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Adherence in Internet Interventions for Anxiety and Depression: Systematic Review

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Abstract

Background: Open access websites which deliver cognitive and behavioral interventions for anxiety and depression are characterised by poor adherence. We need to understand more about adherence in order to maximize the impact of Internet-based interventions on the disease burden associated with common mental disorders.

Objective: The aims of this paper are to review briefly the adherence literature with respect to Internet interventions and to investigate the rates of dropout and compliance in randomized controlled trials of anxiety and depression Web studies.

Methods: A systematic review of randomized controlled trials using Internet interventions for anxiety and depression was conducted, and data was collected on dropout and adherence, predictors of adherence, and reasons for dropout.

Results: Relative to reported rates of dropout from open access sites, the present study found that the rates of attrition in randomized controlled trials were lower, ranging from approximately 1 - 50%. Predictors of adherence included disease severity, treatment length, and chronicity. Very few studies formally examined reasons for dropout, and most studies failed to use appropriate statistical techniques to analyze missing data.

Conclusions: Dropout rates from randomized controlled trials of Web interventions are low relative to dropout from open access websites. The development of theoretical models of adherence is as important in the area of Internet intervention research as it is in the behavioral health literature. Disease-based factors in anxiety and depression need further investigation.

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KEYWORDS

Patient dropouts; depression; depressive disorder, major; anxiety disorders; Internet; mental health services; treatment outcome

Introduction

Web-based interventions are effective for a range of mental health disorders including depression, panic, post-traumatic stress disorder (PTSD), perceived stress in schizophrenia, stress, insomnia, and eating disorders [1]. While efficacy trials of Web interventions show good-to-excellent levels of adherence, open access websites have been associated with poor adherence and dropout, with substantial numbers of users not completing all Web pages and exiting websites before the full completion of an offered program [2,3]. For example, Farvolden [4] found that only 1% of participants completed a 12-week open access panic program, and Christensen and colleagues [5] reported that less than 1% of users completed all modules in an open access website for depression.

There is little reason to expect that the rates of adherence to websites offered as open access on the Web would be as strong as those reported for websites which are examined in the context of an efficacy trial. Open access websites provide information and Web content directly to community users at no, or minimal, cost. Data on adherence from these sites is based on the activity of spontaneous users who “visit” these sites, where many users will have no expectation that they will be offered “programs”. In contrast, data from efficacy trials of websites are based on responses from participants who are recruited to the trial on the basis of elevated symptoms; consent in advance of the trial; are provided with information about its parameters (nature and length of the program, etc); and are required to complete pre- and post-intervention surveys. Nevertheless, we need to know more about the basis of adherence and dropout, not least because there is evidence that greater exposure to website content is associated with increased benefit [6,7]. The Internet platform offers the opportunity to yield a rich source of objective data on engagement and dropout, and, consequently, has the potential to inform adherence research generally. High quality, objectively measurable information on treatment compliance can be obtained from logs of page views, resource downloads, time on site, and other indicators of treatment exposure. High volume Internet sites have the potential to investigate the effect of theory-driven modifications on adherence through the use of high throughput online randomized controlled trials (see, for example, Christensen and Mackinnon [8]).

The present paper has four aims: (1) to undertake a systematic review of the rates of adherence in randomized controlled trials (RCTs) of Internet interventions for anxiety and depression, with the aim of determining rates of attrition in order to confirm that Internet rates of attrition are lower in research trials than open access websites; (2) to collate data from these RCTs to identify predictors of dropout and adherence; (3) to examine the research studies for data on participant's perceptions of adherence and dropout; and (4) to examine the type of analyses that were used to manage “missingness”, given that dropout from RCTs needs to be considered in every analysis of efficacy. To our knowledge, only two papers have reported rates of dropout from open access websites [4,5], but no systematic review of adherence or dropout from RCTs has been undertaken.

This paper begins by providing the context for these aims by defining adherence and dropout, briefly reviewing the research strategies used to investigate adherence in both Internet and non-Internet trials, and describing the evidence arising from these strategies. Research indicates that there are differences in the predictors of adherence for different health conditions [9]. Hence, we restrict our review to websites that target anxiety and depression. A brief discussion of approaches to the statistical analysis of dropout is also presented.

Definitions

Most definitions of adherence are not well suited to the characteristics of e-interventions. For example, the World Health Organization (WHO) describes adherence as the “extent to which a person’s behavior [...] corresponds with agreed recommendations from a health care provider” [10]. This definition clearly does not transfer readily to the Web environment particularly with respect to interventions that are designed to be offered through open access sites, or to interventions that are predicated on self-help models. In the context of this paper, the term *adherence* refers to the extent to which individuals experience the content of the Internet intervention. The term *dropout* is used to describe an individual who fails to complete the research trial protocol associated with an Internet intervention, and thus does not complete trial assessments. These terms correspond reasonably closely to Eysenbach’s terms “non-usage dropout attrition” and “non-usage attrition”, which he applied to the uptake of Internet interventions. Dropout attrition refers to loss of participants from the trial [2]. Non-usage refers to participants’ lack of exposure to the website material. While it is perhaps simpler to use the terms usage and dropout attrition with respect to Web interventions, it is important also to “mainstream” Internet interventions—that is, to provide appraisals of them using terms appropriate to formal non-Internet based trials. For this reason, we use the terms adherence and dropout for the remainder of the article.

Clearly, dropout and treatment adherence refer to interrelated but conceptually distinct constructs. Individuals may drop out of a trial (fail to complete assessments) but have 100% treatment adherence. This occurs, for example, when users continue to undertake the prescribed program even though they have severed contact with the research or clinical team. Others may complete the protocol fully but adhere to the intervention less than 100% of the time. In this case, participants do not undertake the full Web program, although they may continue to complete all assessments.

