawn from the videos were provided whenever possible to facilitate a comprehensive understanding of the themes.

Results

Videos and Statistics

A total of 1155 videos were retrieved under the 3 keywords (Figure 1). After screening, 182 videos were found concerning the public's views or experiences on DFA. Among these, 27 videos were about DFA of 32 children or adolescents (17 males and 15 females) and were analyzed in this report. These included 3 videos concerning both age groups (children/adolescents and adults).

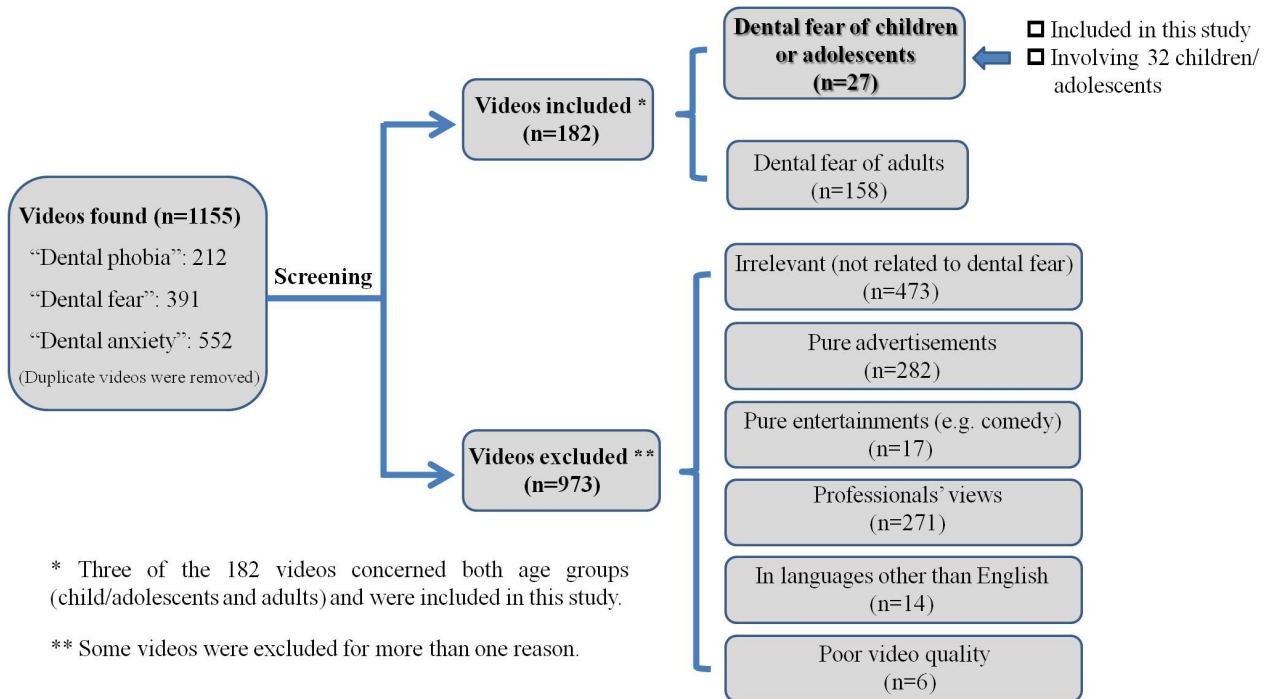
Most videos were uploaded from the United States. Two thirds of the videos were about DFA of children, with the remaining third on DFA of adolescents (Table 1). In over three quarters (21/27, 78%) of the videos, children or adolescents shared their own stories and feelings, whereas in the remaining videos, parents were the proxy informants. The duration of the videos ranged from about half a minute to 10 minutes. Half of the videos lasted 1 to 2 minutes. Most (25/27, 93%) of the videos were uploaded in the past 2 years (2009 and 2010). About half of the videos had been viewed hundreds to thousands of times. Five videos were very popular, with more than 10,000 views each.

Table 1. Video statistics (N=27).

	n (%)
Subject concerned	
Child	18 (67)
Adolescent	9 (33)
Informant(s)	
Self (child/adolescent)	21 (78)
Parent(s)	4 (15)
Both	2 (7)
Video duration	
<1 min	4 (15)
1-2 mins	13 (48)
3-8 mins	6 (22)
9-10 mins	4 (15)
Time being uploaded	
Year 2005-2008	2 (7)
Year 2009	12 (44)
Year 2010 (till August)	13 (48)
Country of origin	
United States	20 (74)
Australia	3 (11)
UK	2 (7)
Afghanistan	1 (4)
Unknown	1 (4)
Number of views	
<100	9 (33)
100-1000	5 (19)
1001-10,000	8 (30)
10,001-100,000	4 (15)
>100,000	1 (4)
Number of rating	
0	18 (67)
1-10	6 (22)
11-100	3 (11)
Number being selected as favourite ^a	
0	18 (67)
1-10	6 (22)
11-100	3 (11)

^aIf a video was selected by a user as “favourite”, the user can keep track of the video from within his/her own account and channel. To a user, his/her favourite videos appear as a special playlist.

Figure 1. Video search and selection results.



Manifestations and Impacts of Dental Fear and Anxiety

Themes emerged from the videos on the manifestations and impacts of DFA are summarized in Table 2. Each theme was

supported by representative quotes and keywords and was organized into 1 of the 3 analytical categories.

Table 2. Manifestations and impacts of DFA on children and adolescents.

Analytical categories	Themes	Quotes/keywords
Immediate physical reactions	Cry, scream, shiver	Not applicable
Psychological responses	Worry, upset, panic	“What if they drill a hole in my teeth?” [video 15] “It breaks bone down.” [video 23] “I dreaded, you know, that procedure.” [video 18] “Total anxiety attack and it was terrible.” [video 24]
	Helplessness, insecurity	“I was scared to have them [wisdom teeth] removed. I was afraid to turn 18.” [video 18]
	Resentment, hatred	“I absolutely hated the dentist. I hated going there.” [video 18]
Uncooperativeness	Refuse to sit in dental chair	Not applicable
	Refuse to open mouth	Not applicable
	Refuse visiting dentist	Parent has to “fight” with children for them to go to clinic. [video 16]

1. Immediate Physical Reactions

To children and adolescents, a visit to the dentist may represent a tremendous challenge. Often seen in the videos were their immediate physical reactions, such as crying piteously, screaming forcefully, and shivering uncontrollably.

I’m still nervous about getting my braces. I’m afraid I am going to be choked like this. What if they drill a hole in my teeth [video 15]

The needle, [I] completely have phobia of needle and I freak out. Total anxiety attack and it was terrible [video 24]

2. Psychological Responses

Psychological responses to DFA appeared as an amalgamation of worry, upset, panic, feeling of helplessness, insecurity, resentment, and hatred towards dentists. In a few videos, some teenagers explicitly expressed worry and panic towards dental treatments.

Removal of wisdom teeth was a nightmare to some adolescents who had undergone or were to undergo the procedure. The night before the scheduled dental appointment, a teenage girl, shaking and smoking in front of the camera, shared her many concerns. She could not stop worrying about the possibility of “break[ing] bone down” during the surgery and that both of her cheeks would be swollen after the surgery [video 23].

A video featured a teenage boy who was overwhelmed by a strong sense of helplessness and insecurity after hearing the terrible stories of his close friends who had undergone wisdom tooth extraction. The fear penetrated so deeply inside him that ultimately he declared that he would rather not to turn 18 just to avoid the possible threat of wisdom tooth extraction. This fear, together with his sympathy towards his friends, gradually fermented into hatred towards dentists.

I was scared to have them removed. I was afraid to turn 18. I absolutely hated the dentist. I hated going there. And I dreaded, you know, the procedure. [video 18]

Table 3. Origins of DFA of children and adolescents.

Analytical categories	Themes	Quotes/keywords
Self experience and parents/peers' influence	Irregular dental attendance	<i>"He is rather stressed about going to the dentist. I'm not sure if it is because we are doing an actual visit or because we have not gone for a while."</i> [video 16]
	Parents' negative statement	Father told her <i>"The dentist would pull your teeth."</i> [video 2]
	Horrible stories from friends	<i>"It was because I had a couple of friends who were having some massive dentistry done. And I felt terrible for them."</i> [video 18]
Dentist/dental auxiliaries	Bad manner	Impatience
	Lack of clinical skills	<i>"It's numb all the way up to my eye and over to the bottom of my chin. And they gave me... I don't know, like six shots of numbing thing and like three of local anaesthetic gel. And I started crying in the chair... He cut my lip."</i> [video 24]
	Improper work ethics	Lack of respect: <i>"So when I told [the dental auxiliary] that I want the hot pink one, she looked at me like I was a little cuckoo."</i> [video 15] Unpunctuality: <i>"First, I waited and waited and waited and waited. It took like forever. Finally they called my name and I got to sit in the death chair."</i> [video 15]
Dental setting/procedure	Dental chair and sound	<i>"Dentists' chairs can be painful places...The sound alone is enough to send someone running."</i> [video 16]
	Injection	<i>"The needle. [I] completely have phobia of needle."</i> [video 24]
	Pain and discomfort	<i>"I'm going to be choked like this...It was really painful... The experience was dreadful overall."</i> [video 15]
	Aesthetic concerns	<i>"I'm expecting the brace to break my appearance...If I go like this [grin], then it'll break my appearance."</i> [video 15]

1. Self-experience and Influence of Parents or Peers

To some children, DFA may be caused by the irregularity of their dental visits, as illustrated by a testimonial from a mother who attributed her son's fear to infrequent dental attendance.

He is rather stressed about going to the dentist. I'm not sure if it's because we are doing an actual visit or because we have not gone for a while [video 16]

Children's fear can be instilled by careless words from parents. A video depicted the destructive behaviors of a young girl who refused to be examined in the clinic. After tiring persuasion and struggle, her mother explained to the dentist that she was acting uncooperatively and irrationally because her father had told her

3. Uncooperativeness

Fearful pediatric patients often refused to sit in the dental chair or open their mouths for oral examination. Parents and dental teams have to struggle to convince or encourage them to cooperate. A mother expressed that her daughter had at last conquered her fear of the dentist, but before that she had to "fight" with her daughter to get the daughter to go to the clinic [video 16].

Origins of Dental Fear and Anxiety

Table 3 summarizes the themes of DFA that emerged from the videos. These fall into three major analytical categories.

in a teasing tone that, "the dentist would pull your teeth" [video 2].

To adolescents, peers' influence should not be underestimated. For a teenage boy who was extremely unwilling to seeing a dentist, what stroke fear into him initially was his friends' story of their negative experience.

It was because I had a couple of friends who were having some massive dentistry done. And I felt terrible for them. [video 18]

2. Dentists and Dental Auxiliaries

Patients' DFA may stem from professionals' bad manners, as shown in an instance of a dentist treating a young girl. Without trying to ease the girl's fear, the dentist rushed through the

procedures, regardless of the child's resistance. During the whole visit, the child could not follow the dentist's instructions well. The dentist behaved impatiently and shone the lamp into the child's eyes to force her to close her eyes. Here are the commands that were uttered by the dentist loudly, sternly, and impatiently.

Close your eyes. Keep it closed. Squeeze squeeze squeeze. Squeeze your eyes all the way. Hold them closed. You are opening. Close your eyes [shines the light]...Stay closed until I tell you to open again. Okay?...We won't be able to do it... Close your eyes...How can I...? [video 7]

Professionals' lack of clinical skills may be another cause of DFA. A teenage girl who had been treated by an incompetent dentist expressed mixed feelings of panic and anger.

It's numb all the way up to my eye and over to the bottom of my chin. And they gave me... I don't know, like six shots of numbing thing and like three of local anaesthetic gel. And I started crying in the chair. It was really painful... He cut my lip. [video 24]

Improper work ethics of the dental team may exacerbate DFA. This happened to a teenage boy who did not feel treated respectfully by a dental auxiliary. While he chose the "hot pink" separator for orthodontic treatment, the dental surgery assistant looked at him as if he was "a little cuckoo" [video 15]. Such response indeed made him embarrassed and upset. In addition, unpunctuality could upset patients and worsen their anxiety before sitting in the dental chair, as expressed by an annoyed teenage boy.

First, I waited and waited and waited and waited. It took like forever. Finally they called my name and I got to sit in the death chair [video 15]

3. Dental Setting and Procedure

Besides the human factors mentioned above, the physical environment of the dental clinic could provoke fear to pediatric patients. Fear can be triggered by many elements in the clinic, from major dental equipments such as the dental chair, called by a teenage boy the "death chair" [video 15], to seemingly trivial details such as dripping sounds from the tap.

Dentists' chairs can be painful places...The sound alone is enough to send someone running [video 16]

In addition, certain dental procedures (eg, injections) were the main reasons for DFA of some pediatric patients.

It was really painful. The needle! [I] completely have phobia of needle and I freaked out [video 24]

Similarly, the expectation of pain and discomfort (eg, choking) can lead to DFA.

I'm going to be choked like this...She twisted and turned all the braces and tucked them on my teeth. It was really painful...I was told that at 6 p.m. my braces will be really sore. She said the brace would hurt really badly for the next three days. So I think I'm going to fall in love with Mr. XXX [a pain relief pill]

because I'm going to be taking that a lot. The experience was dreadful overall [video 15]

Having an attractive appearance means a lot to adolescents. A teenage boy who was going to receive orthodontic treatment worried that the metal bars would make his appearance strange. His aesthetic concerns were the root of his anxiety towards the coming procedures.

I'm expecting the braces to break my appearance... For a whole year, I had an expander which basically expands my jaws... If I go like this [grins], then it will break my appearance [video 15]

Discussion

Internet Social Media as Data Sources for Dental Research

The explosive growth of Internet social media has transformed the ways that individuals communicate with their surroundings and offers a unique opportunity for healthcare research. The vibrant information exchange through Internet social media is bidirectional. While the public can acquire large volumes of health messages readily [22-24], valuable data could be retrieved by health professionals from the Internet social media for research purposes [15-18]. The potential of Internet social media was however largely untapped in dental research. This study therefore addressed this gap and utilized YouTube to solicit the public's views on an important dental issue—DFA in children and adolescents.

Main Findings and Implications

Collectively, the videos revealed multifaceted manifestations, impacts, and origins of DFA among children and adolescents. Although immediate physical response and uncooperativeness were not unexpected, the nature and extent of the psychological impacts were striking. Facing the challenges of a dental visit, some children demonstrate externalizing behaviors such as tantrums, whereas some internalize the fear, which may lead to psychological or behavioral withdrawal, feelings of shame or inferiority, and low self-esteem [25]. The story of the teenage boy who would rather not turn 18 in order to avoid the possible threat of wisdom tooth removal was a vivid testimonial of the profound psychological impact of DFA. It exemplifies how DFA could impair children and adolescents' outlook towards life; something dental professionals should not neglect.

This qualitative study has attached considerable and diverse real life stories to the heterogeneous origins of DFA through 3 pathways, namely direct conditioning via negative dental visit experience, vicarious learning from family and peers, and exposure to negative information [26]. A frequently quoted reason for the initiation and persistence of DFA was the expected pain and discomfort during invasive procedures, such as injections and extractions, and some contextual stimuli, such as syringes and dental chairs. While some of these fear-provoking factors may be alleviated through thoughtful planning of the treatment modality [27] and creative modifications of the physical settings of the clinic [28], some are not easy to change because there are no alternatives. Nonetheless, on an optimistic note, fear and anxiety is a

multi-dimensional construct that consists of somatic, cognitive, and emotional elements [29]. The consequences of traumatic dental procedures depend on the context in which they occur. Previous research has suggested that pain inflicted by a dentist, who was perceived as caring, was likely to have less psychological impact than pain inflicted by a dentist who was cold and controlling [10]. This finding underscores the active role that dental professionals could play in conditioning and moderating patients' response to invasive dental procedures.

Our analysis indeed highlights the importance of dental professionals' manner, clinical skills, and work ethics in reducing DFA of pediatric patients. Children and adolescents lack maturity to fully manage their emotions and control their reactions [30]. Thus, they may require extra patience, which clinicians working with this age group should be prepared to offer. DFA might well arise from a perceived lack of respect, something dentists may tend to neglect when treating young patients. This finding echoes the results of a previous study that ranked dentists' attitudes and comments as one of the most fear-stimulating factors, amidst invasive procedures such as extractions, drilling, and injections [31]. Our findings also highlighted the necessity of adhering to the original appointment time. During prolonged waiting, many elements in the clinic may trigger patients' fear, which can accumulate to an unbearable level. In cases the dentist is unable to treat a patient on time, dental auxiliaries should introduce the patient into the world of dentistry, build a sense of closeness with the patient, and prepare the patient for the upcoming dental procedures. Engaging patients in these activities could avoid the escalation of their DFA during the waiting period.

To assist children and adolescents to experience success in managing their DFA, a partnership between parents and professionals is highly advocated [14]. Nevertheless, parents often feel powerless in managing their children's DFA and blame the negative dental treatment [14], while dentists usually have a different frame of reference and tend to put the blame on parental factors, such as upbringing [32]. There is no doubt that, to children and adolescents, reactions from parents often craft their ways in manipulating their environments and regulating their behavior and are certainly one of the most proximal influences on their DFA [33]. A proliferation of research supports a positive correlation between children's DFA and their parents' DFA or unfavourable attitudes towards dentistry [3]. Our findings unveiled another facet of parental influence on children's DFA. To the young girl who demonstrated a cluster of non-compliance, aggression, and destructive behaviors, her father's careless joking statement, "the dentist would pull your teeth", obviously cast a terrifying image of a dentist, petrified the child, deterred her attempt to cope, and rendered all the efforts of the dental team in vain. Information-giving is an inherent part of child-rearing and is carried out by parents in an almost unceasing fashion [26]. An interesting experiment demonstrated that parents' threatening narratives about a friendly animal instilled high levels of fear in children [34]. This evidence illustrates how information from parents may shape their offspring's view of the world. Thoughtful words from a sensitive parent could be a precious resource for the child to overcome his/her excessive fear and

set the right expectation for the dental visit. Beyond family impact, adolescents are vulnerable to peer influence, which could be a significant source of their DFA. Although it is impossible to isolate teenagers from negative information from their peers, professionals should make parents aware of and sensitive to the potential influence of the information peers impart, so that parents can stand a better chance of protecting their offspring from developing DFA.

Methodological Considerations and Limitations

Our findings can be better understood if the strengths and limitations of this study are recognized. To ensure the authenticity of our report and reduce the chances of exaggerated or biased contents, we excluded videos that were solely for entertainment or advertisement purposes. All videos analyzed in this study thus portrayed genuine experiences, feelings, or views of members of the public. A common concern in studies using social media that is applicable to this study is that they can only capture the views of people who are willing to share their personal feelings in the public forum. Parental control and safety precautions may deter some young children from uploading videos to YouTube. Therefore, it is not expected that the YouTube testimonials reported in this study represent all public opinions. Instead, they are better viewed as a supplement to information solicited from other channels for a more complete picture on DFA. Furthermore, not all age groups are equally attached to social media. Analysis on the YouTube profile of users showed that teens and young adults occupy the biggest proportions of users, while other age groups may be underrepresented [35]. This, however, should not have cast a negative impact on this particular study, since our expected informants were young adults (parents of young children) and teens (adolescents).

Our findings support the value of infodemiological studies using Internet social media to gain a better understanding of health issues [36]. Our study adopted an inductive method, in which themes emerge from data, rather than a deductive method, where themes are hypothesized based on theories and assumptions [11]. Inductive method, by its nature, is open-ended and exploratory, allowing us to discover an unrestricted range of public perspectives without being trapped within the boundary of professionals' assumptions. Our approach of including a layperson with no formal dental background in the review panel may have contributed to obtaining accurate interpretations from the public's perspective. The active participation of this layperson helped to avoid the pitfalls of professionals' presumptions in interpreting at least 6 videos.

In this study, we included all eligible YouTube videos into the analysis, rather than drawing a sample from the YouTube platform. However, relevant videos on DFA of children and adolescents appeared in a relatively small volume (N=27). This may be due to children and adolescents' limited ability in expressing themselves, which is a common concern for research in this age group. YouTube provides a channel for obtaining precious information from this often inaccessible group and their parents so that their voices can be heard and their feelings can be captured. The limited number of videos did not allow for data saturation in our analysis. Nevertheless, most of the

themes emerged repetitively from the videos, supporting the relevance of these themes to children and adolescents.

Conclusions

This qualitative study suggests that DFA in children and adolescents has multifaceted manifestations, impacts, and origins. Some of the themes only become apparent when using Internet social media. The novel and previously neglected themes emerged in this study can be attributed to the free sharing platform provided by YouTube, the candid in-depth testimonials in the videos, and the utilization of qualitative analysis, which allows the interpretation of the deep meanings of the informants. Our findings attached real life narratives to some of our existing knowledge on DFA and unveiled some missing pieces of the

puzzles, which could be corroborated through further studies incorporating in-depth interviews with patients and parents.

The profound impacts of DFA on children and adolescents reinforce the idea that managing DFA should be a starting point in patient management. In light of its diverse origins, DFA could be better prevented and intercepted through coordinated efforts of dentists, dental auxiliaries, pediatric patients, and their parents. Thoughtful approaches before, during, and after the dental visit contribute in one way or another to a pleasant and productive dental experience. Successful DFA management not only paves the road to satisfactory clinical outcome and better oral health, but also builds confidence in pediatric patients and may help them regulate their emotions while facing other challenges in life.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

List of videos included in the study.

[[PDF File \(Adobe PDF File\), 29KB - jmir_v15i2e29_app1.pdf](#)]

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Abbreviations

DFA: dental fear and anxiety

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Original Paper

How "Community" Matters for How People Interact With Information: Mixed Methods Study of Young Men Who Have Sex With Other Men

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Abstract

Background: We lack a systematic portrait of the relationship between community involvement and how people interact with information. Young men who have sex with men (YMSM) are a population for which these relationships are especially salient: their gay community involvement varies and their information technology use is high. YMSM under age 24 are also one of the US populations with the highest risk of HIV/AIDS.

Objective: To develop, test, and refine a model of gay community involvement (GCI) factors in human-information interaction (HII) as applied to HIV/AIDS information among YMSM, specifically examining the role of Internet use in GCI and HII.

Methods: Mixed methods included: 1) online questionnaire with 194 YMSM; and 2) qualitative interviews with 19 YMSM with high GCI levels. Recruitment utilized social media, dating websites, health clinics, bars/clubs, and public postings. The survey included questions regarding HIV/AIDS-related information acquisition and use patterns, gay community involvement, risk behaviors, and technology use. For survey data, we tested multiple linear regression models using a series of community- and information-related variables as dependent variables. Independent variables included community- and information-related variables and demographic covariates. We then conducted a recursive path analysis in order to estimate a final model, which we refined through a grounded theory analysis of qualitative interview data.

Results: Four community-related variables significantly predicted how people interact with information (HII variables): 1) gay community involvement (GCI), 2) social costs of information seeking, 3) network expertise accessibility, and 4) community relevance. GCI was associated with significantly lower perceived social costs of HIV/AIDS information seeking ($R^2=0.07$). GCI and social costs significantly predicted network expertise accessibility ($R^2=0.14$). GCI predicted 14% of the variance in community relevance and 9% of the variance in information seeking frequency. Incidental HIV/AIDS information acquisition (IIA) was also significantly predicted by GCI ($R^2=0.16$). 28% of the variance in HIV/AIDS information use was explained by community relevance, network expertise access, and both IIA and information seeking. The final path model showed good fit: the RSMEA was 0.054 (90% CI: .000-.101); the Chi-square was non-significant ($\chi^2(11)=17.105$; $P=.105$); and the CFI was 0.967. Qualitative findings suggest that the model may be enhanced by including information sharing: organizing events, disseminating messages, encouraging safety, and referring and recommending. Information sharing emerged under conditions of pro-social community value enactment and may have consequences for further HII. YMSM with greater GCI generally used the Internet more, although they chatted online less.

Conclusions: HIV/AIDS-related HII and associated technology uses are community-embedded processes. The model provides theoretical mediators that may serve as a focus for intervention: 1) valuing HIV/AIDS information, through believing it is relevant to one's group, and 2) supportive and knowledgeable network members with whom to talk about HIV/AIDS. Pro-social community value endorsement and information sharing may also be important theoretical mediators. Our model could open possibilities for considering how informatics interventions can also be designed as community-level interventions and vice versa.

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KEYWORDS

Community; health informatics; information use; information seeking; incidental information acquisition; relevance; social networks; HIV/AIDS; information sharing; mixed methods; consumer health informatics

Introduction

Experts increasingly recognize that human-information interaction (HII)—including acquisition, sharing, management, and use of information—is a social phenomenon. A host of research approaches have shed light on this social character, from interactionism to network analysis [1]. This socially oriented research has provided several valuable insights regarding HII in human communities, including the possibility of information technology (IT) use to establish and reinforce community identities, and the potential of IT deployed in geographic communities to shift the nature and extent of ties between residents [1]. We have also learned that the situational relevance of information varies by community, leading to selective information acceptance in different groups [2]. Additionally, Chatman's "Theory of Information Poverty" tells us that social costs associated with seeking certain forms of information within a community may result in information avoidance [2,3]. Despite these observations, we lack a systematic portrait of the relationship between people's everyday community involvements and their HII, including *how important* community involvement might be in the emergence of these patterns [1,4]. Moreover, there has been little dialogue between the fields of community informatics and health informatics, despite growing interest in embedding social influence in consumer health informatics (CHI) applications [5]. Therefore, our objective in this paper is to develop, test, and refine a model of community involvement factors in HII, as applied to the specific situation of HIV/AIDS among young men who have sex with men (YMSM) aged 18-24. Young men offer a particularly salient population in which to examine the relationship between community involvement and HII, since their gay community involvement varies [6], and their use of information technologies is high [7,8]. With a goal of informing HIV/AIDS prevention, we also focused on YMSM because they are one of the highest HIV/AIDS risk groups in United States [9].

The health domain offers a critical context in which to understand the role of community involvement in HII. Disease prevalence, incidence, and outcomes may all vary at a group level. In the case of HIV/AIDS in the United States, men who have sex with men (MSM) have long had disproportionately high rates of this disease, with the rate of new infections particularly high among African-American MSM [10-12], as well as those under age 24 [9]. Not all MSM identify as gay or bisexual; thus, public health practitioners created the term "men

who have sex with men" to highlight the fact that many men who engage in same-gender sexual contact do not identify as gay or bisexual, although they may be behaviorally at risk for HIV infection [13]. Flores and colleagues [14] distinguish between identity, which they call the "self-view" of sexual identity, and community involvement, which they call the "social-normative view." The social-normative view reflects one's social and psychological connection to the gay community, which in turn affects the extent to which a person is influenced by that group. Even among people who identify as gay or bisexual, gay community involvement—factors such as socializing with other MSM or participating in lesbian, gay, bisexual and transgendered (LGBT) organizations—varies. Notably, non-gay *identification* among MSM may be particularly common among African Americans and Latinos [15,16]; however, gay community *involvement* varies less by race than *identity* does [14]. Understanding an MSM's extent of gay community involvement may be particularly relevant to HII because it refers to connection to the group rather than internal perceptions of self. Thus, we outline below a series of hypotheses about potential relationships between these two aspects of behavior in our study population.

Due to the historical and present burden of HIV/AIDS among MSM, gay communities have mobilized an unprecedented response to the disease. Indeed, gay communities led the formation of many organizations and publications that develop and disseminate information about HIV/AIDS prevention and treatment [17-19]. Gay community settings are also frequently the focus of HIV/AIDS prevention efforts (eg, [20-22]). Due to the high prevalence of HIV/AIDS among MSM, members of this population may also be more likely to know people with HIV/AIDS (PHAs)—a social network factor associated with talking more and knowing more about the disease [23]. Thus, even though gay communities are not devoid of HIV-related stigmatization [24], we contend that YMSM who are more involved in the gay community will experience greater exposure to positive attitudes towards PHAs that circulate among some gay community segments and that they will also be exposed more to norms that support acknowledging and responding to personal risk for HIV/AIDS. Therefore, we hypothesize that:

H1: YMSM who are more involved in the gay community will report fewer perceived social costs of HIV/AIDS-related information seeking.

Kippax et al argued more than 20 years ago that MSM who are more involved in the gay community have more access to "informed social support" [25]. This thesis suggests a greater

tendency for a man's close associates to discuss HIV/AIDS with him and for these associates to be knowledgeable about the disease. Therefore, we hypothesize that:

H2: YMSM who are more involved in the gay community will have greater network access to HIV/AIDS expertise. Those who perceive fewer social costs of seeking HIV/AIDS information will also have more of this access.

A belief that HIV/AIDS is relevant to one's community may also be a consequence of HIV/AIDS prevention efforts and personal acquaintance with PHAs. Moreover, people may be more likely to look for information that is perceived as relevant to their community [2]. Hence, we posit that:

H3: YMSM who are more involved in the gay community will believe that HIV is more relevant to their community.

Young MSM who are more involved in the gay community may frequently encounter an HIV/AIDS information-rich environment [26] and thus may be more frequently "exposed" [27] to such information "incidentally" [28] through people, documents, or the Internet. Thus, YMSM who are more involved in the gay community may also be more likely to have been exposed to HIV prevention messages and testing through venues such as bars, events, and gay websites [29]. Exposure to HIV/AIDS information through public health campaigns is also associated with supplementary information seeking [30]. Furthermore, knowing a PHA may give rise to more "network-mediated opportunities"—socially comfortable opportunities for asking questions about HIV/AIDS [27]. Prior research conducted in rural Canada also shows that higher levels of HIV/AIDS-related expertise and resources in a community may predict information acquisition success among its members [1]. Therefore, we hypothesize that:

H4: YMSM who are more involved in the gay community will report more incidental acquisition of HIV/AIDS information.

H5: YMSM who are more involved in the gay community will report more HIV/AIDS-related information seeking. People who perceive fewer social costs of HIV/AIDS information seeking, who see the disease as more relevant to their community, and who obtain HIV/AIDS information incidentally more often will also seek this information with more frequency.

People do not use all the information to which they have access. What factors determine information use? Certainly, information must be acquired before it is used. However, information provided by strong network ties [31] or perceived as collectively relevant may be more likely to be used [2]. Therefore, we contend:

H6: YMSMs' use of HIV/AIDS information will be predicted by greater gay community involvement, higher levels of HIV/AIDS information acquisition (seeking information, incidental exposure), greater perceived relevance of HIV/AIDS

to one's community, and more network access to HIV/AIDS information ("network expertise accessibility").

A Model of Community Involvement Factors in Human-Information Interaction

In addition to testing these hypotheses separately, we estimate a model (Figure 1) that considers each of these community involvement factors simultaneously. This model allows us to test the possibility of mediating effects of community factors in HII, while comparing the relative importance of these factors. Our model posits that gay community involvement will exert both direct and indirect effects on information acquisition and use. Thus, we forward the following hypotheses concerning indirect effects:

H7: Community involvement will exert indirect effects on information seeking through its effect on social costs of information seeking and community relevance.

H8: Community involvement will exert indirect effects on information use through its influence on information acquisition, perceived community relevance, and network expertise accessibility.

Model Refinement

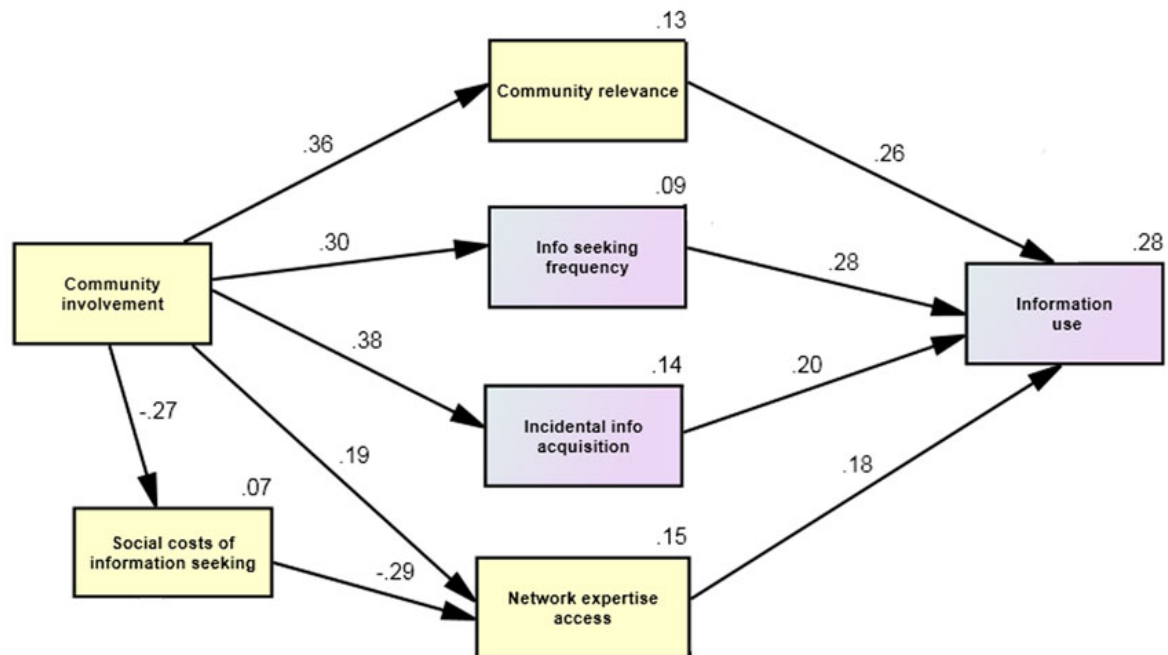
Finally, through an inductive portion of the research, we assess the potential for new community involvement-related variables to explain the dependent variables included in the model. Therefore, we pose the following research question:

RQ1: What additional gay community-related factors, if any, may help to explain HIV/AIDS-related HII among YMSM?

Technology and Community

Although each of the above HII processes may involve technologies, a focus on health informatics draws our attention to the extent of technological mediation of MSM's gay community involvements and HII. According to studies, Internet use may be fundamentally changing gay communities in western countries (eg, [32,33]). Gay bars and other face-to-face settings are increasingly supplanted by use of the Internet to meet sex partners [34,35], sparking efforts to develop and test online HIV prevention initiatives [36]. MSM, including youth who may lack offline gay/bisexual associates, also report frequenting gay websites to meet friends [37,38]. The Internet may also facilitate offline community involvement by connecting people to gay groups and events [39]. In addition, advocates of a range of causes increasingly engage in online social activism [40]. Given these observations, we hypothesize that:

H9: YMSM who are more involved in the gay community will use technologies to socialize with others more, as well as to acquire HIV/AIDS information online more than YMSM who are less involved.

Figure 1. Model of community involvement factors in human-information interaction.

Methods

Mixed Methods Study

As part of a larger investigation of HIV testing among YMSM, we conducted a parallel, mixed methods study [41] including: 1) an online survey and 2) qualitative, in-depth, individual interviews. Eligibility criteria included identifying as a man who has had sex with other men in the past 6 months, being age 18 to 24, and living in southeastern Michigan. To further our goal of informing HIV/AIDS prevention, the research focused on YMSM in this age group due to the alarming 22% increase in new HIV infections in MSM under age 24 between 2008 and 2010 [9]. We obtained a Certificate of Confidentiality from the National Institutes of Health, providing assurance to respondents that their identities and information would be safe from disclosure even if requested by subpoena. The research was conducted between summer 2010 and spring 2011. The study received ethical approval from the Health Sciences and Behavioral Sciences Institutional Review Board of the University of Michigan.

Online Survey

Participants

We used an online questionnaire to survey a convenience sample of 194 YMSM. To engage an ethnically diverse sample, we recruited via a variety of venues, eg, social media websites, dating websites, health clinics, bars/clubs, public postings, LGBT organizations, AIDS Service Organizations (ASOs). Participants in the individual interviews were also invited to complete the online survey.

Survey Procedures

Participants completed an online self-administered survey after indicating comprehension of the informed consent material and agreement to participate in the study. The survey was pilot-tested and was administered on a dedicated website using Sawtooth software. The survey took 30-45 minutes to complete. The overall survey was distributed over 108 screens with an average of 6 questions per screen; however, skip-response patterns were used, thus reducing survey length for most participants. The survey included questions regarding HIV/AIDS-related information acquisition and use patterns, gay community involvement, risk behaviors, and technology use. Participants were also able to save in-progress surveys and return later for completion. Participants did not have the opportunity to review their responses, and there were no completeness checks, prior to submission. Each participant received a \$25 e-gift card for participating.

Web survey data were collected on a secure server under 128-bit SSL encryption and a firewall. After downloading, data were expunged from the server. To prevent multiple entries [42], we used participants' email, IP address, browser/operating system, and time taken to complete survey to flag potential fraudulent/duplicative cases. We cross-checked email and IP addresses through web applications (eg, Facebook, IP lookup), without keeping this information or linking it to data. If verified, we treated a case as unique; otherwise, we did not use the entered data. We had 824 unique site visitors, as counted by unique IP address. We recorded 1034 survey entries, which included 194 eligible and complete cases, 16 incomplete entries, and 264 entries that were ineligible for study participation based on eligibility criteria. In addition, we detected 559 fraudulent

entries, which were removed from our dataset. Our recruitment rate was 79.69% and, after excluding fraudulent cases, our completion rate was 92.38%. After verification, data were de-identified and transferred into SPSS software.

Survey Measures

Gay Community Involvement

We initially used an established, 17-item measure of gay community involvement [43]. When subjected to a principal axis factor analysis with varimax rotation, one factor was produced with an Eigenvalue of 5.13 and explained 31.273% of the variance. This factor was used to create a 5-item scale of gay community involvement, which included items such as, “In your opinion, do you feel that you are a part of the gay community in your area?”, “How many of your friends are men who also have sex with other men?”, “How much of your leisure time do you spend with men who also have sex with other men?” and “In a typical week, if you hang out with men who also have sex with other men, how much time do you spend at meetings or organizations?” This scale, which measured both behavioral and affective dimensions of community involvement, had good internal reliability (Cronbach alpha=.872).

Community to Which You Most Belong

To assess the possibility that YMSM had alternative community affiliations that might affect their HIV/AIDS-related HII, we asked participants to complete the following open-ended survey question, “People have different definitions for the term ‘community’. Thinking about the different communities that you belong to, please indicate below what is the community that you feel like you belong to the most.” Participants’ responses to this question were then content-analyzed by assigning emergent categories to these responses [44].