Figure 1. The relationship between dropout and adherencein a two-arm trial

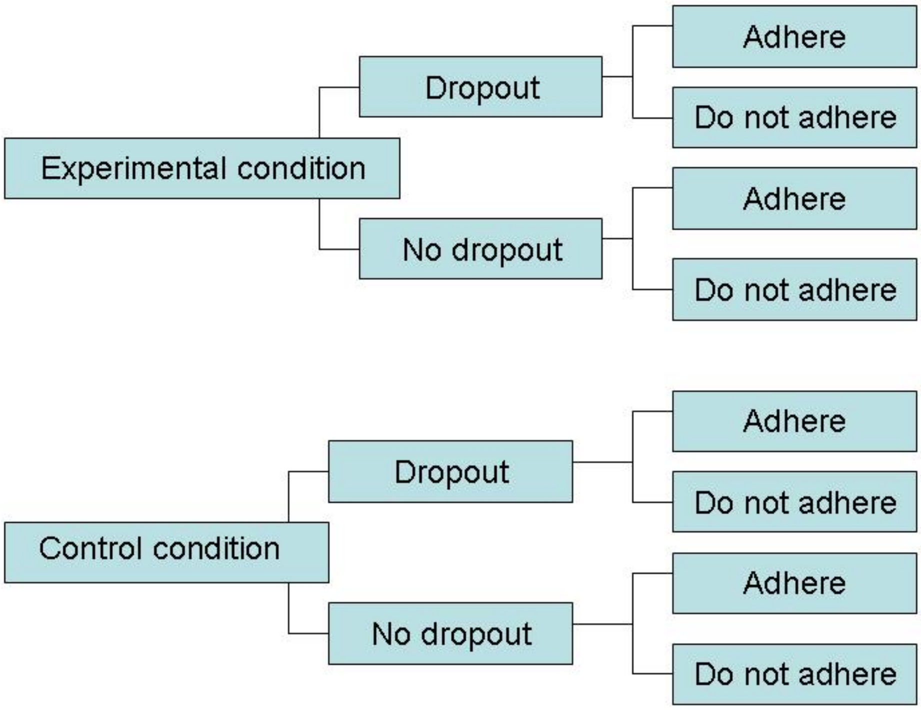

Figure 1 outlines the potential range of outcomes of dropout and adherence in terms of a two-arm research trial. This represents a simplified analysis because there may be degrees or levels of adherence and dropout. Participants may complete an interim follow-up but not the final follow-up, or miss interim assessments but complete final assessments, and so on (ie, participants are classified as dropouts at various stages of the study).

The figure serves as a schematic to highlight important questions, such as how adherence is measured if participants drop out informally or formally by withdrawing their consent. Dropout increases progressively with program length [11], so direct comparisons of percentage dropout are not appropriate unless the length of the programs are roughly equivalent. Within the research trial context, dropouts have been subclassified as *no shows*, (those who do not proceed to the consent or treatment stage and do not complete assessments), *early dropouts* (those who drop out relatively early in a program and complete only one or very few assessments), or *late dropouts* [12]. The term *early completer* has been used to refer to those who benefit from the intervention but do not complete the protocol. In the Web context, these participants have been referred to "e-attainers" [8].

Strategies to Studying Adherence

Three general approaches are undertaken to investigate adherence in both Web and non-Web environments. The first approach involves using correlational or regression analyses within trials to establish associations between adherence and various personality, demographic, and service delivery factors. Common variables investigated include aspects of service delivery, therapist factors, rewards and incentives, program duration, the nature of the medium of delivery, and personality factors, including expectations, self-determination, self-efficacy, or support from partners and friends (Davis and Addis [12], page 347). Disease-specific effects such as disease severity predict adherence, with a high level of emotional distress leading to early dropout [12]. Demographic variables, such as age, socioeconomic status, education, and marital status typically do not predict patient adherence across a range of health conditions [13]. For depression, the results from 14 epidemiological studies failed to indicate any clear predictors of adherence to medication regimes, although adverse side effects reduced adherence [14]. The amount of variance explained by these investigations is low. Moreover, these categories do not take into account the unique type and range of adherence variables associated with Internet delivery, and additional work is needed to investigate "computer factors" rather than therapist factors. With respect to e-health applications, one example of this correlational approach is a study of 82,000 users of an open access website for depression [15].

A second approach involves the use of post-test questionnaires to obtain retrospective analyses of people's perceptions of trial participation, barriers to the use of the treatment, and other factors. An example of this approach is Ritterband's follow-up interview which has been used to identify barriers to seeking out and using a paediatric website [16].

A third approach involves the experimental manipulation of variables believed to be causal in promoting adherence. A recent review summarized the effects of 38 systematic reviews of the effectiveness of adherence interventions across a range of disease conditions and intervention types published between 1990 and 2005 [9]. Interventions to improve adherence were classified into four types: technical solutions (such as simplifying doses); behavioral interventions; educational programs; and social support interventions. This review revealed that less frequent medication schedules (fewer but higher dose tablets) increased adherence (for most targeted disorders, with the exception of depression, see Yildiz et al [17]), as did behavioral interventions which provided reminders, used monitoring, or introduced rewards. Educational interventions were successful when patients were trained in cognitive problem solving or when they were taught motivational techniques. However, knowledge alone was not successful. Little evidence was found for the effectiveness of social support interventions. A number of studies investigated adherence to anxiety and depression interventions [9]. These interventions were complex, involving many components of collaborative care. Consequently, the specific components that were critical in improving adherence were difficult to identify [14], although collaborative care produced better adherence than educational interventions directed at the provider [10,18]. To date, in the e-health field, there has been little experimental manipulation of factors likely to increase adherence in e-health trials.

Approaches Missing Data Arising From Dropout

Intention to treat analyses (ITT), where all participants in the trial are analyzed regardless of whether they drop out, is recommended for publication in most large-scale research studies, although the extent to which this approach is undertaken in RCTs of Internet trials is not known. ITT analyses take into account bias arising from selective attrition and hence are preferred over completer analyses, where only those completing the protocol are analyzed. Missing data for ITT approaches can be managed in a number of ways, including through the use of last observation carried forward (LOCF) imputation. However, more advanced methods which include the use of multiple imputation [19,20] and maximum-likelihood based methods [21], are more likely to yield valid outcomes. The use of ITT and methods to manage missing data is examined in the present review.

Methods

Study Selection

Relevant studies were identified using the methodology employed in our previous systematic reviews of RCTs of mental health Internet interventions [1,22]. The databases of PubMed, PsycInfo, and Cochrane Register Randomized Controlled Trials were searched using the key terms "Internet OR Web" together with search strategies designed to capture randomized controlled trials. Criteria for inclusion of a study in the current review were that it (1) involved a self-help website for a depressive or anxiety disorder; (2) tested the efficacy of a self-help psychoeducational or skills training intervention; (3) employed a randomized controlled trial design; and (4) incorporated a control group that was not subjected to an active treatment intervention. Only peer reviewed published articles were included in the analysis. Dissertations and published poster abstracts were excluded. Because our previous reviews collected information prior to 2007, we updated the search to include papers published before February 2009. For this update, a total of 1177 abstracts were retrieved from the searches conducted in PubMed, PsycInfo, and Cochrane Controlled Trials. Of these, 1154 papers were excluded because they did not describe a self-help website for a depression or anxiety disorder, 2 were excluded because the intervention they described did not test the efficacy of a psychoeducational or skills training program, 3 were excluded because they did not employ a randomized controlled trial design, 7 were excluded because they used a control group that was subjected to an active treatment, and 2 were excluded because they were not published as a peer reviewed paper. The remaining 9 studies met the criteria for inclusion in the review, and we added them to the original 14 studies.

Coding of Study Characteristics

Sample Size

The number of participants in the study intervention was recorded.

Dropout

Dropout was defined as the number of individuals who failed to complete the research protocol. Typically, these figures were derived from the trial flow diagram. Thus, dropouts were those who failed to complete post-treatment or follow-up assessments once they had been accepted into the trial.

Adherence

Adherence was defined as an indicator of the extent to which individuals used the material on the website. Information on adherence was collected and reported with respect to logons, time on site, and number of modules attempted.

Predictors of Adherence or Dropout

We also recorded any reported association between a predictor (gender, severity) and any dropout or adherence measure.

Reason for Dropout

Any data on the reason for dropout was recorded.

Types of Statistical Analyses

Analyses were classified as either completer or intention to treat (ITT), with the method used to handle missing data noted.

Results

There were 8 trials of depression interventions, 1 trial of a depression, anxiety, and stress intervention, 1 trial of a generalized anxiety disorder (GAD) intervention, 5 trials of panic disorder (PD) interventions, 4 trials of social phobia (SP) interventions, and 4 trials of Post Traumatic Stress Disorder (PTSD) interventions (Table 1).

Table 1. Summary of included randomized controlled trials of Internet interventions for anxiety and depression

	Sample size N = total I = Intervention C = Control	Dropout N = total I = Intervention C = Control	Adherence to treatment	Predictors of dropout/adherence	Self-reported reason for dropout?	Type of statistical analysis: ITT, NMAR, MAR, LOCF
Depression						
Andersson et al 2002 [23] (6 modules)	N = 117 I = 53 C = 64	Post-treatment: N = 66 (56.4%) I = 23 (43.4%) C = 43 (67.2%) 1 year: N = 96 (82.1%) I = 46 (86.8%) C = 50 (78.1%)	Not reported. Mean posting on discussion board = 8.7 (SD = 21.5)	Response rate higher in control group at post-treatment.	No formal measure described. Reported reasons: lack of time, programme too fast, lack of ideal environment to complete programme, programme is impersonal and too extensive.	Completers. Multiple regression
Andersson et al 2005 [24] (5 modules + discussion group)	N = 117 I = 57 C = 60[a]	Post-treatment: N = 85 (72.6%) I = 36 (63.1%) C = 49 (81.6%) 6 months: N = 71 (60.7%) I = 36 (63.1%) C = 35 (58.3%)[b]	Mean number of modules completed = 3.7 out of 5 (SD = 1.9) Total postings on the discussion board: I = 233 C = 842 (C > I, $P < .05$)	Lower withdrawal for control than treatment group participants at 3 months. (100% intervention completed; 71% Control group completed). No significant differences in depressive symptoms (BDI) or age, gender, educational level, place of living, or quality of life between dropouts and completers at 3 months.	No formal measure described. Main reported reason: treatment was too demanding.	ITT LOCF, ANOVA
Christensen et al 2004 [6] Griffiths et al 2004 [25] Mackinnon et al 2008 [26] (12 month follow-up) (5 modules)	N = 525 I(i) = 165 I(ii) = 182 C = 178 *I(i) = BluePages depression informationI(ii) = MoodGYM*[c] *CBT*	Post-treatment: N = 435 (82.8%) I(i) = 140 (84.8%) I(ii) = 136 (74.7%) C = 159 (89.3%) 6 months: N = 352 (67%) I(i) = 115 (69.6%) I(ii) = 106 (58.2%) C = 131 (73.6%) 12 months: N = 325 (61.9%) I(i) = 107 (64.8%) I(ii) = 94 (51.6%) C = 124 (69.6%)	Mean BluePages visits = 4.49 (SD = 1.4) Mean MoodGYM exercises completed = 14.8 (SD = 9.7) (51%)	Greater dropout for MoodGYM (CBT) than BluePages (depression information) ($P = .0001$) Baseline depressive symptoms (CES-D) and knowledge of psychological treatments lower among dropouts ($P < .01$) Males more likely to be lost to follow-up at 12 months.	No	ITT LOCF
Clarke et al 2002 [27] (7 content chapters)	N = 299 I = 144 C = 155	4 weeks: N = 158 (52.8%) 8 weeks: N = 195 (65.2%) 16 weeks: N = 196 (65.6%) 32 weeks: N = 177 (59.2%)	Not reported. Mean logons: I = 2.6 (SD = 2.5; range 1-20)	Baseline depressive symptoms (CES-D) lower in those who completed at least one follow-up questionnaire ($P < .05$). Age, gender, recruitment group did not predict dropout.	No	ITT random effect regression analyses