Social Costs of Information Seeking

Based on Chatman’s theory of information poverty and its insight regarding the potential social costs of information seeking in marginalized groups [2], we adapted an existing, 15-item scale regarding the social costs of information seeking in a workplace setting [45]. When subjected to a principal axis factor analysis with varimax rotation, one factor was produced with an Eigenvalue of 9.399 and explained 62.660% of the variance. A 5-item scale was then created that asked about participant agreement with the statement, “It would not be socially acceptable in my community to look for this information...”, with response options referring to HIV-related matters such as how to use a condom and where to obtain an HIV test. Responses were on a 5-point Likert scale (1=Strongly disagree, 5=Strongly agree). The scale has excellent internal reliability (Cronbach alpha=.965). Due to the high skewness of this variable, it was log-transformed for further analyses.

Community Relevance

Again, based on Chatman’s theory of information poverty [2], we created a 3-item scale that assessed the perceived relevance of HIV/AIDS information to one’s community. These items included: “HIV/AIDS is an important issue in my community” and “Men who have sex with men need to know everything they can about HIV/AIDS.” Responses were on a 5-point scale

(1=Strongly disagree, 5=Strongly agree). Principal axis factor analysis with varimax rotation revealed a single factor with an Eigenvalue of 2.396 and explained 79.875% of the variance. The scale had high internal reliability (Cronbach alpha=.874).

Network Expertise Accessibility

This variable was calculated to refer to the availability of HIV/AIDS information from people close to the participant or those identified by the participant as people with whom they discussed “important personal matters,” including those with whom they have discussed or would feel comfortable discussing HIV/AIDS prevention and testing. After naming each network member, participants were asked to state whether they had ever discussed HIV/AIDS with that person and whether they considered that person “knowledgeable about HIV prevention.” Responses were on a 4-point scale (1=Completely disagree, 4=Completely agree). For each network member, an “expertise accessibility” multiplier variable was created for discussion of HIV/AIDS and the participant’s rating of that network member’s knowledge of HIV/AIDS. Then, a variable was created for “Total network expertise” accessibility, which summed the scores of expertise accessibility for all network members. Due to significant skewness, this variable was then log-transformed for statistical analyses.

Frequency of HIV/AIDS Information Seeking

This 1-item measure was adapted from the National Cancer Institute’s Health Information National Trends Survey (HINTS) [46]. The question asked: “In the past 12 months, how often have you looked for HIV/AIDS information from any source? By ‘source’ we mean people, organizations, documents, or the Internet.” Responses were on a 5-point scale (1=Never, 5=Very often).

Incidental Information Acquisition (IIA) Frequency

This 4-item scale was developed based on extant theory regarding non-purposeful information acquisition, including the role of an information-rich environment in facilitating such acquisition [26,47-49]. Responses were on a 4-point scale (1=Never, 4=A lot). A principal axis factor analysis with varimax rotation revealed that a single factor with an Eigenvalue of 2.39 explained 59.475% of the variance. Based on factor loadings, a final 3-item scale was created that included these items: “I accidentally find information about HIV/AIDS while I look for information about other topics”, “I learn unexpected things about HIV/AIDS when I watch television or read the newspaper”, and “I learn unexpected things about HIV/AIDS when I talk to other people.” This scale had good reliability (Cronbach alpha=.798).

Frequency of Information Use

We developed an original 15-item scale that assessed use of HIV/AIDS information for a variety of topics relevant to HIV/AIDS risk and prevention. Principal axis factor analyses with varimax rotation showed that a single factor with an Eigenvalue of 8.962 explained 59.744% of the variance. Thus, a 10-item scale was created with responses to the question “In which of the following ways did you use the HIV/AIDS information that you got in the past 12 months? Did you use the information to...”. Options included finding a place to get

tested for HIV, deciding whether to ask a partner his HIV status, deciding whether to get tested for HIV, and deciding whether to ask a partner to obtain an HIV test. Responses were on a 5-point scale (1=Never, 5=A great deal). The scale had excellent reliability (Cronbach alpha=.937).

Technology Access

Participants were asked whether or not they have technologies that may provide Internet access, including desktop/laptop computers, cell phone/smartphone, PDA, e-readers, music players, and game consoles.

Internet Use Levels

Participants were asked how often they use the Internet at a variety of locations. Options included home, school, work, public library or community center, mobile device, or other. The response scale varied from “Less often than every few weeks or never” to “Several times a day”. Due to high levels of Internet use in the sample, binary variables were then created across all Internet access locations to note whether the participant “Uses the Internet several times a day” or “Uses the Internet less than several times a day”.

Technology-Mediated Personal Network Member Communication

As mentioned, participants were asked to specify up to 7 people with whom they discussed “important personal matters”. Each participant was asked how often they communicate weekly with each of these named network members using the Internet, phone (not including texting), or face to face. They were also asked how many texts they sent per day to that person. Daily texts were then transformed into a weekly value. Following this, the proportion of overall daily contacts with each network member through each communication medium was calculated. This number was then used to calculate an overall average for each communication media for each participant across all of their network members.

Personal Network Members Met Online

Participants were asked how they met each of their network members. Response options included family, school, social gathering/through friends, online, work, and other. A binary variable was created to indicate whether a network member was met online. The total number of network members whom the participant had met online was then calculated. Because this was a highly skewed variable, this number was transformed into a binary variable for each participant for whether or not he had met any network members online.

Internet Use For Online Dating

Participants were asked how many times in the past 2 months they had used the Internet to: 1) find someone to date, or 2) to “hook up” (ie, have a sexual encounter). The 7-point response scale ranged from “Never” to “More than once a day”. Because these variables were skewed, a binary variable was created to reflect whether or not the person had used the Internet for either purpose in the past 2 months.

Time Spent Chatting With Other MSM Online

Participants were asked how much time they spend hanging out with other MSM by “chatting on the Internet”. The 4-point

response scale ranged from 1=Not at all to 4=More than 10 hours.

Online HIV/AIDS Information Seeking Frequency

Participants were asked how much they had used three online source types to obtain HIV/AIDS information in the past 12 months. Options included “Internet sites for men who have sex with men”, “Social networking sites (like Facebook or Twitter)”, and “All other Internet sites”. The 4-point response scale ranged from 1=Never to 4=Often. A principal axis factor analysis with varimax rotation was conducted, producing one factor with an Eigenvalue of 2.52 that explained 75.075% of the variance. Values on this new scale were skewed, and therefore, were classified as never, often, or rarely/occasionally using any online HIV/AIDS information source.

Demographic Covariates

Participants were asked to state their age, race (White/European American, Black/African American, Asian, Native American/Alaska Native, Hawaiian/Pacific Islander and Other), ethnicity (Hispanic/Latino or not), sexual identity (gay/bisexual/heterosexual), and highest level of education completed. Due to the disparity between whites and African-American and Latino MSM in new HIV infections, a binary “minority” variable was created for African Americans and Latinos. Due to the distribution of the education variables, we also created a binary education variable to indicate whether the participant had a high school education or an education beyond high school.

Statistical Analysis of Survey Data

We calculated descriptive statistics about the respondents’ gay community involvement, categories for the community to which they most belong, HII, technology use, and demographics. We then tested multiple linear regression models that took each of the key community- and information-related variables as the dependent variables. The independent variables in these models included community- and information-related variables, as well as demographic covariates. Assumptions for multiple linear regressions were met. Skewness and kurtosis values for the dependent and independent variables were within range for normality, and residuals plots and partial plots looked acceptable. Lack of multicollinearity among the predictors was indicated by all Pearson’s correlation measures being < 0.7 , variance inflation factor values < 10 , and tolerance values > 0.10 . Cook’s d values were well below 10, so no outliers affected the results. Once the initial regressions were conducted, those results were used to determine which paths to include in a final model. Structural equation modeling software (SPSS Amos, version 20) was used to perform recursive path analysis with observed variables and to estimate the model. Because of power considerations, sample size did not allow for reliable testing of model fit; therefore, fit statistics are reported only briefly in the analyses.

Qualitative Interviews

Interview Participants

Due to the modest levels of variance in HII predicted by our regression models ($R^2=0.07-0.28$), we conducted a focused

analysis of interview data to identify additional gay community involvement factors that may help explain HIV/AIDS-related HII among YMSM (RQ1). Our initial interview sample included 29 YMSM who were recruited via social media websites, dating websites, health clinics, bars/clubs, public postings, LGBT organizations and ASOs. To permit in-depth examination of our research question, we theoretically sampled [50] a subset of 19 interview participants (drawn from the original 29) with the highest levels of gay community involvement, as determined by perceptions of belonging to their local gay community, involvement in gay-related organizations, and the prevalence of other MSM in their social networks. Seven of these participants were current or previous volunteers or paid staff for HIV prevention initiatives sponsored by LGBT organizations and/or ASOs.

Interview Procedures

In-depth, semi-structured interviews [51] were conducted using an interview guide with open-ended questions, follow-up questions, and probes [52]. The interviews focused on participants' perceptions of community, their HIV/AIDS-related HII, and their HIV testing decisions and experiences. Interviews lasted from 45 to 90 minutes. Interviews were audio-recorded and transcribed. Participants' social networks were elicited with name-generator questions [53], followed by visualization exercises [54] that gathered data about network structure and demographics. Each participant received a \$30 gift card for participating.

Qualitative Analysis of Interviews

We conducted a grounded theory [50] analysis of interview transcripts using the constant comparison method [55]. Initially, we conducted open coding [50] using gerunds so as to focus on actions and processes [56], followed by axial coding [50] in order to define conditions, actions/interactions, and consequences associated with our emergent core category. Selective coding [50] and memoing were also pursued to further define and interrogate this category [56].

Results

Participant Characteristics

Survey participants' average age was 20.66 (see Table 1). More than half of the sample (57.2%) was Black/African American, and 18% of participants were Hispanic/Latino. Approximately half of the sample (52.6%) had a high school education or less. The majority identified as gay (84.5%), with 13.5% identifying as bisexual. Fifteen participants (11.6%) reported that they had received an HIV-positive test result.

The majority felt that the community to which they most belonged was the Gay/Queer/LGBT community (65.8%), with the next most common response being none (10.2%). Several YMSM defined their primary community as smaller subgroups of people united around alternative principles, such as shared values (3.7%) or friendship/kinship (4.8%). However, it is likely that these groups included other MSM, since 4 (25%) of the participants who chose these smaller subgroups also indicated that "some" or "all" of their friends were MSM, and 8 (50%) stated that "a few" were. A minority of participants (15.5%)

"most belonged to" an alternative social group. The most frequently named alternative social groups were school/workplace (7.0%), city/neighborhood (2.1%), style/fashion subculture (2.1%), sports/recreation (1.6%), ethnic/cultural group (1.6%), and churches (1.1%). There was a large association [57] between naming Gay/Queer/LGBT as one's key community and our aforementioned measure of gay community involvement ($\eta=0.519$; CI 0.414-0.648).

As might be expected with a web survey sample, participants were heavy Internet users, with 89.7% of respondents using the Internet several times a day (see Table 2). Participants also had significant access to technological devices—100% of participants had access to at least one. Of these, 80.5% had a cell phone, 65.6% an iPod/MP3 player, 61.5% a laptop computer, and roughly half (53.2%) a game console. As for uses of technology, participants indicated that an average of 43% of their weekly contacts with their close network members were through texts. An average of 12% of interactions took place on the Internet, 12% were on the telephone, and 19% were face to face. Although just over a third of the participants had used the Internet to meet other men for dating or sex in the past 2 months, only 13.4% said that they had met one of the people that they discuss "important personal matters with" online. A large proportion (41.9%) did not spend any time chatting with other MSM online in a typical week. At the same time, 33.5% of respondents said that they spent 3 hours or more per week doing so. Despite their significant Internet usage, a small proportion (7.7%) had frequently obtained HIV/AIDS information online in the past year, and 58.7% of all participants had looked for HIV/AIDS information online at least rarely in the past 12 months. However, 31.3% indicated that they had not done so at all in that time. The most popular online source for HIV/AIDS information was Internet sites for MSM: 100 participants (51.5%) had used this source at least rarely over the previous year.

Like the survey participants, the mean interview participant age was just under 21, and the majority was African American and gay-identified (see Table 3). A similar proportion of the samples was also Hispanic/Latino (17.5% of survey participants vs. 15.8% of interviewees). A small minority of both samples were HIV-positive.

Survey Results

Prediction of Community and Information-Related Variables

Table 4 shows that gay community involvement was not associated with demographic covariates, including age, education, or minority status. Similarly, minority status was independent of gay identity ($\chi^2(1)=.019$; $P=.890$). In support of Hypothesis 1, gay community involvement was associated with significantly lower perceived social costs of information seeking. The covariate of having more than a high school education was associated with more perceived social costs. Overall, however, only a small proportion (9%) of the variance in social costs was explained by gay community involvement and education, with most of the variance (7%) explained by community involvement.

In support of Hypothesis 2, gay community involvement and social costs had significant associations with access to HIV/AIDS expertise in personal networks. On an unadjusted basis, participants with more education and those who were racial/ethnic minorities had less access to HIV/AIDS expertise in their networks, but these effects disappeared after adjustment for community involvement and social costs. 14% of the overall variance in network expertise was accounted for in the final model.

Community relevance was predicted on an unadjusted basis by community involvement, social costs, and network expertise access, although it was not predicated on any demographic covariates. However, the final model, which accounted for 14% of the variance in community relevance, included only community involvement as a significant predictor. Thus, Hypothesis 3 was supported.

Table 5 shows that, in accordance with Hypothesis 4, gay community involvement was a significant predictor of incidental information acquisition (IIA), both before and after adjustment. Sixteen percent (16%) of the variance in IIA was explained by community involvement. Younger men and those with more education reported more IIA, but these effects disappeared after adjustment. Similarly, a marginally significant relationship between community relevance and IIA disappeared after adjustment.

Hypothesis 5 also received support. Those with greater gay community involvement had sought HIV/AIDS information more frequently than those with less involvement. Social costs of information seeking, community relevance, and IIA were all significant predictors of information seeking frequency on an unadjusted basis. However, each of these effects disappeared in the full regression model, leaving only community involvement as a significant gay community-related predictor. This result meant that Hypothesis 7 was unsupported, since social costs and community relevance could not act as mediators between community involvement and information seeking without these variables having a direct association with information seeking. As for covariates, minority men sought HIV/AIDS information more frequently than whites; this variable was significant in the final model, although its contribution to prediction was smaller than community involvement (R^2 change=5% of the variance in information seeking). For information-seeking frequency, 9% of the variance was predicted by such gay community involvement alone (see Figure 1).

The most robust regression model sought to predict HIV/AIDS information use, with 28% of the variance in the model explained by included variables: community relevance, network expertise access, and both IIA and information seeking. Therefore, Hypothesis 6 was supported. The magnitude of effect for community relevance (path coefficient=.273) was comparable to that for incidental information acquisition and seeking (path coefficients=.215 and .284, respectively). Significant direct effects for information use disappeared once adjusted for its mediators. Thus, all effects for community involvement on information use were indirect, providing support for Hypothesis 8 (see Table 6).

Therefore, overall, four community-related variables were significant in predicting the amount of information acquisition and/or use: 1) community involvement, 2) social costs of information seeking, 3) network expertise accessibility, and 4) community relevance. The final path model predicted 28% of the variance in information use, 14% of the variance in incidental information acquisition, and 9% of the variance in information seeking (see Figure 1). Furthermore, without the effects of information acquisition on information use, the variables of community involvement, community relevance, and network expertise access alone explain 17% of the variance in information use.

Model of Community Involvement Factors in Human-Information Interaction

A recursive path analysis with observed variables was estimated with AMOS structural equation modeling software version 19. The resulting model is depicted in Figure 1. Table 6 contains coefficients for direct and indirect effects. Demographic covariates (education, race) offered little improvement in the prediction of HII dependent variables, and thus, they were excluded from the final model. The final model showed good fit: the root mean square error of approximation (RMSEA) was 0.054 (90% CI 0.000-0.101), the Chi-square was non-significant ($\chi^2(11)=17.105$; $P=.105$), and the overall Comparative Fit Index (CFI) was 0.967.

Technology, Community, and Information Interaction

Hypothesis 9 received partial support. Significant positive relationships exist between gay community involvement and use of the Internet at least several times a day ($r_{pb}=0.153$, $P=.040$) and online information seeking regarding HIV/AIDS ($r=.302$, $P<.001$). However, a significant negative relationship exists between gay community involvement and hours spent chatting with other MSM on the Internet ($r=-.175$, $P=.018$). In addition, no significant relationships exist between gay community involvement and the proportion of network contacts via texting ($r=-.080$, $P=.456$) or the Internet ($r=-.152$, $P=.108$). Furthermore, there were no significant relationships between gay community involvement and online dating ($r_{pb}=-0.113$, $P=.129$) or having met at least one close network member online ($r_{pb}=-0.047$, $P=.531$).

Interview Results

Due to the modest predictive power of the existing model for HII-related dependent variables, we sought to refine our model by investigating what additional gay community-related factors, if any, may help to explain HIV/AIDS-related HII among YMSM (RQ1). Our grounded theory analysis of interview transcripts yielded a key category: *information sharing*. Analyses showed that the conditions that facilitated information sharing were YMSMs' endorsement of *enacting pro-social community values* (see Table 7). Accordingly, 9 YMSM defined community as *looking out for each other*, particularly when under some form of attack or threat, and an additional 9 understood community as *working together*, or striving for common goals. Because HIV/AIDS was seen to be a serious threat to the community (*community relevance*), YMSM sought to enact their pro-social community values by *making a*

difference in reducing the burden of HIV/AIDS in their community. A key aspect of making a difference for these YMSM was *informing community*; indeed, some youth believed that information sharing was a key characteristic of “community” as a value.

Information sharing included the following key actions/interactions: *organizing events*, such as community discussions or video screenings; *disseminating messages* through flyers, t-shirts, workshops or other media; *encouraging safety* through interpersonal discussions with friends and acquaintances; and *referring and recommending*, so as to connect friends with HIV testing sites or other help sources.

A consequence of information sharing was *interacting with more information*. Indeed, information sharing emerged as a potential correlate of all HII variables included in our model. For example, information sharing motivated *information seeking* about the disease, since one needed to acquire information before sharing it. This information seeking often involved longer-term activities such as attending HIV/AIDS-related workshop series, internships or training, as well as episodic

activities such as Internet searching and asking questions. Sharing information also comingled with efforts towards *countering stigmatization* of both HIV/AIDS-related help seeking and PHAs—which could ultimately affect perceived *social costs of information seeking*. Furthermore, information sharing—especially if formalized through volunteer or paid work with LGBT organization or ASOs—often placed YMSM in information-rich environments that facilitated ongoing *incidental information acquisition*. Information sharing efforts also led participants into contact with other people who were knowledgeable about HIV/AIDS, especially other volunteers or coworkers. Such *network expertise accessibility* meant that participants had many network-mediated opportunities [27] for asking questions about HIV/AIDS (information seeking). Furthermore, YMSM made a strong connection between information sharing and their *information use* for making decisions about their sexual health. In particular, sharing information appeared to increase participants’ personal motivation for safer sex and HIV testing and their associated commitment to acting as role models for others.

Table 1. Survey participant demographics (n=194).

	Number	Valid Percent
Age, mean (SD)	20.66 (1.71)	
Race ^a		
Black/African American	111	57.2
White/European American	75	38.7
Native American/Native Hawaiian/Pacific Islander	10	5.2
Asian	12	6.2
Other	13	6.7
Hispanic/Latino	34	17.5
Education		
Some high school	10	5.2
High school/GED	92	47.4
Technical school	3	1.5
Some college	69	35.6
Bachelor's/graduate degree	18	9.8
Sexual identity ^a		
Gay	154	84.5
Bisexual	26	13.5
Heterosexual	5	3.6
Other	6	3.1
HIV-positive	15	11.6
Primary community membership		
Gay/Queer/LGBT	123	65.8
None	19	10.2
School/Workplace	13	7.0
Family/friends	9	4.8
Values-based community (eg, communication, love, togetherness, beauty)	7	3.7
City/neighborhood	4	2.1
Style/fashion (eg, urban prep, stoner)	4	2.1
Sports/recreation	3	1.6
Ethnic/cultural group	3	1.6
Church	2	1.1

^a More than one response possible.

Table 2. Survey participants' technology use and information interaction (n=194).

	Number	Valid Percent
Technology access		
Desktop computer	71	36.8
Laptop computer	118	61.5
Cell phone (including smart phones such as iPhone, Android, BlackBerry or similar device)	153	80.5
PDA or personal data device	17	8.9
E-reader (eg, Kindle, iPad)	36	18.6
iPod or MP3 player	126	65.6
Game console (eg, Xbox, Playstation)	100	53.2
Internet use levels		
Several times a day	174	89.7
At least once a day	18	9.3
Less than once a day	2	1
Personal network member communication		
Mean proportion on Internet (SD)	0.12 (0.13)	
Mean proportion on texting (SD)	0.43 (0.19)	
Mean proportion on phone (not including texting) (SD)	0.12 (0.11)	
Mean proportion on face-to-face (SD)	0.19 (0.15)	
Met at least one personal network member online	24	12.4
Internet use for online dating	70	36.5
Time spent chatting with other MSM online per week		
More than 10 hours	27	14.1
3-10 hours	37	19.4
Up to 3 hours	47	24.6
Not at all	80	41.9
HIV/AIDS information seeking frequency – all sources		
Very often	27	13.9
Often	31	16.0
Sometimes	72	37.1
Rarely	37	19.1
Never	27	13.9
Online HIV/AIDS information seeking frequency (n=166)		
Often	15	7.7
Occasionally or rarely	99	59.6
Never	52	31.3

Table 3. Interview participant demographics (n=19).

	Number	Valid Percent
Age, mean (SD)	20.79 (1.96)	
Race^a		
Black/African American	12	63.2
White/European American	4	21.1
Native American/Native Hawaiian/Pacific Islander	2	10.5
Asian	1	5.3
Hispanic/Latino	3	15.8
Sexual identity^a		
Gay	13	68.4
Bisexual	6	31.6
HIV-positive	1	5.3

^a More than one response possible.

Table 4. Linear regressions for community-related variables.

Independent variable		Dependent variable							
		Gay community involvement (GCI)		Social costs of HIV/AIDS information seeking		Network access to HIV/AIDS expertise		Community relevance of HIV/AIDS information	
		Beta	P	Beta	P	Beta	P	Beta	P
Age	Unadj.	-.070	.346	-.103	.154	.079	.272	.011	.881
	Adj.	—	—	—	—	—	—	—	—
Education level	Unadj.	.001	.988	.163	.023	-.269	<.001	-.083	.256
	Adj.	—	—	.164	.022	-.057	.422	—	—
Racial /ethnic minority	Unadj.	.064	.393	-.075	.296	-.173	.016	-.003	.968
	Adj.	—	—	—	—	-.031	.654	—	—
Gay community involvement (GCI)	Unadj.	—	—	-.272	<.001	.271	<.001	.356	<.001
	Adj.	—	—	-.272	<.001	.318	<.001	.303	<.001
Social costs of HIV/AIDS information seeking	Unadj.	—	—	—	—	-.345	<.001	-.242	.001
	Adj.	—	—	—	—	-.149	.044	-.142	.062
Network access to HIV/AIDS expertise	Unadj.	—	—	—	—	—	—	.184	.011
	Adj.	—	—	—	—	—	—	.053	.485
Community relevance of HIV/AIDS information	Unadj.	—	—	—	—	—	—	—	—
	Adj.	—	—	—	—	—	—	—	—
Incidental HIV/AIDS information acquisition frequency	Unadj.	—	—	—	—	—	—	—	—
	Adj.	—	—	—	—	—	—	—	—
Frequency of HIV/AIDS information seeking	Unadj.	—	—	—	—	—	—	—	—
	Adj.	—	—	—	—	—	—	—	—
R ² adjusted		—		.091		.135		.139	

Table 5. Linear regressions for information interaction variables.

Independent variable		Dependent variable					
		Incidental HIV/AIDS information acquisition frequency		Frequency of HIV/AIDS information seeking		HIV/AIDS information use for decision making	
		Beta	<i>P</i>	Beta	<i>P</i>	Beta	<i>P</i>
Age	Unadj.	-.130	.070	.065	.368	-.026	.724
	Adj.	-.031	.686	—	—	—	—
Education level	Unadj.	.180	.012	.001	.984	.008	.913
	Adj.	.168	.030	—	—	—	—
Racial /ethnic minority	Unadj.	-.030	.675	.234	.001	.092	.200
	Adj.	—	—	.226	.001	—	—
Gay community involvement (GCI)	Unadj.	.378	<.001	.301	<.001	.257	<.001
	Adj.	.368	<.001	.192	.020	-.059	.448
Social costs of HIV/AIDS information seeking	Unadj.	.012	.868	-.194	.007	-.108	.135
	Adj.	—	—	-.100	.175	—	—
Network access to HIV/AIDS expertise	Unadj.	-.014	.850	.071	.324	.244	.001
	Adj.	—	—	—	—	.192	.005
Community relevance of HIV/AIDS information	Unadj.	.137	.058	.206	.004	.375	<.001
	Adj.	.020	.784	.103	.173	.273	<.001
Incidental HIV/AIDS information acquisition frequency	Unadj.	—	—	.162	.024	.274	<.001
	Adj.	—	—	.083	.274	.215	.002
Frequency of HIV/AIDS information seeking	Unadj.	—	—	—	—	.371	<.001
	Adj.	—	—	—	—	.284	<.001
R ² adjusted		.157		.143		.278	

Table 6. Standardized total, direct and indirect path coefficients for model (see Figure 1) (N=194).

Parameter estimate	Standardized Total effects			Standardized Direct effects			Standardized Indirect effects		
	Est. ^a	CI	P	Est.	CI	P	Est.	CI	P
GCI – Social costs of information seeking	-.272	(-.358 - -.138)	.032	-.272	(-.358 - -.138)	.032	—	—	—
GCI – Network expertise access	.271	(.141-.388)	.011	.271	(.141-.388)	.011	—	—	—
GCI – Community relevance	.356	(.246-.463)	.009	.356	(.246-.463)	.009	—	—	—
GCI – Incidental information acquisition	.378	(.257-.476)	.011	.378	(.257-.476)	.011	—	—	—
GCI – Information seeking frequency	.301	(.174-.382)	.018	.301	(.174-.382)	.018	—	—	—
GCI – Information use	.300	(.234-.361)	.013	—	—	—	.300	(.234-.361)	.013
Social costs of information seeking – Network expertise access	-.293	(-.386 - -.173)	.020	-.293	(-.386 - -.173)	.020	—	—	—
Social costs of information seeking – Information use	-.053	(-.095 - -.025)	.007	—	—	—	-.053	(-.095 - -.025)	.007
Network expertise access – Information use for decision making	.181	(.097-.273)	.008	.181	(.097-.273)	.008	—	—	—
Community relevance – Information use for decision making	.261	(.160-.386)	.005	.261	(.160-.386)	.005	—	—	—
Incidental information acquisition – Information use for decision making	.198	(.072-.285)	.021	.198	(.072-.285)	.021	—	—	—
Information seeking frequency – Information use for decision making	.276	(.169-.373)	.012	.276	(.169-.373)	.012	—	—	—

^a Est. = estimate.

Table 7. HIV/AIDS information sharing.

Cate- gories	Concepts	Sample participant quotations
Conditions: Enacting pro-social community values		
	Looking out for each other	<i>"A group of people who look out for one another, nurture each other, fight for each other..."</i> <i>"...having somebody's back..."</i>
	Working together	<i>"I hear the word 'community', I hear unity in it, so that means everyone must come together to be one unit...everyone working together equally, picking up the slack ..."</i> <i>"...a group of people that... try to do anything that will work for...the common good for the group..."</i>
	Making a difference	<i>"HIV and AIDS...I grew a passion for it...knowing that it was something out there that was destroying the community...I...can have a big impact on...protecting people from [it]."</i>
	Informing community	<i>"...when I hear 'community'...that brings to my head friends, family helping out each other and informing each other about certain things and having each other's backs."</i> <i>"...when...I talk about safe sex with people, that's...my community..."</i>
Actions/Interactions: Information sharing		
	Organizing events	<i>"...a lot of people...were starting to get infected and... your heart hurt... ...it just led to this...urgent need to talk to us... ...[so we organized] a community discussion...because it seems like we'd get the information, then it dies..."</i>
	Disseminating messages	<i>"...mostly...the gay community has it and people have died from it ... made me feel sad, and [I] wanted... help... I use to volunteer...like do flyers..."</i>
	Encouraging safety	<i>"...if you are around me, I'm gonna pull you in, like '...just protect yourself ...that's your body'...talking to people..."</i>
	Referring and recommending	<i>"...I send them random texts, send them Facebook messages, 'have you gotten tested yet?'... 'do you want to go out tonight? Yeah, let's go get tested [for HIV].'"</i>
Consequences of information sharing: Interacting with more information		
	Information seeking	<i>"...learning this information and being able to put it back into the community. It's kind of my purpose..."</i>
	Countering stigmatization and the social costs of information seeking	<i>"...if they see somebody, they be like 'ok well I just met this person but he have HIV so I'm not going to talk to him'...I try to get them out of that..."</i>
	Incidental information acquisition	<i>"I know the signs, symptoms... how to test people... by watching, paying attention, going through it, trying to help out...if you volunteer at enough places you'll get the knowledge of [HIV/AIDS]..."</i>
	Network expertise accessibility	<i>"I had, the fortune of having a friend who was HIV positive and so he told me about his viral count and having to manage his medications and...health... that's where I got a lot of my information..."</i>
	Information use	<i>"... how can I tell one person or teach a person of how to protect themselves when I'm not doing it myself? So it put me on my Ps and Qs...more about safer sex..."</i> <i>"...before I joined that [HIV prevention program], I didn't count oral sex as sex, I didn't use...condoms..."</i>

Discussion

Results of this study support our central premise that HIV/AIDS information interaction and gay community involvement are related among YMSM. Gay community involvement was a significant predictor of all HII-related variables included in the study: social costs, community relevance, network expertise access, incidental information acquisition, information seeking, and information use. The overall model also predicted a non-trivial, although modest, amount of the variance in information acquisition frequency (9-14%) and information use (28%). Moreover, community-related variables alone explained 17% of the variance in information use. Community-related variables were also stronger predictors of HII than

demographics. Furthermore, our data offer insight into *how* community matters: YMSM who are more involved in the gay community acquire more HIV/AIDS information, see that information as more relevant, and have more knowledgeable, close network members with whom they may discuss that information. Each of these factors appear to contribute to HIV/AIDS information use. People who are more involved in the gay community also perceive fewer social costs in relation to looking for HIV/AIDS-related information, which correlates with more access to knowledgeable people in one's network. Qualitative findings also suggest that community involvement may be related to enacting pro-social community values through information sharing. In turn, information sharing may be associated with each of the other HII variables included in the

model. Overall Internet use and online HIV/AIDS-related information seeking were also correlated with gay community involvement, and Internet sites for MSM were the most used online information sources. However, some aspects of the role of technologies in the community-HII relationships are ambiguous, since some technology uses were related to community involvement, one social use was negatively related, and some social uses had no relationship at all.

Our findings suggest that HIV/AIDS-related HII and associated technology uses are community-embedded processes, yet the majority of HIV/AIDS-related informatics interventions to date attempt to influence individual-level constructs, such as knowledge, attitudes, and self-efficacy [58]. Results suggest that this approach, while valuable, may be insufficient because it does not account for the social contexts of information acquisition and use. Thus, existing interventions may not be positioned to account for differential reception of interventions within communities, and unplanned uses and effects. Indeed, our related work shows that when they are available within high-prevalence communities, technologies may be incorporated into HIV/AIDS-related communication processes in surprising ways [59]. Moreover, clinically oriented health informatics research documents the unplanned consequences of health information technology deployed in clinical settings (eg, [60,61]). Attention to the community-embedded nature of HIV/AIDS information and technologies may help us to more effectively conceptualize, design, and deploy informatics interventions that respond to the unique needs and characteristics of different groups. Additionally, by focusing primarily on individuals, informatics interventions miss the potential for community-level intervention and effects. They also do not consider the potential importance of pro-social information sharing and the potential for promoting information sharing through social media, texting, and other technologies. However, the community informatics field has shown the potential for technologies to be used to develop local social networks and facilitate collective action [62-65]. Given that offline activism and volunteering may be effective community-based HIV/AIDS prevention strategies [66], our research suggests that we may benefit from considering how informatics interventions can also be designed as community-level interventions and vice versa.

Our model is strengthened by inclusion of theoretical mediators that help explain the effect of community involvement on information acquisition and use. Therefore, we offer the first quantitative assessment of important concepts that have emerged from qualitative field work in information science, such as social costs of information seeking and collective relevance (eg, [2,67]). Moreover, this is one of the first studies to highlight information sharing as a potentially important form of community-embedded HII. Such confirmation and extension help answer calls for increased insight into information production, acquisition, and use in everyday life [1,4,68]. Moreover, this model suggests potential bases for community-level interventions. For example, the model's mediators suggest that gay community involvement provides two resources that may be critical for the use of acquired HIV/AIDS information: 1) valuing of that information through a belief that it is relevant to one's group, and 2) supportive and

knowledgeable network members with whom one can talk about HIV/AIDS. This finding opens previously unrealized possibilities for both public health and informatics interventions, such as potentially providing community-based services that help MSM understand the relevance of HIV/AIDS information and support them in discussing HIV/AIDS information with knowledgeable people whom they trust. Our research also suggests, as we have argued elsewhere, that stigma-reduction interventions may improve access to HIV/AIDS information in communities [3]. We also highlight the fact that interventions that engage at-risk groups in preventing HIV/AIDS among their members (eg, [69]) may have under-acknowledged consequences for information sharing in a variety of forms. In these senses, we advocate broadening the public health field's conception of community-level HIV/AIDS interventions to highlight information interaction as a focus for intervention, as well as a desired outcome of our efforts. In an era of reduced funding, current and future mediators included in this model may prove to be especially valuable outcome measures for community-level interventions within the context of public health practice.

Our findings raise questions about the potential role of information interaction in observed relationships between gay community involvement and HIV risk behavior. MSM who are more involved in the community have more sexual partners [34], particularly if they frequent gay bars/clubs [70]. Greater attendance at gay bars/clubs is also correlated with more high risk sexual behavior [14,70,71], partly due to its association with number of sexual partners [70] and exposure to alcohol and other drugs [35]. However, involvement in other gay community activities, such as sports teams, gay organizations, ASOs, and political activism may be protective [25,66,72,73]. An Australian study showed that HIV testing among MSM was associated with having more gay friends [74]. One study and a theoretical model suggest that such protective effects may be linked to the effect of community involvement on safer sex self-efficacy [66,70]. Researchers also posit that a protective effect for ASO involvement may be linked to positive peer norms regarding condom use, more positive self-identity, and lower levels of alienation [66]. Despite these observed correlations, we know little about potential mechanisms that may underlie such community involvement-risk behavior associations [70]. Our results therefore generate a novel, information-based hypothesis at the community involvement-HIV risk nexus. The next step in investigating potential associations is to establish a connection between community-embedded information interactions and risk behavior. While such a connection largely remains to be demonstrated, promising study results reported elsewhere show that information acquisition and use are significant predictors of MSMs' intentions to seek HIV testing [75]. Our qualitative results also suggest a potential association between information sharing and use of information to make sexual health-related decisions. Further research within larger samples is needed to rigorously assess these potential associations.

While our research focuses on YMSM and gay community involvement, our findings may have relevance for other illnesses and community contexts, since prior research in other contexts

has shown that communities may vary widely with regard to media and community organization involvement in health communication [76]. Furthermore, there is varied health knowledge in different communities [77-79]. Geographic communities experiencing health disparities may also have a higher prevalence of ambient, negative health messages [80] and have fewer exposures to positive health promotion messages [81]. One study also revealed that one's participation in health communication activities in one's local community is linked to understanding how to prevent illnesses prevalent in that community [82]. Although suggestive, further research is needed to determine whether the relationships included in our HIV/AIDS-related model hold in such varied health and community contexts and with what effects.

The overall finding that YMSM with greater involvement in the gay community used the Internet more resonates with research conducted in the general adult American population. Internet communication facilitates maintenance of a wide range of geographically dispersed relationships [83] that seamlessly shift between different communication media. The popularity of texting to communicate with participants' close network members is also in concordance with this prior research [83]. However, results showing that those who spend more time chatting with other MSM online were less involved in the gay community were unexpected. Specific types of online activities may have an impact on friendship formation and feeling a part of the community. On the other hand, given that our measure of gay community involvement included time spent at meetings and organizations, there may be a simple time tradeoff at play, with people who spend a great deal of time chatting online having less time to devote to such organizational involvements. Nevertheless, this could mean that different technologically mediated strategies for community building among MSM would differ in effectiveness. Such possibilities merit further investigation.

Limitations

Although the purpose of the study was to identify whether and how much community involvement predicted human-information acquisition, the overall magnitude of prediction for information seeking and incidental acquisition were relatively low ($R^2=9\%$ and 15% , respectively). Although better for information use (28%), the magnitude remains modest.

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Following a tradition of research in information science (eg, [84]), further variables concerning the user's situation may offer additional explanatory power. Furthermore, one may argue that YMSM may have had multiple community affiliations and that these affiliations could have confounded relationships at the gay community-HII nexus. However, participants were given the opportunity to name the community to which they most belonged, with the majority (65.8%) specifying the Gay/Queer/LGBT community and a minority (15.5%) identifying alternative communities—each of which lacked the historical and present burden of HIV/AIDS that is found in the Gay/Queer/LGBT community. Therefore, we do not expect that alternative community affiliations would be an important predictor of HIV/AIDS-related HII in our sample. Due to limited power based on the small sample size ($n=194$) and the pre-selection of variables, model fit statistics should be interpreted with caution. Finally, further research is needed through offline survey modes with men of all ages and in other geographical areas to assess the generalizability of this study's findings to the larger MSM community and to assess the potential place of information sharing in a refined model. Furthermore, the model currently focuses specifically on the case of MSM and HIV/AIDS; applicability to other communities and diseases awaits verification.