	Sample size N = total I = Intervention C = Control	Dropout N = total I = Intervention C = Control	Adherence to treatment	Predictors of dropout/adherence	Self-reported reason for dropout?	Type of statistical analysis: ITT, NMAR, MAR, LOCF
Clarke et al 2005 [28] (7 content chapters)	N = 255 I(i) = 75 I(ii) = 80 C = 100 *I(i) = website + postcard remindersI(ii) = website + telephone reminders*	5 weeks: N = 164 (63.1%) I(i) = 36 (48%) I(ii) = 48 (60%) C = 77 (77%) 10 weeks: N = 173 (67.8%) I(i) = 43 (57.3%) I(ii) = 50 (62.5%) C = 80 (80%) 16 weeks: N = 169 (66%) I(i) = 46 (61.3%) I(ii) = 43 (53.8%) C = 80 (80%)	Not reported. Mean logons: I(i) = 5.9 (SD = 6.2; range 1-33) I(ii) = 5.6 (SD = 5.8; range = 1-27)	Baseline depressive symptoms (CES-D) and age lower in those who completed at least one follow-up questionnaire ($P < .05$). Gender not a predictor. Control participants more likely to complete a follow-up assessment. Mean logons did not differ between postcard & telephone reminder conditions ($p > .05$).	No	ITT random effect regression analyses – REML
Patten 2003 [29] (4 content modules)	N = 786 I = 420 C = 366	1 month: I = 418 (99.5%) C = 363 (99.2%) 2 months: I = 412 (98.1%) C = 361 (98.6%) 3 months: I = 406 (96.7%) C = 358 (97.8%)	Not reported. Mean duration signed-on = 50 min	None reported.	No	Completers
Spek et al 2007 [30] Spek et al 2008 [31] (12 month follow-up) I(i) = 8 modules I(ii) = 10 sessions	N = 301 I(i) = 102 I(ii) = 99 C = 100 *I(i) = Internet CBTI(ii) = Group CBT*	Post-treatment: N = 181 (60.1%) I(i) = 67 (65.7%) I(ii) = 56 (56.6%) C = 58 (58%) 12 months: N = 190 (63.1%) I(i) = 58 (56.8%) I(ii) = 66 (66.6%) C = 66 (66%)	Mean modules/sessions completed: I(i) = 5.5 out of 8 (78.1%) I(ii) = 9.1 out of 10 (98.3%) Completed whole course: I(i) = 48.3% I(ii) = 94.5%	Less treatment completion in Internet intervention group.	No formal measure described. Main reason reported: lack of time.	ITT MI

	Sample size N = total I = Intervention C = Control	Dropout N = total I = Intervention C = Control	Adherence to treatment	Predictors of dropout/adherence	Self-reported reason for dropout?	Type of statistical analysis: ITT, NMAR, MAR, LOCF
Warmerdam et al 2008 [32] (I(i) = 9 lessons, I(ii) = 5 lessons)	N = 263 I(i) = 88 I(ii) = 88 C = 87 *I(i) = Cognitive Behavioral Therapy (CBT)I(ii)=Problem Solving Therapy (PST)*	5 weeks: N = 184 (69.9%) I(i) = 61 (69.3%) I(ii) = 52 (59.1%) C = 71 (81.6%) 8 weeks: N = 173 (65.8%) I(i) = 51 (57.9%) I(ii) = 51 (57.9%) C = 71 (81.6%) 12 weeks: N = 151 (57.4%) I(i) = 46 (52.2%) I(ii) = 42 (47.2%) C = 63 (72.4%)	Completed at least 1 module: I(i) = 80 (90.9%) I(ii) = 74 (84.1%) Completed at least 3-4 lessons: I(i)=63 (71.6%) I(ii) = 49 (55.7%) Completed whole course: I(i) = 34 (38.6%) I(ii) = 33 (37.5%)	Lower withdrawal in control group compared with both intervention groups. Participants who completed post-treatment measures more likely to be born in the Netherlands and older.	No formal measure described. Reported reasons: other treatment; feeling better; lack of time; and problems understanding the program.	ITT LLM using REML
Depression, anxiety and stress						
van Straten et al 2008 [33] (4 modules)	N = 213 I = 107 C = 106	Post-treatment: N = 177 (83.1%) I = 81 (76%) C = 96 (91%)	Completed 1 module = 97 (90.6%) Completed 2 modules = 79 (73.8%) Completed 3 modules = 70 (65.4%) Completed whole course = 59 (55.1%)	Post-treatment measure response rate higher among more educated participants and those without alcohol problems. Married participants more likely to complete the intervention.	No	ITT MI
Generalised anxiety disorder						
Kenardy et al 2003 [34] (6 modules) Kenardy et al 2006 [35] (6 month follow-up)	N = 83 I = 43 C = 40	Post-treatment N = 75 (90.4%) I = 37 (86%) C = 38 (95%) 6 months N = 42 (50.6%) I = 19 (44.2%) C = 23 (57.5%)	Average modules completed = 3.33 out of 7 (SD = 2.10). Mean logons = 7.76 (SD = 7.31). Mean access time = 90.37 minutes (SD = 111.29).	Baseline depressive symptoms (CES-D), anxiety sensitivity (ASI) lower among completers than dropouts. At 6 months: No differences between those who dropped out in this period and those who did not.	No formal measure described. Main reason reported: time constraints. At 6 months: No reasons for additional dropout between post-test and 6 months reported.	Completers. Excluded outlier (high post test results in the intervention group; n = 1).
Panic disorder						
Carlbring et al 2001 [36] (6 modules)	N = 41 I = not reported C = not reported	Post-treatment: N = 36 (87.9%) I = 4 dropouts C = 1 dropout	Completed all modules: 100% (excluding participants who dropped out)	None reported.	No formal measure described. Reported reasons: I = lack of time (n = 3); serious physical illness (n = 1). C = no reason given.	ITT LOCF

	Sample size N = total I = Intervention C = Control	Dropout N = total I = Intervention C = Control	Adherence to treatment	Predictors of dropout/adherence	Self-reported reason for dropout?	Type of statistical analysis: ITT, NMAR, MAR, LOCF
Carlbring et al 2006 [37] (10 modules)	N = 60 I = 30 C = 30	Post-treatment: N = 57 (95%) I = 28[d] (93.3%) C = 29 (96.6%) 9 months: I = 26 (86.6%) C = not collected	Completed all modules = 24 (80%); Mean number of modules completed = 8.9 (SD = 2.6). One participant completed 0 modules.	None reported.	No formal measure described. Reported reason: shortage of time (n = 1).	ITT LOCF
Klein and Richards, 2001 [38]	N = 23 I = 11 C = 12	Post-treatment: N = 22 (95.7%) C = not reported I = not reported	Not reported.	None reported.	No	Completers
Klein et al 2006 [39] (6 modules)	N = 55 I(i) = 19 I(ii) = 18 C = 18 *I(i) = Online CBTI(ii) = Manualized CBT*	Post-treatment: N = 46 (83.6%) I(i) = 18 (94.7%) I(ii) = 15 (83.3%) C = 13 (72.2%)	Those lost to follow-up did not complete the intervention.	Condition did not affect attrition.	No formal measure described. Reported reasons: I(i) = bipolar disorder episode (n = 1). I(ii) = depressive episode (n = 1); treatment perceived to be ineffective (n = 1); lack of motivation (n = 1). C = monitoring led to recurrence of ‘bad’ memories (n = 1); no reason given (n = 4).	ITT LOCF
Richards et al 2006 [40]	N = 32 I(i) = 12 I(ii) = 11 C = 9 *I(i) = Online CBTI(ii) = Online CBT + stress management*	Post-treatment: N = 27 (84.4%) I(i) = 10 (83.3%) I(ii) = 10 (90.9%) C = 7 (77.8%)	Not reported.	Completers frequency of emails I(i) = 15.3 (SD = 12.8) I(ii) = 11.6 (SD = 13.3)	No formal measure described. Reported reasons: I(i) = lack of motivation, episode of depression I(ii) = wish to commence SSRI C = no reason given.	ITT LOCF
Social phobia						
Andersson et al 2006 [41]	N = 64 I = 32 C = 32	Post-treatment: N = 62 (96.9%) I = 30 (93.8%) C = 32 (100%) 12 months: N = 49 (76.6%) I = 29 (90.6%) C = 20 (62.5%)	Completed all modules = 20 (62.5%) Mean modules completed = 7.5 (SD = 2.4)	None reported.	No formal measure described. Reported reason: lack of time.	ITT LOCF