Conclusion

This research showed that, in a web-based sample of young MSM, gay community involvement was a significant predictor of a series of HIV/AIDS-related information interaction and technology use variables. Moreover, our model demonstrated that greater information use was predicted by social costs of information seeking, perceived community relevance, and network expertise accessibility. We also highlight the potential importance of a new variable, information sharing, at the community-HII nexus. Our findings suggested partial support for our hypothesis that YMSM who were more involved in the gay community would make heavier use of technologies to socialize with others. Together, these findings suggest that HIV/AIDS information interaction and technology use should be conceptualized as community-embedded processes as well as individual ones. Such recognition highlights the potential for novel, community-level health informatics interventions, while allowing us to perceive informational dynamics underlying community life that we did not see before.

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Abbreviations

ASO: AIDS Service Organization
CHI: consumer health informatics
GCI: gay community involvement
HII: human-information interaction
IIA: incidental HIV/AIDS information acquisition
IT: information technology
MSM: Men who have sex with men
PHA: people with HIV/AIDS
YMSM: young men who have sex with men

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Original Paper

If We Offer it, Will They Accept? Factors Affecting Patient Use Intentions of Personal Health Records and Secure Messaging

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Abstract

Background: Personal health records (PHRs) are an important tool for empowering patients and stimulating health action. To date, the volitional adoption of publicly available PHRs by consumers has been low. This may be partly due to patient concerns about issues such as data security, accuracy of the clinical information stored in the PHR, and challenges with keeping the information updated. One potential solution to mitigate concerns about security, accuracy, and updating of information that may accelerate technology adoption is the provision of PHRs by employers where the PHR is pre-populated with patients' health data. Increasingly, employers and payers are offering this technology to employees as a mechanism for greater patient engagement in health and well-being.

Objective: Little is known about the antecedents of PHR acceptance in the context of an employer sponsored PHR system. Using social cognitive theory as a lens, we theorized and empirically tested how individual factors (patient activation and provider satisfaction) and two environment factors (technology and organization) influence patient intentions to use a PHR among early adopters of the technology. In technology factors, we studied tool empowerment potential and value of tool functionality. In organization factors, we focused on communication tactics deployed by the organization during PHR rollout.

Methods: We conducted cross-sectional analysis of field data collected during the first 3 months post go-live of the deployment of a PHR with secure messaging implemented by the Air Force Medical Service at Elmendorf Air Force Base in Alaska in December 2010. A questionnaire with validated measures was designed and completed by 283 participants. The research model was estimated using moderated multiple regression.

Results: Provider satisfaction, interactions between environmental factors (communication tactics and value of the tool functionality), and interactions between patient activation and tool empowerment potential were significantly ($P < .05$) associated with behavioral intentions to use the PHR tool. The independent variables collectively explained 42% of the variance in behavioral intentions.

Conclusions: The study demonstrated that individual and environmental factors influence intentions to use the PHR. Patients who were more satisfied with their provider had higher use intentions. For patients who perceived the health care process management support features of the tool to be of significant value, communication tactics served to increase their use intentions. Finally, patients who believed the tool to be empowering demonstrated higher intentions to use, which were further enhanced for highly activated patients. The findings highlight the importance of communication tactics and technology characteristics and have implications for the management of PHR implementations.

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KEYWORDS

personal health record; technology acceptance; secure messaging; patient-centered care; employer sponsored PHR

Introduction

Background

Patient-centered care is a core component of the Institute of Medicine's quality aims and of the Affordable Care Act of 2011. Policy initiatives for health care transformation envision a health care system that is patient-centric [1], where the patient is a focal and engaged player in managing his/her health and health care. A critical element of this vision is patient empowerment with tools and technologies that support health information management, exchange, and use [2-4]. Personal health records (PHRs) are an important class of health information management tools that enable patients to store, retrieve, and manage their personal health information and ultimately, to stimulate health action [5]. However, while approximately 70 million people in the United States have access to some type of PHR [6] and despite the value potential of PHRs for engaging consumers as active participants in their health and well-being, the volitional uptake of PHRs has been slow. Although adoption rates of PHRs are not widely reported in the literature, studies [6] noted that the adoption of PHRs by patients is generally modest. A consumer survey conducted in 2011 revealed that broad-based consumer adoption of PHRs is not occurring, with only 7% of consumers reporting they had ever used a PHR. Google's announcement that it plans to close its health records service [7] in 2012 further underscores the limited diffusion of consumer controlled PHRs, a phenomenon not restricted to the United States alone [8].

An alternative to the consumer controlled PHR is one offered by employers as a service to their employees [9]. This mode of PHR delivery addresses one of the critical concerns voiced by consumers in regard to PHRs they adopt on their own, which is, entering and updating personal health information. Additionally, the employer may be in a better position than third parties to alleviate employee's concerns about security, another significant impediment to PHR use [10,11]. However, within the context of such employer-sponsored PHRs, there is limited research examining various aspects of PHR deployment and acceptance, and many unanswered questions remain [12,13].

The aim of this paper was to understand the factors that influence individuals' intentions to use a PHR provided by the employer. Our specific focus was on understanding what influences the behavior of early adopters of PHRs, so that PHR adoption can be accelerated. We report findings from the deployment of a PHR implemented by the Air Force Medical

Service (AFMS) at Elmendorf Air Force Base in Alaska in December 2010. The PHR tool supported entry and management of health information directly by patients, integrates with the patients' clinical records, offered access to a wide range of educational materials, and supported secure patient-provider messaging (SM).

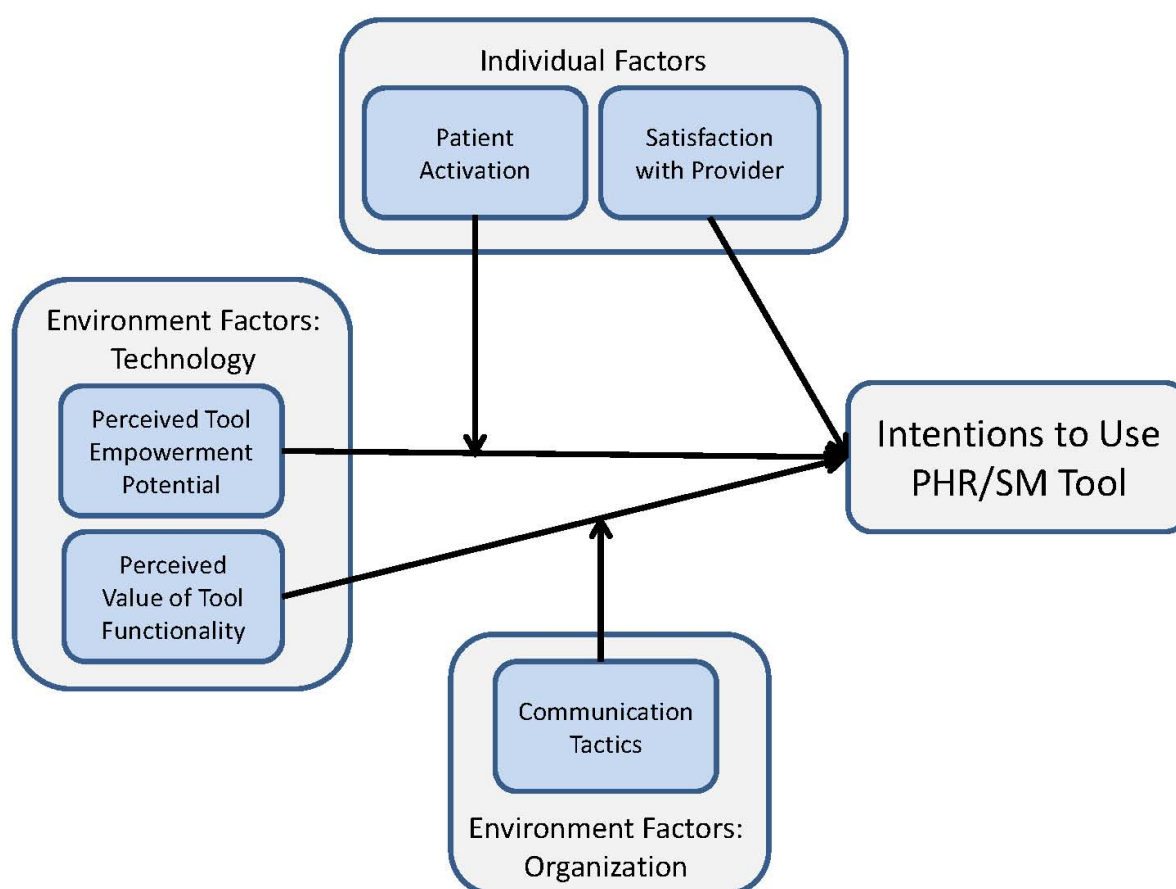
Studies of consumer health information technology acceptance have limited their focus to patient demographics and health variables or general perceptions of the technology (eg, ease of use and usefulness) [14-18]. While these studies provide valuable insight into the individual technology adoption process, there is limited understanding of factors driving PHR acceptance in employer-sponsored contexts, especially those factors associated with the deploying organization. Further, there is a paucity of work examining how usage intentions are formed in the initial stage after the adoption decision has been made. We addressed these gaps in knowledge by developing and testing a model that was theoretically grounded and incorporated factors uniquely relevant to the deployment context. The social cognitive theory (SCT) [19] provided the theoretical foundation for the research model. Factors studied included perceptions of the technology, communication tactics deployed by the employer, and individual characteristics of patient activation and satisfaction with their provider. Findings from a detailed survey of 283 early adopters provided insight into patients who were more likely to use the PHR and the actions an organization could proactively take to influence usage intentions.

Theoretical Foundation and Research Hypotheses

SCT describes individual behavior as mutually dependent upon contextual or environmental factors, and individual factors that reflect the individual's prior history, skills, and innate propensities. SCT is a robust theory that has been successfully applied to explain phenomena across various domains including behavior towards information technology [20], organizational behavior, training and education, and the psychology underlying individual choices [19,21-25].

The PHR acceptance model is depicted in [Figure 1](#). Drawing on SCT, we hypothesized that individual and environmental factors, specifically, technology and organization, will interact to influence acceptance of the tool. We measured individual acceptance of the PHR by self-reported behavioral intention to use the tool—a widely used dependent variable in technology acceptance research [18,26-29] with strong predictive power for actual use behavior [29-31].

Figure 1. PHR acceptance model.



Individual Factors

SCT asserts that an individual's background, expectations, traits, and skills influence their decisions and behavior [19]. Factors especially salient in the context of PHR adoption are patients' satisfaction with their health care provider [32-35] and the extent to which patients believe they are in control of their own health care (ie, patient activation) [36-38]. With regard to the patient-provider relationship, the effect of a positive relationship on adherence to recommended treatment regimens is well documented [32-34]. Studies have generally been conducted in the context of chronic disease conditions where frequent interactions with the provider were required and sustained effort was needed of the patient to manage his/her disease (eg, HIV or diabetes) [32-34]. Collectively, this prior work demonstrated that stronger patient-provider relationships could increase positive health-related intentions and behaviors.

Research on technology acceptance and use and the patient-provider relationship has shown the effect of technology use on various aspects of the relationship and not the reverse [39-41]. One exception was observed in a qualitative study of patient focus groups conducted by Zickmund et al [35]. Their findings indicated that interest in using a patient portal was negatively associated with satisfaction with the patient-provider relationship. However, they attributed the limitations of their work to a small sample size, selection bias, and the focus on a

single disease (diabetes), and called for more studies on the association between the patient-provider relationship and the use of technology that facilitates health information availability and communication with providers. Drawing upon the stronger evidence in support of a positive association between the patient-provider relationship and positive health action in the more widely studied treatment regimen contexts, and to the degree that a PHR facilitates greater attention to health-related issues, we hypothesized that a positive patient-provider relationship would amplify intentions to use the PHR.

Hypothesis 1: Satisfaction with the health care provider is positively associated with intentions to use the PHR tool.

Studies have shown that patients who demonstrated higher levels of knowledge, skill, and confidence in their ability to self-manage their health (ie, they are "activated") exhibited healthier behaviors including reading about drug interactions, exercising, and eating right [36]. Highly activated patients with chronic conditions were more likely to adhere to prescribed medications, use self-management services (including the use of educational websites), and follow suggested self-management behaviors [36-38]. Patient activation is akin to self-efficacy, which is a central construct in the person component of SCT. Both patient activation and self-efficacy refer to an individual's perception of their ability to accomplish a particular task, in this case, health self-management. Based on prior findings, we expect that patients with higher levels of activation will be more

likely to accept a technology designed to provide them with access to their health information and facilitate interactions with their providers. However, we expect patient activation to moderate one of the environmental factors of interest in this study, therefore we do not hypothesize a main effect of patient activation on behavioral intentions.

Environment Factors

According to SCT, perceptions concerning the environment, including available technologies and mass media communications, can promote or inhibit relevant behaviors. In the context of this study, PHRs represent a mechanism through which an individual can gain access to their medical record and securely message their provider. We examined 2 factors associated with perceptions of the tool. First, we studied the influence of perceptions about the value of specific functions provided by the tool on use intentions. Second, we examined the influence of a more affective perceptual measure, which captured patients' beliefs about how the use of the tool might empower them, on behavioral intentions. We also investigated the influence of communication tactics, an organizational factor, on use intentions.

Technology Factors

The basic form of PHRs typically store medical information and allow users to access, add to, or modify this information [42]. The functionality present in the system implemented by the AFMS at Elmendorf incorporated additional capability to access educational material and securely message providers. Patients who believe that information availability and a new way to communicate with providers affords them greater control over their health care situation, may be more motivated to accept the technology. This effect will be stronger for patients who are already highly knowledgeable about their health status and confident in their ability to self-manage their health. High levels of activation combined with a belief that the PHR tool will result in further empowerment through the increased access to information, enhanced control, and better organization should amplify usage intentions.

Hypothesis 2: Patient activation will enhance the positive association between tool empowerment potential and intentions to use the PHR tool.

PHR tools in general can incorporate a wide range of functions that support different tasks and activities, each of which has distinctive instrumental value for patients [42]. For example, the PHR tool examined in this study allowed the patient to access medical information from any Web-enabled computer anytime, track lab results, record immunizations, receive health-specific reminders, and securely message the provider. Research has shown that the perception of tool value is a strong driver of technology acceptance [29]. Therefore, we expect that patients who find the PHR functionality useful will be more likely to accept the technology. However, we hypothesize that the relationship between PHR functionality and behavioral intentions is moderated by the communications the patient receives from the organization about the PHR. Therefore, we focused on the interactive effect of these factors.

Organizational Factor

An important aspect of the environment that influences behavior is the information received through mass communication [43]. SCT is grounded in the notion that most external stimuli influence behavior through cognitive processes that determine which external events will be attended to, retained, and deemed important. Communication tactics reflect the extent to which an individual hears about the PHR through different channels such as email messages, posters, recorded phone messages, or providers. Organizations often design marketing messages to raise awareness of the benefits of the system to increase adoption of the technology. Patients who reported being exposed to more of these messages should be more aware of the benefits of the system. When this awareness of benefits is combined with the perception that the PHR functionality is of value, higher intentions to use the PHR should result.

Hypothesis 3: Communication tactics will enhance the positive association between perceptions of the technology features and intentions to use the PHR tool.

Methods

Data Collection Site

To test the research hypotheses, we collected data during the first 3 months post go-live of the deployment of the PHR with secure messaging tool implemented at Elmendorf Air Force Base in Alaska in December 2010. Approximately 26,000 individuals over the age of 18 were enrolled for receipt of health care at the Elmendorf military treatment facility (MTF) provided by a medical group staff of approximately 150. Initial goals associated with the PHR project included improving the quality of health care patients received, increasing staff productivity, decreasing staff workload, and enabling patients to have more control over their own health information. The tool was named "MiCare" to signal to patients that it would afford them greater control over their care.

Procedure

Several weeks in advance of system go-live, patient registration cards were provided to the MTF. To register, patients visited the MTF and showed their military ID to the registration staff located at enrollment desks in the lobby. Once their information was entered into the system, the system automatically generated an email with a link to complete the registration process. Registered users' data was extracted from existing Air Force medical databases to populate the PHR. Periodic updates kept the data current and consistent with the clinical "database of record". Once the registration process was completed, the user could access the PHR tool from any Web-enabled computer (a screenshot of the Home tab is provided in [Multimedia Appendix 1](#)).

After initial registration, users received an email requesting their participation in an electronic survey to measure baseline expectations about the system and other individual characteristics. If the user chose not to participate in the survey at the initial request by selecting the "not now" option, 2 reminder emails were sent, one week apart. If the user agreed to complete the survey, the system assigned a unique identifier

to the respondent to de-identify them for study purposes while also facilitating the matching of survey responses with existing data from military databases. We obtained patient demographics and health condition variables from existing Air Force databases to serve as control variables.

Measurements

We used multi-item scales for all variables, relying on prior research for scales wherever possible. Because the data collection occurred prior to hands-on use of the tool, items were worded to reflect the respondent's *expectations* about the use of the system (eg, for each of the features of the tool listed below, please indicate how useful you believe it *will* be for your personal health information management), formed on the basis of information they received about the tool. Drawing upon prior work in technology acceptance and use [44-45], the survey included a validated 3-item measure for future use intentions to measure the degree to which the patient planned to utilize the tool in the future, scored on a 7-point Likert scale, with anchors of "strongly disagree" (1), "neutral" (4), and "strongly agree" (7).

To gain a more granular understanding of the types of functionality that would be most valuable for patients, the survey included a list of 17 PHR features (eg, link to information about potential drug interactions, store and manage medical images, record and manage health care expenses) that respondents scored on a 1-7 Likert Scale anchored with "not at all useful" (1), "neutral" (4), and "very useful" (7). These features were selected based on the specific requirements that had been identified during the extensive requirements analysis performed by the research team and the software contractor who developed the PHR system for the Air Force. Requirements analysis included interviews with 20 patients and 3 patient focus groups. For tool empowerment potential, we developed a 5-item scale that tapped into the patients' beliefs about whether the use of the tool would make the individual feel more empowered, more in control, more informed, better prepared, and more organized.

Baseline patient activation (the knowledge, skill, and confidence for self-management) was assessed using the 13-item patient activation scale from Hibbard et al [37] that has been validated across a number of studies. Respondents indicated their overall satisfaction with their provider using 3 items scored on a 7-point Likert scale. To evaluate the effectiveness and reach of the different communication tactics, we asked respondents how much they had heard about the PHR pilot through 9 different communication channels, including posters, website, base newspaper articles, and recorded phone messages.

Because computer skills have been previously linked to PHR adoption behavior [46], for control purposes, we asked respondents to rate their computer skills. Additional controls from the military databases included gender, age, sponsor pay grade, and the total number of chronic disease diagnoses such as asthma, hypertension, diabetes, etc, to serve as a proxy for

general health. Finally, the survey contained an open-ended question asking users to provide any other comments or feedback they had.

Prior to conducting the full study, we did extensive pre-testing of the survey instrument to ensure that the scales were valid and reliable, and that respondents interpreted each question the way it was intended. The final survey contained a total of 81 items, together with 1 open-ended response. We performed cognitive testing with 6 subjects who completed the survey while 2 researchers were present, and provide feedback on the format and wording of the questions. This was followed by a field pre-test where we solicited patients in a military treatment facility that was different from the main study site. We obtained responses from 38 patients. Analysis of the pre-test data supported the validity and reliability of the measurement scales. We also confirmed that the survey could be completed by the respondent in less than 10 minutes.

Results

Descriptive Statistics of the Sample

The adoption trajectory of the system over the first 3 months post go-live is shown in Figure 2. Over this time period, of the approximately 26,000 adult patients invited to register, 1801 completed the registration, yielding an adoption rate of 7%. We received 283 responses to the email survey requests, which represent a 16% response rate. Of the survey respondents, 64% (181/283) were female. Over half of the respondents rate their computer skills as quite extensive or very extensive.

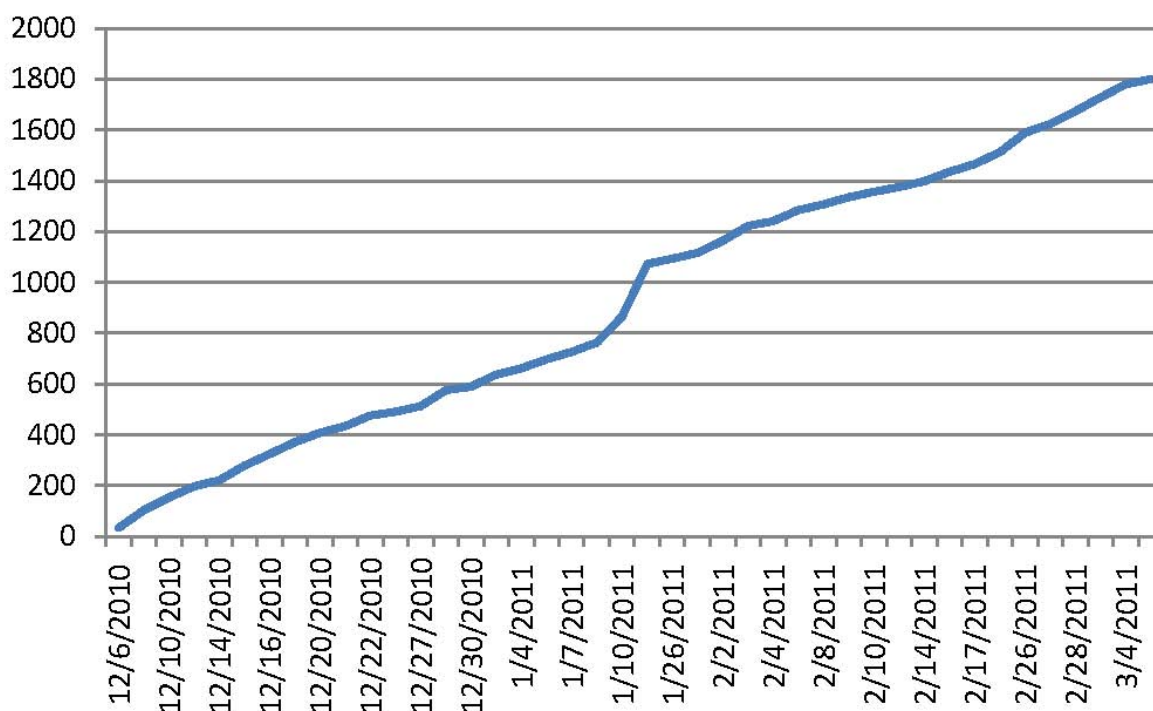
Table 1 summarizes demographic information for: (1) the Elmendorf population, (2) the early adopters of the PHR, and (3) our survey sample. The survey sample was significantly older, higher paid, more sick, and more likely to be female than the Elmendorf population. The survey sample was also older, higher paid, more sick, and more likely to be active duty than early adopters who chose not to complete the survey. These differences were consistent with findings from other studies which examined usage patterns of secure messaging and found usage to be higher for women, individuals with higher levels of education, and increased morbidities [47,48]. Education information was not available from the Air Force databases, but income was often correlated with education [49]. Since registration for the PHR was done at the MTF upon presentation of a military ID, it is possible that individuals seeking treatment for an illness or older patients who required more clinic visits tended to enroll more than others simply because they visited the clinic. More dependents enrolled for the PHR, yet more active duty personnel responded to the survey requests. This may reflect a greater sense of duty or responsibility to participate in the research on the part of the active duty personnel. A comparison of mean scores on summated scales between early versus late responders to the survey revealed no significant differences [50].

Table 1. Demographic profile of early adopters.

Variable	Elmendorf Population (1) N=26,096	PHR Early Adopters (2) N=1518	Survey Respondents (3) N=283
Demographics			
Gender, (Male=1, Female=0)	0.46	0.37, (1) ^a	0.36, (1) ^a
Age, years	40.0	32.1, (1) ^a	47.2, (1) ^a ,(2) ^a
Sponsor pay grade, numeric scale 1-9	5.48	5.40, (1) ^a	5.69, (1) ^a ,(2) ^a
Number of dependents, sum	0.72	0.63	0.60
Dependents vs active duty, (Dependent = 1, active duty = 0)	0.52	0.64, (1) ^a	0.55, (2) ^a
Medical Condition			
Average total chronic diseases, sum	0.39	0.49, (1) ^a	0.63, (1) ^a ,(2) ^a

*This variable is significantly different from the same variable in columns (1) or (2), as labeled in the heading.

Figure 2. Baseline patient enrollment.



Data Analysis

We first performed factor analysis to confirm the psychometric properties of the measurement scales. Principal components factor analysis of the 17 items used to assess the importance of various features of the PHR tool yielded a two-factor solution. The first factor consisted of 9 items related to the tool’s capability to store and track patient historical information, and therefore, we labeled it the “record keeping” feature of the tool. The second factor consisted of 8 items related to the tool’s potential to provide the patient “health care process management support” (eg, exchanging information between providers, reminders about appointments). All constructs and the

corresponding items used for the statistical analysis are presented in [Multimedia Appendix 2](#).

The patient activation items loaded on 2 factors that represent different stages of patient activation [36,37]. The first 7 items loaded together to form a factor representing a patient’s belief about their role in self-health management and their confidence and knowledge in their own ability to take action (PA-knowledge/beliefs). The last 6 items loaded on the second factor that captures a patient’s actual actions and ability to maintain appropriate self-health activity when under stress (PA-actions/maintenance). In addition, the 9 communication tactics deployed loaded on 2 factors. The first factor included 7 communication mechanisms that were impersonal in nature,

(eg, posters, emails) while the second included 2 personal communication mechanisms (ie, registration desks, providers/staff). [Table 2](#) shows the reliability (Cronbach alpha), means, and SDs for the variables and correlations between the constructs. Summated scales for all research constructs were used in the statistical analysis.

We estimated the research model using moderated multiple regression in SPSS. Intention to use was regressed on all the independent variables shown in [Figure 1](#). We first entered the control variables into the regression, followed by the main effects. To model the hypothesized moderating relationships,

we included 6 additional variables representing the product of PA-knowledge/beliefs and Perceived Tool Empowerment Potential, PA-actions/maintenance and Perceived Tool Empowerment Potential, Impersonal Communication Tactics with the 2 factors for Perceived Value of Tool Functionality, and Personal Communication Tactics with the 2 factors for Perceived Value of Tool Functionality. The regression equation included control variables for gender, age, sponsor pay grade, computer skill level, dependent status, and general health. A confidence level of 95% was utilized for the purposes of hypothesis testing. We used a listwise deletion procedure for missing data.

Table 2. Descriptive statistics: reliability, means, SDs, and correlations (N=283).

Construct	Reliability (# of items)	Mean (SD)	1	2	3	4	5	6	7	8	9
Intentions	.91(3)	5.98 (1.15)	1								
PA-knowledge/ beliefs	.90(7)	6.40 (0.71)	.48**	1							
PA-actions/ maintenance	.89(6)	5.62 (1.11)	.31**	.58**	1						
Provider satisfaction	.96(3)	6.05 (1.26)	.44**	.50**	.40**	1					
Tool empowerment potential	.95(5)	5.97 (1.06)	.67**	.48**	.29**	.40**	1				
Record keeping functions	.94(9)	6.26 (1.12)	.51**	.41**	.31**	.34**	.53**	1			
Health care process management support functions	.95(8)	6.29 (1.07)	.57**	.41**	.26**	.35**	.64**	.84**	1		
Communication tactics (impersonal)	.83(7)	2.10 (1.08)	-.03	-.01	.16*	-.05	.10	-.01	.04	1	
Communication tactics (personal)	.72(2)	3.03 (1.29)	.16*	.07	.10	.07	.24**	.11	.16*	.37**	1

* $P < .05$

** $P < .01$

[Figure 3](#) summarizes the results of the regression analysis and depicts the significant predictors of use intentions for the PHR tool. Provider satisfaction was significantly associated with intentions to use. PA-actions/maintenance positively influenced the relationship between tool empowerment potential and intentions to use the tool, while PA-knowledge/beliefs did not. Intentions to use the tool were highest for patients indicating high levels of competence in managing their own health (PA-actions/maintenance) who also believed the tool was likely to make them feel empowered. PA-actions/maintenance had little effect on intentions for patients who did not believe the tool would make them feel empowered.

Both personal and impersonal communication tactics interacted with perceived value of the health care process management support features of the tool to increase use intentions. Intentions to use were highest for patients who perceived the health care process management support feature to be very useful and who also heard a lot about the tool through either personal or

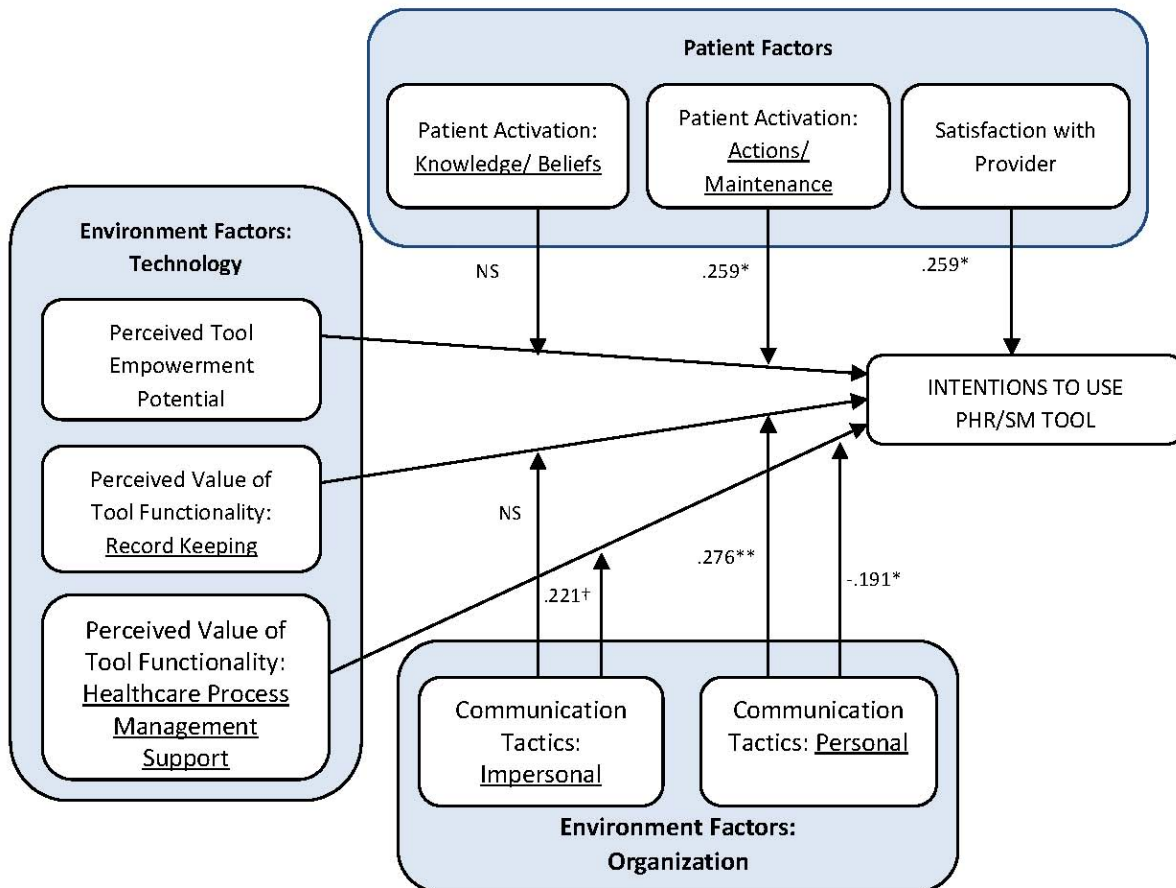
impersonal communication channels. Contrary to what was hypothesized, communication tactics that were more personal in nature had a negative interactive effect on the relationship between value of the record keeping function of the PHR and intentions to use. Hearing a lot about the tool through personal communications tended to decrease a patient's intentions to use the tool when their perceptions of the usefulness of the record keeping functions of the tool were high. If the patient's perceptions of the usefulness of the record keeping functions of the tool were low, hearing a lot about the tool through personal communication tactics had no influence on intentions.

Interaction effects for personal communication tactics and perceived value of the PHR tool on use intentions are depicted in [Figure 4](#). Impersonal forms of communication had no influence on the relationship between the perceived usefulness of the record keeping functions of the PHR and intentions to use.

In summary, hypothesis 1, predicting a significant relationship between satisfaction with health care provider and intentions to use the PHR tool, was supported. The results also partially support hypothesis 2, which proposed a significant positive interaction between the perceived value of the PHR tool and patient activation in their effects on intentions to use (the interaction was significant for PA-actions/maintenance but not

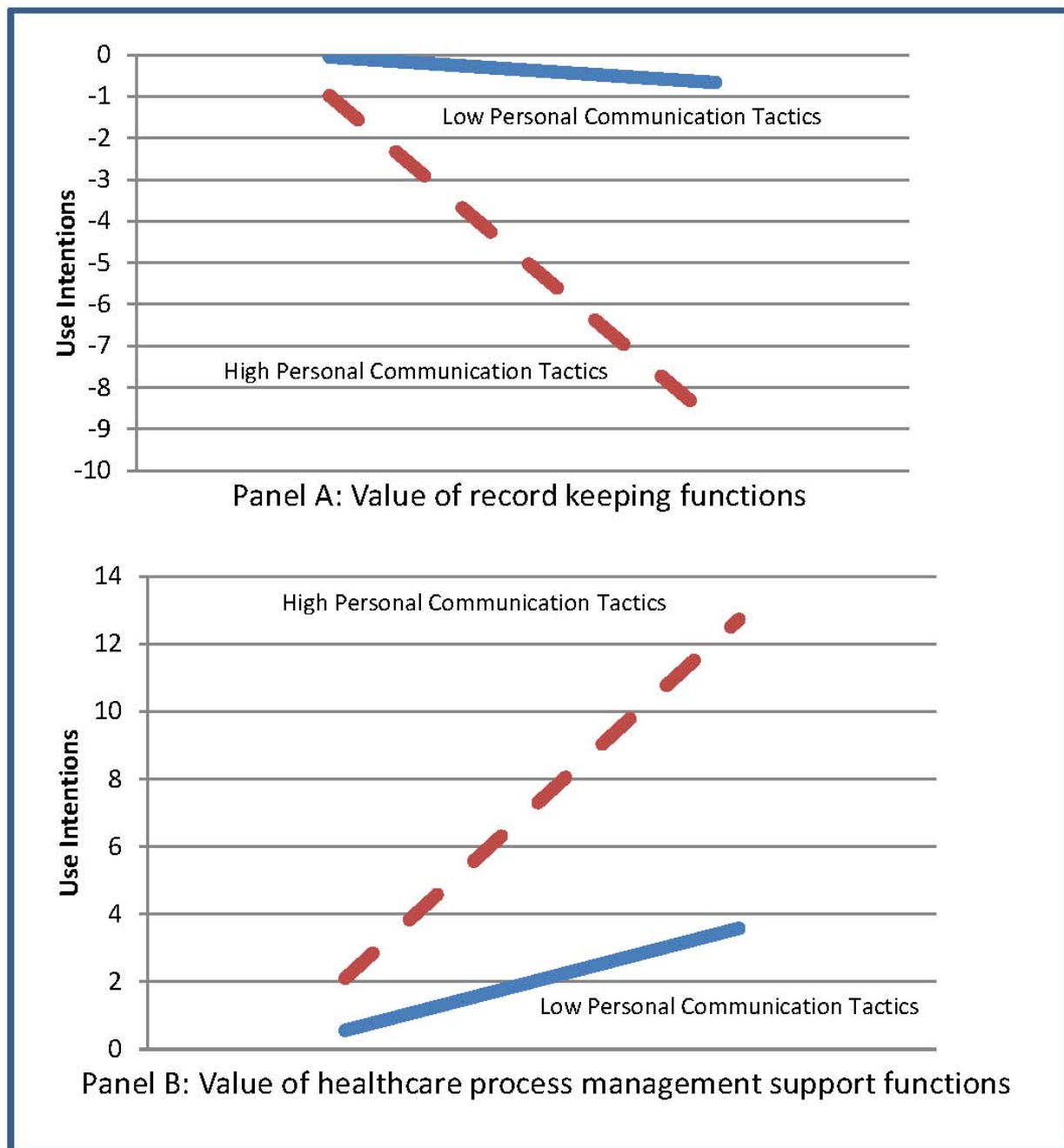
for PA-knowledge/beliefs). Finally, we found partial support for hypothesis 3, which proposed that communication tactics conditioned the effects of perceived value of record keeping and health care management process support functions on intentions to use. Collectively the hypothesized predictors explained 42% of the variance in behavioral intentions to use the PHR tool.

Figure 3. Results of model estimation.



Notes: + p<.1* p<.05, ** p <.01, NS not significant

Figure 4. Interactions between perceived value of tool functionality and personal communication tactics.



Discussion

Principal Findings and Implications

In this study, we used SCT as the basis for building and testing a model to predict patient acceptance of a PHR tool sponsored by the employer. Our findings supported a mutual and reciprocal relationship among the individual and environmental determinants of behavioral intentions to use the PHR. We found evidence that patients who were more satisfied with their providers were more likely to accept the PHR tool. In addition, perceptions of the 2 factors present in the environment, the technology, and organizational communication tactics, interacted to influence behavioral intentions. Finally, patient activation, reflecting the extent to which individuals felt confident in health

self-management, interacted with perceptions of the tool’s ability to empower the individual, a technology environmental factor.

It is widely known that a strong patient/provider relationship can result in better patient outcomes [28-30], yet little is known about the effects of this relationship on consumer health IT acceptance. This study demonstrated that the reach of a strong connection extends to patient acceptance of new technologies as well. Although there has been limited studies to date, there are indications that operational and productivity gains may be realized with patient use of systems such as the one studied here [51-53]. More benefit can be gained by all members of the patient-provider system if providers can encourage patients to use the PHR systems more rapidly and extensively by fostering stronger relationships with them.