	Sample size N = total I = Intervention C = Control	Dropout N = total I = Intervention C = Control	Adherence to treatment	Predictors of dropout/adherence	Self-reported reason for dropout?	Type of statistical analysis: ITT, NMAR, MAR, LOCF
Carlbring et al 2007 [42] (9 modules)	N = 57 C = 30 I = 30	Post-treatment: N = 55 (96.5%) C = 28 (93.3%) I = 28 (93.3%) 12 months: I = 27 (90%) C = Not collected	Completed whole course = 27 (93.1%) Completed 4 modules = 1 (3.4%) Completed 1 module = 1 (3.4%)	None reported.	No formal measure described. Reported reasons for dropout: I = began other therapy (n = 1); No computer access (n = 1) C = began other therapy (n = 1) Reasons for not completing treatment: lack of time	Analysis excluded two participants after randomization but included two partially treatment compliant participants and one participant who did not return post-survey using LOCF.
Titov et al 2008 [43] (6 modules)	N = 105 I = 50 C = 55	Post-treatment: N = 93 (88.6%) I = 44 (88%) C = 49 (89.1%)	39 (78%) completed whole course	None reported	No formal measure described. Reported reasons: lack of time and motivation (n = 2); exposure too anxiety provoking (n = 1); programme not helpful (n = 1); overseas holiday (n = 1); change in work or study commitments (n = 3); medical complications (n = 1); no reason (n = 2)	ITT LOCF
Titov et al 2008 [44]	N = 88 I = 43 C = 45	Post-treatment: N = 78 (88.6%) I = 38 (88.4%) C = 40 (88.8%)	33 (73.3%) completed whole course Mean modules completed: 5.5 out of 6	None reported.	No formal measure described. Reported reasons: programme not helpful (n =1); symptoms improved significantly (n = 1)	ITT LOCF
Post traumatic stress disorder						
Hirai and Clum 2005 [45]	N = 36 I = 18 C = 18	Post-treatment: N = 27 (75%) I = 13 (72.2%) C = 14 (77.8%)	Not reported.	No demographic differences were found between completers and those who dropped out.	No	Completers
Knaevelsrud et al 2007 [46] (10 sessions)	N = 96 I = 49 C = 47	Post-treatment: N = 87 (90.6%) I = 41 (83.7%) C = 46 (97.9%) 3 months: I = 41 (83.7%) C = not assessed	Not reported	None reported	No formal measure described. Reported reasons include: technical problems (with network and computer) and emotional distress.	ITT LOCF

	Sample size N = total I = Intervention C = Control	Dropout N = total I = Intervention C = Control	Adherence to treatment	Predictors of dropout/adherence	Self-reported reason for dropout?	Type of statistical analysis: ITT, NMAR, MAR, LOCF
Lange et al 2001 [47]	N = 30 I = 15 C = 15	Post-treatment: N = 25 (83.3%) C = 12 (80%) I = 13 (86.7%)	Not reported.	Participants who dropped out showed lower baseline intrusion scores (Impact of Events scale).	No formal measure described. Reported reasons: No quiet place for writing; could not focus on one trauma; ceased studies; marked improvement so saw no value in continuing.	Completers
Lange et al 2003 [48]	N = 184 I = 122 C = 62	Post-treatment: N = 101 (54.9%) I = 69 (56.6%) C = 32 (51.6%) 6 weeks: I = 57 (46.7%) C = not collected	Completed treatment = 78 (63.9%)	Compliance with treatment higher for women, for older people, for those who lived with a partner, those less experienced with a computer. Education, time since trauma, amount disclosed about trauma, and psychological functioning did not predict adherence. Compliance with protocol was not predicted by any of the variables investigated.	Formal questionnaire administered. Reasons for dropout: Technical problems with computer (n = 18, 41%) Preference for face-to face contact (n = 13, 29.5%) Burden of writing about stressful events (n = 13, 29.5%) 6 weeks Reported reasons: failure to respond; sought 'other treatment'; did not wish to wait.	Completers

Note: ITT = Intention to treat; NMAR = Not Missing at Random; MAR = Missing at Random; LOCF = Last Observation Carried Forward; REML = Restricted Maximum Likelihood Estimation; LLM = Linear Mixed Modelling; MI = Multiple Imputation using NORM procedure in statistical package R; CBT = cognitive behavioral therapy.

[a] Control involved an online discussion group.

[b] had received intervention at 3 months.

[c] The same website can be offered both as open access site directly to the community or as a Web-based intervention offered in a randomized controlled trial.

[d] In contrast to the authors of some papers, the dropout rate is calculated strictly using the number randomized as the denominator. Hence figures may differ from those reported by authors in some cases (e.g., Carlbringet al 2007 [42]).