We found that use intentions were significantly affected by the perceived value of the various features offered in the PHR, but this relationship was contingent on the communication tactics deployed by the employer. For patients who did not perceive PHR functionality as valuable, communication efforts had no significant influence on intentions. However, for patients who perceived the health care process management support features of the tool to be of significant value, communication efforts served to increase their intentions to use the tool. This was true for both impersonal and personal forms of communication. Intriguingly, for patients who perceived the record keeping functions to be particularly important, personal communication

had a negative influence on intentions to use the PHR while impersonal change management efforts had no influence on the relationship.

One possible explanation for the findings related to the communication tactics and the two types of functionality and intentions is in the specific capabilities and benefits stressed in the materials used by the implementation team throughout the project, that is, the content of the communication. [Textbox 1](#) depicts these themes, the majority of which relate to exchanges between the health care system and the patient (what we label as health care process management support functions) and less about the patient's personal record-keeping functions.

Textbox 1. Key Phr Capabilities and Benefits Used in Marketing Materials.

MiCare allows you to take command of your health care:

- request your next appointment
- request medication renewals
- receive your test and lab results
- maintain a PHR to manage your health
- communicate online with your health care team about non-urgent symptoms
- avoid unnecessary office visits and telephone calls
- request a copy of your immunization record
- access a large library of patient education materials

Because the content of communication materials focused on health care process management support functions, it may be that the record-keeping functionality available within the tool was inadvertently downplayed. Perhaps, in personal exchanges with providers and staff or at registration desks (ie, personal communication), the emphasis may have been even more on the health care process management functions. As a result, patients may have walked away from these interactions with the impression that record keeping functions were minimally provided in the tool or not at all provided. For patients who perceive functionality to be very useful, if they were given the impression it was not available in the tool during these personal communications, it would likely lower their intentions to use it. An important implication of this finding is that communications from providers, staff, and other volunteers working at information/registration desks must convey balanced messages about the functionality of the tool.

We also found evidence of a positive interaction between the tool's empowerment potential and patient activation on intentions to use the PHR. Patients who indicated the tool would make them feel more organized and in control of their health information demonstrated higher intentions to use, which was enhanced for highly activated patients. Thus, patients who were beginning to take actions to manage their own health and felt confident they could maintain these activities going forward were more likely to use the tool when they believed it would further enhance their capabilities to self-manage their health condition.

Limitations

Our study has some limitations that also represent useful opportunities for future work. First, we examined overall provider satisfaction. Future research could investigate patient satisfaction with their provider at a more granular level (eg, competence, thoroughness, respectful attitude, active listening skills, responsiveness to questions) to determine if specific dimensions of provider satisfaction influence technology acceptance [54]. Second, we examined intentions and not actual behavior. However, a robust body of evidence demonstrated that intentions predict behavior [29-31], thereby mitigating this concern. Future work should attempt to measure actual use of the PHR. Third, the sample only included those who registered for the system, that is, the early adopters. While the sampling procedure allowed us to determine whether the hypothesized factors explain variance in behavioral intentions for this population, surveying those who did not register for the system would provide useful insight into factors driving non-adoption. Although the hypothesized model explains substantial variance in intentions to use, a related opportunity for future work is to extend the model to include additional organizational factors such as management support and training that have been shown in prior work to predict use intentions [24]. Fourth, a survey response rate of 16% (283/1801) resulted in a sample that was large enough to test the proposed research model. However, results must be interpreted keeping the possibility of response bias in mind. Demographics of the survey respondents are consistent with other work that has examined the usage of other health information technologies by patients. Fifth, although we had a detailed list of all communication tactics employed during the rollout, we studied the content of communication at a

high-level, focusing only on the themes used in the communication material. Future research could conduct more detailed qualitative analyses of how employees respond to different communication channels and content, and the quality of the channels to better understand what type of messages are more likely to promote greater use intentions. Finally, with respect to generalizability of findings, the hypothesized relationships are derived from a strong evidence base of theory and prior empirical work. Thus, although the study needs to be replicated across different types of organizations before broader generalizations can be made, we expect the findings to extend to contexts that are similar in that the employer is providing the PHR as a service to the employee and usage of the system is volitional rather than mandated.

Conclusions

Despite significant policy interest in promoting patient empowerment and the use of consumer health IT and mounting evidence suggesting that PHR use can reduce medical errors [55] and improve the patient-provider relationship [56] among other positive outcomes, the adoption and use of PHRs by consumers has been disturbingly slow [12]. Success of PHR technology may well lie in sponsorship by an organization such as an employer, insurer, or provider. This study is among the first to provide insight into factors that an organization could leverage to increase acceptance of a sponsored PHR.

Our study reinforces findings in other areas of health, which stress the importance of an involved patient. Just as it is less realistic to expect a hypertensive patient to consistently test blood pressure levels at home, exercise to lose weight, and follow other health-management behaviors in the absence of understanding about the health condition or a lack of confidence

in his/her capability of self-management [37], it is less realistic to expect a similar patient to accept and consistently use a PHR. Hibbard et al [38] found that patient activation could be changed and that improvement in activation levels resulted in improved self-management behaviors. Providers who were able to improve patient activation levels may deliver more effective and efficient care [38]. PHR acceptance may improve to the same extent as providers are willing to motivate and increase the levels of patient activation through a variety of different interventions (eg, seminars, disease managers, counseling). Further underscoring the importance of the provider's role in the process is the finding suggesting the positive effect of a satisfactory patient-provider relationship in PHR acceptance. Finally, we demonstrated that it is not sufficient for potential adopters to find PHR functionality useful, as the main effect of perceived usefulness was not significant in predicting use intentions. High intentions to use the PHR were created by a combination of patients' perceived usefulness and the communication tactics used during system rollout. This suggests that communication from the employer on the capabilities and benefits of the system sends a powerful advocating message to the individuals that, when combined with their own perceptions of the value of the system, translates into high intentions to use the system. The health care process management support function of the PHR represents a two-way street between the patient and provider (eg, scheduling appointments, exchanging messages). It is not surprising that the patient needs to perceive that the other party in the exchange believes in the benefits of the system as well. Communication tactics help reinforce this message. Organizations planning a PHR implementation should carefully craft a communication strategy suited to their organization's needs to improve the likelihood of a high adoption rate, resulting in the highest return on their investment in the technology.

Conflicts of Interest

None declared.

Multimedia Appendix 1

PHR/SM home tab.

[[JPG File, 101KB - jmir_v15i2e43_app1.jpg](#)]

Multimedia Appendix 2

Measures used in study.

[[PDF File \(Adobe PDF File\), 11KB - jmir_v15i2e43_app2.pdf](#)]

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Abbreviations

AFMS: Air Force Medical Service
MTF: military treatment facility
PHR: personal health record
SCT: social cognitive theory
SM: secure patient-provider messaging

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Original Paper

ICDTag: A Prototype for a Web-Based System for Organizing Physician-Written Blog Posts Using a Hybrid Taxonomy-Folksonomy Approach

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Abstract

Background: Medical blogs have emerged as new media, extending to a wider range of medical audiences, including health professionals and patients to share health-related information. However, extraction of quality health-related information from medical blogs is challenging primarily because these blogs lack systematic methods to organize their posts. Medical blogs can be categorized according to their author into (1) physician-written blogs, (2) nurse-written blogs, and (3) patient-written blogs. This study focuses on how to organize physician-written blog posts that discuss disease-related issues and how to extract quality information from these posts.

Objective: The goal of this study was to create and implement a prototype for a Web-based system, called ICDTag, based on a hybrid taxonomy–folksonomy approach that follows a combination of a taxonomy classification schemes and user-generated tags to organize physician-written blog posts and extract information from these posts.

Methods: First, the design specifications for the Web-based system were identified. This system included two modules: (1) a blogging module that was implemented as one or more blogs, and (2) an aggregator module that aggregated posts from different blogs into an aggregator website. We then developed a prototype for this system in which the blogging module included two blogs, the cardiology blog and the gastroenterology blog. To analyze the usage patterns of the prototype, we conducted an experiment with data provided by cardiologists and gastroenterologists. Next, we conducted two evaluation types: (1) an evaluation of the ICDTag blog, in which the browsing functionalities of the blogging module were evaluated from the end-user's perspective using an online questionnaire, and (2) an evaluation of information quality, in which the quality of the content on the aggregator website was assessed from the perspective of medical experts using an emailed questionnaire.

Results: Participants of this experiment included 23 cardiologists and 24 gastroenterologists. Positive evaluations on the main functions and the organization of information on the ICDTag blogs were given by 18 of the participants via an online questionnaire. These results supported our hypothesis that the use of a taxonomy-folksonomy structure has significant potential to improve the organization of information in physician-written blogs. The quality of the content on the aggregator website was assessed by 3 cardiology experts and 3 gastroenterology experts via an email questionnaire. The results of this questionnaire demonstrated that the experts considered the aggregated tags and categories semantically related to the posts' content.

Conclusions: This study demonstrated that applying the hybrid taxonomy–folksonomy approach to physician-written blogs that discuss disease-related issues has valuable potential to make these blogs a more organized and systematic medium and supports the extraction of quality information from their posts. Thus, it is worthwhile to develop more mature systems that make use of the hybrid approach to organize posts in physician-written blogs.

KEYWORDS

Web-based systems; medical; physician; blogs; folksonomy; taxonomy; collaborative tagging; ICD-11

Introduction

Background

Web 2.0 allows users to interact and collaborate with each other in a social media dialogue [1]. Examples of Web 2.0 applications include social networking sites, blogs, wikis, video sharing sites, mashups, and folksonomies [1]. Web 2.0 applications are increasingly used by the medical community to create, consume, and share health information online [2]. Eysenbach [3] identified three main user groups of Web 2.0 applications in health care: patients, health professionals, and biomedical researchers. Research studies have highlighted the potential of Web 2.0 to fulfill part of eHealth's promise to improve medicine and promote health care [4]. Research has also emphasized that Web 2.0 applications offer powerful means of sharing health information [5], which could create novel methods for seeking information to aid clinical decisions [6].

Blogs, podcasts, and wikis are among the common Web 2.0 tools that are being actively explored for their use in the health care context [7]. Blogs are emerging as a valuable tool to support the medical field and have been reported to have the ability to affect learning experiences for students, clinicians, and patients and to motivate collaboration in digital realms [8]. Blogs with primary topics related to medicine or health care are termed medical blogs [9]. Medical blogs constitute an important part of the public medium of medicine [10] because they offer novel channels that reach a wider range of medical audiences [10] and provide new avenues for medical bloggers to disseminate health-related information [11]. Medical blogs are categorized according to their author into blogs that are written by health professionals or patients [12]. Blogs written by health professionals can be classified into two main types, physician-written and nurse-written [13]. Patients use blogs to share their own health and disease experiences [13]; some examples include the My Breast Cancer blog and Diabetes Mine blog. In contrast, health professionals use blogs to share their practical knowledge and skills [13]. Examples of such blogs include CasesBlog, and Kevin MD.

Blogging has become rapidly more common in the health care community [14]. Concurrently, health consumers are generating a significant amount of content through blogs [2]. Thus, health consumers and health professionals can infer new medical knowledge from the large amount of information found on medical blogs. However, the extraction of quality health-related information or medical terms from medical posts is challenging primarily because medical blogs do not feature clear standards that support content retrieval based on medical terminologies. To achieve better retrieval results, medical blogs require more systematic methods to organize posts [15]. One of the widely used methods to organize blog posts is the addition of metadata by the creator or viewer. Such metadata can be added in two different ways [16,17]: (1) associating free keywords, and (2) using predefined categories.

Associating Free Keywords

Tagging has become a very popular technology in the blogosphere [18]. Tags are keywords attached to blog posts to help describe the post content [18]. Users tag posts by describing them in the form of freely chosen *text* labels [19]. Medical blogs that offer tagging functionality allow users to provide free form words that describe the post's content to ease future retrieval of the post. For example, if a user writes a post about a new treatment for leukemia, he can add tags related to it such as blood cancer, surgery, and chemotherapy. During the creation of a post, tags are normally written in a text box.

When many users provide tags for shared resources, the tagging activities are termed collaborative tagging [20]. The main tangible product of collaborative tagging is a social classification system called "folksonomy", which is a conflation of the worlds "folk" and "taxonomy" [21]. Folksonomies represent non-hierarchical groups of terms that describe and organize Web resources for future retrieval, discovery, or sharing purposes [22]. Folksonomies offer great features, including their low cost, ease of use, and the reflection of users' vocabulary [23]. In addition, collaborative tagging systems can rapidly produce useful folksonomies for online medical resources [24]. However, folksonomies lack semantic precision [25] and are not sufficient for information search and retrieval [16] because tagging activities are based on a free annotation style that does not include any vocabulary control [23].

Using Predefined Categories

Users must choose among different categories to select the one that best defines the content of their posts. Generally, these categories are chosen from a taxonomy, which is a set of controlled vocabulary terms. Taxonomies are limited hierarchical structures [17] that represent coherent and complete systems of meaningful labels that systematically organize a given domain [25]. Medical blogs that use taxonomic classification of posts allow users to assign a particular post to a specific category. Categories can be chosen from a fixed list defined by the blog creator. For example, the WebMD blog offers categories such as "Allergies", "Asthma", and "Herpes" to categorize related posts. However, the creation and the maintenance of taxonomies are expensive and time-consuming [26]. Furthermore, content navigation support using taxonomies is often constrained because taxonomies are defined by domain experts; therefore, taxonomies do not reflect the user vocabulary [27].

Applying either one of the two aforementioned metadata addition approaches to describe blog posts has limitations. However, by combining both methods, a hybrid taxonomy-folksonomy approach is obtained by which hierarchical taxonomy terms can be combined with user-generated tags to enrich the meanings of these tags [25]. This hybrid approach might improve both the organization of and navigation for the blog posts, which leads to better content

discovery and retrieval results [25,27]. In the context of medical blogs, this hybrid approach is a very promising method for improving the tagging activities and facilitating the production and extraction of quality information from medical posts. However, standard models and mechanisms should be defined to explore how this hybrid approach could be applied to medical blogs.

We proposed a prototype for a Web-based system, called ICDTag, which allowed physicians to organize posts using a hybrid taxonomy-folksonomy approach. By using this approach, physicians could categorize posts according to a fixed set of medical categories (which represents taxonomy) or tag posts with freely chosen words (which represents a folksonomy). The system also supported the extraction of information from medical posts. As described earlier, there are various types of medical blogs. However, the ICDTag system was particularly designed for physician-written blogs. Physician-written blogs can be written by single or multiple authors. Some of these blogs are related to medical topics and others to social interests of physicians. This study focused on physician-written blogs discussing medical issues where different posts were written by multiple physician authors. Physician-written blogs were selected because they were better suited to generating and extracting medical information for three reasons. First, physicians are a major component of the medical blogging community [10]. Second, physicians are actively using blogs with professional content [10]. Third, physician-written blogs that discuss medical issues, including diseases, trials regarding particular treatments, or other professional experiences [13] are more likely to provide medical-related information.

Physicians can categorize their posts using categories from the Content Model for the 11th version of International Classification

of Diseases (ICD-11) (see Figure 1, a technical report on the Content Model for the ICD-11 revision [28]). These categories are stored in ICDTag database. The Content Model of ICD-11 was chosen as a categorization scheme for the following reasons:

1. ICD is a public global standard that organizes and classifies information about diseases and related health problems [29].
2. ICD-11 is scheduled to be released in the year 2015 [30], and it is currently being revised by the World Health Organization (WHO). This revision requires a Web-based process powered by collaboration and social features [31] with thousands of medical experts contributing to, evaluating, and reviewing the evolving content online [32].
3. The revision process of ICD-11 can utilize physician-written blogs as organized online sources that can yield thousands of medical-related concepts generated by health professionals.

The categories of ICD-11 Content Model could only be used to code disease-related content such as type of disease, clinical descriptions, signs and symptoms, and treatments. Other content that was not related to diseases such as procedures and experiments were not covered by these categories. Thus, the ICDTag system was meant only for blog posts that discuss disease-related content and users of ICDTag should be aware that they should only write disease-related posts.

By achieving its objectives, the ICDTag system introduced a systematic model that made physician-written blogs a more standardized, organized, and systematic medium. The ICDTag system supported the extraction of quality information from their posts, which made these blogs a more valuable source of online health information for health consumers.

Figure 1. The categories of the ICD-11 Content Model.

1. ICD Concept Title
2. Hierarchy, Type and Use
 - 2.1. Parents
 - 2.2. Type
 - 2.3. Use
3. Textual Definition(s)
4. Inclusion, Exclusion, and Index
 - 4.1. Base Index
 - 4.1.1. Synonyms
 - 4.1.2. Narrower Terms
 - 4.2. Base Exclusion
 - 4.3. Inclusions
5. Clinical Description
 - 5.1. Body System(s)
 - 5.2. Body Part(s) [Anatomical Site(s)]
 - 5.3. Morphologically Abnormal Structure
6. Manifestation Properties
 - 6.1. Signs & Symptoms
 - 6.2. Findings
7. Causal Properties
 - 7.1. Agents
 - 7.2. Mechanisms
 - 7.3. Risk Factors
 - 7.4. Genomic Characteristics
8. Temporal Properties
9. Severity Properties
10. Functional Properties
11. Specific Condition Properties
12. Treatment Properties
13. Diagnostic Criteria
14. External Causes

Methods

Study Design

We implemented 4 main steps to conduct this study:

1. Design a Web-based system of ICDDTag.
2. Implement a Web-based prototype that meets the design specifications.
3. Run an experiment to analyze the usage patterns for the Web-based prototype.

4. Evaluate the Web-based prototype.

The following subsections give an overview of the ICDDTag system and describe its design aspects. Then, the implementation and functionality of the prototype are described. Finally, the evaluation of the ICDDTag prototype is discussed.

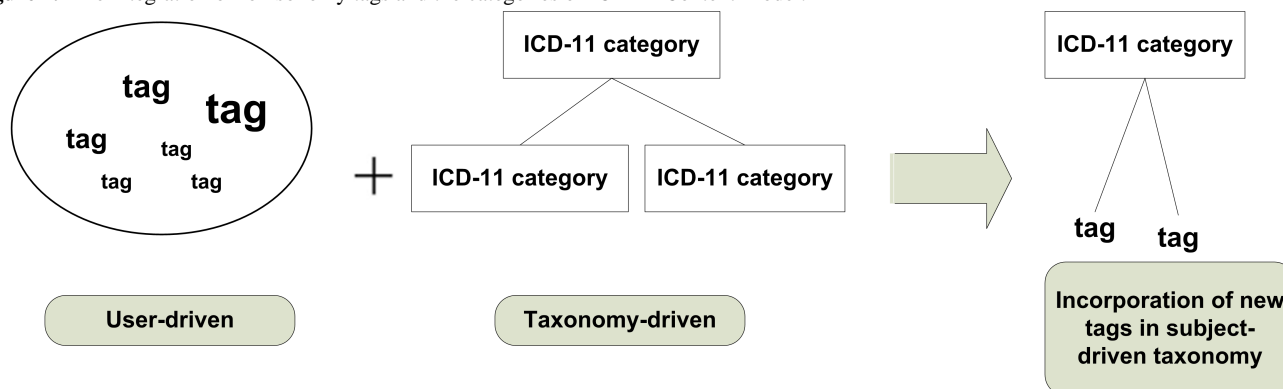
Overview of ICDDTag

ICDDTag is a Web-based system in which users perform a combination of hierarchical classification and collaborative tagging to organize and annotate physician-written blog posts. The classification was based on the ICD-11 categories listed in the ICD-11 Content Model, which are shown in Figure 1. The ICD-11 categories were considered metadata that could be added to user-generated tags to achieve a better organization of posts. The tagged posts were aggregated in Extensible Markup Language (XML) format to facilitate exporting data to other

applications. To achieve its goal, ICDDTag operated in 2 main phases:

1. The ICDDTag first used a hybrid taxonomy-folksonomy approach to classify and annotate blog posts as follows based on professional taxonomy (each post must be categorized by its creator into one category from the ICD-11 categories), and folksonomy (tags were collaboratively added by users as free text to describe posts). Because each post was already categorized with an ICD-11 term, the tags for a given post would be classified under the specified ICD-11 category (see Figure 2).
2. After the taxonomy-folksonomy classification phase, ICDDTag aggregated the information for posts that have been tagged a sufficient number of times and represented it as XML files.

Figure 2. The integration of folksonomy tags and the categories of ICD-11 Content Model.



The Taxonomy-Folksonomy Approach

The hybrid taxonomy-folksonomy approach of ICDDTag allowed users to assign ICD-11 categories to blog posts when creating the posts. Afterwards, users could collaboratively tag posts using free-text words or phrases. Consequently, each blog post will have two attributes, a category (which belonged to a professional taxonomy) and a set of tags added by users (which represented a folksonomy), as shown in Figure 2. The category attribute described the semantic value of the post because categories represented meaningful medical terms from the ICD-11 Content Model, whereas the set of tags represented the social value because tags were added by users in an online community (ie, a medical blog).

ICDDTag Modules

The main contribution that ICDDTag provided was to combine the benefits of taxonomies and folksonomies applied to physician-written blogs to improve the blogs' organization and content retrieval. The system architecture was based on 2 modules:

1. *Blogging module*: this module was implemented as one or more group blogs (ie, blogs in which posts were written by more than one author) that interacted with users and posts in two different modes, the uploading mode and the

browsing mode. In *uploading mode*, users had the option to create posts. When uploading a new post, the creator must provide a title and an ICD-11 category for the post. In *browsing mode*, the users could either browse the available posts and tag them, or search for posts using a search component.

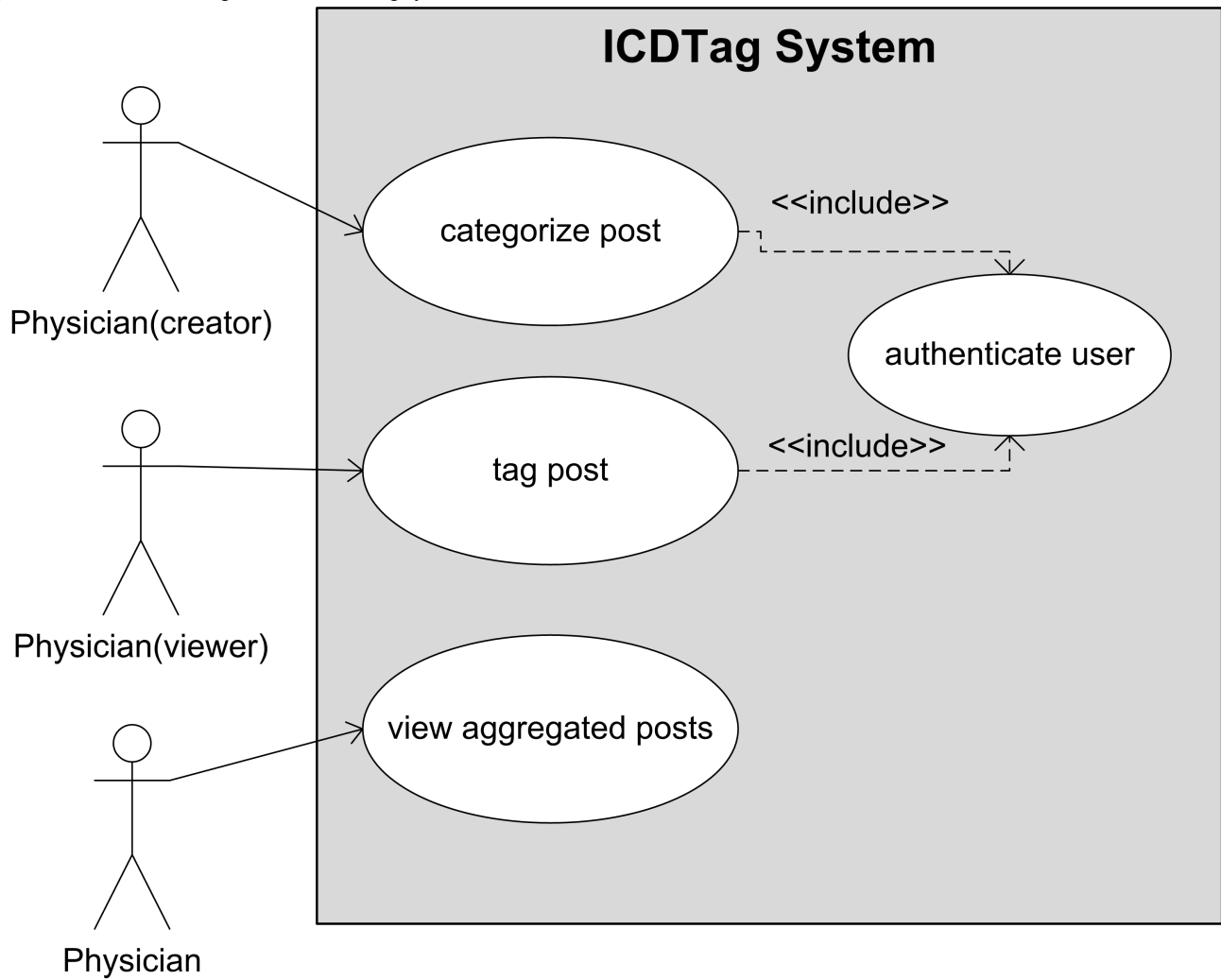
2. *Aggregator module*: the aggregator module was implemented as a server-side component that aggregated tagged posts from the mounted blogs into an aggregator website.

User Interaction Patterns

We described the main interactions between the ICDDTag system and its users using a Unified Modeling Language (UML) use case diagram, which is shown in Figure 3.

Physicians were the typical users of ICDDTag. A physician could access the system from two different perspectives. First, a physician could authenticate himself and access a blog as a creator or a viewer to categorize or to tag medical posts, respectively. Through his categorizing or tagging activity, every physician contributed to the enrichment of the data collected by the system. Second, physicians could access the aggregator website to view the aggregated content without contributing to its enrichment.

Figure 3. UML use case diagram for the ICDTag system.



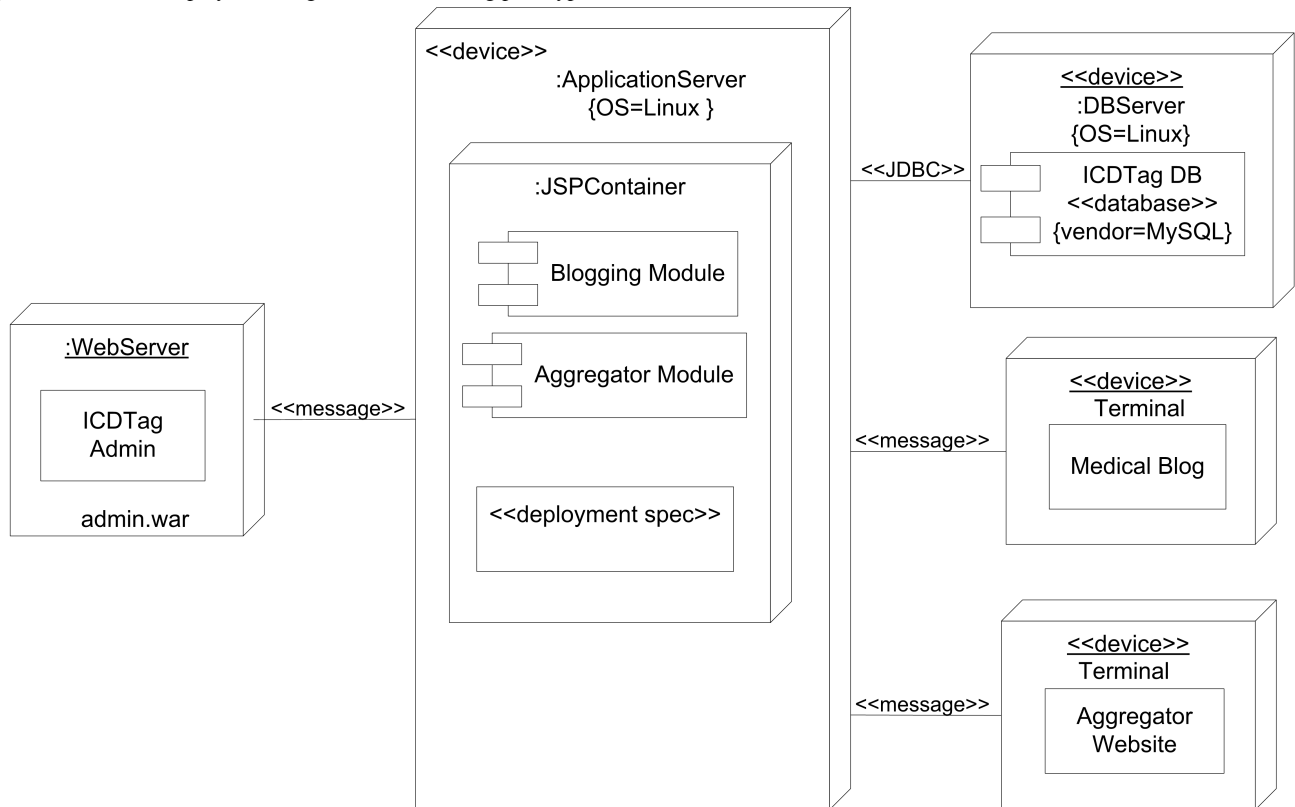
Development of the ICDTag Prototype

We implemented a Web-based prototype for ICDTag based on the design specifications. The blogging module for the prototype included two blogs, the cardiology blog and the gastroenterology blog. The two blogs were accessed by two groups of physicians, cardiologists, and gastroenterologists. The aggregator website collected the aggregated posts from both blogs. The following section discusses the implementation tools for the prototype.

Implementation Tools

The ICDTag prototype was implemented using Java Server Pages (JSP) as a Web application that runs inside the Tomcat Web container. MySQL was used as a database server. The handling of blog entries was performed using the user’s Web browser. The aggregator was implemented as a standalone website that stored the information for the aggregated posts as XML files. Figure 4 shows the UML deployment diagram for the ICDTag prototype.

Figure 4. The UML deployment diagram for the ICDTag prototype.



ICDTag.jar

Detailed Functionality of the ICDTag Prototype

In this section, we describe the details of the functions of the prototype and provide some examples.

Blogging Module

As described above, this module included one or more blogs with 2 modes for each blog, uploading and browsing. To access either of the two modes, users were required to login using a username and password.

Uploading Mode

Authenticated users of a blog could create posts as text, audio, or video. Upon creating a new post, the user was asked to classify the post with a category. The categories were provided via a drop-down list that included all of the ICD-11 categories; the list was retrieved from the ICDTag server, as shown in [Figure 5](#).

[Figure 6](#) illustrates an example of the uploading mode prototype interface where the user had uploaded a stomach image as a new post, provided a title for the post, and selected “ICD concept title” to categorize the post using the provided ICD categories list.

Figure 5. The detailed architecture of ICDDTag.

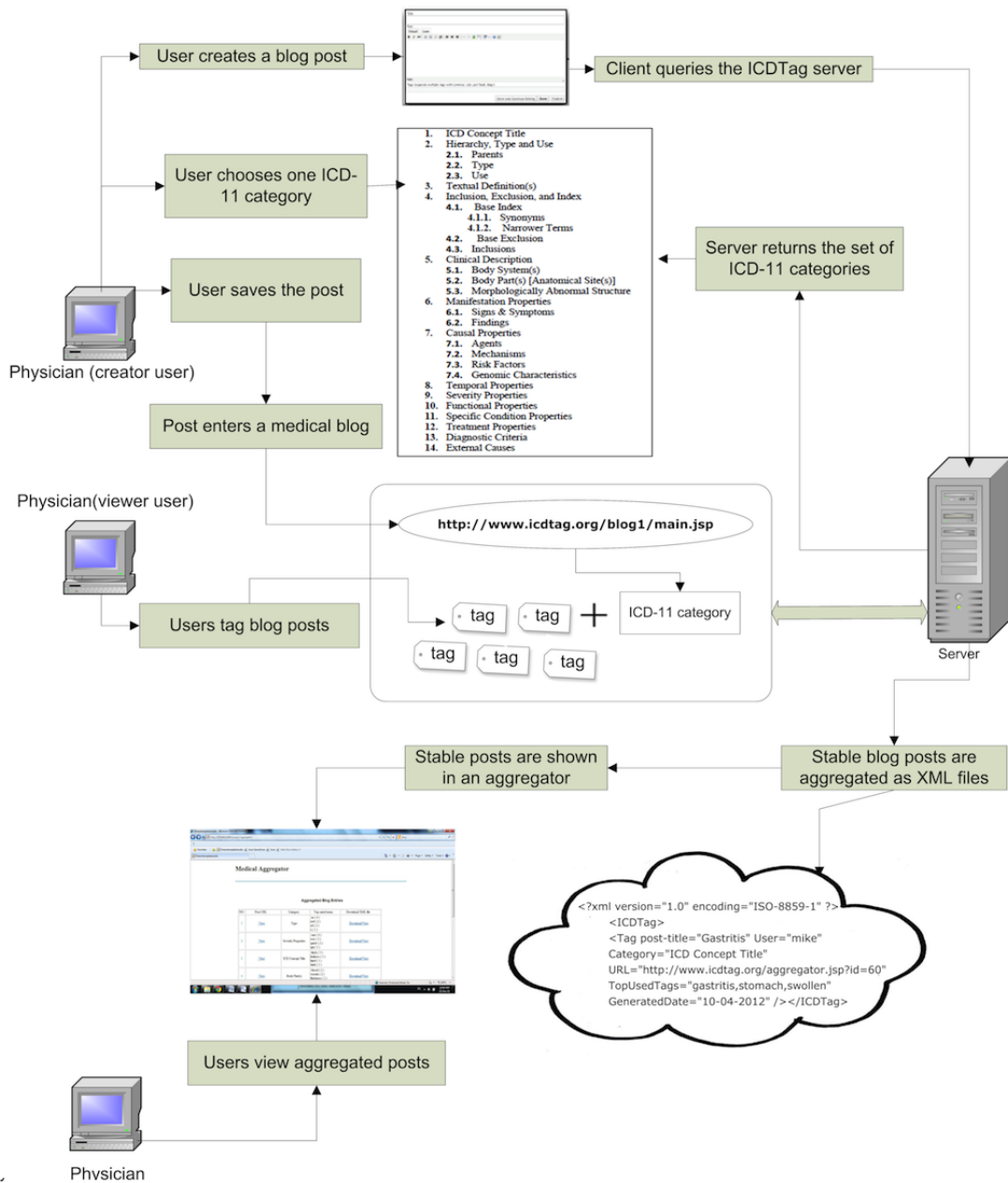
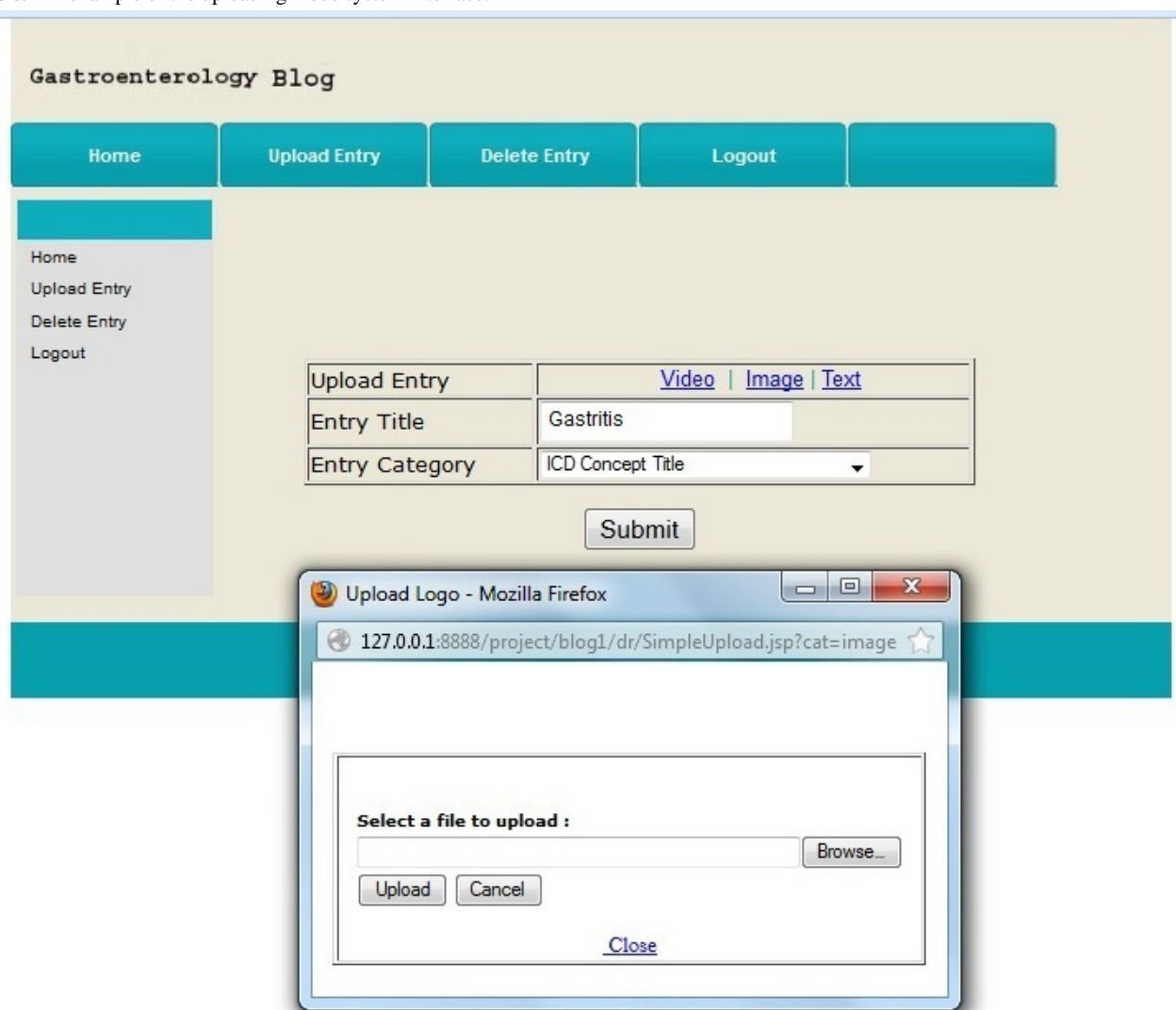


Figure 6. An example of the uploading mode system interface.