Rates of Dropout/Non-completion of Study Protocol

Completion of protocol rates for depression sites ranged from a low of 43% [23] to a high of 99% [29], with some trials indicating poorer retention after a longer follow-up [26]. All studies reported lower rates of completion in the experimental intervention group relative to the control with the exception of Spek et al [30]. The one GAD trial reported a 6-month follow-up retention of 44% in the experimental group [34]. Trials for PD reported high rates of retention—approximately 80 - 90% for the experimental group, but these were based on small numbers of participants, and rates of dropout were often not reported separately for experimental and control conditions. Rates of completion for the SP interventions were approximately 90% at 12-month follow-up. Rates for PTSD ranged from 87% at post-treatment [47] to 47% at 6 week follow-up [48].

Adherence

Adherence data were reported using indications such as number of log ons, duration of Web exposure, number of modules or exercises completed, and number of postings on bulletin boards. Although rates varied considerably, adherence to the complete online treatment was approximately 50 - 70% for depression sites and 50% for the sole GAD intervention [34]. Rates of adherence to the PD interventions were reported as high as 80 - 100% [36,37]. The SP trials reported 70 - 90%, and one of the PTSD trials reported a rate of 64% [48].

Predictors of Adherence

For depression, predictors found to be associated with increased adherence were lower baseline rates of depression, younger age, and poorer knowledge of psychological treatments. Education or quality of life, when measured, did not predict adherence.

For GAD, lower symptom levels predicted better adherence. Data for PD trials were scant. One trial of a PTSD intervention reported higher adherence with treatment for women, older persons, those who lived with a partner, and those less experienced with a computer.

Self-Reported Reason for Dropout

Only one study conducted a formal survey of the reasons for dropout [48]. However, the following were mentioned as reasons for dropout in the Internet intervention group or, where separate data were not provided, in the group of participants as a whole: time constraints [23,30,31,32,34,36,37,41,42,43], lack of motivation [39,40,43], technical or computer-access problems [42,46,48], depressive episode or physical illness [39,40], the lack of face-to-face contact [48], preference for taking medication [40], perceived lack of treatment effectiveness [39,43,44,47,48], improvement in condition [29,32,44,47], and burden of the program [23,48].

Methods to Analyze Missing Data

For depression, four approaches to missing data were used: analysis of completers only [23, 29]; intention to treat (ITT) using last observation carried forward (LOCF) [6,24,25,26]; mixed models with maximum likelihood estimation (REML) [27,28,32], the latter being one of the best of the approaches and standard good practice [49]; and multiple imputation [30,31], also a recommended strategy [50]. For GAD, a completer analysis was conducted. Panic disorder studies reported two approaches: four studies used ITT with LOCF [36,37,39,40] and one analyzed completers alone [38]. All of the social phobia studies utilized LOCF. Three PTSD studies used completer analyses [45,47,48], and one study used ITT with LOCF [46].

Discussion

Findings

Relative to reported rates of dropout from open access sites, the present study found that the rates of attrition in RCTs were lower, ranging from a high loss of 50% to a low of 1% over various follow-up periods. Treatment adherence was relatively high, at over 50%. These rates are relatively similar to those in randomized controlled trials of non-Internet-based interventions for generalized anxiety disorder and depression, with a recent review suggesting attrition rates are about 15% on average for GAD, but the rate of dropout ranged from 0 - 50% [51]. Our findings suggest that there is nothing particularly non-adherent about an Internet intervention per se when delivered in the context of a randomized controlled trial. However, these findings confirm that dropout is much less dramatic than that associated with open access websites. As such, the findings clearly articulate the need to compare rates of adherence for open access interventions against appropriate benchmarks. In our view, the rates of adherence for open access websites should be compared to rates of adherence reported for traditional health services provided by practitioners face to face (Meichenbaum and Turk [52], page 25). Where reported, these data show that adherence rates are high in face-to-face treatment as well, with as many as 70% of patients missing by a third session, and hypothetical attrition curves indicating that almost 100% of users are non-adherent after 10 sessions. Stress, exercise, or smoking programs have estimated discontinuation rates of between 20 - 80% (see Turk and Meichenbaum [13], page 249), while anti-depressant medication is discontinued by approximately 40 - 80% (see Sabate [10], page 66).

The findings from our review of RCTs also need to be compared to other recent work on rates of adherence in Web treatments, including a recent review of barriers to the uptake of computerized cognitive behavior programs [53]. This review differs substantially from ours in that it used an integrative methodology (combining both qualitative and quantitative work), reported work up to July 2005 only, reviewed computer-based interventions in addition to Internet-based ones, and focused on CBT style interventions only. Its focus was also substantially different because it covered acceptability and satisfaction in addition to dropout. This review reported that a medium of 83% of participants completed the study (ie, did not dropout) and a medium of only 56% completed a course of the program in data from quantitative studies. Although these rates cannot be compared formally, they appear to be slightly lower than those of the present review. The medium dropout rate of interventions from the depression studies was 60%, while the adherence level ranged between 38 - 78%, depending on which outcome measure was used.

In our study, predictors of adherence were similar to previously identified factors [9], including disease severity, treatment length, and chronicity. Very few studies formally examined reasons for dropout, and it was noted that personal circumstances “played a major role, including travel (for those studies based around a clinic computer)” (see Waller and Gilbody [53], page 3). Most studies also failed to use appropriate statistical techniques to analyze missing data.

Limitations of the Study

Measures of adherence to websites did vary across studies, and we acknowledge that the use of different methods (log ons vs modules completed, etc) will yield different measures of adherence, and that these measures will not necessarily correlate strongly. Website design will be another important factor in determining the type and richness of particular outcome measures. Further research is needed to determine whether a universal indicator of adherence using diverse measures could be developed. For example, a “percent” of adherence might be a useful approach. Both a strength and a limitation of the present study was its focus on anxiety and depression websites. Although beyond the scope of the present paper, there is a clear need to consolidate information about reliable predictors of adherence across other physical and mental disorders and diseases, and to identify both disease-specific and generic predictors.

The focus of this paper was to examine adherence in RCTs. It was not possible to compare directly the rates of adherence between open access services and trial-based Web interventions. To our knowledge the open access websites reported in the introduction are the only ones for which there is published data. With further publication of data for open access sites, it may be possible to undertake a formal review of predictors and rates.

Once sufficient trials and evaluations have been conducted within open access sites and websites used as part of RCT trials, techniques to develop appropriate quantitative comparisons between efficacy and effectiveness studies could be systematically employed to compare these rates (see Hunsley and Mash [54]).