Browsing Mode

Within the browsing mode, authenticated users of a blog have the option to view or search for posts of that blog using 2 hyperlinks, “View Posts” or “Search Posts”.

The “View Posts” Hyperlink

Users could view posts created by others and tag them (see [Figure 7](#)); these posts were already categorized with ICD-11 categories.

When typing a tag, the user was given auto-completion suggestions from a pre-existing set of tags provided by other users for the same post. Users also have the choice to assign new tags that did not already exist. A tag could be a single word or a phrase. However, if the tag consisted of more than one

word, each word of the phrase was considered a standalone tag. [Figure 8](#) illustrates an example of the browsing mode prototype interface where the user was tagging a lung image with the word “swollen”.

A good number of tags to add to each post in a blog were 5-15 tags [33]. The browsing mode allowed a total of 10 tagging activities for each post. After a post had been tagged 10 times, the 3 most commonly used tags were identified and displayed below the post, and no additional tagging was allowed for this post; we refer to such a post as a stable post. The information for stable posts included the user who created it, the URL, the category, and the set of most commonly used tags. This information was sent to the aggregator module of the ICDTag server. [Figure 9](#) shows an example of a stable post.

Figure 7. The View Posts mode.

Gastroenterology Blog

Home

Registration

User Login


Browse

Upload

More
[Home](#)
[Registration](#)
[User Login](#)
[Browse](#)
[Upload](#)

[View Posts](#) | [Search Posts](#)

Achalasia



Posted by :ghannam
 Category :ICD Concept Title
[Add tag](#)

Food Poisoning

Food borne illness or food poisoning is caused by consuming food contaminated with pathogenic bacteria, toxins, viruses, prions or parasites. Symptoms begin several hours after ingestion and depending on the agent involved, can include one or more of the following: nausea, abdominal pain, vomiting, diarrhea, fever, headache or tiredness. In most cases the body is able to permanently recover after a short period of acute discomfort and illness. However, food borne illness can result in permanent health problems or even death, especially in babies, pregnant women, elderly people, sick people and others with weak immune systems. Similarly, people with liver disease are especially susceptible to infections from *Vibrio vulnificus*, which can be found in oysters.

Posted by :matani
 Category : Signs & symptoms
[Add tag](#)

Figure 8. Tagging a post.

Home | Registration | User Login | Browse | Upload

[View Posts](#) | [Search Posts](#)

Gastritis



Posted by :amjad
Category :ICD Concept Title
[Add tag](#)

DIVERTICULITIS

Symptoms of diverticulitis
few days. They include: B
eating

Posted by :amjad
Category : Signs & symptoms
[Add tag](#)

Digestive system

The digestive system co
intestine, large intestine and anus. This system functions to digest large particles of food into small

Worse over a
gry and not

h, small

Figure 9. A stable post.

Registration | User Login | Browse | Upload

[View Posts](#) | [Search Posts](#)

Gastritis



Posted by :Mike
Category : ICD Concept Title
Top used Tags: Gastritis (4) - stomach (2) - swollen (1)

The “Search Posts” Hyperlink

The browsing mode included a search component that accepted search keywords from the user. The component searched the whole blog tags against the keywords, and retrieved all posts that were tagged by those keywords. Then, it presented

the results in a tabular format. Each result included the matching tag, the Uniform Resource Locator (URL) associated with the post, and the post’s category. Users could follow the URL to view the corresponding post’s data. [Figure 10](#) shows an example of a search query and the results.

Figure 10. An example of a tag search.



Aggregator Module

This module collected the information for stable posts from different blogs in ICDTag and sent it to the aggregator website, which was the central point for compiling and displaying this information. Users did not need to login to access the aggregator website. For each stable post within the browsing mode, a number of items were aggregated: the creator for the post, the ICD-11 category, the 3 most commonly used tags, and the URL

for the post. The aggregated data were shown in the aggregator website in reverse chronological order (see [Figure 11](#)). Users could hover over items to view a summary of posts, their categories, and the most commonly used tags. The frequency of each tag was shown in parentheses next to the tag. In addition, the module converted the information for each stable post into XML format and produced an XML file for it. The XML files could be viewed or downloaded by users. [Figure 12](#) illustrates an example of such an XML file.

Figure 11. An example of the data being shown on the aggregator website.

Medical Aggregator

Aggregated Blog Entries

NO	Post URL	Category	Top rated terms	Download XML file
1	View	ICD Concept Title	amyloidosis (5) cardiac (2) disease (2)	Download/View
2	View	ICD Concept Title	heart (4) CHD (2) plaque (2)	Download/View
3	View	ICD Concept Title	pressure (4) blood (2) level (1)	Download/View

Figure 12. An XML fragment representing a stable post.

```
<? xml version="1.0" encoding="ISO-8859-1" ?>
<ICDTag>
  <Tag post-title="Gastritis" User="mike"
  Category="ICD Concept Title"
  URL="http://www.icdtag.org/aggregator.jsp?id=60"
  TopUsedTags="gastritis,stomach,swollen"
  GeneratedDate="10-04-2012" />
</ICDTag>
```

Evaluation of the ICDTag Prototype

The ICDTag system served two main purposes. First, to achieve better organization methods for physician-written blog posts based on a combination of user-defined tags and ICD-11 categories. Second, to aggregate quality information from these posts.

We conducted an experiment in which some physicians who were familiar with medical blogs were asked to use the ICDTag prototype. The goal of the experiment was to analyze the dynamics and usage patterns of the prototype. After the completion of the experiment, we conducted 2 types of evaluations of the prototype:

1. Evaluation of the ICDTag blog: the main functionalities in the browsing mode of the blogging module were evaluated

from the end-user's perspective using a quantitative evaluation (an online questionnaire).

2. Evaluation of information quality: the quality of content in the aggregator module was assessed from the perspective of medical experts using quantitative quality assessment (an emailed questionnaire).

These two evaluations enabled us to assess the effectiveness of the prototype in achieving the 2 purposes above.

Experimental Setup

The ICDTag prototype was made available online on December 15, 2011. For the experiment, we involved 2 groups of medical doctors: (1) 25 cardiologists for the cardiology blog, divided into 5 creators and 20 viewers, and (2) 25 gastroenterologists for the gastroenterology blog, divided into 5 creators and 20 viewers.

The role of the creators was to upload and categorize medical posts, whereas the role of the viewers was to browse and tag the uploaded posts.

To identify potential users, we accessed different medical blogs, medical aggregator websites, health-related websites, and Yellow Pages directories, which listed the contact information and specializations of medical doctors. Through this process, we collected the contact information of hundreds of cardiologists and gastroenterologists. Invitations to use the Web-based prototype were sent via email to 200 cardiologists and 200 gastroenterologists on December 19 and 20, 2011. The invitation email specified that participants must be familiar with medical blogs that were written in English. The email also guaranteed confidentiality and informed the participants that the results of the study would be published in an academic journal. A reminder email was sent after two weeks. One month after the first invitation, the overall response rate was 35 out of 200 cardiologists (17.5%) and 49 out of 200 gastroenterologists (24.5%). Of the respondents, 31 cardiologists and 47 gastroenterologists agreed to participate in the experiment. The 25 physicians from each group who agreed the earliest were selected. The selected cardiologists included 23 males and 2 females. All of these physicians have postgraduate or higher education degree in cardiology. The selected gastroenterologists included 16 males and 9 females. All of these physicians have postgraduate or higher education degree in gastroenterology. The first 5 selected respondents from each group were assigned the role of creator, and the remaining selected respondents were assigned the role of viewer.

We sent an email to the 5 creator users from both groups that contained simple instructions on how to create medical posts and provided the login information for the uploading mode (ie, username and password for each creator). Multimedia Appendix 1 presents the ICDTag user manual for creator users. The users were specifically informed that the content of their posts should be categorized using the categories of ICD-11 Content Model. A number of email conversations with users regarding the use of the ICDTag blog were held.

The creators from both groups were given a period of one month starting on February 6, 2012, to complete their task. Each creator user was required to sign up and upload 2 posts (in the form of text, images, or videos) to the corresponding ICDTag blog (ie, the cardiology blog or the gastroenterology blog). By March 7, 2012, all of the users had logged in as creators, and a total of 10 posts were uploaded to each of the 2 blogs.

As in collaborative tagging systems, tags were not mandatory in the ICDTag blogs. However, in this experiment, we required the viewers to tag posts in order to test the collaborative tagging functionality of ICDTag blogs.

We sent an email to the 20 viewers in each group on March 9, 2012, that described the functionality of tagging and provided the login information for the browsing mode (ie, username and password for each viewer). Multimedia Appendix 2 presents the ICDTag user manual for viewer users. The viewers were given a period of one month to log in and tag posts on the corresponding ICDTag blog. Each viewer was required to assign at least 2 tags to their chosen posts. At the end of the month,

the records in the ICDTag database demonstrated that 18 and 19 users had logged on to the cardiology blog and the gastroenterology blog, respectively. A small number of viewers did not use the blogs (2 for the cardiology blog and 1 for the gastroenterology blog) for unknown reasons. However, this did not affect the experiment because a considerable number of tags (61 tags for the cardiology blog and 72 tags for the gastroenterology blog) were added to posts of both blogs.

Evaluation of the ICDTag Blog

After the completion of the experiment, we performed a quantitative evaluation. The purpose of this evaluation was to confirm whether the prototype accomplished its first objective of achieving better organization methods for medical posts. We implemented an online questionnaire containing 2 parts. The first part consisted of 8 questions to collect demographic information for the participants and to identify their level of expertise regarding medical blogs. Most of the questions in this part were derived from another study examining the blogging habits of medical bloggers [34]. The questions in the second part were specifically designed to measure the users' evaluation of the ICDTag blogs in 3 areas: (1) ease of navigation, (2) search functionality, and (3) organization of information. These 3 areas were selected because they reflect the effectiveness of the main functions of a blog. The evaluation for each area consisted of 5 statements to be rated on a 5-point Likert scale, ranging from "strongly disagree" (1) to "strongly agree" (5). Multimedia Appendix 3 presents the complete form for the online questionnaire. The respondents were selected amongst the viewer users of the cardiologist and gastroenterologist groups who participated in our previous experiment; they have already used the functions included in the ICDTag blogs. On April 10, 2012, we sent another email to the 18 and 19 viewers from the cardiologist and gastroenterologist groups. The email contained brief information and the URL link for the online questionnaire. The evaluators were given a due date of April 25, 2012 to fill in the online questionnaire. By this date, 18 forms were completed. Descriptive analysis (ie, calculation of the mean and standard deviation) of the quantitative data was conducted with the SPSS 16.0 statistical software.

Evaluation of Information Quality

To confirm whether the prototype had accomplished its second objective of extracting quality information from physician-written blogs, a quantitative quality assessment was performed by medical experts on the collected data on the aggregator website to assess how well the aggregated tags and ICD-11 categories were semantically related or connected to the content of the posts. We used the term "relatedness" to refer to this evaluation measure.

Because the aggregated posts belonged to two different fields of medicine, cardiology and gastroenterology, we selected two groups of medical experts, 3 cardiologists, and 3 gastroenterologists. The chosen experts from the two groups had at least 10 years experience in the field and were familiar with the ICD classification system.

The experts from the two groups were contacted via email. The experts were informed that their participation was needed as

part of scholarly research with the potential for generation of new and useful knowledge for health informatics and that the results of this study would be published in an academic journal.

After they had agreed to participate, each expert of the cardiology group was provided via email with the data for the 5 aggregated cardiology posts and each expert of the gastroenterology group was provided via email with the data for the 6 aggregated gastroenterology posts. The provided data for each post included the post content, the assigned ICD-11 category, and the 3 most commonly assigned tags. The experts were asked to fill in an emailed questionnaire form.

The questionnaire form for both groups contained the same 2 questions for each post. One question asked the expert to rate how well the ICD-11 category related to the post's content, and the other question asked the expert to rate how well the tags related to the post's content. Each question was rated on a 5-point Likert scale, ranging from "strongly disagree" (1) to "strongly agree" (5). The questionnaire forms for the cardiology and gastroenterology groups contained a total of 10 and 12 questions, respectively. The experts were given a period of 2 weeks to return the completed questionnaires. After 2 weeks, all the forms were received. Descriptive analysis (ie, calculation of the mean and SD) of the quantitative data was conducted with SPSS 16.0 statistical software.

Results

Overview

In the following subsections, we present the dynamics and patterns of categorization and tagging activities within the experiment. In addition, we listed the results of the two evaluations, the evaluation of the ICDTag blog and the evaluation of information quality.

Usage of ICD-11 Categories

Based on the ICDTag specifications, each blog should have two types of users, creators and viewers. In the blogging module, the creators were required to classify their own medical posts according to the ICD-11 categories. Each post must be classified with one ICD-11 category. As described earlier, in our experiment, 10 posts were created on each of the cardiology and gastroenterology blogs. [Tables 1](#) and [2](#) show the distinct ICD-11 categories used to classify the posts of both blogs.

Tag Usage

At the end of the experiment, 61 tags were generated in the cardiology blog with an average of 3.39 tags per user. Of these tags, 42 (69%) were distinct tags and 19 (31%) were repeated tags. For the gastroenterology blog, 72 tags, including 38 (53%) distinct tags and 34 (47%) repeated tags, were generated with an average of 3.79 tags per user. We calculated the distribution of the tags over ICD-11 categories. Specifically, we counted how many tags were classified under each of the ICD-11 categories in both blogs. [Tables 3](#) and [4](#) show the distribution of tags for the cardiology blog and the gastroenterology blog, respectively.

A few tags were misspelled by users (2 and 3 misspelled tags for the cardiology blog and the gastroenterology blog, respectively). However, none of the misspelled tags were reused by the other users.

Stable Post Aggregation

After the experiment's completion, we identified 5 stable posts from the cardiology blog and 6 stable posts from the gastroenterology blog. These posts were sent to the aggregator website. [Figure 13](#) shows a screenshot for the aggregated posts in our experiment.

Figure 13. Collected posts on the aggregator website.

1	View	ICD Concept Title	amyloidosis (5) cardiac (2) disease (2)	Download/View
2	View	ICD Concept Title	heart (4) CHD (2) plaque (2)	Download/View
3	View	ICD Concept Title	pressure (4) blood (2) level (1)	Download/View
4	View	ICD Concept Title	heart (3) hypertension (2) arterial (1)	Download/View
5	View	ICD Concept Title	VSD (3) holes (2) septum (2)	Download/View
6	View	ICD Concept Title	esophagus (3) disorder (2) reduced (1)	Download/View
7	View	ICD Concept Title	liver (3) virus (3) infection (2)	Download/View
8	View	ICD Concept Title	peptic (2) gastric (2) PUD (2)	Download/View
9	View	ICD Concept Title	intestine (3) food (3) damage (2)	Download/View
10	View	ICD Concept Title	chronic (3) inflammatory (2) disease (1)	Download/View
11	View	ICD Concept Title	Gastritis (4) stomach (2) swollen (1)	Download/View

Evaluation of the ICDTag Blog

We analyzed the characteristics of the respondents (see [Table 5](#)). Most of the 18 respondents were aged between 30 and 49 (6 females, 33% and 12 males, 67%). Half of the respondents were from Asia, 5 from North America, 2 from Africa, 1 from Europe, and 1 from South America. Seven (39%) of the respondents were cardiologists, and 11 (61%) were gastroenterologists. All of the respondents have postgraduate or higher levels of medical education. Fifteen of the respondents (83%) read medical blogs, and 3 of them (17%) write medical posts.

The mean score for the users' evaluation of the ease of navigation was 3.94 (79%). The mean score and standard deviation values for the individual statements are presented in [Table 6](#). The mean score of users' evaluations of the search functionality was 3.68 (73.6%). The mean scores and standard deviation values for the individual statements are presented in [Table 7](#). The mean score of users' evaluations of the

organization of information was 3.89 (78%). The mean score and standard deviation values for the individual statements are presented in [Table 8](#).

Evaluation of Information Quality

The mean score of relatedness of the ICD-11 categories to the posts' content for the aggregated cardiology posts was 3.93 (79%). The mean score and the SD values for the responses of the experts to each question are shown in [Table 9](#). The mean score of relatedness of the user tags to the posts' content for the 5 aggregated cardiology posts was 4.2 (84%). The mean score and the SD for the experts' responses to each question are shown in [Table 10](#).

The mean score of relatedness of the ICD-11 categories to the posts' content for the aggregated gastroenterology posts was 3.94 (79%). The mean score and the SD for the experts' responses to each question are shown in [Table 11](#). The mean score of relatedness of the user tags to the posts' content for the 6 aggregated gastroenterology posts was 4.17 (84%). The mean

score and the SD for the experts' responses to each question are shown in [Table 12](#).

Analyses of the Results

In the following subsections, we discuss our experimental data analyses. We then discuss the results of the two evaluations, the users' evaluation of the ICDTag blog and the information quality evaluation.

Usage of Categories

The ICD-11 Content Model contains a list of categories and subcategories (see [Figure 1](#)). In our experiment, only 4 ICD-11 categories were used to classify the posts in both blogs (see [Tables 1](#) and [2](#)). This classification pattern can be explained by the fact that creators preferred to use ICD-11 categories such as "Sign and Symptoms" rather than subcategories such as "Mechanisms" to classify posts.

Usage of Tags

The results indicated that both blogs contained a considerable amount of distinct and repeated tags. This reflects the viewers' behavior with regards to using new or existing tags and that the viewers were able to provide new tags or follow other user's tags. Both types of tags are required in collaborative tagging systems. While new tags are useful to describe and classify posts, repeated tags are required for post aggregation. In addition, the percentage of repeated tags in both blogs indicated that most of the users had benefited from the auto-completion

functionality that suggested tags provided by other users. Additionally, most tags in both blogs were under the "ICD concept title" category (see [Tables 3](#) and [4](#)). This was logical because the majority of posts from both blogs already belonged to this category.

Users' Evaluation of the ICDTag Blog

The percentages of the users' evaluation of the 3 areas, ease of navigation, search functionality, and organization of information, were 79%, 74%, and 78%, respectively. These results indicate that users have positively evaluated the main functions and the organization of information in the ICDTag blogs. These results supported our hypothesis that the use of a taxonomy-folksonomy approach in physician-written blogs has significant potential to improve the browsing and searching functions for blog viewers.

Quality of Aggregated Information

The mean scores of the relatedness of tags in both blogs (4.2 and 4.17) were higher than the mean scores of the relatedness of categories (3.93 and 3.94). These results can be explained by the different natures of tags and categories. Categories were more general ways to describe resources than tags. However, the results of the quality assessment suggested that there was an overall agreement among medical experts that the generated tags and categories were semantically related to the content of the corresponding posts, which demonstrates that the ICDTag prototype—from the perspective of medical experts—was able to produce quality information using its aggregator website.

Table 1. The ICD-11 categories used to classify posts (for the cardiology blog).

ICD-11 categories used	Number of posts (N=10) n (%)
ICD concept title	6 (60)
Signs & symptoms	3 (30)
Treatment properties	1 (10)

Table 2. The ICD-11 categories used to classify posts (for the gastroenterology blog).

ICD-11 categories used	Number of posts (N=10) n (%)
ICD concept title	6 (60)
Signs & symptoms	2 (20)
Treatment properties	1 (10)
Body system	1 (10)

Table 3. Distribution of tags over ICD-11 categories (for the cardiology blog).

ICD-11 categories used	Number of tags (N=61) n (%)
ICD concept title	45 (74)
Signs & symptoms	14 (23)
Treatment properties	2 (3)

Table 4. Distribution of tags over ICD-11 categories (for the gastroenterology blog).

ICD-11 categories used	Number of tags (N=72) n (%)
ICD concept title	60 (83)
Signs & Symptoms	6 (8)
Treatment Properties	2 (3)
Body System	4 (6)

Table 5. Participant characteristics.

Questionnaire response option	Number (N=18) n (%)
Gender	
female	6 (33)
male	12 (67)
Age	
18-29	0 (0)
30-49	17(94)
50-64	1 (6)
≥65	0 (0)
Area of residence	
Africa	2 (11)
Antarctica	0 (0)
Asia	9 (50)
Australia	0 (0)
Europe	1 (6)
North America	5 (28)
South America	1 (6)
Medical specialization	
Gastroenterology	11 (61)
Cardiology	7 (39)
Medical education	
Graduate education	0 (0)
Postgraduate education	13 (72)
Residency	3 (17)
Fellowship	1 (6)
Board certification	1 (6)
Level of expertise using medical blogs	
Read medical blogs	1 (6)
Read blogs and comment on medical posts	6 (33)
Read blogs and tag medical posts	8 (44)
Write medical posts	3 (17)
I have my own medical blog	0 (0)

Table 6. Results of the navigation ease evaluation.

	Mean (SD) (score 5)
It was easy to browse posts	4.28 (0.46)
It was easy to browse posts by categories	3.94 (0.24)
It was easy to browse posts by tags	4.17 (0.38)
It was easy to browse posts via creator	3.72 (0.46)
Clicking on links took me to what I expected	3.61 (0.70)

Table 7. Results of the search functionality evaluation.

	Mean (SD) (score 5)
The search interface is clear	3.72 (0.46)
The search interface is understandable	3.78 (0.55)
It is easy to search for posts by keywords	3.89 (0.76)
The search results are precise	3.28 (0.46)
The way the search results are organized is clear	3.72 (0.46)

Table 8. Results of the information organization evaluation.

	Mean (SD) (score 5)
The blog provided useful support information (messages and hints) for different tasks	3.89 (0.32)
The organization of information on ICDTag blog was clear	4.11 (0.32)
The blog provided sufficient descriptive information for posts (eg, title, creator, tags, and date)	3.83 (0.51)
The information for each post (eg, title, content, creator, tags, and date) were listed clearly	3.78 (0.55)
The blog was better organized than other medical blogs I have been working with.	3.83 (0.71)

Table 9. Relatedness of the ICD-11 categories to the aggregated cardiology posts.

	Mean (SD)
Was the assigned ICD-11 category related to the content of post 1?	4.67 (0.58)
Was the assigned ICD-11 category related to the content of post 2?	3.67 (0.58)
Was the assigned ICD-11 category related to the content of post 3?	4 (1.00)
Was the assigned ICD-11 category related to the content of post 4?	4.33 (0.58)
Was the assigned ICD-11 category related to the content of post 5?	3 (0.00)

Table 10. Relatedness of the most commonly used tags to the aggregated cardiology posts.

	Mean (SD)
Were the assigned tags related to the content of post 1?	4.33 (0.58)
Were the assigned tags related to the content of post 2?	4.67 (0.58)
Were the assigned tags related to the content of post 3?	4 (1.00)
Were the assigned tags related to the content of post 4?	4 (0.00)
Were the assigned tags related to the content of post 5?	4 (1.00)

Table 11. Relatedness of the ICD-11 categories to the aggregated gastroenterology posts.

	Mean (SD)
Was the assigned ICD-11 category related to the content of post 1?	3.67 (0.58)
Was the assigned ICD-11 category related to the content of post 2?	3.67 (1.15)
Was the assigned ICD-11 category related to the content of post 3?	4 (1.00)
Was the assigned ICD-11 category related to the content of post 4?	4.33 (0.58)
Was the assigned ICD-11 category related to the content of post 5?	4 (0.00)
Was the assigned ICD-11 category related to the content of post 6?	4 (1.00)

Table 12. Relatedness of the most commonly used tags to the aggregated gastroenterology posts.

	Mean (SD)
Were the assigned tags related to the content of post 1?	4.33 (0.58)
Were the assigned tags related to the content of post 2?	4.33 (0.58)
Were the assigned tags related to the content of post 3?	4 (1.00)
Were the assigned tags related to the content of post 4?	4.33 (0.58)
Were the assigned tags related to the content of post 5?	4 (1.00)
Were the assigned tags related to the content of post 6?	7.67 (0.00)

Discussion

General

In this paper, we introduced ICDTag, a Web-based prototype system that follows a new approach to systematically organize and aggregate physician-written blog posts using a combination of ICD-11 categories and user-generated tags as metadata. The blogging module allowed physicians accessing ICDTag blogs to categorize posts with ICD-11 categories and to collaboratively tag posts using their own keywords. Thus, each post had two attributes, a category (which belonged to the ICD-11 taxonomy) and a set of tags added by users (which represented a folksonomy). The aggregator module gathered stable posts (ie, posts that had been tagged a sufficient number of times) from the ICDTag blogs and displayed them on an aggregator website.

The data provided by the physicians during the experiment were used to analyze the usage patterns of the ICDTag prototype. Then, we conducted 2 types of evaluations: (1) an evaluation of the ICDTag blog (quantitative evaluation) to evaluate the main functions of ICDTag blogs from the perspective of end-users, and (2) an evaluation of the information quality (quantitative quality assessment) to evaluate the quality of the aggregated information from the perspective of medical experts. The results of the quantitative evaluation demonstrated that users have positively assessed the browse and search functionalities and the organization of the ICDTag blogs. In addition, the assessment of information quality demonstrated that the aggregated tags and categories were judged to be semantically related to the posts' content. Therefore, we can conclude that the ICDTag prototype has met its objective of making physician-written blogs a better-organized medium that can produce quality information. By using the hybrid taxonomy-folksonomy approach, ICDTag has the valuable potential to improve both the structure and quality of content

of physician-written blogs. Thus, developing more mature systems that apply the taxonomy-folksonomy approach to physician-written blogs or to other types of medical blogs to make them a more valuable and reliable source of health information for online medical communities is worthwhile. The hybrid approach can also be explored in other social media such as medical wikis and medical forums. By using the hybrid approach, physicians will be able to contribute to social media by adding their own tags to better organize online medical resources.

In future work, we could investigate the extent to which the aggregated tags of ICDTag can represent or produce new medical terms that can be used by medical community. However, this requires a larger trial and an analysis of tags on terminological levels by medical experts.

Comparison of the ICDTag Hybrid Approach with Others

The ICDTag system applies a hybrid taxonomy-folksonomy approach to yield better organization methods for medical posts. There are four hybrid approaches to taxonomy and folksonomy, namely, coexistence of taxonomy and folksonomy, folksonomy-directed taxonomy, taxonomy-directed folksonomy, and folksonomy hierarchies/ontologies [35]. Our approach falls under the coexistence category. In this section, we compared our approach with existing studies that discussed the coexistence approach.

Kiu and Tsui [27] introduced the TaxoFolk algorithm that integrates folksonomies into taxonomy to enhance knowledge classification and the navigation of Web resources. Although the TaxoFolk and ICDTag approaches share the common concept of using a hybrid taxonomy-folksonomy classification of resources, the manner in which this classification is produced differs. Whereas TaxoFolk produces the classification by

applying data-mining techniques to tags extracted from a collaborative tagging tool, the ICDTag approach produces the classification by grouping the most-used tags under ICD-11 categories.

Sommaruga et al [36] introduced the “tagsonomy”, which is a mechanism to facilitate information retrieval on a website using a hybrid taxonomy-folksonomy approach. The ICDTag and tagsonomy approaches have similar objectives. However, they are different in the way the users provide tags. Tags in tagsonomy are not the result of explicit tagging processes. Instead, tags in tagsonomy are derived from the users’ search keywords, whereas in the ICDTag approach, tags are explicitly provided by the blog viewers, which makes the tags better reflect the users’ vocabulary.

Hence, for such hybrid approaches to capture more of the user-added value, tagging activities must be explicit and contributed by the users. Thus, our approach is an efficient way of using a taxonomy-folksonomy structure in medical online communities.

Limitations

This study used the Content Model of ICD-11 to categorize posts. The categories of this model describe only disease-related attributes including diseases, signs, symptoms, and abnormal findings. Other medical attributes such as procedures and experiments cannot be described using these categories. Therefore, our results were limited to physician-written blog posts that discuss disease-related content only.

Another limitation of this study was that the sample of physicians and medical experts included only two medical specialties (cardiology and gastroenterology). Although different specialties require different functions of information systems, the focus of our system was on categorization and tagging functions that we believed were similar for any medical specialty. The categorization functionality was similar because our prototype used a general medical classification scheme (ie, ICD-11 Content Model) that could be applied to any medical field. In addition, the concept of tagging online medical resources should still be the same for different medical specialties. However, to truly generalize our findings, a larger trial must be conducted that includes blogs covering different medical specialties.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

ICDTag User Manual (for creator user).

[[PDF File \(Adobe PDF File\), 1MB - jmir_v15i2e41_app1.pdf](#)]

Multimedia Appendix 2

ICDTag User Manual (for viewer user).

[[PDF File \(Adobe PDF File\), 1MB - jmir_v15i2e41_app2.pdf](#)]

Multimedia Appendix 3

Questionnaire for evaluating ICDTag blog.

[[PDF File \(Adobe PDF File\), 260KB - jmir_v15i2e41_app3.pdf](#)]

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Abbreviations

- ICD-11:** 11th version of International Classification of Diseases
JSP: Java Server Pages
UML: Unified Modeling Language
URL: Uniform Resource Locator
XML: Extensible Markup Language

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Original Paper

Measuring Actual eHealth Literacy Among Patients With Rheumatic Diseases: a Qualitative Analysis of Problems Encountered Using Health 1.0 and Health 2.0 Applications

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Abstract

Background: The Internet offers diverse opportunities for disease management, through information websites (Health 1.0) and interactive applications such as peer support forums, online consults, and insight into electronic medical records (Health 2.0). However, various skills are required to benefit from Health 1.0 and Health 2.0 applications for one's own health, known as eHealth literacy.

Objective: To study the eHealth literacy of patients with rheumatic diseases and the types of problems they encounter when using the Internet in relation to their disease.

Methods: In two studies, patients were asked about their current disease-related Internet use and their eHealth literacy was observed during performance tests. In study 1, 15 patients (aged 39-74) performed 6 information-retrieval tasks on the Internet (Health 1.0). In study 2, 16 patients (aged 24-72) performed 3 Health 2.0 tasks on a hospital-based online Web portal and 2 Health 2.0 tasks on interactive websites. Participants were asked to think aloud while performing the assignments, and screen activities were recorded. Types and frequency of problems were identified by 2 independent researchers and coded into categories using inductive analysis.

Results: Almost all patients in our studies had searched the Internet for information about rheumatic diseases in the past. Fewer patients had used Health 2.0 applications, but many were nevertheless enthusiastic about the possibilities from Health 2.0 applications after finishing the assignments. However, nearly all participants experienced difficulties, and a substantial number of participants were not able to complete all of the assignments. Encountered problems could be divided into 6 sequential categories: (1) operating the computer and Internet browser, (2) navigating and orientating on the Web, (3) utilizing search strategies, (4) evaluating relevance and reliability, (5) adding content to the Web, and (6) protecting and respecting privacy. Most severe difficulties occurred in levels 3 and 4—in formulating a search query, evaluating the source of the information, and in scanning a website for relevant information.

Conclusions: Many patients have insufficient skills to properly use Health 1.0 and Health 2.0. Formulating proper search strategies and evaluating the found information caused problems among the majority of patients. Concerning Health 2.0, use and awareness of these applications is low and patients should be guided in the use of them. Our findings may contribute to the awareness of patients' eHealth literacy problems among health professionals, and stress the importance of usability guidelines in Web design.

KEYWORDS

eHealth; literacy; Internet; online; health information; Health 2.0; skills; health care

Introduction

Since patients with chronic diseases are encouraged to become more empowered and to play a larger role in the management of their own disease, easily accessible health information is essential [1]. Currently, the Internet is one of the main sources of health information and research shows that many patients use it frequently [2,3]. Online access to health information is a positive development; studies have shown that people with chronic diseases who use the Internet have better self-care practices than those who do not [4,5]. With the improved Web technology (Web 2.0), the Internet has become more than an online encyclopedia. Not only can information be received from the Internet, but people can also add content to the Internet themselves. Health 2.0 is a term that is used for these interactive applications within health care [6]. This evolution of the Internet means that patients can communicate together online to share and find acknowledgement of their disease experiences through peer support forums [7], social network websites, and health care rating sites. Furthermore, hospitals are increasingly offering patients Interactive Health Communication Applications, which are Web-based portals that enable patients to participate online in their treatment, by communicating with care providers, monitoring symptoms using online diaries, and by accessing their electronic medical records. All these Health 2.0 applications have great potential and could change health care in a positive way [6,8,9]. Nevertheless, using the Internet in relation to health requires a certain level of eHealth literacy, which covers a diverse range of skills [10,11]. Norman defines eHealth literacy as “the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem” [11]. It should be noted, however, that this definition is limited to skills needed for Health 1.0 applications and that additional skills are needed for typical Health 2.0 applications [12].

A number of previous studies have shown that using the Internet to collect information requires skills on several levels. On a lower level, operational and navigation skills are essential—the competence to use a computer and an understanding of the World Wide Web and its multi-layer structure (including competencies to operate Internet browsers and search engines). On a higher level, people need skills to find and judge information, which requires the ability to generate relevant search queries, choose relevant information from the enormous amount of search results, and judge the reliability and validity of the information [13,14]. Research on Internet skills of people has so far focused on the general healthy population [13,15], and to a larger extent on adolescents and students [16-19]. Skills of patients with chronic diseases have not been studied yet, so it is unclear to what extent patients can benefit from the large amount of online information that is being offered. Additionally, studies up until now have not taken into account interactive Health 2.0 applications [12]. Using Health 2.0 applications asks

for additional skills, such as being able to express oneself clearly in online social interactions, the ability to distinguish professional from non-professional advice [12], and protecting one’s privacy and respecting that of others when adding content to the Internet [6]. Due to the rapid developments on the Internet and the shift to Web 2.0 applications, these skills should be taken into account to measure the complete spectrum of eHealth literacy. The aim of this study was to gain an in-depth insight into Health 1.0 and 2.0 literacy skills of patients with rheumatic diseases.

Methods

Study Components

Two performance tests were conducted to investigate the skills of patients when using online information, communication, and participation sources with regard to rheumatic diseases. Study 1 was predominantly aimed at information retrieval through health-related websites and reading along on peer support forums (Health 1.0), study 2 was aimed at the use of interactive online applications (Health 2.0). In both studies, a qualitative design was used to get in-depth insight into patients’ strategies when using both kinds of applications. Patients were observed and were asked to think aloud [20] while performing various online assignments.

Participants

Participants in study 1 were selected from an existing patient panel, which was initiated in cooperation between the University of Twente and Twente’s largest hospital, both located in Enschede, the Netherlands. Patients who are registered on this panel (n=146) are willing to volunteer in rheumatology research. A convenience sample from this panel was selected, based on attendance of these panel members at the research meeting introducing the upcoming study. Panel members that were present (n=30) were asked to fill out a form with their contact information if they were willing to participate in the study. Half of the panel members (15/30, 50%) filled out the form, and were subsequently called to explain the process of the study and to schedule an appointment. All appointments, except 2, took place at the university, to ensure that all participants were tested in the same environment. The 2 patients preferred to be interviewed at their home due to the travel distance. In study 2, participants were selected from the consult database of the rheumatology clinic of University Medical Centre, Utrecht. Participants who had a visit scheduled at the outpatient department of the clinic received an invitation letter by their nurse practitioner. Patients who were not able to speak Dutch and patients who needed an intensive infusion treatment during their hospital visit (which could cause limited mobility, tiredness, and nausea) were excluded. In total, 45 letters explaining the purpose and the process of the study were sent. The researcher called each recipient a few days after the letters were received to ask if they were willing to participate. Of the 45 patients, 17 (38%) gave

their consent. An appointment for this study was scheduled on the same day as their existing upcoming appointment in the hospital. In both studies, patients were asked to sign an informed consent form at the beginning of the session, which included information on the recording, anonymity, and confidentiality of the data, and the possibility to end the session at any moment. In total, 15 patients participated in study 1 and 16 patients in study 2. One participant dropped out during study 2 because he felt uncomfortable in the test setting. After these sessions, data saturation was reached, meaning that no more new information of value could be obtained (no new problems occurred during the last 3 observations) [21].

Procedure and Materials

The sessions started with a short survey which assessed demographic information (age, gender, and education), illness related information (diagnosis and disease duration), and Internet experience (amount of Internet use, years of Internet experience, self-perceived Internet skills, and usage of health-related applications on the Internet). The survey also contained a questionnaire on rheumatic-related physical problems when using a computer [22]. When all the items were completed, the practical component of the session started. In both studies, all participants used the same hardware, with the same settings. According to the thinking-aloud method [20], subjects were explicitly instructed to think aloud as they executed the assignments, which allowed the interviewer to get a better understanding of the cognitive processes the participant used to search and judge the information, and to formulate questions or messages. It was emphasized that the assignments were not to test the quality of participants' Internet skills, but solely to observe how they used the Internet. The online assignments were recorded using Morae Recorder version 3.2.1 (TechSmith, Okemos, MI, USA), which captured images, sounds, and all screen activities. A description of all assignments is shown in

Textboxes 1 and 2. In study 1, participants could search the Internet freely during the assignments and skills on several levels were needed to complete the assignments (see **Textbox 1**). Assignment 2 was the only exception in this study, where all patients were limited to performing the assignment on a single website (the website of the Dutch rheumatology association), which served as a reference to test patients' operational skills of the computer and Web browser. In study 2, assignments 1, 2, and 3 had to be performed on a research account of a hospital-based Web portal, and assignments 4 and 5 on specific interactive websites (see **Textbox 2**). These assignments were specifically aimed at measuring Health 2.0 related skills, as patients were asked to add their own content. The assignments asked for skills in addition to information retrieval, such as expressing oneself in online social interactions, distinguishing professional from non-professional advice, and protecting one's privacy and respecting that of others. The Health 1.0 assignments contained pilot tests investigating the relevance of the assignments to rheumatology patients, to ensure that the information-retrieval assignments reflected realistic scenarios. The Health 2.0 assignments were built based on results from previous studies [2,23], which highlights information that patients would find relevant and useful. We therefore only asked nurse practitioners to help us frame the scenarios for the Health 2.0 assignments. In both studies, the order of the assignments was randomized for each participant, because a learning effect was expected during the assignments. By randomizing the sequence of the assignments, this effect would not occur at the same assignments for every patient. At the end of study 2, participants were asked if they would use the interactive application in the future, what they would use it for, and how they would take privacy issues into account, after each assignment. These interviews were video-recorded with the Morae Recorder as well.

Textbox 1. Description of Health 1.0 Assignments in Study 1.

1. Formulate a disease-related question you have searched for in the past, and show how you would approach this on the Internet.
2. Open a well-known Dutch rheumatology website [24] and perform the following assignments: find a specific page using the menu structures, download a PDF file, close the additional window, go one page back, use the search engine to search for "osteoarthritis", open the fourth search result and save that page using the favorites bar.
3. You have had sore wrists and hands for a while and you think it might be osteoarthritis. Retrieve the symptoms of osteoarthritis on the Internet and mention 4 of them.
4. You are using MTX medication for your rheumatic symptoms, but as a side effect you feel nauseated. Retrieve 3 tips from fellow patients on a patient support forum on how to lessen nausea as a side effect from this medication.
5. You are experiencing sore feet due to your rheumatic symptoms and you want to buy adapted shoes to relieve the pain. Find 4 key issues to consider when buying adapted shoes.
6. You would like some advice on how to exercise properly in spite of your arthritis. Find a physical therapist in your neighborhood that is familiar with therapy for rheumatic diseases.

Textbox 2. Description of Health 2.0 Assignments in Study 2.

1. Use your electronic medical record to: (a) find and interpret your latest lab results and compare them to your previous values, and (b) to interpret the accompanying treatment plan.
2. Monitor disease symptoms by: (a) filling out a disease diary for one day, and (b) interpret two previous diaries.
3. Use an e-consult (electronic or online consult) application to: (a) find and interpret a closed e-consult, and (b) to write a new e-consult in which you ask advice on how to bring your medication with you on vacation to Morocco.
4. Open a peer support forum [25] and: (a) retrieve 2 tips from fellow patients on nausea as a side effect from MTX medication, and (b) add your own tip on this subject.
5. Open a health care rating website [26], find your hospital and: (a) read 2 reviews, and (b) add your own review about the hospital (you do not have to send it).

Data Analysis

Descriptive analyses of patients' socio-demographics, health characteristics, health-related Internet use, and rheumatic-related physical problems when using a computer were performed with SPSS Statistics, version 20.0 (IBM SPSS Inc, Chicago, IL, USA). Performances on the assignments were analyzed using Morae Manager version 3.2.1 (TechSmith, Okemos, MI, USA). In study 1, 2 researchers inductively developed a coding scheme in which all patients' actions were independently coded and categorized into main categories and further into subcategories [27]. To get an indication of the number of participants that experienced problems in each category, we counted the number of patients that experienced each defined problem in a specific assignment, and we counted the number of individual participants that experienced each defined problem in the total test (see Table 4, last column). The difficulty of the assignments was then accessed based on the number of participants that experienced more than one problem in each assignment (see Table 4, bottom row). Study 2 used the same coding scheme as study 1 but was expanded to account for Health 2.0 literacy problems. In both studies, 3 other outcomes per participant were measured. First, completion of the assignment was registered as "completed independently", "completed with help" (when a hint or intervention from the research leader was needed), or "not completed". The research leader only provided assistance if a patient said he or she was about to give up on the assignment. If the patient did not say this, but was clearly lost or frustrated, the research leader asked the patient if he/she would have quit during a similar search at this point if he/she were at home. If the answer was yes, the research leader provided some assistance. Due to the variation in determination among patients to finish the assignments independently, the moment until assistance was offered varied between 1 minute and 20 minutes. Second, the time needed to perform the assignment was registered, but only for the participants that completed the assignment. Finally, the performance was registered, which was scored as "good", "reasonable", or "poor", according to the skills participants used to execute the assignment. The performance was rated as "good" when both researchers agreed that the operational skills and strategic skills were adequate, "reasonable" if not all skills were shown convincingly, and "poor" if patients showed severe problems on all skill levels. The interviews in study 2 were transcribed

verbatim and coded inductively. Differences in codes and the distribution among the codes were discussed between the researchers before and during the study for each patient until consensus was reached. In case of doubts (which occurred in a few occasions), a third independent researcher was involved to come to a conclusion.

Results

Participants

Participants' characteristics are shown in Table 1. The majority of the participants were female, and the mean age was 56.4 and 48.6 for study 1 and 2, respectively. Most participants were diagnosed with rheumatoid arthritis and had the disease for several years. Table 2 shows participants' current, disease-related Internet use. Most participants used the Internet on a regular basis and rated their own Internet skills as "good". The large majority of participants had searched for online disease-related information (28/31, 90%). Some Health 2.0 applications were used by a substantial group of participants, such as using health care reviews (10/31, 32%), ordering medications online (10/31, 32%), or sending an e-consult (9/31, 29%). However, fewer participants used other Health 2.0 applications, such as adding content to a peer support forum (4/31, 13%) or posting a health care review (1/31, 3%).

Physical Problems When Operating the Computer

Computer-related problems caused by physical impairments in the questionnaire were reported by 7 participants in study 1 (7/15, 47%), and 6 participants in study 2 (6/16, 38%, data not shown). Problems were related to their chair (8/31, 26%, mainly finding a comfortable chair, or a good position in the chair), keyboard (8/31, 26%, mainly pressing individual keys, finding a good position for their hands, and becoming stiff or tired from typing), the mouse (7/31, 23%, mainly double clicking, finding a good position for their hand and becoming stiff or tired from using the mouse), and the monitor (7/31, 23%, mainly finding a good position and getting tired from looking at the screen). During the performance of the assignments, 3 participants mentioned difficulties due to physical impairments (3/31, 10%); 1 participant had to stand up for a while to stretch her legs and 2 participants mentioned they had trouble typing, 1 due to a wrist splint.

Table 1. Participants' socio-demographics and illness related information in the 2 studies.

Characteristic	Study 1 (n=15) n (%)	Study 2 (n=16) n (%)
Gender		
Male	3 (20)	3 (19)
Female	12 (80)	13 (81)
Age		
Mean (SD)	56.4 (10.5)	48.6 (14.2)
Range	39-74	24-72
Education		
Low	4 (26)	4 (25)
Middle	2 (13)	6 (38)
High	9 (60)	6 (36)
Diagnosis		
Rheumatoid Arthritis	10 (67)	12 (75)
Osteoarthritis	3 (20)	0 (0)
Ankylosing Spondylitis	0 (0)	3 (19)
Other rheumatic disease	3 (20)	1 (6)
Unknown	1 (7)	0 (0)
Years since diagnosis		
Mean (SD)	13.5 (13.1)	9.1 (7.4)
Range	3-52	2-25

Table 2. General and disease-related Internet use in the 2 studies.

	Study 1 (n=15) n (%)	Study 2 (n=16) n (%)
Amount of Internet usage		
(Almost) everyday	11 (73)	14 (88)
Several days a week	3 (20)	1 (6)
About 1 day a week	1 (7)	0 (0)
(Almost) never	0 (0)	1 (6)
Internet experience in years		
≥ 5 years	13 (87)	14 (88)
< 1 year	2 (13)	2 (12)
Self-assessed Internet skills		
Excellent	0 (0)	1 (6)
Good	6 (40)	6 (38)
Average	3 (20)	3 (19)
Reasonable	6 (40)	4 (25)
Poor	0 (0)	2 (13)
Number of respondents who have ever online:		
searched for information on rheumatic diseases	13 (87)	15 (94)
read a peer support forum or social media website	8 (53)	8 (50)
read a health care review	5 (33)	5 (31)
ordered medications at the pharmacy	4 (27)	6 (38)
asked a question to their health care provider	2 (13)	7 (44)
monitored disease symptoms	5 (33)	0 (0)
logged onto their own electronic medical record	2 (13)	3 (19)
scheduled an appointment with their health care provider	4 (27)	0 (0)
posted a message on a peer support forum or social media website	1 (7)	3 (19)
shared personal medical information with others	2 (13)	1 (6)
joined an online self-management course	1 (7)	0 (0)
posted a health care review	1 (7)	0 (0)

Study 1

Execution of Health 1.0 Assignments and Problems Encountered

Table 3 shows that the first 3 information-retrieval assignments (retrieving information someone had previously searched for, performing operational assignments, and finding 4 symptoms of osteoarthritis) went rather well for most participants. The last 3 assignments (searching for tips from fellow patients, finding key aspects of adapted shoes, and finding a specialized

physiotherapist in the neighborhood), however, were more difficult. These assignments could not be completed by almost half of the participants, many performed poorly in searching for the right answer and the median times to complete these assignments were greater than the first 3 tests.

Observed problems among participants when performing the 6 Health 1.0 assignments could be coded into 4 categories (see Table 4): (1) operating the computer and Internet browser, (2) navigating and orientating, (3) utilizing search strategies, and (4) evaluating relevance and reliability of Web content.

Table 3. Completion, performance, and time needed for completion on the Health 1.0 assignments (n=15).

Assignment	1 ^{a,g} n (%)	2 ^{b,h} n (%)	3 ^c n (%)	4 ^d n (%)	5 ^e n (%)	6 ^f n (%)
Completion						
Independently	11 (79)	8 (57)	12 (80)	7 (47)	8 (53)	8 (53)
With help	0 (0)	1 (7)	0 (0)	2 (13)	0 (0)	0 (0)
Not completed	3 (21)	5 (36)	3 (20)	6 (40)	7 (47)	7 (47)
Performance						
Good	4 (29)	9 (64)	7 (47)	4 (27)	6 (40)	5 (33)
Reasonable	7 (50)	3 (21)	6 (40)	4 (27)	4 (27)	5 (33)
Poor	3 (21)	3 (21)	2 (13)	7 (47)	5 (33)	5 (33)
Duration to complete the assignment (seconds) ⁱ						
Median	177	192	225	563	311	268
Minimum	60	103	115	274	247	186
Maximum	848	234	488	1095	512	524

^aretrieve previous searched disease information

^bperform operational assignments

^csearch for 4 symptoms of osteoarthritis

^dsearch for 3 tips from fellow patients on MTX side effects

^eretrieve 4 key aspects when buying adjusted shoes

^ffind a physiotherapist specialized in rheumatic diseases in your neighborhood

^gA participant had never searched for information on her rheumatic disease (n=14).

^hA mistake occurred due to a change in the texts on the particular website that was used. This change in text occurred between the time of the pilot study and the first official session and was therefore, unfortunately, discovered during the first session. Therefore, the data of participant 1 could not be used (n=14).

ⁱThe times of participants who did not complete the assignment were not included.

Table 4. Problems and number of participants experiencing those problems in Health 1.0 assignments (n=15).

Assignment	1 ^{a,g} n (%)	2 ^{b,h,i} n (%)	3 ^c n (%)	4 ^d n (%)	5 ^e n (%)	6 ^f n (%)	Total ⁱ n (%)
Operating the computer and Internet browser							
Operating the keyboard/locating keys	2 (14)	1 (7)	0 (0)	1 (7)	1 (7)	0 (0)	5 (33)
Controlling the mouse/clicking the mouse	4 (29)	3 (21)	2 (13)	2 (13)	3 (20)	1 (7)	6 (40)
Using of the URL bar to open a Web address	1 (7)	8 (57)	0 (0)	0 (0)	0 (0)	0 (0)	9 (60)
Losing track of the cursor	0 (0)	1 (7)	1 (7)	2 (13)	2 (13)	1 (7)	6 (40)
Closing the Internet browser	3 (21)	1 (7)	3 (20)	2 (13)	3 (20)	3 (20)	5 (33)
Using and closing more windows	0 (0)	4 (29)	0 (0)	2 (13)	0 (0)	1 (7)	6 (40)
Using the scroll bar	1 (7)	0 (0)	0 (0)	0 (0)	1 (7)	0 (0)	2 (13)
Participants with > 1 problem per assignment	2 (14)	5 (36)	2 (13)	2 (13)	2 (13)	1 (7)	6 (40)
Navigating and orientating							
Using and understanding a PDF file	2 (14)	0 (0)	0 (0)	1 (7)	0 (0)	0 (0)	2 (13)
Keeping orientation on a website	0 (0)	1 (7)	2 (13)	2 (13)	2 (13)	1 (7)	4 (27)
Using dropdown lists	1 (7)	9 (64)	0 (0)	0 (0)	1 (7)	1 (7)	9 (60)
Recognizing and using Web links	2 (14)	3 (21)	2 (13)	2 (13)	3 (20)	2 (13)	7 (47)
Using a search engine within a website	0 (0)	3 (21)	0 (0)	0 (0)	0 (0)	0 (0)	3 (20)
Participants with > 1 problem per assignment	0 (0)	3 (21)	2 (13)	1 (7)	3 (20)	1 (7)	5 (33)
Utilizing search strategies							
(Too) broad search query	6 (43)	n/a	5 (33)	12 (80)	6 (40)	9 (60)	15 (100)
(Typing) errors in search query	4 (29)	5 (36)	7 (47)	3 (20)	3 (20)	2 (13)	14 (93)
Choosing a relevant search result	5 (36)	n/a	8 (53)	9 (60)	7 (47)	7 (47)	13 (87)
Keeping focus on the needed information	5 (36)	0 (0)	2 (13)	6 (40)	5 (33)	7 (47)	11 (73)
Participants with > 1 problem per assignment	8 (57)	0 (0)	8 (53)	12 (80)	5 (33)	9 (60)	14 (93)
Evaluating relevance and reliability							
Not checking the source of the information	8 (57)	n/a	14 (93)	14 (93)	13 (87)	12 (80)	14 (93)
Opening only one search result	4 (29)	n/a	11 (73)	13 (87)	7 (47)	7 (47)	15 (100)
Searching in commercial websites	2 (14)	n/a	2 (13)	2 (13)	6 (40)	4 (27)	11 (73)
Scanning a website for relevant information	3 (21)	0 (0)	5 (33)	7 (47)	4 (27)	3 (20)	12 (80)
Selecting a relevant answer	3 (21)	n/a	3 (20)	4 (27)	8 (53)	6 (40)	11 (73)
Participants with > 1 problem per assignment	6 (43)	n/a	14 (93)	14 (93)	12 (80)	12 (80)	14 (93)

^aretrieve previous searched disease information

^bperform operational assignments

^csearch for 4 symptoms of osteoarthritis

^dsearch for 3 tips from fellow patients on MTX side effects

^eretrieve 4 key issues when buying adjusted shoes

^ffind a physiotherapist specialized in rheumatic diseases in your neighborhood

^gA participant had never searched for information on her rheumatic disease (n=14).

^hA mistake occurred due to a change in the texts on the particular website that was used. This change in text occurred between the time of the pilot study and the first official session and was therefore, unfortunately, discovered during the first session. Therefore, the data of participant 1 could not be used (n=14).

ⁱThis assignment was aimed at operational and navigation skills, therefore most strategic skills were not applicable (n/a)

^jThe number of participants that experienced this particular problem at least once during the complete tests (6 assignments). The numbers in the rows do not add up, since one patient could experience the same problem during several assignments.

Operating the Computer and Internet Browser

The first category of problems concerned operating the computer and Internet browser. Participants experienced difficulties when using the hardware of the computer, and when using the main buttons and fields in the Internet browser. Concerning the hardware of the computer, 5 participants experienced problems when using the keyboard, mainly to locate keys. Difficulties operating the mouse were experienced by 6 participants during one or more assignment, especially keeping control over movements of the mouse, and double clicking on buttons. Regarding the use of the Internet browser, 9 participants did not use the address bar when asked to navigate to a particular Web address, but they used the search engine to type in the Web address. One participant asked, "If I type something in Google, do I have to type '.nl' at the end?" [Female, 62 years old]. Six participants lost track of the cursor when they wanted to type something in a field, which would cause confusion (eg, "Where am I?" [Female, 39 years old]). The buttons in the browser that caused the most problems were the close button, the multiple tabs, and the scroll bar. Five participants did not know how to close the Internet browser during one or more assignments after an assignment had ended. Two of them continuously clicked on the 'back' button to go back to the beginning of the search.

Is it necessary to do what I'm doing now? Should I click this button ("back") until the arrow disappears? Or can I just close it all at once, without erasing anything? [Female 62 years old]

Another participant minimized the window instead of closing it, and one participant tried clicking on the stop button of the address bar. In assignment 2, where patients were explicitly asked to open and close a second tab, 4 participants were not able to fulfill the task. Participants did not seem to understand that they had 2 separate tabs open, parallel to each other, so they were not aware that they could close 1 tab, while keeping the other open. Problems associated with the scroll bar included lose of control over the scroll function, which caused the text to speed by. Overall, operational problems were not assignment-specific and did not occur too often for most patients; 6 participants experienced problems repeatedly.

Navigating and Orientating

The second category of problems concerned navigating and keeping orientation in the Internet browser and on websites. Overall, the multilayer structure of the Internet caused problems, which was often observed when a PDF file was opened. A few participants did not understand that a PDF file is not a website, and that a PDF file has a different navigation structure, in which scrolling is much more important and Web links often do not exist. Furthermore, because websites often combine navigation structures (such as navigation trails [ie, breadcrumbs], navigation buttons/tabs, or internal hyperlinks), keeping orientation sometimes caused difficulties among patients. The different navigation structures should enable visitors to retrieve webpages via different routes. However for 4 participants this caused disorientation in one or more assignments. These patients did not notice that the different navigation structures led to the same website and they lost track of their location in the Web page, or they thought the page was still loading, while they were

actually already on it. When navigating through a website, dropdown lists, Web links and search engines were often not used as intended. Not all participants understood that dropdown lists function as a "hidden" menu, therefore, the mechanism of the list was problematic for many of them. Particularly in a double dropdown list, where a dropdown list unfolds into another dropdown list (which was used in assignment 2), 9 participants experienced difficulties, since they were not able to click on a button before the list closed again. Seven participants experienced several problems with Web links in one or more assignments, for example not recognizing a relevant link or clicking on a word that was not a link (eg, "Shouldn't there be a little hand here?" [Female, 52 years old]). Interestingly, a small group of participants generated a large amount of the problems encountered during navigation and orientation. These were the same participants that experienced the most operational problems.

Utilizing Search Strategies

A third category of problems was observed in participants' search strategies. The majority of these problems occurred in the first stage of the search where the search query was formulated. Often participants started searching with only one query, which was too broad to complete the assignment. A few participants did not seem to understand that they could adjust or expand their query and they blamed the computer for not being able to find the right information. A second major problem in formulating a search query was typing and spelling errors.

When I click on this (search result) I expect to find the right information. That is what I expect from the computer. [Female, 63 years old]

At home I would get my dictionary. [Female, 39 years old]

Not all participants were aware of their mistakes and did not use the autocorrect function from Google, which led to flawed search results, or very few search results. A frequent problem in the second stage of participants' search strategies occurred in selecting a website from the list of search results. Many participants randomly chose one of the first search results on top of the page. When selecting a search result, they did not seem to look at the URL or the description of the site just below to get an indication of the content of the website, "I just try the first one." [Female, 45 years old]. Only 1 participant in a single assignment looked further than the first page with search results. One participant mentioned that, "the most important results are shown on the first page anyway" [Male, 62 years old], however, some participants did not seem to realize that the search results extended after the first page. The last problem in applying a logical search strategy was the loss of focus on the required information. Patients became distracted by other information they found interesting (eg, "Here I read osteoarthritis is hereditary, my sister recently has sore shoulders as well" [Female, 74 years old]). Overall, all participants experienced difficulties in their search strategies at some point. However, most participants showed a learning curve and altered their search strategies as the study progressed, while 4 patients did not seem to be aware of their mistakes and used the same trial-and-error method in several assignments.

Evaluating Relevance and Reliability

The last category of observed problems, evaluating relevance and reliability of Web content, caused the largest number of problems. Almost none of the participants consciously checked the source or the topicality of the information. No one verified the information they found on one website with information from another website. Participants only opened a second search result when they could not find the correct answer in the first one. However, not all participants seemed to understand that they could go back to the list of search results to explore a different website. One woman was searching on a peer support forum for people suffering from hyperhidrosis (excessive sweating), instead of a peer support forum for rheumatoid arthritis, but did not go back to the search results to something relevant. Eventually she asked the research leader, "Are you sure the information can be found on a patient forum?" [Female, 39 years old]. Many participants did not seem to be aware of different sources of information. Only 3 participants made a remark about the occurrence of sponsored hits at the top and on the right side of the search results. Furthermore, when searching on a website, many participants did not scan the website for relevant information to fulfill the assignment. Participants would select buttons with irrelevant titles and read webpages verbatim without considering the relevance of the information. In the peer support forum, this occurred regularly. One participant selected a random topic on rheumatoid arthritis "keep having knee pains" and read all the messages out loud, even though they were not relevant for the assignment. In fact, she commented that, "there are so many messages here, and you need to work through them all. What a waste of time" [female, 59 years old]. Many participants did not give different value to the information provided by different sources, such as a

commercial company, a peer support forum, or a national foundation.

Study 2

Execution of Health 2.0 Assignments and Problems Encountered

In study 2, the majority of the participants completed all assignments, most of them without help (Table 5). Not all participants were able to start and complete all assignments, because they were tired after completing 3 or 4 assignments, or because they had to leave for their doctors' consult. Ten participants (10/16, 63%) started all assignments and 9 participants (9/16, 56%) completed all assignments. Assignments 2 (filling out a diary), 3a (writing an e-consult) and 5b (posting a health care review) were the most difficult for participants as these assignments required addition of content to the Web. The minimum and maximum duration varied widely between participants within each assignment, which was an indication of the different skill-levels between participants. From the interviews, we found that almost all participants had no experience with the assignments. No one had monitored their disease symptoms before or posted a health care review. One patient (1/16, 6%) had previously sent an e-consult, 3 patients (3/16, 19%) had posted a message on a peer support forum, and 3 patients (3/16, 19%) had consulted their electronic medical records before. Nevertheless, after finishing the assignments, the patients perceived the e-consult and access to the electronic medical record components especially valuable. Eleven patients (11/16, 67%) would like to use an e-consult in the future, and 14 patients (14/16, 89%) reported they would open their electronic medical records at home.

Table 5. Completion, performance, and time needed on the Health 2.0 assignments (n=16).

Assignment	1a ^a n (%)	1b ^b n (%)	2a ^c n (%)	2b ^d n (%)	3a ^e n (%)	3b ^f n (%)	4a ^g n (%)	4b ^h n (%)	5a ⁱ n (%)	5b ^j n (%)
Number of participants who started the assignment, n	15	15	16	16	15	15	12	10	15	15
Completion										
Independently	12 (80)	14 (93)	10 (63)	11 (69)	9 (60)	13 (87)	10 (83)	8 (80)	12 (80)	10 (67)
With help	3 (20)	1 (7)	3 (19%)	2 (13%)	2 (13)	1 (7)	0 (0)	1 (10)	1 (7)	0 (0)
Not completed	0 (0)	0 (0)	3 (19%)	3 (19%)	4 (27)	1 (7)	2 (17)	1 (10)	2 (13)	5 (33)
Performance										
Good	11 (73)	11 (73)	8 (50)	11 (69)	9 (60)	13 (87)	6 (50)	7 (70)	10 (67)	8 (53)
Reasonable	1 (7)	3 (20)	4 (25)	0 (0)	1 (7)	0 (0)	4 (33)	1 (10)	5 (33)	4 (27)
Poor	3 (20)	1 (7)	4 (25)	5 (31)	5 (33)	2 (13)	2 (17)	2 (20)	0 (0)	3 (20)
Duration^k										
Median	151	119	265	66	163	115	270	262	159	226
Minimum	57	24	92	27	71	24	128	156	101	108
Maximum	746	263	782	156	544	723	629	1406	674	672

^ause electronic medical records to find and interpret lab results

^buse electronic medical records to interpret treatment plan

^cmonitor disease symptoms by filling out a diary

^dmonitor disease symptoms interpreting 2 previous diaries

^euse e-consult to write a new e-consult

^fuse e-consult to read a previous e-consult

^guse a peer support forum to find 2 tips

^huse a peer support forum to add your own tip

ⁱuse a health care rating website to read reviews

^juse a health care rating website to post a review.

^ktime is in seconds and the time of participants who did not fulfill the assignment is not included in this median

Many of the problems encountered in study 2 corresponded to those found in study 1. However, it should be noted that in study 2, the participants were somewhat assisted, as they were guided to specific websites. Therefore we restricted the report of results in study 2 to an overview of the observed additional problems in Health 2.0 assignments in category 4 (evaluating relevance and reliability), category 5 (adding personal content to the Web in assignments 2a, 3a, 4b, and 5b, see Table 6), and category 6 (protecting and respecting privacy).

Evaluating Relevance and Reliability

A new subcategory in evaluating relevance and reliability, which was added to the findings of study 1 was reading and interpreting the information correctly (not shown in Table). This category had to be added since information on the specified Web portal was always reliable, and mostly relevant, but participants still had to read and interpret the information correctly. This was of particular concern in assignment 1, in which participants had

to interpret several lab results and compare them to previous values. Reading and interpreting the information correctly caused problems among 7 participants, mostly because they had difficulties to see which lab results were the most recent, and because they did not take into account the given information about reference values. Four participants assumed that increased lab values were always bad (eg, "The levels are higher than the last time, that is bad, right?" [Female, 24 years old]), and 3 participants reported that they did not know if the values worsened or not (eg, "I'm no expert in this; I have never studied these things." [Female, 65 years old]). Only 1 participant reported she would be worried if those were her personal data and she would call her doctor immediately. The other participants reported that they probably would have heard it from their rheumatologist if anything was wrong, or they would ask about it in their next consult, call their care provider, or send an e-consult.

Table 6. Health 2.0 problems with adding personal content to the Web, including amount of participants experiencing those problems (n=16).

Assignment	2a ^a	3a ^b	4b ^c	5b ^d	Total ^e
	n=16	n=15	n=10	n=15	n=16
	n (%)	n (%)	n (%)	n (%)	n (%)
Number of participants who experienced problems associated with adding personal content to the Web					
Using proper fields for adding data	3 (19)	6 (40)	5 (50)	3 (20)	10 (63)
Using capital letters and punctuation marks	11 (69)	8 (53)	4 (40)	2 (13)	13 (82)
Spelling	5 (31)	2 (13)	4 (40)	2 (13)	8 (50)
Using appropriate header and sender information	n/a ^f	7 (47)	6 (60)	0 (0)	10 (63)
Formulating a question or message	4 (25)	7 (47)	2 (20)	4 (27)	10 (63)
Participants with > 1 problem per assignment	6 (38)	10 (67)	3 (30)	5 (33)	14 (88)

^amonitor disease symptoms filling out a diary

^buse e-consult to write a new e-consult

^cuse a peer support forum to add your own tip

^duse a health care rating website to post a review

^eThe number of participants which experienced this particular problem during the complete test (5 assignments). The numbers in the rows do not add up because one patient could experience the same problem during several assignments.

^fusing headers and sender information was not applicable in assignment 2

Adding Personal Content to the Web

Difficulties with adding personal content to the Web existed in several subcategories and were related to the correct formulation of the message or question to be placed on the Web (Table 6). First, there were several practical issues in adding content to the Web. Some participants experienced difficulties in using the proper fields for their information. For example, when writing an e-consult, 1 participant wrote her question in the subject field. Other participants forgot to fill in a subject for the e-consult, or an addressee to send the e-consult to. As a result, the send button did not become active. Not all participants understood this, and 3 participants thought that the e-consult was sent anyway (eg, "He is sending my message now, right?" [Female, 24 years old]). Subsequently, there were many minor problems with the actual writing of a message, namely spelling errors, lack of punctuation, and capital letters. These errors could influence the readability of the content and how well the message was understood. Third, several participants found it difficult to reflect on whom the reader of their message would be, and what tone would be appropriate. For example, when writing an e-consult to their care provider in the personal Web portal, it would be convenient to use a header and conclude with a name, surname, and maybe a patient number. However, when writing on a peer support forum, messages can be more informal and one might explicitly not conclude the message with a name (or use a nickname) for privacy matters (see next section). Some participants did not seem to be aware of this difference. Lastly, and perhaps most importantly, half of the participants showed problems in the actual formulation of a message or a question. They were not able to reflect on what information was necessary for the reader to understand their message or question. Also, participants used incomplete sentences in their messages (eg, "Sometimes have feeling in rheumatology that things are intertwined, mb too busy" [Female, 35 years old]), or asked an

irrelevant question (eg, "Don't I need medication because it's so warm over there?" [Male, 48 years old]).

Protecting and Respecting Privacy

The last category of observed problems comprised of the protection of one's own privacy and respecting that of others. During the assignments, it was difficult to code how participants handled their privacy, because the assignments were fictional and participants did not actually have to save or send their added content. Very few participants mentioned their privacy during the assignments, therefore, the findings presented here are based on what participants mentioned during the assignments and on the interviews afterwards. Concerning access to electronic medical records or using e-consult, no one made a remark about privacy during the assignment or in the interview afterwards. Apparently, all participants were confident that their data was secure in the Web portal. Nevertheless, 3 participants would not monitor their disease symptoms due to privacy issues, although this assignment was performed on the same Web portal. Two participants did not like the idea of putting all their information online for anyone to view and access.

I am an Internet user from a previous generation; I don't put down my whole life story online. It might go wrong and then all my information is out in the open. [Female, 35 years old]

One participant read the accompanying text when filling out her diary, and saw that her care providers had access to the monitored data as well, which discouraged use.

Oh, my care provider is reading along? For me that's a reason not to use it! [Female, 57 years old]

With regard to the 2 assignments outside of the Web portal (using a peer support forum and a health care rating site), more participants seemed aware of privacy issues. A message was added to the peer support forum by 1/9 (11%) participants, 4 mentioned only their surname, and 5 participants did not sign

their message at all. However, in 8 occasions, it was not clear if this was on purpose or not, because participants did not explain their choice. Only 1 participant specifically said that they did not want to be judged by the readers, and therefore left out their name. Of these 9 participants, 4 would use a peer support forum in the future. All these participants reported that they would only write general information about themselves and that they would never write anything about others without their consent. Out of the 10 participants that filled in a health care review, 8 would use the website again in the future. However, only 2 participants would use the website to complain about a care provider, when a mistake was made, "I would only report it if a mistake was made, for I would hope to prevent that for someone else" [Female, 45 years old]. The other participants would not use the website to place a negative review because they would rather speak to their care provider in person about the issue and do not want to negatively sway the opinion of others.

Relationship Between Patient Characteristics and eHealth Literacy

We explored if there were any correlations between the performance on the assignments, patients' age, level of education, and perceived Internet skills ([Multimedia Appendix 1](#)). We found that patients who are higher educated, younger, and have higher self-perceived Internet skills, on average completed more assignments independently, performed better, and encountered fewer problems. However, these data should be interpreted with care, as the sample size was small.

Discussion

In these 2 studies, a representative sample of patients with rheumatic diseases performed Health 1.0 and Health 2.0 assignments on the Internet. While a substantial number of patients experienced physical uneasiness when using the computer (eg, stiffness and tiredness) for the questionnaire, only 3 participants mentioned actual physical problems during the assignments. Nevertheless, using the Internet for health-related searches for a restricted amount of time seemed to be feasible for most participants. Furthermore, our results showed that a substantial group of patients were not able to fully use disease-related Internet applications for their own benefit. Problems in Health 1.0 information retrieval were found in 4 categories: (1) operating the computer and Internet browser, (2) navigating and orientating, (3) utilizing search strategies, and (4) evaluating relevance and reliability, which corresponds largely with categories found in a previous study by Van Deursen and Van Dijk among healthy people [28]. About one-third of the participants in our study had severe problems in operating the computer, the Internet browser, and in navigating and orientating on the Web. While these problems were often overcome, they did cause a substantial amount of inefficiency and frustration, withholding participants from fully using all the options the computer and Internet offers. Moreover, the more complex information and evaluation skills caused frequent problems for most of the patients. Many struggled with choosing a relevant search query, selecting a reliable search result, and browsing a website to find the right answer to a

specific question. It seemed that a substantial part of the sample was using a trial-and-error method for searching the Internet. Strikingly, only 3-4 participants out of 15 were critical about the websites they visited and the information they retrieved from the Internet. The remaining participants did not seem to be aware of the source of the information, who exploited the website they searched on, and when the information was last updated. This is worrisome, since previous research studies have shown that many rheumatology-related websites provide unreliable information [29].

Although studies have been conducted to evaluate particular Health 2.0 applications [30,31], to our knowledge, no previous studies have been performed on Health 2.0 literacy of patients with chronic diseases and their ability to perform a variety of Health 2.0 assignments. This approach has enabled us to study Health 2.0 skills rather than evaluating the usability of a single application. During the assignments, we observed problems with operation, navigation, and information skills that corresponded with problems found in the Health 1.0 applications. However, since we provided patients with the direct website of the Health 2.0 applications, the Health 1.0 skills were not fully examined in this part of the study and the focus was on specific Health 2.0 problems. Most patients had little or no experience in using services to communicate with other patients, care providers, or with checking their own health status online, which corresponds with previous research among rheumatology patients [2]. Problems in doing so were mostly found in evaluating relevance and reliability (category 4) and in 2 additional categories: (5) adding personal content to the Web, and (6) protecting and respecting privacy. When adding personal content, several patients had trouble with using the content fields correctly, formulating a message and writing it down properly, and keeping in mind who the readers of the message will be. With reference to privacy issues, participants often mentioned being reluctant to add content to the Web. It was difficult for the participants to reflect on the reader of their information and what impact it would have on privacy when posting a message. Overall, it seemed that due to a lack of experience in online communication, many patients were insecure about when and how to use Health 2.0 applications. This lack of Health 2.0 use was seen in previous research as well [32]. Interpreting personal health records caused some problems, mostly because patients were not able to locate the relevant information and to put the information in the right context. This was partly due to incorrect interpretation of numbers, which also relates to numeracy skills [33]. Problems with interpreting electronic medical records are concerns that health professionals have previously reported [34,35]. Nevertheless, the action that patients would take in reaction to their personal data was generally appropriate. Keeping patients' records clear and limited to the essence of the content would presumably overcome most of the observed difficulties [35]. After finishing the Health 2.0 assignments, many patients were enthusiastic about the possibilities the Internet could provide, and to become more involved in their own health care process, especially by using the applications that were provided by their own hospital. Two thirds of all participants would like to use e-consult in the future, and almost all patients reported they would open their electronic medical records at home, now that

they have seen the service. Many patients were simply unaware of their options and/or anxious to use them themselves before the study. Therefore, patients need to be guided and encouraged to use Health 2.0 applications, and they should be informed by care providers about the privacy disclosures in such applications.

A limitation of our studies was the research setting in which participants performed the assignments. Although we aimed to formulate assignments that were relevant to patients with rheumatic diseases and stressed that the study was not an exam, patients were probably more nervous than if they were in a natural setting. Participants were also probably focused on completing the assignments quickly, which could influence the quality with which they performed. Furthermore, in several Health 2.0 assignments, patients were asked to spontaneously formulate a fictive question or message, which turned out to be difficult for some participants and might have complicated the assignment. Nevertheless, our studies demonstrate that most patients have considerable problems with using the Internet for health-related purposes. Although our studies were restricted to patients with rheumatic diseases, we feel that our results are generalizable for other health conditions, especially as only a minority of the participants' perceived physical problems during the tests. Moreover, the assignments used in our performance tests (eg, using e-consults, health care rating sites and peer support forums) might be relevant to patients with different conditions. Because of the qualitative nature of our studies, we cannot draw strong conclusions on the most frequent eHealth literacy problems that patients encounter, and on which groups of patients encounter most problems. However, our studies showed that the majority of participants experienced difficulties on several levels, even though our research population was heterogeneous in age, education level, and had quite some experience in using the Internet. Previous research has shown that a higher education does not guarantee better Internet skills [36,37] and other studies among higher educated populations confirm these results. For example, Hughes et al [38] showed that doctors often choose their search results based on navigational bias and a focus on what is known, and Stellefson et al [39] found that many health professional college students are rather unconfident when evaluating information from the Internet. Furthermore, a younger age and more Internet experience might enhance operational skills, but previous studies have found that strategic eHealth literacy problems are still frequently present among students who grew up using the Internet [16,17,19]. Some exploratory analysis on our data, however, indicated that patients with a higher educational level, younger age, and higher perceived Internet skills completed more assignments, performed better, and encountered fewer problems. All in all, it should be acknowledged that a broad range of eHealth literacy problems exist, but future research

should focus on which groups of people struggle with specific categories of eHealth literacy problems.

From our results, it seemed that several shifts were necessary to make online information, communication, and participation services more beneficial in rheumatology. First of all, the problems that were observed in these studies cannot solely be attributed to the patients' skills, since the usability of Health 1.0 and Health 2.0 applications also plays a major role in overcoming operation, navigation, and information problems. Websites and interactive applications should be designed in a user-centered manner to overcome problems that many novice Internet users may experience [2,10,23,40]. In order to reach this, guidelines should be followed to focus on keeping a website plain and simple regarding navigation structures and usage of buttons [41]. Furthermore, it is essential that texts are written on a level that is understandable for the majority of the population [42]. Usability of Health 2.0 applications could, moreover, be increased by explaining their function, use, and privacy procedures in the application itself, for example using demonstration videos. Finally, to ensure that usability goals are reached, websites should be tested with representative end-users in several stages of the development [43,44]. Health care organizations could also play a role in tuning the level of online applications to patients' eHealth literacy, by developing websites and Web portals which provide reliable and valuable information [25]. Second, patients should be informed and educated about proper use and protection of privacy on the Web. This could be realized in (online) eHealth literacy courses, which seem to be promising [45,46]. Third, tools could be developed which care providers could use in consult, in order to gain attention among patients for both the possibilities and the risks of the Internet [47]. A final necessity that follows from our results, is an eHealth literacy measurement instrument that can identify a broad range of skills. The eHEALS scale by Norman [48] or the Functional, Communicative, and Critical health literacy scale by Ishikawa [49] offer good starting points for this area, provided that Health 2.0 skills measures are added.

In conclusion, patients with rheumatic diseases often seek online disease-related information, and online interactive applications that help patients to get more involved in learning and caring for their disease are promising. However, the majority of the patients lack the skills to use both Health 1.0 and Health 2.0 properly for their own benefit. Problems include operating, navigating, searching the Internet, critically evaluating online content, and adding personal content while keeping privacy in mind. To decrease these problems, changes should be made in the design process of websites and online applications. Awareness, measurement, and education in eHealth literacy should also be increased.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Completed tasks, performance, and number of encountered problems related to education level, age, and perceived Internet skills in studies 1 and 2.