Implications for Future Work

The findings from our review reinforce conclusions that have been drawn from traditional intervention research. Little is known about the specific component factors that improve adherence in health interventions. Research within this area is essentially atheoretical, and a coherent approach is required. Given the importance of adherence research, and the unique advantage of Web-based data collection for analyzing adherence, we suggest a potential research agenda to advance this area.

A first step requires the adoption of a theoretical approach to the understanding of dropout and adherence. The framework adopted by WHO [10] identifies five dimensions to pursue: health system factors, socioeconomic factors, therapy-related factors, condition-related factors, and patient-related factors. Historically, the emphasis has been on patient factors. For example, according to Davis and Addis, "What is needed are theories which link specific client characteristics and treatment processes onto attrition" [12] (page 347). However, there is now recognition that health systems factors seem critical. A substantial body of research on depression interventions in primary care emphasizes the importance of case management and continuity of care for efficacy and adherence [55]. These findings, together with the overall greater adherence rates achieved within the context of RCTs, point to the potential benefits of incorporating simple procedures such as monitoring and follow-up to increase adherence. This in turn suggests that attention to behavior theory/modification approaches may yield the greatest benefits for increasing adherence to open access websites. Information on the effectiveness of types, frequency, and size of rewards, as well as information on appropriate reinforcement schedules, is likely to be highly useful in developing comprehensive adherence programs. The lessons learned within research contexts for improving adherence to trial protocols [51] might be profitably employed in the design of better treatment delivery systems in community practice, although recommendations such as "if in doubt, screen out" are counter-productive to the aims of open access websites, which aim to reach individuals who are not yet committed to a treatment program. Research from the Internet intervention field already suggests that substantial gains might be achieved by using email tracking. Clarke et al [28], when comparing the outcomes of two trials of the Overcoming Depression on the Internet (ODIN) website, reported that reminders (both telephone and email) were likely to be the crucial factor in determining retention (and improvement). Studies of established Internet-based treatment programs indicate that high rates of adherence are indeed possible if case management and continuity of care principles are followed [56]. It is not yet known whether tailoring improves adherence in mental health, although this is often promoted as the cornerstone of health promotion campaigns, and it forms a rich area for potential investigation.

Other authors have pointed to the potential of a range of theoretical models other than those based on behavior theory/modification to inform programs for increasing adherence at an individual level, although these focus to a greater degree on person, rather than systems, factors. The health belief model [57] attempts to predict behavior on the basis of a person's perception of the risks associated with a health condition, as well as beliefs about the costs, potential side effects/difficulties, and benefits of treatment. The protection motivation theory, the theory of reasoned action, the theory of planned behavior, the social-cognitive theory, and models based on self-efficacy [57] have also been proposed as theoretical models that might inform adherence practice.

A second area likely to advance our understanding of website adherence involves research into the methods by which technology engages users. Eysenbach [2] has cited specific factors such as usability and other technological factors that will have an impact on adherence. This research agenda potentially covers a range of areas: (1) the generic ways in which humans interact with the technology associated with the Internet (such as frequency of use); (2) the specific methods used by individuals to interact with intervention programs as realized on a website (such as skipping sections, completing online assessments); and (3) the means by which users engage preferentially with certain names or brands of website. The latter includes research into the nature of trust (see, for example, Corritore et al [58]). An example of (2), above, is research into the effectiveness of various forms of the presentation of multimedia (see, for example, Sun and Cheng [59]). The investigation of the ways in which humans interact with computers and the Internet (as in (1), above) is also a potentially interesting area for future research. Many users report forming attachments to their computers (an observation that can be confirmed by undertaking a quick search on Google with the phrase "I love my computer"), and a better understanding of the "computer therapeutic alliance" might well be justified.

Internet interventions have a number of unique features that may impact on adherence rates. These features include the ease with which the interventions can be accessed, the expectations of users, the level of contact with a health professional, and the presence of rewards or motivators. Although evidence is lacking, Internet delivery may increase adherence relative to face-to-face interventions for individual users who respond to the interactivity, tailoring, and online rewards associated with some websites. One hypothesis worthy of investigation is that Internet delivery creates a technology "alliance", reflecting the attraction or attachment which develops between people and electronic gadgets and computers. Moreover, the hypothesis that websites attract people who prefer treatment delivered anonymously, prefer distal contact, or are housebound because of mental or physical disability requires testing.

A third issue that warrants further detailed investigation is the role of disease factors and their influence on treatment uptake and maintenance. The cognitive and emotional characteristics of individuals with depression (or anxiety) are likely to impact their choice of treatment, their treatment uptake, and their rates of adherence. As part of their condition, individuals with depression may believe that they do not deserve treatment or that their treatment is unlikely to be effective and, as a consequence, they may be more likely to drop out. Depressed individuals may simply not be able to face using a computer. Intervention programs that directly address “cognitive dysfunctional thoughts” about treatment outcomes may produce better adherence and outcomes.

This review also identified a number of methodological improvements that are needed to advance the area. Often terms such as adherence, compliance, attrition, and dropout are not operationalized and are used interchangeably. Many studies fail to measure adherence to treatment. Statistical approaches to handling missing data are limited. Use of mixed models with REML approaches to missingness, rather than the use of biased methods such as LOCF or limited methods such as completer analyses, are to be encouraged [49,50]. There may be a need for reanalysis of research trials which are already published.

Finally, it is appropriate to consider the implications of these findings for identifying ways of reducing the high attrition rates on open access websites. Based on the data from RCTs, it seems likely that adherence to open access sites might immediately be improved if users were to consent to the use of automated reminders and messages. It is likely that the use of automated reminders will be successful across a range of interventions, not just those directed at anxiety and depression. Research investigating the acceptability and effectiveness of such a tracking procedure for open access sites should be accorded a high level of priority.

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Conflicts of Interest

HC and KG have developed online psychoeducational and automatic psychological skills training programs (eg, MoodGYM, BluePages Depression Information, e-couch).