[\[PDF File \(Adobe PDF File\), 35KB - jmir_v15i2e27_app1.pdf\]](#)

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Original Paper

What Do Electronic Health Record Vendors Reveal About Their Products: An Analysis of Vendor Websites

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Abstract

Background: Purchasing electronic health records (EHRs) typically follows a process in which potential adopters actively seek information, compare alternatives, and form attitudes towards the product. A potential source of information on EHRs that can be used in the process is vendor websites. It is unclear how much product information is presented on EHR vendor websites or the extent of its value during EHR purchasing decisions.

Objective: To explore what features of EHR systems are presented by vendors in Ontario, Canada, on their websites, and the persuasive means they use to market such systems; to compare the online information available about primary care EHR systems with that about hospital EHR systems, and with data compiled by OntarioMD, a regional certifying agency.

Methods: A list of EHR systems available in Ontario was created. The contents of vendor websites were analyzed. A template for data collection and organization was developed and used to collect and organize information on the vendor, website content, and EHR features. First, we mapped information on system features to categories based on a framework from the Institute of Medicine (IOM). Second, we used a grounded theory–like approach to explore information for building consumer confidence in the vendor and product, and the various persuasive strategies employed on vendor websites. All data were first coded by one researcher. A peer reviewer independently analyzed a randomly chosen subset of the websites (10 of 21; 48%) and provided feedback towards a unified coding scheme. All data were then re-coded and categorized into themes. Finally, we compared information from vendor websites and data gathered by OntarioMD.

Results: Vendors provided little specific product information on their websites. Only two of five acute care EHR websites (40%) and nine of 16 websites for primary care systems (56%) featured seven or all eight of the IOM components. Several vendor websites included system interface demonstrations: screenshots (six websites), public videos or slideshows (four websites), or for registered viewers only (three websites). Persuasive means used by vendors included testimonials on 14/21 (67%) websites, and directional language. Except for one free system, trial EHR versions were not available. OntarioMD provided more comprehensive information about primary care systems than the vendors' websites. Of 14 points of comparison, only the inclusion of templates and bilingual interfaces were fully represented in both data sources. For all other categories, the vendor websites were less complete than the OntarioMD site.

Conclusions: EHR vendor websites employ various persuasive means, but lack product-specific information and do not provide options for trying systems on a limited basis. This may impede the ability of potential adopters to form perceptions and compare

various offerings. Both vendors and clients could benefit from greater transparency and more specific product information on the Web.

Trial Registration: N/A

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KEYWORDS

Electronic health record; Vendors; Diffusion of Innovations; Websites

Introduction

Purchasing electronic health record (EHR) systems is a process in which potential buyers and users often seek and assess information about the products in question and compare alternatives. EHR is often a new technology to the people who use it, introducing new ways of performing clinical and administrative tasks. As such, it may be regarded as an innovation. Rogers' [1] diffusion of innovations theory suggests that the process of adopting innovations (the innovation decision process) typically follows five stages: knowledge, persuasion, decision, implementation, and confirmation. Most relevant to this work is the *knowledge* stage in which adopters learn about the existence of an innovation (awareness knowledge), gain basic knowledge of how to use it (how-to knowledge), and understand the underlying principles behind it (principles knowledge). This is followed by the *persuasion* stage, in which potential adopters actively seek more information about the innovation, evaluate its characteristics, form positive or negative attitudes toward it, and subsequently adopt (eg, purchase) or reject the innovation at the *decision* stage.

For EHRs, the adoption decision process involves a planning phase that includes needs assessment, identifying champions, gaining buy-in from stakeholders, workflow analysis, understanding financial issues, and goal setting [2,3]. This is followed by a system selection phase in which information is sought from various sources including vendors and general consultants[4], visits to practices that have installed systems of interest, and product demonstrations [2,3]. At this stage, according to Lorenzi et al [3], "the internet provides a valuable source of information regarding specific EHR system products, capabilities, and the selection process" (p.8). In particular, vendor websites could play an important role in making an adoption decision by creating awareness, providing how-to and principle knowledge, and using various persuasive means to affect potential adopters' perceptions of EHRs. However, to the best of our knowledge, no systematic efforts have been made to examine whether EHR vendors use their websites to present the information typically gathered in the pre-decision stages of Rogers' innovation-decision process.

To contribute to filling this gap, we studied the information provided on websites of EHR vendors operating in Ontario, Canada. The term EHR is used here broadly to encompass computerized systems containing patient information for direct clinical use. For simplicity, we use the term for both stand-alone electronic medical records (EMRs), in which information "can be created, gathered, managed, and consulted by authorized clinicians and staff within one health care organization" [5] (p. 6), and interoperable EHR systems, which may be operated by

clinicians and staff across various health care organizations. The following research questions were investigated:

RQ1: What and how much product-specific information do Ontario EHR vendors reveal on their own websites or on external websites?

First, we examined what vendors reveal about the functional characteristics of their EHR products by looking for product-specific information related to eight core EHR functionalities defined by the Institute of Medicine (IOM) [6]. As a subset of this question, we explored what similarities and differences in this product-specific information exist between acute care (hospital-based) and primary care (family practice) EHR vendor websites.

Second, we compared the product-specific information presented on vendor websites with information presented on an external website. The selected external website is operated by a provincial agency (OntarioMD), which assists physicians in the transition from paper to electronic records and acts as a certifying body for primary care EHRs in Ontario [7].

RQ2: In what ways do Ontario EHR vendor websites attempt to persuade users to purchase their products?

For this purpose we looked at what persuasive means are used by vendors on their websites and considered how they could influence potential adopters' perceptions of the systems. As a subset of this question, we also explored what differences in the persuasive means employed exist between acute care (hospital-based) and primary care (family practice) EHR vendor websites.

Methods

Vendor Website Selection

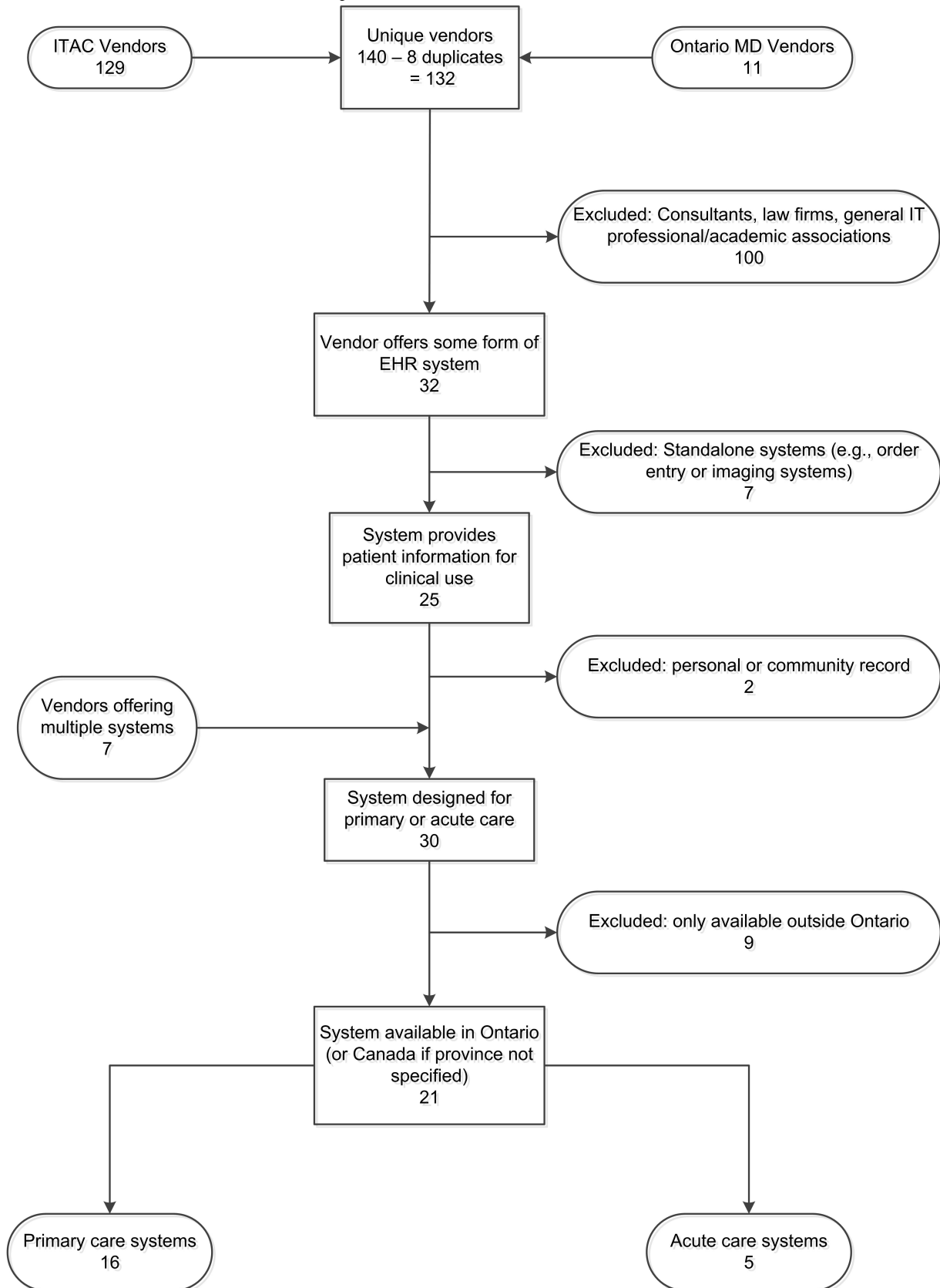
Figure 1 presents the website selection process. We compiled a list of EHR vendor websites for systems available in the province of Ontario, Canada, from two sources. The first is OntarioMD [7] (11 vendors), a provincial agency that works closely with physicians to provide support for the transition from paper to electronic records. It certifies primary care EHRs, so that physicians adopting them are eligible for funding from the province of Ontario under the Physician IT Program [8]. OntarioMD also publishes vendor responses to a number of standard questions on their website. The second is the Information Technology Association of Canada (ITAC) Health members list [9] (129 vendors), which was used to identify acute care EHR vendors and additional non-certified primary care vendors. This list contains contact information for information technology organizations that are active in the health

care sector. ITAC Health, formerly known as the Canadian Healthcare Information Technology Trade Association (CHITTA) [10], is an established national industry association and so was considered a reputable, consistent, and reasonably comprehensive source of information.

After removing duplicates (8 vendors), systems were included based on: 1) specific mention of being or description of a product that could correspond to an EHR in the broad sense described above, 2) being designed and marketed for either primary or acute health care organizations but not for patients,

3) maintaining patient profiles and documentation for direct clinical use, and 4) availability and implementation in Ontario. These criteria excluded consultants, law firms, general IT, professional, and academic associations (100 websites). Specialized software such as computerized provider order entry systems not integrated within an EHR suite and picture archiving and communication systems (7 systems), personal or community health records (2 systems), and systems not available in Ontario (9 systems) were also excluded. Seven vendors offered multiple systems; therefore, the final list includes 21 systems (16 primary care and 5 acute care EHRs).

Figure 1. A flow chart of the vendor website selection process and results.



Data Collection and Analysis

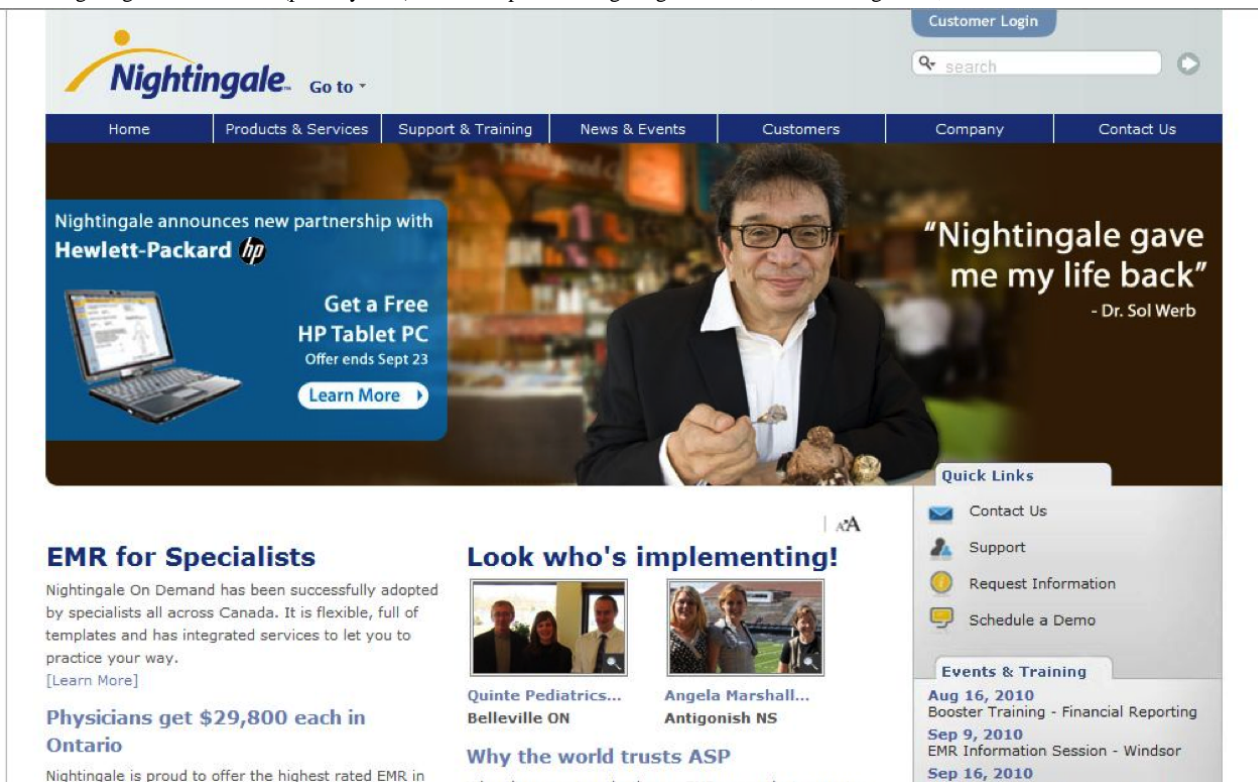
Each vendor website was examined for a number of general and system-specific characteristics. No pre-existing methodology was found for evaluating and classifying discrete

website content elements independent of external accuracy or credibility. Therefore, an interpretive approach to data collection and analysis was employed. Based on a preliminary review of websites, as well as information from the literature, a template for data collection and organization was developed ([Multimedia](#)

Appendix 1) and used to collect and organize information on the vendor, website content, and EHR system features. As described in detail below, product-specific and persuasive features were analyzed using framework analysis [11] and grounded theory-like [12,13] approaches, respectively. Finally,

we compared the information presented on vendor websites with the information from OntarioMD website. Multimedia Appendix 2 and Multimedia Appendix 3 illustrate screen captures from vendor websites, and Figure 2 presents an example homepage.

Figure 2. Nightingale On Demand (primary care). From: <http://www.nightingalemd.ca>; taken on August 25, 2010.



Information About System Features

The first analysis addressed information related to EHR system features and specifications across both primary and acute care systems. This information was compiled from website texts (paragraphs or feature lists) and nontextual features, such as screenshots or other graphics. Data were drawn both from vendor websites and the OntarioMD site. Several possible frameworks for analyzing product-specific characteristic were examined including EHR component models and frameworks from HIMSS Analytics [14], Gartner Inc. [15], and IOM [6]. The IOM framework was selected for being the most detailed, comprehensive, and from an internationally reputable organization. Taking a framework analysis approach [11], data from websites were mapped to the eight core functionalities of an EHR as defined by the IOM [6]:

1. health information and data;
2. results management (eg, images, clinical dashboard, alerts);
3. order entry and management (eg, computerized provider order entry, prescribing);
4. decision support (eg, drug interactions, prevention and detection alerts);
5. electronic communication and connectivity (eg, email, integrated records);
6. patient support (eg, patient education content);
7. administrative processes (eg, patient scheduling, billing);

8. reporting and population health management (eg, quality indicators, national registries).

Each EHR system's website was evaluated for a description of at least one feature in each of the eight EHR functionalities (or components) defined by the IOM. Features not explicitly mentioned were not considered present in the analysis. For instance, a website not stating that patient data were stored or displayed by the system would not meet the first functionality, although it would be reasonable to assume that the system must contain some patient data in order for any other functions to operate.

Analysis of Persuasive Features

Since a suitable analytic framework for evaluating persuasive features was not found, a grounded theory-like approach was employed to develop the themes on the basis of content extracted throughout the study from all of the websites included in this analysis. The first part of this evaluation focused on information presented to build *consumer confidence* in the vendors, their websites, and by extension, their products. The second part of the analysis focused on the *direct persuasive strategies* employed. We followed a typical iterative process of open coding, consensus building, re-coding, and category/theme development as described below. This strategy highlighted trends in vendor website information content and delivery and facilitated an investigation of the differences between primary and acute care vendor websites.

First, open coding [12] was employed. To ensure trustworthiness, a peer reviewer independently analyzed a randomly chosen subset of the websites (10 of 21; 48%) and provided feedback towards a unified coding scheme. All data were then re-coded and categorized into broad recurring themes that emerged. Category-building was also influenced by constructs designed by other researchers [16,17]. Finally, findings related to each of the categories were summarized for all vendor websites.

Comparison of Vendor Websites and OntarioMD Information

A comparison of online information sources about EHR systems was performed for primary care systems certified by OntarioMD.

Systems with multiple certified versions were considered a single entity for comparison. Based on the OntarioMD information, 14 data points for each certified system were collected, and each point was checked to see if it also appeared on the corresponding vendor's website.

Results

A list of 120 ITAC Health members and 12 OntarioMD-certified systems was compiled in August 2010. From this list, 21 websites representing systems from 19 different vendors met the inclusion criteria. Table 1 presents a list of vendors and systems and their respective websites. Of these websites, 5 (24%) were for acute care systems and 16 (76%) for primary care systems.

Table 1. List of all systems included for analysis.

Vendor name	Product name (with version if available)	Vendor homepage (as of August 2010)	Archived homepage (13 Feb 2013)
Primary care EHR^a systems			
ABELSoft Corp.	ABELMed EHR-EMR/PM v11 ^b	http://www.abelsoft.com/	http://www.webcitation.org/6EPAunGBO
Alphaglobal-IT	Globe Med v1.0 ^b	http://www.alpha-it.com	http://www.webcitation.org/6EP8OzEd7
Alphaglobal-IT	Universal eHealth MD (UHM) v5.0 ^b	http://www.alpha-it.com	
CLINICARE Corp.	EliteCare v6.7 ^b	http://www.clinicare.com/	http://www.webcitation.org/6EP8eZ5t1
Eclipsys Corp.	Sunrise Ambulatory Care	http://www.eclipsys.com/	No longer available
EMIS Inc.	EMIS system	http://www.emis.ca/	No longer available
GE Healthcare	Centricity	http://www.gehealthcare.com/	http://www.webcitation.org/6EP8tnrNO
Healthscreen Solutions Inc.	HS Practive v4.0 ^b	http://www.healthscreen.com/	http://www.webcitation.org/6EP8wsiyc
Jonoke Software Development Inc.	JonokeMed 5.1 ^b	http://www.jonoke.com/	http://www.webcitation.org/6EP90N0Mh
(McMaster University, Department of Family Medicine)	OSCAR v9.06 (sometimes known as OSCAR McMaster) ^b	http://oscarcanada.org/ or http://oscarmcmaster.org/	http://www.webcitation.org/6EP95PrX5
MD Physician Services Software Inc.	PS Suite v5.1 ^b	http://www.practicesolutions.ca/index.cfm/ci_id/47452/la_id/1.htm	http://www.webcitation.org/6EP97aVj1
Nightingale Informatics Corp.	Nightingale On-Demand v8.3 ^b	http://www.nightingalemd.ca/	http://www.webcitation.org/6EP9AE9V5
Optimed Software Corp.	Accuro	http://www.optimedsoftware.com/index.php	http://www.webcitation.org/6EP9CAzP
P & P Data Systems Inc.	Clinic Information System (Clinic/Enterprise/Practice Editions, v.7.4.5) ^b	http://www.p-pdata.com/	http://www.webcitation.org/6EP9ErrmK
xwave	Bell Aliant xwaveEMR v8 ^b	http://www.xwave.com/	http://www.webcitation.org/6EP9GYkai
York-Med Systems Inc.	York-Med MD Suite v8.6 ^b	http://www.york-med.com/	http://www.webcitation.org/6EP9Jhe3k
Acute care EHR systems			
B Sharp Technologies Inc.	B Care	http://www.bsharp.com/	http://www.webcitation.org/6EP9LSAke
Cerner Corp.	PowerChart EMR	http://www.cerner.com/public/default.asp?id=18731	No longer available
Eclipsys Corp.	Sunrise Clinical Manager	http://www.eclipsys.com/	No longer available
QuadraMed Corp.	QCPR	http://www.quadramed.com/	http://www.webcitation.org/6EP9RGAzO
TELUS Health Solutions	Oacis	http://telushealth.com/en/default.aspx	http://www.webcitation.org/6EP9UrNsc

^a Most of the primary care systems are in fact EMRs, but for simplicity we decided to use a single term (EHR) throughout.

^b System certified by OntarioMD.

Information About System Features

In general, vendors provided little specific product information on their websites, and this was more pronounced for acute care vendor websites than primary care sites. As described in [Table](#)

2, none of the five acute care systems websites presented all eight IOM system components. On their respective websites, QuadraMed's QCPR noted seven functionalities, while Cerner's PowerChart mentioned only two. Furthermore, no single component was seen in all five systems. The importance of

communication between providers was emphasized, with four system websites noting some form of secure electronic mail or messaging, as well as the ability to order tests or receive results electronically. Clinical decision support, such as drug-drug interactions, was also claimed on four of the five websites.

In contrast, many of the websites for primary care systems featured seven or all eight of the IOM components. ABELMed, JonokeMed, OSCAR, Practice Solutions PS Suite, and xwaveEMR described all functionalities, while another four

systems were missing only one component. All 16 primary care systems met the definitions for the health information and administration functionalities. Primary care systems generally presented more components than acute care systems. The least commonly found component on websites of both types of systems was information on patient education features, which generally consisted of handouts and reference materials to be given to patients, outlining the details of relevant conditions, diagnoses, and treatment plans.

Table 2. Core functionalities of EHRs presented on websites (Y=website contains the feature).

Vendor (System)	Health info ^a	Results ^b	Order entry ^c	Decision support ^d	Connect ^e	Patient support ^f	Admin ^g	Reports ^h	Total
Primary care EHR systems									
ABELSoft (ABELMed)	Y	Y	Y	Y	Y	Y	Y	Y	8
AlphaIT (GlobeMed)	Y	Y	Y	Y	Y	Y	Y	–	7
AlphaIT (UHM)	Y	Y	Y	Y	Y	Y	Y	–	7
Clinicare (EliteCare)	Y	Y	Y	–	Y	–	Y	–	5
Eclipsys (Sunrise Ambulatory Care)	Y	–	Y	Y	Y	–	Y	–	5
EMIS	Y	Y	Y	Y	Y	–	Y	–	6
GE (Centricity)	Y	–	Y	Y	–	–	Y	Y	5
Healthscreen (HS Practice)	Y	–	–	–	–	–	Y	Y	3
Jonoke (JonokeMed)	Y	Y	Y	Y	Y	Y	Y	Y	8
Nightingale (On-Demand)	Y	–	Y	Y	Y	–	Y	Y	6
Optimed (Accuro)	Y	Y	Y	–	Y	–	Y	–	5
OSCAR	Y	Y	Y	Y	Y	Y	Y	Y	8
P&P Data Systems (CIS)	Y	Y	Y	Y	Y	–	Y	Y	7
Practice Solutions (PS Suite)	Y	Y	Y	Y	Y	Y	Y	Y	8
xwave (xwaveEMR)	Y	Y	Y	Y	Y	Y	Y	Y	8
York-Med (MD Suite)	Y	Y	Y	Y	Y	–	Y	Y	7
Acute care EHR systems									
B Sharp (B Care)	Y	–	–	–	Y	–	–	Y	3
Cerner (PowerChart)	–	–	Y	Y	–	–	–	–	2
Eclipsys (Sunrise Clinical Manager)	–	Y	Y	Y	Y	–	–	Y	5
QuadraMed (QCPR)	Y	Y	Y	Y	Y	Y	Y	–	7
Telus (oacis)	Y	Y	Y	Y	Y	–	–	Y	6
	19	15	19	17	18	8	17	13	

^a Health information & data

^b Results management

^c Order entry/management

^d Decision support

^e Electronic communication & connectivity

^f Patient support

^g Administrative processes

^h Reporting & population health management

Persuasive Features

The main findings related to building consumer confidence and use of direct persuasive strategies for both acute and primary care vendor websites are discussed in detail below.

Information Building Consumer Confidence

The following aspects related to building consumer confidence in the vendors, their websites, and by extension, their products were identified: (1) last date of update; (2) external connections

(ie, affiliations with or certification by associations, partners, and suppliers); and (3) customer support (eg, documentation, technical support, contact information). Findings related to each of these aspects are summarized in [Table 3](#). First, the majority of sites were updated in 2010, the year in which data collection took place (11 of 16 (69%) primary care vendors, and 3 of 5 (60%) acute care vendors). Of the seven remaining sites, five were updated in 2008 or 2009, one was updated in 2007, and one had no update information.

Table 3. Means for establishing consumer confidence presented on vendor websites.

Vendor (System)	Last update	Affiliates	Client support ^m
Primary care EHR systems			
ABELSoft (ABELMed)	2010	ONMD ^a , MS ^b	24/7 helpdesk
AlphaIT (GlobeMed)	2010	–	Client section ⁿ
AlphaIT (UHM)	2010	–	Client section ⁿ
Clinicare (EliteCare)	2008	IBM	Support section
Eclipsys (Sunrise Ambulatory Care)	2010	–	Standard only
EMIS	2010	MS ^b , HP ^c	Standard only
GE (Centricity)	2010	–	Customer portal ⁿ
Healthscreen (HS Practice)	2008	OMA ^d , COFP ^e	Physician section ⁿ
Jonoke (JonokeMed)	2009	BBB ^f , Apple, CHITTA ^g , Dell, LaCie	Client section ⁿ
Nightingale (On-Demand)	2010	ONMD ^a	Client section ⁿ , unlimited tech support, documentation
Optimed (Accuro)	2010	Clinicare	Standard only
OSCAR	2010	ONMD ^a , McMaster	Not standard; user society, listservs, blog
P&P Data Systems (CIS)	2010	ONMD, Dell, MS ^b , HP ^c , Sun	Client section ⁿ , remote desktop
Practice Solutions (PS Suite)	2010	CMA ^h , ONMD ^a	Client portal ⁿ
xwave (xwaveEMR)	2009	Bell Aliant, GE ⁱ , ONMD ^a , ITAC Health	Client section ⁿ , helpdesk
York-Med (MD Suite)	2007	ONMD ^a	Helpdesk, webcasts
Acute care EHR systems			
B Sharp (B Care)	2009	MS ^b , Sun, client list	Standard only
Cerner (PowerChart)	2010	CCHIT ^j	Standard only
Eclipsys (Sunrise Clinical Manager)	2010	–	Standard only
QuadraMed (QCPR)	n/a	HIMSS ^k , AHIMA ^l	Client section ⁿ
Telus (oacis)	2010	–	Only phone, email

^a OntarioMD^b Microsoft^c Hewlett-Packard^d Ontario Medical Association^e College of Ontario Family Physicians^f Better Business Bureau^g Now ITAC Health^h Canadian Medical Associationⁱ General Electric^j Certification Commission for Health Information Technology^k Healthcare Information and Management Systems Society^l American Health Information Management Association^m Client support includes standard contact information (phone, email, mailing address, optional fax) unless otherwise stated.ⁿ Viewer must be logged in.

Second, most vendors noted affiliations with technology companies or health-related associations on their websites. Six vendors did not have any affiliates or partners listed. Of the

three acute care vendors who mentioned other organizations, Cerner and QuadraMed listed American health care associations (the Certification Commission for Healthcare Information

Technology and the American Health Information Management Association, respectively). The third vendor, B Sharp, listed affiliations with technology companies such as Microsoft and Sun and displayed a client list of Ontario health care organizations.

Eight of the twelve primary care vendors with systems certified by OntarioMD (67%) mentioned this certification. However, this certification was not emphasized by most vendors and was separated from information about the system or mentioned only as a news item; only ABELMed conspicuously displayed the OntarioMD logo on its homepage. Seven primary care vendors listed affiliations with technology companies such as Dell and Microsoft. A number of health organizations were seen as well, such as the Ontario Medical Association (Healthscreen) and CHITTA/ITAC Health (Jonoke and xwave). Additionally, the Canadian Medical Association and McMaster University are unique in that they are the parent organizations of Practice Solutions and OSCAR, respectively.

All vendors but two provided “standard” contact information on their websites (phone number, online contact, mailing address, and possibly a fax number). The two that did not were OSCAR, which does not have a central location or head office, and Telus, which provided only a phone number and email address. OSCAR did not provide conventional contact information, but as an open source project there are listservs and blogs providing online support. Free membership in the OSCAR User Society was also encouraged to connect with other users, and the software source code is freely available. Third-party service providers support OSCAR implementations on a paid basis [18].

Of the acute care vendors, only QuadraMed went beyond the standard information to include a client-only section. In contrast, a number of primary care vendors mentioned providing 24/7 support in the form of phone lines or online help. One vendor (York-Med) advertised regular continuing education webcasts

for clients. Thirteen of the 16 vendors (81%) provided some sort of client-only section on their website, presumably containing documentation and resources.

In order to give potential customers a better idea of their product, some vendors provided a demonstration of their system interface. Six websites posted only screenshots, three posted videos that were only available to viewers who logged into the site, and four had publicly available video demos. Of these four (AlphaIT UHM, OSCAR, Practice Solutions PS Suite, and xwaveEMR), only AlphaIT UHM and OSCAR went beyond a slideshow format and showed the system in active use. The full version of OSCAR can also be freely downloaded.

Direct Persuasive Strategies

The main categories of direct persuasive strategies used by vendors that emerged from the data were: (1) directional text (ie, text that encourages the user to identify with the system through the use of possessives, such as “your organization” or “your patients”); (2) customer testimonials; (3) online product demonstrations; and (4) topics addressed (general discussion topics around EHRs such as privacy and security concerns, cost savings or return on investment, and digitization of existing records). Table 4 provides an overview of vendors’ use of these direct persuasive strategies. Most vendors had some form of testimonial on their website. Seven of the 21 systems (33%) did not have testimonials, but three of those had space set aside for future testimonials. Of the 14 systems with testimonials, 12 were for primary care systems. Only two of the acute care vendors had testimonials (B Sharp and Telus), and one of these was on a PDF brochure instead of on the webpage itself. The most common form of testimonial was a short quote, often with part or all of the user’s name and organization. Some vendors extended the testimonials into case studies, going more in-depth into the client’s practice and implementation. EMIS and Telus each used a video testimonial instead of text.

Table 4. Direct persuasive strategies employed on vendor websites ^a.

Vendor (System)	Client Testimonials				Product Demos			Topics Discussed				Total
	Blank Page	Short Text	Long Text	Video	Image	Video	Mock Site	1 ^b	2 ^c	3 ^d	4 ^e	
Primary care EHR systems												
ABELSoft (ABELMed)	–	Y	–	–	–	–	–	Y	–	Y	–	3
AlphaIT (GlobeMed)	Y	–	–	–	–	O	–	–	–	–	–	2
AlphaIT (UHM)	Y	–	–	–	–	Y	–	–	–	–	–	2
Clinicare (EliteCare)	–	Y	–	–	Y	–	–	–	–	–	–	2
Eclipsys (Sunrise Ambulatory Care)	–	–	–	–	–	–	–	Y	Y	–	–	2
EMIS	–	Y	–	Y	–	–	–	Y	–	Y	–	4
GE (Centricity)	–	–	–	O	–	O	–	Y	–	Y	–	4
Healthscreen (HS Practice)	–	Y	–	–	–	–	–	Y	–	Y	–	2
Jonoke (JonokeMed)	–	Y	–	–	Y	–	–	Y	Y	Y	–	5
Nightingale (On-Demand)	–	–	Y	–	–	O	–	–	–	–	–	2
Optimed (Accuro)	–	Y	–	–	Y	–	–	Y	–	–	Y	4
OSCAR	–	–	Y	–	Y	Y	O	–	–	Y	–	5
P&P Data Systems (CIS)	–	Y	–	–	Y	–	–	–	Y	–	Y	4
Practice Solutions (PS Suite)	–	–	Y	–	–	Y	–	–	Y	Y	Y	5
xwave (xwaveEMR)	–	–	Y	–	–	Y	–	–	Y	Y	Y	5
York-Med (MD Suite)	–	Y	–	–	–	–	–	–	–	Y	–	2
Acute care EHR systems												
B Sharp (B Care)	–	Y	–	–	–	–	–	–	Y	–	–	2
Cerner (PowerChart)	–	–	–	–	–	–	–	–	Y	–	–	1
Eclipsys (Sunrise Clinical Manager)	–	–	–	–	–	–	–	Y	Y	–	Y	3
QuadraMed (QCPR)	Y	–	–	–	–	–	–	Y	Y	–	Y	4
Telus (oacis)	–	–	–	Y	Y	–	–	Y	Y	Y	–	5
Total	3	9	4	3	6	7	1	10	10	10	6	

^a Labels: Y: Website contains feature; O: Website contains feature, but viewer must be logged in; –: Website does not contain feature.

^b 1: Quality of care

^c 2: Integration/interoperability

^d 3: Costs/Return on investment

^e 4: Practice efficiency/productivity

The use of text speaking directly to the intended audience was prevalent across vendor websites, with the single exception of the QuadraMed site. Other sites discussed their systems in relation to “your practice” and “your organization”. Some primary care vendors described features from a clinician’s point of view, using statements such as “you can easily draw pathology” (ABELMed) or “you [can] add sketches or pictures to a record” (JonokeMed). This directional text, combined with the use of testimonials, made it clear what audience each site intended to reach. The acute care vendors directed their sites to health organization executives and administration, or the people within the organization responsible for selecting and purchasing institutional software. In contrast, primary care sites were aimed

very directly at physicians who owned their own practices or were part of a small group practice.

All of the vendors, except for Clinicare, went beyond system-specific issues and included general discussions surrounding the adoption of EHRs and implications for practice. Topics discussed by acute care EHR vendors included integration of data within an organization or with external organizations, and the resulting improvements in quality of care, resource efficiency or productivity. Primary care EHR vendor websites discussed the impact of EHR adoption on practice administration and workflow. Related to this, a number of vendors emphasized the training and support they provide to ease the transition and ensure that physicians are able to use

EHRs comfortably. Several vendors stated that paper charts could be scanned into the system. Finally, nine of the primary care EHR vendors (56%) discussed the potential cost savings and return on investment. While none of the vendors quoted a price for their product (except for OSCAR, which is free), many stated that their systems would help offset costs through efficient billing and administration, eg, “Fee for Service physicians... will see an immediate improvement in cash flow, which can lead to significant savings to the practice over time.” (ABELMed Inc).

Comparison of Vendor Websites and OntarioMD Information

The overlap between the information on vendor and OntarioMD websites for the 12 certified primary care systems is presented in Table 5. Vendor websites only contained a subset of the data gathered from the OntarioMD site; none of the vendors included all of their OntarioMD information on their own website. Of the 14 points of comparison between the OntarioMD data and the vendor websites, only the inclusion of templates and

bilingual interfaces are fully represented in both data sources. For all of the other categories, the vendor websites were less complete than the OntarioMD site. None of the data missing from the OntarioMD information were subsequently found on vendor websites, and the vendor websites often did not go into as much detail as OntarioMD did. This was particularly noticeable for technical configuration specifications, which were broken down into optimal implementations for three specific scenarios in OntarioMD. Sites that provided configuration details, such as OSCAR and ABELMed, tended to provide general guidelines regarding compatible equipment and leave details such as the number of computers required to the discretion of the practice. Notably, a number of categories from OntarioMD website are not truly applicable to OSCAR, which is an open source system. Although it lists McMaster University as its vendor in OntarioMD, this is not the same vendor-product relationship as other systems, since third-party providers would handle services such as remote server management and backup.

Table 5. Information overlap between OntarioMD and vendor websites.

System Information	Source (Ontario MD or Vendor)		
	OntarioMD only	Both	Neither
Size of User Base	4	6	2
Training Program	4	8	0
Support Program	3	9	0
Frequency of System Upgrades	8	4	0
Conversion of Electronic Data	6	6	0
Health Card Validation	5	7	0
Data Entry Templates	0	12	0
Bilingual Interface	0	2	10
Clinical Coding Systems	2	10	0
Configuration Specifications	8	4	0
Remote Server Management	6	6	0
Member of a Vendor Collaborative Network	2	1	9
Health Canada Medical Device Licensing	1	1	10
CanadianEMR Rating	9	1	2
Total	58	77	33

Discussion

The main finding of this study is that vendors, especially of acute care EHRs, provide little product-specific information on their websites. Instead, they try to create favorable attitudes towards EHRs in general, and their products in particular, by other means such as customer testimonials and use of language directed at potential adopters. Obviously, vendor websites are only one source of information about EHRs. Other sources include advertisements in professional journals, salespeople, and peers [2,3,19]. However, the Internet is often the first place people turn to when they seek information about a product [20]. Potential EHR adopters are likely to turn to it at the knowledge stage of the innovation-decision process to become aware of

potential offerings and gain basic how-to and principle knowledge. Therefore, the dearth of product specific information on vendor websites could render potential adopters unable to evaluate the various offerings and reach an informed adoption or rejection decision. In particular, the lack of screen captures and demos could make it hard for potential adopters to assess the ease of using the system. Screen captures and demos may also help in forming a mental model of the system [21,22] and thus gaining principle knowledge.

In other domains, many software vendors provide trial versions of their products. Often, fully functional software is free to use for a limited time (eg, SPSS [23]; McAfee Antivirus [24]). In other cases a free “demo” version with limited functionality is provided (eg, RealPlayer [25], Malwarebyte Anti-Malware [26])

[27]. Interestingly, except for OSCAR, which is free, neither of these free trial options was offered by any of the vendors. This may be due to vendors' reluctance to expose their products to competitors. Additionally, to fully function, EHRs often need to interface with other systems such as laboratory and back-office (eg, billing) [20]. This interoperability may not be possible with free trial versions and, therefore, vendors may prefer live on-site demonstrations over providing a free trial demo. Nevertheless, the lack of trial versions may, to some extent, hinder EHR adoption.

Second, we found that vendors of primary care EHRs provide more information about their products on their websites than vendors of acute care systems. This could be explained by differences in procurement processes. In hospitals, procurement often involves a request for information or proposals (RFI and RFP, respectively) [28]. Vendors may provide detailed information about their products in their responses to RFIs or RFPs and therefore do not feel the need to include it on their websites. In primary care, it is often independent physicians who make purchase decisions, for which they review the various alternatives without going through a formal RFP process [2]. This may also explain why there is often more information on the OntarioMD website than on the individual vendor websites: as physicians must apply for provincial funding through OntarioMD, this would probably be the first place they look for information, and it provides them with a one-stop shop that contains standard information on all certified systems in Ontario. Vendors know that and therefore may not bother with providing complete information on their websites.

Limitations and Directions for Future Research

One challenge of working with websites is that they are extremely dynamic. Changes to websites may include design modifications, changes to content by the website owner or creator, as well as by others (especially with the advent of Web 2.0), changes to the link structure (both from and to the website), change of location, or removal of the website [29]. Our study

captures only a snapshot from 2010, when data were collected. Since then, many sites have been revamped (eg, Eclipsys has been merged into Allscripts; xwave was purchased by Bell and renamed Bell EMR), and some now provide additional information.

All data for this study were taken at face value from the various websites, without accessing the EHRs themselves to verify claims. Gaining access to all systems and producing an impartial comparison would be a valuable information resource. Related to this, substituting the comparison criteria that we used (taken from the IOM) with a different set of criteria, such as technical specifications, would also create a useful information resource that does not currently exist. Additionally, this study included only systems available in Ontario, Canada, and the findings may not apply to other jurisdictions. Similar studies in other jurisdictions could reveal whether our results are indicative of wider trends. Finally, in this study, we looked only at the information presented on vendor websites but not at whether and to what extent it actually affects adoption decisions. It would be interesting to explore the relationships between information on vendor websites and actual EHR adoption levels (eg, market shares). Future research may also look at what other information sources and communication channels are used by physicians and health care organizations in the EHR adoption-decision process, how these resources affect their decisions, and to compare this process with other products and industries (eg, automobile [20]).

Conclusion

To our knowledge, this study is the first systematic attempt to analyze information presented on EHR vendor websites. Our findings suggest that vendors use various persuasive means to create user confidence and affect their perceptions of EHR systems; however, there is often a lack of specific product information. Greater transparency and provision of concrete product information may benefit both vendors and clients.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Vendor website analysis data collection form.

[[PDF File \(Adobe PDF File\), 71KB - jmir_v15i2e36_app1.pdf](#)]

Multimedia Appendix 2

Power Point presentation of home pages of vendor websites included in the analysis. Screen captures taken at the time of data collection (August 2010).

[[PPTX File, 2MB - jmir_v15i2e36_app2.pptx](#)]

Multimedia Appendix 3

This Power Point presentation includes screen captures from vendor websites that demonstrate systems' interfaces. Screen captures taken at the time of data collection (August 2010).

[[PPT File \(Microsoft PowerPoint Presentation\), 1MB - jmir_v15i2e36_app3.ppt](#)]

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Abbreviations

CHITTA: Canadian Healthcare Information Technology Trade Association

EHR: Electronic Health Record

EMR: Electronic Medical Record

IOM: Institute of Medicine

ITAC: Information Technology Association of Canada

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Original Paper

Eight Questions About Physician-Rating Websites: A Systematic Review

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Abstract

Background: Physician-rating websites are currently gaining in popularity because they increase transparency in the health care system. However, research on the characteristics and content of these portals remains limited.

Objective: To identify and synthesize published evidence in peer-reviewed journals regarding frequently discussed issues about physician-rating websites.

Methods: Peer-reviewed English and German language literature was searched in seven databases (Medline (via PubMed), the Cochrane Library, Business Source Complete, ABI/Inform Complete, PsycInfo, Scopus, and ISI web of knowledge) without any time constraints. Additionally, reference lists of included studies were screened to assure completeness. The following eight previously defined questions were addressed: 1) What percentage of physicians has been rated? 2) What is the average number of ratings on physician-rating websites? 3) Are there any differences among rated physicians related to socioeconomic status? 4) Are ratings more likely to be positive or negative? 5) What significance do patient narratives have? 6) How should physicians deal with physician-rating websites? 7) What major shortcomings do physician-rating websites have? 8) What recommendations can be made for further improvement of physician-rating websites?

Results: Twenty-four articles published in peer-reviewed journals met our inclusion criteria. Most studies were published by US (n=13) and German (n=8) researchers; however, the focus differed considerably. The current usage of physician-rating websites is still low but is increasing. International data show that 1 out of 6 physicians has been rated, and approximately 90% of all ratings on physician-rating websites were positive. Although often a concern, we could not find any evidence of "doctor-bashing". Physicians should not ignore these websites, but rather, monitor the information available and use it for internal and external purpose. Several shortcomings limit the significance of the results published on physician-rating websites; some recommendations to address these limitations are presented.

Conclusions: Although the number of publications is still low, physician-rating websites are gaining more attention in research. But the current condition of physician-rating websites is lacking. This is the case both in the United States and in Germany. Further research is necessary to increase the quality of the websites, especially from the patients' perspective.

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KEYWORDS

Physician rating websites; patient narratives; public reporting; transparency; systematic review

Introduction

Creating more transparency about the quality of health care providers has become a major challenge in delivering more effective and efficient health care quality [1,2]. According to the theory of Public Reporting (PR), patients are expected to inform themselves about the quality of participants in the health care system (eg, physicians, hospitals, health plans) before making decisions and selecting health care providers [3-5]. The newest development within this movement is physician rating websites, which are gaining popularity among patients [6-8]. It is noteworthy that there are already PR instruments in place, such as the New York State Cardiac Surgery Reporting System (CSRS) (eg, [9-11], Nursing Home Compare [12], or the German Klinikführer Rhein-Ruhr [13]. However, physician-rating websites are a consumer-driven alternative [14]. Traditional PR initiatives generally assess the quality of care of health care providers by measuring adherence to clinical guidelines, and some also include information on patients' satisfaction [2]. In contrast, the primary focus of physician-rating websites lies in rating and discussing the performance of physicians; however, one can also find addresses, opening hours, and certification of the physicians [2]. Although the usefulness of physician-rating websites has been seen as critical [6], greater importance must be assumed [7,15].

In this paper, we summarize the existing literature on physician-rating websites based on a systematic review of published articles. Our objective was to provide a structured, comprehensive overview of the available evidence on physician-rating websites. Therefore, we addressed the following eight topics: 1) What percentage of physicians has been rated? 2) What is the average number of ratings on physician-rating websites? 3) Are there any differences among rated physicians related to socioeconomic status? 4) Are ratings more likely to be positive or negative? 5) What significance do patient narratives have? 6) How should physicians deal with physician-rating websites? 7) What major shortcomings do physician-rating websites have? 8) What recommendations can be made for further improvement of physician-rating websites?

Methods

For this review, we adhered to guidelines from the Cochrane Collaboration [16], the Institute for Quality and Efficiency in Health Care [17], the Hannoveraner Konsensus [18], and the NHS Economic Evaluation Database [19]. In total, we searched the following seven databases: Medline (via PubMed), the Cochrane Library, Business Source Complete, ABI/Inform Complete, PsycInfo, Scopus, and ISI web of knowledge. Articles published prior to May 2012 were eligible for inclusion. We

also included commentaries, discussion papers, etc., if published in peer-reviewed journals. The focus of the article had to deal with websites on which individual physicians (ie, not entire hospitals) could be rated.

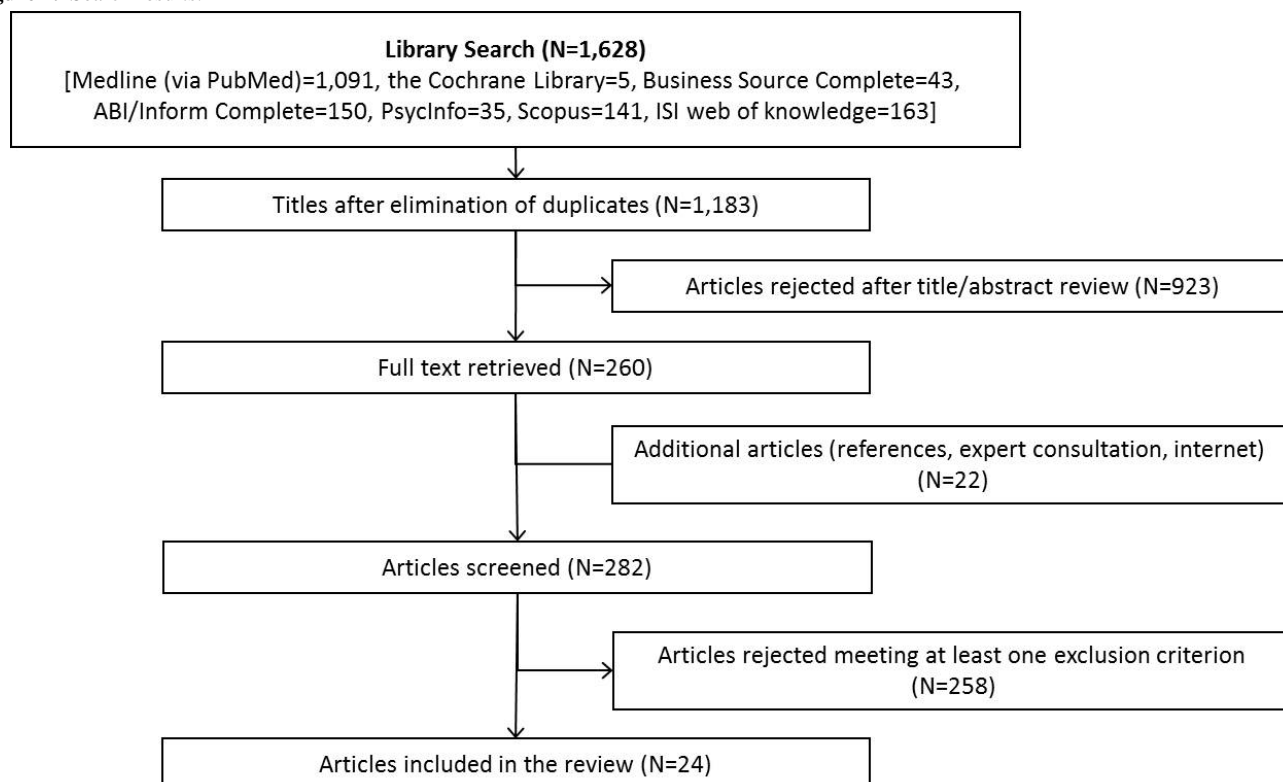
Our search strategy was segmented into two components (the search history is available upon request from the first author). The first component referred to physicians (eg, physicians, doctors, or health care providers), and the second to online rating websites (eg, rating sites, rating websites, review sites, review websites, websites to assess, Internet ratings, online ratings, web ratings, online reviews, opinion websites, experience websites, online physician ratings, online doctor ratings, online provider ratings, or public reporting). Search terms included both singular and plural. Search terms from previously published studies were used (eg, [2,6,14,20-22] and further expanded. To ensure that relevant documents would not be missed, we also searched the Internet via Google, Google Scholar, and reviewed reference lists.

Two authors independently reviewed all papers generated by the search procedure and assessed their eligibility for inclusion (discussion between the 2 authors resolved the few disagreements). They also independently extracted relevant information from identified articles. Both authors used the same abstraction form, containing the following elements: authors, year of publication, country, assessed physician-rating websites, and the information relevant to our questions (see above). Again, discussion between the 2 authors resolved the few minor differences that emerged. Due to heterogeneity of the studies, no study appraisal was carried out. As a minor requirement, we defined publishing in a scientific journal with a peer-review process.

Results

Search Results

The initial search identified 1628 articles. After eliminating duplicates and a review of titles and abstracts, 260 studies remained for detailed reflection (see Figure 1). Screening of reference lists, expert consultation, and Internet searches yielded 22 additional articles. Finally, 24 articles met our inclusion criteria. It is worth mentioning that the papers included vary considerably by inclusion criteria and focus. The result is a wide range in the number of included studies. Furthermore, all studies were published either in English or German. We did not find a study containing an English language abstract in another language (eg, Spanish, French) during our review process. Most papers have been published by US (n=13) or German authors (n=8). Two studies were published in 2007, five studies in 2009, eight in 2010, four in 2011, and five in 2012.

Figure 1. Search results.

Question 1: What Percentage of Physicians Has Been Rated?

First, we investigated the number of ratings on physician-rating websites. One study estimated the number of ratings on physician-rating websites from a national perspective. Data for US physicians obtained from RateMDs showed that 16% (112,000 out of approx. 700,000) of national physicians were assessed by January 2010 [7]. Some studies regarded a sample of physicians to conduct analyses. Lagu and colleagues showed that 81 out of 300 Boston physicians had been rated (27%) [2]. In another study, Mostaghimi and colleagues counted that, out of 250 randomly selected internal medicine physicians, 53 physicians (21%) were rated on Healthgrades, 13 (5%) on RateMDs, and 1 physician on Wellness (0.4%), respectively. Most of the 250 physicians had still not been rated (Healthgrades: 69%, RateMDs: 61%, Wellness: 98%, respectively) [23]. In 2009, the percentage of rated physicians for ten different specialty/region combinations on five German physician-rating websites varied between 0% (eg, for urologists in Frankfurt) and 100% (radiologists in Hannover). The overall mean percentage of rated physicians was reported to be at between 3.36% (Patienten-empfehlen-Ärzte) and 25.78% (Medführer), respectively [21]. In a recently published study, between 3% and 28% of a random sample of physicians had been rated at least once [24].

Question 2: What Is the Average Number of Ratings on Physician-Rating Websites?

Regarding the average number of ratings per physician on physician-rating websites, results for the American physician-rating website RateMDs were reported to be 2.7 mean ratings (range = 1-103) in 2009 [25] and 3.2 in January 2010

[7]. Nearly half of the physicians had only a single rating on RateMDs in 2010, and the number of physicians with five or more ratings was 12.5% [7]. For a sample of 300 Boston physicians, 190 reviews had been posted in total, ie, the mean number of ratings was 0.63 per physician. If only rated physicians ($n=81$) were analyzed, the mean number increased to 2.35 ratings [2]. Regarding a subsample of 250 randomly selected physicians in Boston, between one and four reviews could be found with 29% on Healthgrades, 39% on RateMDs, and 2% on Wellness, respectively. On Healthgrades, only 3 physicians (2%) had more than five reviews; no physician with five or more ratings could be found on RateMDs or Wellness [23]. German results from 2010 show similar findings; the number of ratings for physician-rating websites was reported to be 600,000 for Jameda, 450,000 for DocInsider, 150,000 for Arztauskunft, and 73,000 for Imedo, respectively. Compared to the total number of physicians in the German outpatient sector (approximately 150,000), the highest mean of approximately four evaluations per physician could be tracked on the website Jameda [6]. Another study determined a mean number of ratings of between 1.1 and 3.9; the maximum number of ratings per physician varied across the physician-rating websites at between 3 and 27 [24].

Question 3: Are There Any Differences Among Rated Physicians Related to Socioeconomic Status?

There is little evidence available to answer the question of whether there are differences among rated physicians according to their socioeconomic status. Only three studies provided evidence relevant to this question. One previously published study showed that 74% of rated physicians were male (national average 72%). It was also shown that physicians who were board certified, and those who had at least one paid malpractice

claim, were more likely to be rated. The authors could further show that younger physicians were much less likely to be rated. Graduates of more highly ranked medical schools and those of lower-ranked medical schools were rated with nearly the same frequency [7].

With respect to subgroups of physicians, Lagu and colleagues determined the number of rated generalists (37) and subspecialists (38) to be quite similar [2]. In absolute terms, primary care physicians were more likely to be rated than other specialties such as surgeons or obstetrics/gynecologist [7]. Another study showed that nonsurgical subspecialties, as well as OBGYN (Obstetrics Gynecology) & IVF (in-vitro fertilization), were most rated (22% and 19%, respectively). The lowest percentage of ratings was determined for doctors specialized in physical medicine and general surgery (1% and 2%, respectively) [25]. In relative terms, compared with the national physician composition, rated physicians were most likely to be obstetrician/gynecologists (32%). The likelihood of being rated for other specialties was calculated as follows: 25% of medical specialists, 20% of surgeons, 16% of primary care physicians, and 7% of physicians classified as other specialists (such as radiologists, pathologists, and anesthesiologists) [7]. Black et al showed that nonsurgical subspecialty and internal medicine physicians have been rated most (28% and 13%, respectively). In contrast, general surgery and physical medicine physicians have been rated the least (3% and 1%, respectively) [25]. Also, the numbers of individual ratings varied across specialty; the highest numbers were counted for OBGYN and IVF, dermatology, and cosmetic surgery (mean 4.4 individual ratings) and the lowest for pediatrics and general surgery (mean 1.8 ratings) [25].

Question 4: Are Ratings More Likely to Be Positive or Negative?

In total, six studies provide information on the results of the ratings. Two studies focused on the US site RateMDs and found the overall reviews to be quite positive. On a scale of 1 to 5, the mean score was reported to be 3.93 [7] and 3.82 [25], respectively. A comprehensive analysis of German physician-rating websites confirmed that most ratings were positive. Here, the mean rating was between 1.1 and 1.5 (3-point scale, 1 “good”, 3 “poor”) [24]. When assessing the 10 most commonly visited US physician-rating websites, the aggregated mean ratings were as follows [22]: 77 out of 100 when using a 100-point scale (SD 11), 3.84 out of 5 (77%) for sites using a 5-point scale (SD 0.98), and 3.1 out of 4 (78%) for sites using a 4-point scale (SD 0.72). It was further reported that the percentage of reviews rated ≥ 75 on a 100-point scale was 61.5%, ≥ 4 on a 5-point scale was 57.74%, and ≥ 3 on a 4-point scale was 74.0% [22]. On RateMDs, 45.80% of the physicians received the best score and only 12% were rated with the worst score [7]. Other studies do not provide a mean rating but give further information about the percentage of positive and negative reviews. Lagu und colleagues did the same when they reported that the vast majority (88%) of reviews were positive, only six percent were negative, and six percent were neutral [2]. On Canadian RateMDs, 70% of the comments were reported to be favorable and about 30% comments were negative [26].

Exploring in more detail, the rating differences between physician groups was assessed in some studies. Gao et al found similar mean ratings for physicians in primary care (4.02), medical specialties (3.96), surgeon and surgical specialties (3.89), and obstetrician/gynecologists physicians (4.01). They further demonstrated that physicians listed within the group of other specialties had lower ratings (3.59) [7]. Others reported the highest mean scores for pediatricians, general surgery, and subspecialty surgery (4.22, 4.10, and 4.07, respectively) [25]. Lagu et al determined that generalists and subspecialists had a similar percentage of positive, negative, and neutral reviews [2]. Furthermore, male physicians, younger physicians, board-certified physicians, and those graduating from a top-50 medical school were shown to have statistically significant better ratings [7].

Question 5: What Significance Do Patient Narratives Have?

Patients have the choice of writing narrative commentaries in free text form on 86% of English-language and German-language physician-rating websites [14]. Physicians' critiques often concern these narratives, as they might provide the opportunity for doctor-bashing, defamation, etc. However, obtaining actionable information might help physicians to change communication style, facility, or staff. Such information may be better obtained by those narratives, rather than by a scaled survey displaying numbers or stars. A single quantitative rating of 1 out of 5 stars does not provide further assistance for improvement. But, if comments show that the exam rooms were dirty, then the provider will better understand the low rating [22].

Numbers on how many physicians have been rated by means of a patient narrative are quite scarce. According to US evidence, there is at least one narrative rating for approximately 17% of physicians [2]. Alemi and colleagues showed that the mean number of patient narratives per physician for a sample of 200 rated physicians by means of a patient narrative was 9 (range from 1 to 57, SD 8.10) [27]. Furthermore, the authors found that narratives were mostly positive (89%) [2]. In another study, Lopez et al qualitatively analyzed 712 narratives for internists and family practitioners from RateMDs and Yelp and found that 63% of the narratives contained positive comments [8]. In an analysis of 995 narratives from RateMDs, it could be determined that 69% (688) were praise, 21% (210) were complaints, and 10% (97) were both [27]. This result was confirmed by Black et al, showing that positive terms (54.1%) were more frequent than negative terms (16.0%) [25]. Thereby, the five most common positive terms were good, knowledgeable, best, excellent, and wonderful. In contrast, the most common negative terminology found was rude, bad, worst, horrible, and terrible [25]. The mean length of the narratives on RateMDs was 19.3 words [25]. Finally, Alemi and colleagues coded narratives with several reasons for dissatisfaction into nine categories, such as (1) physician-related concerns, (2) staff-related issues, (3) getting in to be seen, etc. As a result, most comments were related to aspects of category 1 (eg, doctor's advice and treatment, time doctor takes, explanations provided by the doctor) and category 2 [27].

Question 6: How Should Physicians Deal With Physician-Rating Websites?

Many physicians are uncertain about how to deal with physician-rating websites. Authors seem to agree that physician-rating websites will play a major role in health care in the future, and physicians should therefore not underestimate, but instead recognize, the popularity of such websites [23,25,28,29]. Physicians should be further aware of the fact that not only patients, but also insurance companies or even other physicians check these sites; the latter, for instance, to get information about job candidates [30].

Physicians should perform “self-audits” on popular physician-rating websites to search for available information [23,30], like their scores [29]. Therefore, it may be helpful if a staff member monitors these sites on a regular basis. If nothing else, physician-rating websites often provide incorrect demographic information (eg, incorrect address, links to old practices, opening hours), which should be corrected [23,30]. Next, physicians should use the ratings in order to evaluate their patients’ satisfaction [31]. Since existing measures of patient experiences do not seem to facilitate a good understanding for health care providers, personalized feedback on physician-rating websites may be advantageous. Rather than departmental reports or annual surveys, anonymous Internet-based reviews may help health care providers improve the quality of care [25]. Furthermore, measures such as medical training rarely give the opportunity to hear what patients want or value because in the real workplace, disappointed patients rarely tell doctors their true opinions. So, patients’ true thoughts on what makes a good doctor, what they value, etc., can be understood [29].

In the case of negative reviews, it is best not to respond online to try to refute the negative review point by point [30]. Further, negative reviews may help providers to create a more patient-centered office environment. Negative interpersonal reviews underscore the importance of a well-perceived bedside manner for a successful patient-physician interaction. Staff, access, etc., affect patient’s reviews as well [8]. However, the challenges of finding a remedy for negative ratings are daunting. An alternative option is to treat the problem before it becomes a problem. The legal company Medical Justice offered to provide doctors with a contract for treatment that includes a clause requiring patients to ask their doctor’s permission before posting a review to a website [30,32,33] (it is worth mentioning that the company has since stopped that practice). Another approach is to politely encourage satisfied patients to submit their own reviews on the most popular physician-rating websites [26,30]. Additionally, positive comments from patients should be posted on one’s own website [30]. Finally, physicians should not make a referral decision based upon results on physician-rating websites, as results related to patient satisfaction and outcome measures are not risk-adjusted and therefore cannot be regarded as reliable [6].

Question 7: What Major Shortcomings Do Physician-Rating Websites Have?

Next, we discuss the major shortcomings of physician-rating websites.

1. Due to incomplete databases, it is shown that many physicians are not even listed on physician-rating websites [34,35]. For example, out of a random sample of 298 German physicians, between 75% and 98% of the physicians could be found [24].
2. On most physician-rating websites, only a small number of physicians have been rated so far [6,23,31,32,35]. As mentioned previously, only 16% of practicing US physicians have received at least one rating on RateMDs in 2010 [7], and only a low number of physicians has more than one rating (eg, only 2% had more than five reviews on Healthgrades in 2008) [23].
3. Patient opinions are unstructured, and ratings systems, as well as the presented information, are different on each physician-rating website [14,22,24]. One study showed that 35 different dimensions of care were rated on physician-rating websites [22]. Thus, meaningful information cannot be provided [31], and conducting physician-patient review meta-analysis or comparisons is difficult [24,35].
4. There is still no (gold) standard for surveys implemented on physician-rating websites for measuring patient satisfaction [14,24,28]. Some authors suggest that long surveys with preset questions are missing a great deal of information and force patients to distort their ideas to fit the questions asked [27]. In addition, star-rating systems may be crude and have dubious validity in the way that different categories are aggregated into an overall score [33]. One study showed that surveys vary significantly with respect to certain quality parameters in order to identify a good doctor’s practice [21].
5. Although a broad range of information is available on many physician-rating websites, the data are unlikely to reflect the quality of a physician. Most information is related to structural quality and patient satisfaction. Furthermore, significant measures such as outcomes and patient satisfaction are not risk-adjusted and, thus, are not likely to reflect the quality of care, but more the case mix of patients served [6].
6. Abuse is likely on physician-rating websites [6,21,28], and this leads to potential damage for both doctors (defamation) and patients (misinformation). As individuals can rate anonymously, it is impossible to tell if the rater is a patient or someone posing as a patient [29,32,33]. However, it is worth mentioning that physicians also seem to manipulate information on physician-rating websites [2].
7. Feedback, delivered anonymously, has limited ability to be related to specific incidents. So, it is unlikely that a doctor can learn from posted comments [36].
8. In case physicians disagree with a comment, they may not be able to respond to negative reviews, as they are bound by privacy laws and a duty to preserve the confidentiality of patient information [29,37]. In addition, only a few physician-rating websites allow physicians to respond to negative comments [37].
9. There is still a great lack of evidence of physician-rating websites’ effects on physicians’ performance, patient outcomes, or the public’s trust in health care [20]. There is further a lack of knowledge on how physician-rating

websites might be used by patients, why they are used, and the usefulness of the information gathered [38].

- In general, the role of patients as reviewers of health care quality is still seen controversially: one argues that patients are not skilled or knowledgeable enough to assess the technical quality of care received [37,38]. Others state that patients' experience is an important component of measuring the quality of care [38].

Question 8: What Recommendations Can Be Made for Further Improvement of Physician-Rating Websites?

Several strategies have been suggested for further improvement of physician-rating websites. These address some of the limitations mentioned above:

- Some authors discuss whether a simple One Feedback Question containing a single question such as "Would you recommend Dr X to a loved one?" may be as useful as the multitude of specific questions. The authors base their recommendation on the fact that there is a high correlation between the overall rating and the other dimensions of care rated [22]. Alemi et al suggest a 2-question survey: the "Minute Survey". The first question asks patients to rate their overall experience. The second question asks: "Tell us what worked well and what needs improvement" [27].
- Many surveys on the physician-rating websites should be revised to improve the usefulness of the ratings [21]. Here, certifications from professional societies and public institutions entailing not only formal and legal standards, but also specifications for a suitable representation and operationalization of patients' experience and satisfaction were proposed. Therefore, a transparent process allowing participation by various stakeholders is essential [14].
- Narrative comments to allow patients to write in specific feedback should be integrated in order to: (1) enable peer-to-peer communication amongst users [24], and (2) provide physicians with actionable information for change (see above) [22].
- Patient narratives should be moderated, ie, there should be an option for the health care provider to comment on the rating [32,33,37]. Only then could a feedback loop be generated between patients and providers that would create value for both patients and providers [33,37].
- Additional information should be considered on the physician-rating websites such as number of published scientific articles, outcome measures, clinical quality related to quality indicators, numbers treated with a certain disease, etc. [6,28]. Medical malpractice information should be addressed if the information source is recognized as authoritative (eg, licensing boards) [32]. Outcome measure scores must be risk-adjusted [6].
- A minimum number of ratings (eg, 5-10) should be determined before publication is carried out [6,20,37]. This would reduce the impact of extreme opinions, and peer review would allow for the differentiation and elimination of defamations [20].
- Certain quality strategies should be established to advance measures against fraud [21], eg, to remove ratings when

meeting certain conditions—an IP address is traced to a medical practice, a lot of postings appear to come from the same source [33], or to apply adequate word filters and manual provider review before publication [21].

- Quality standards for physician-rating websites should be considered by the providers of the websites. An example of this would be the quality criteria list developed by the German Agency for Quality in Medicine (ÄZQ), containing 40 questions and defining main quality standards regarding data privacy, transparency in terms of operators and funding, a clear and understandable assessment procedure, etc. [31].
- physician-rating websites should be specifically tailored to the needs of vulnerable subgroups of the population. Preferably, aspects such as accessibility and the clarity of information should be improved [20].
- Rules of behavior should be stated on each physician-rating website [37]. One example can be found on NHS Choices (eg, Category 12 Conduct, b. Postings should relate to your own personal experience).

Further recommendations advise that inappropriate content must be edited, users must register with an email [37], physician-rating websites should not contain advertising or official messages, as consumers value independence [38], and that ratings must be transmitted to the provider, albeit anonymously [38].

Discussion

Physician-rating websites have been gaining much attention in many industrialized countries recently [7]. Discussions about prevalence of these websites, current usage, the main shortcomings, whether physicians have to worry about these rankings, and how physicians should handle these websites have frequently been raised. The aim of this review was thus to provide an overview of the empirical evidence and expert opinions, which were published in peer-reviewed journals. This paper adds to the literature by summarizing published knowledge with respect to eight ex-ante defined questions, which are deemed important in this context. To our knowledge, this is the first detailed systematic review related to physician-rating websites.

Question 1: What Percentage of Physicians Has Been Rated?

Five papers were identified, and they all concluded that only a small percentage of physicians have been rated so far on a physician-rating website (eg, 16% of US physicians on RateMDs). As a result, the ratings shown are not likely to be representative of average patient experiences or consumers [6,23,29,30,36,37]. However, physician-rating websites have been gaining an increasing number of ratings over the last years (a 100-fold increase in the United States from 2005 to 2010) [7]. One reason for the low usage might be that patients are still unaware of these websites. A representative survey of 2048 German citizens showed that only 10% of respondents had used physician-rating websites in 2011; however, the number in 2010 was only 7% [39].

Question 2: What Is the Average Number of Ratings on Physician-Rating Websites?

Regarding the mean number of ratings on physician-rating websites, US results were reported to range between 0.63 [2] and 3.2 ratings per physician [7]. German results ranged between 0.5 and 4 ratings per physician [6,24]. Thereby, most ratings are given for a low percentage of physicians, meaning that most physicians still remain unrated and those rated have a larger number of ratings. A large US study reported that half of the physicians had only a single rating, and the number of physicians with five or more ratings was 12.5% on RateMDs in 2010 [7]. Consequently, the benefit of such sites for patients still remains limited because more physicians must be rated. The mean number of ratings has to increase to provide a larger benefit to society. However, this might be solved with an increasing awareness level of rating portals.

Question 3: Are There Any Differences Among Rated Physicians Related to Socioeconomic Status?

In total, three studies provided evidence on this question. Certain factors seem to increase the likelihood of being rated on a physician-rating website, such as being older, being male, being board certified, and having at least one paid malpractice claim. Furthermore, some specialties such as primary care physicians and obstetrician/gynecologists seem to influence the likelihood of being rated [7]. Specifically, this includes physicians who have more direct patient contact or those who treat population groups who are more likely to use the Internet actively, such as a younger and female patient population [7].

Question 4: Are Ratings More Likely to Be Positive or Negative?

Some authors expressed concerns whether physician-rating websites might become a channel for disgruntled patients [7]. However, this cannot be confirmed, since international results showed that most ratings express a positive opinion about physicians. One US study determined 88% positive, 6% negative, and 6% neutral ratings [2]. A comprehensive US study confirmed this by showing the mean ratings according to different scoring scales [22]. In sum, studies confirmed that most reviews are on the extreme end, meaning either positive or negative. The studies suggest that most ratings are positive and therefore that some physicians' concerns may be exaggerated [37].

Question 5: What Significance Do Patient Narratives Have?

Our results show that, up to this point, a low number of physicians have been rated by means of a patient narrative; one US study reported a number of 17% [2]. Furthermore, most opinions in narratives are positive (numbers range between 63% and 89%, respectively) [2,8,27]. Physicians' concerns are about "doctor-bashing", defamation, etc. However, no evidence has been found to sustain this concern. Adequate measures seem to be in place before comments are published. German physician-rating websites were reported to have implemented adequate word filters, manual provider review, etc. [21], which seem to be effective. Thus, the risk of defamation of physicians in patient narratives seems to be low. Furthermore, it is worth

mentioning that physicians also seem to manipulate information on physician-rating websites [2].

Question 6: How Should Physician Deal With Physician-Rating Websites?

According to the literature, physician-rating websites might play a major role in future health care; therefore, physicians should not underestimate, but instead recognize, the popularity of such websites [23,25,28,29]. We showed that getting an overview of the physician-rating websites is recommended, as well as staying on top of the available information on a regular basis. However, no general guidelines are available on how to deal with physician-rating websites. While some may continue to ignore physician-rating websites (due to higher age, little engagement, etc.), others may seek this information in order to be informed, and still others will try to obtain as many positive reviews as possible.

Question 7: What Major Shortcomings Do Physician-Rating Websites Have?

While some flaws are of minor importance, there are also some very major ones. In our estimation, the most important flaw is that physician-rating websites are not able to identify the best physician for a specific intervention or disease. Therefore, the information provided is both too little and not (disease) specific enough. However, it should be debated whether physician-rating websites are really supposed to achieve that. It is more likely that physician-rating websites can give some limited impression of, and only of, patient satisfaction and some structural information. But even these results have to be viewed with caution [6,21,28].

Question 8: What Recommendations Can Be Made for Further Improvement of Physician-Rating Websites?

Frequently discussed improvement recommendations relate to the feedback survey. Some argue that a long and detailed survey is necessary to assess the quality of care received. However, the more questions a patient has to answer, the less likely they are to complete the survey [22]. Therefore, a single question is supposed to be sufficient. However, internationally established and validated instruments, such as the Patient Satisfaction Questionnaire from RAND Health (50 items), are more detailed and contain more questions to derive specific results. Consequently, from a researcher's point of view, the application of validated instruments should be preferred.

It also seems to be the predominant opinion that narrative comments should be integrated on physician-rating websites [22,24]. Of course, this also means that the physician-rating website provider has to establish certain quality measures. However, from the point of view of a patient or physician, the benefits justify it. If physician-rating websites are intended to provide real support to patients, then additional information has to be integrated on the websites, and outcomes must be risk-adjusted [6]. For other sectors of health care (eg, hospitals), risk-adjusted outcome measures are increasingly available. In Germany, the Aqua Institut (www.sgg.de) provides quality indicator data about most German hospitals, and a growing segment of this data is available for PR. In the United States,

the Centers for Medicare and Medicaid Services (CMS) offer the website, Hospital Compare. Thus, in the outpatient sector, both outcome information and ratings from patients are available. However, measures about physicians are less available. In Germany, the Aqua Institut has recently started to collect outcome measures about physicians. In the United States, the CMS recently launched Physician Compare, a website publishing data on quality measures for covered professional services provided to Medicare beneficiaries. Consequently, we expect a growing number of risk-adjusted outcome quality indicators to be available in the future for PR about physicians' quality as well.

Limitations

Our systematic review has several limitations. It was based on searches in seven databases, and we included articles containing at least an abstract in English. So, it is possible that additional papers exist that were not included. We further concentrated on papers dealing with websites on which individual physicians can be rated. Consequently, knowledge coming from the assessment of websites on which provider organizations or entire hospitals can be rated is not included in our review. Due to the time constraints of our research (up to May 2012), it may be the case that some recently published papers are not included. By focusing only on peer-reviewed literature, we may have missed information in the grey literature that could also have been of interest in attempting to answer some of our questions. Furthermore, due to study heterogeneity, we did not carry out any study appraisal. Before conducting this review, we conducted some interviews with physicians, patients, and physician-rating website providers to get an impression of important questions. However, there may be other relevant questions to discuss, which we did not identify.

Conclusions

To our knowledge, this is the first systematic review of physician-rating websites. Our research shows that the current usage of physician-rating websites, with respect to the number of ratings, is still low but is increasing. Most ratings express positive opinions; this is true for the results of both

predetermined rating systems and patient narrative comments. Although negative ratings were mentioned across the different studies, there was no evidence that they are worse via this particular mechanism. Consequently, we could not find any evidence of doctor-bashing in any of the studies. Physicians should not ignore these websites but instead should monitor the available information and use it for internal and external purposes. Several shortcomings limit the significance of the results published on physician-rating websites, and some suggestions on improvement were shown to address them.

The literature suggests several fields for future research. These include investigating how to generate and communicate adequate information for patients. Although a lot of information is provided on physician-rating websites, it remains unclear why patients use these platforms and what the relevant information is about physicians that should be considered for publication on physician-rating websites [28,38]. In this regard, it remains unclear whether patients actually understand the information provided enough to make correct choices [37,38]. Furthermore, research should specifically consider the requirements of disadvantaged people (eg, culture, sex, age, education, socioeconomic group, disability, and health status) to find out whether there are any barriers for certain population groups when seeking and using information provided on physician-rating websites [20,28,38]. The cost-effectiveness of physician-rating websites must be investigated to assess whether [28] the effects of the websites (eg, patient steering, quality improvement) are large enough to be viewed as money well spent. In this context, the usability of physician-rating websites seems to be crucial. Studies have shown these sites to be neither user-friendly nor patient-centered [2]. Others state that the handling of some physician-rating websites is too complex for some users with respect to the clarity of the physician-rating website or offered search options [34]. Finally, policy makers could contribute to the development of such sites by establishing a regulatory framework to foster the availability of data assessing the quality of care of physicians. This data then could be used for PR. Therefore, experience from the German inpatient sector (see above) could be used.

Conflicts of Interest

None declared.

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