References

1. Griffiths KM, Christensen H. Review of randomized controlled trials of Internet interventions for mental disorders and related conditions. Clin Psychol 2006;10(1):16-29. [doi: 10.1080/13284200500378696]
2. Eysenbach G. The law of attrition. J Med Internet Res 2005;7(1):e11 [FREE Full text] [Medline: 15829473] [doi: 10.2196/jmir.7.1.e11]
3. Glasgow RE. eHealth evaluation and dissemination research. Am J Prev Med 2007 May;32(5 Suppl):S119-S126. [Medline: 17466816] [doi: 10.1016/j.amepre.2007.01.023]
4. Farvolden P, Denisoff E, Selby P, Bagby RM, Rudy L. Usage and longitudinal effectiveness of a Web-based self-help cognitive behavioral therapy program for panic disorder. J Med Internet Res 2005;7(1):e7 [FREE Full text] [Medline: 15829479] [doi: 10.2196/jmir.7.1.e7]
5. Christensen H, Griffiths KM, Korten AE, Brittliffe K, Groves C. A comparison of changes in anxiety and depression symptoms of spontaneous users and trial participants of a cognitive behavior therapy website. J Med Internet Res 2004 Dec 22;6(4):e46 [FREE Full text] [Medline: 15631970] [doi: 10.2196/jmir.6.4.e46]
6. Christensen H, Griffiths KM, Jorm AF. Delivering interventions for depression by using the internet: randomised controlled trial. BMJ 2004 Jan 31;328(7434):265 [FREE Full text] [Medline: 14742346] [doi: 10.1136/bmj.37945.566632.EE]
7. Christensen H, Griffiths KM, Mackinnon AJ, Brittliffe K. Online randomized controlled trial of brief and full cognitive behaviour therapy for depression. Psychol Med 2006 Dec;36(12):1737-1746. [Medline: 16938144] [doi: 10.1017/S0033291706008695]
8. Christensen H, Mackinnon A. The law of attrition revisited. J Med Internet Res 2006;8(3):e20; author reply e21 [FREE Full text] [Medline: 17032636] [doi: 10.2196/jmir.8.3.e20]
9. van Dulmen S, Sluijs E, van Dijk L, de Ridder D, Heerdink R, Bensing J. Patient adherence to medical treatment: a review of reviews. BMC Health Serv Res 2007;7(1):55 [FREE Full text] [Medline: 17439645] [doi: 10.1186/1472-6963-7-55]
10. Sabate E. World Health Organization. Adherence to Long-term Therapies: Evidence for Action. 2003 URL: http://www.who.int/chp/knowledge/publications/adherence_full_report.pdf [accessed 29 Mar 2009] [WebCite Cache ID 5dcF67Mk6]
11. Christensen H, Griffiths K, Groves C, Korten A. Free range users and one hit wonders: community users of an Internet-based cognitive behaviour therapy program. Aust N Z J Psychiatry 2006 Jan;40(1):59-62. [Medline: 16403040] [doi: 10.1111/j.1440-1614.2006.01743.x]
12. Davis MJ, Addis ME. Predictors of attrition from behavioral medicine treatments. Ann Behav Med 1999;21(4):339-349. [Medline: 10721442] [doi: 10.1007/BF02895967]
13. Turk DC, Meichenbaum D. Adherence to self-care regimens: the patient’s perspective. In Sweet JJ, Rozensky RH, Tovian SM, editors. Handbook of Clinical Psychology in Medical Settings. New York, NY: Plenum Press; 1991:249-266.

14. Pampallona S, Bollini P, Tibaldi G, Kupelnick B, Munizza C. Patient adherence in the treatment of depression. Br J Psychiatry 2002 Feb;180(2):104-109 [FREE Full text] [Medline: 11823317] [doi: 10.1192/bjp.180.2.104]
15. Batterham PJ, Neil AL, Bennett K, Griffiths KM, Christensen H. Predictors of adherence among community users of a cognitive behavior therapy website. Patient Preference and Adherence 2008;2:97-105.
16. Ritterband LM, Borowitz S, Cox DJ, Kovatchev B, Walker LS, Lucas V, et al. Using the internet to provide information prescriptions. Pediatrics 2005 Nov;116(5):e643-e647 [FREE Full text] [Medline: 16263978] [doi: 10.1542/peds.2005-0404]
17. Yildiz A, Pauler DK, Sachs GS. Rates of study completion with single versus split daily dosing of antidepressants: a meta-analysis. J Affect Disord 2004 Feb;78(2):157-162. [Medline: 14706727] [doi: 10.1016/S0165-0327(02)00300-2]
18. Vergouwen ACM, Bakker A, Katon WJ, Verheij TJ, Koerselman F. Improving adherence to antidepressants: a systematic review of interventions. J Clin Psychiatry 2003 Dec;64(12):1415-1420. [Medline: 14728101]
19. Little RJA, Rubin DB. Statistical Analysis with Missing Data. New York, NY: J. Wiley & Sons; 1987.
20. Rubin DB. Multiple Imputation for Nonresponse in Surveys. New York, NY: J. Wiley & Sons; 1987.
21. Verbeke G, Molenberghs G. Linear Mixed Models for Longitudinal Data. New York, NY: Springer; 2000.
22. Griffiths K, Farrer L, Christensen H. Clickety-click: e-mental health train on track. Australas Psychiatry 2007 Apr;15(2):100-108. [Medline: 17464651] [doi: 10.1080/10398560601123716]
23. Andersson G, Strömgren T, Ström L, Lyttkens L. Randomized controlled trial of internet-based cognitive behavior therapy for distress associated with tinnitus. Psychosom Med 2002;64(5):810-816 [FREE Full text] [Medline: 12271112] [doi: 10.1097/01.PSY.0000031577.42041.F8]
24. Andersson G, Bergström J, Holländare F, Carlbring P, Kaldo V, Ekselius L. Internet-based self-help for depression: randomised controlled trial. Br J Psychiatry 2005 Nov;187(5):456-461 [FREE Full text] [Medline: 16260822] [doi: 10.1192/bjp.187.5.456]
25. Griffiths KM, Christensen H, Jorm AF, Evans K, Groves C. Effect of web-based depression literacy and cognitive-behavioural therapy interventions on stigmatising attitudes to depression: randomised controlled trial. Br J Psychiatry 2004 Oct;185(4):342-349 [FREE Full text] [Medline: 15458995] [doi: 10.1192/bjp.185.4.342]
26. Mackinnon A, Griffiths KM, Christensen H. Comparative randomised trial of online cognitive-behavioural therapy and an information website for depression: 12-month outcomes. Br J Psychiatry 2008 Feb;192(2):130-134 [FREE Full text] [Medline: 18245031] [doi: 10.1192/bjp.bp.106.032078]
27. Clarke G, Reid E, Eubanks D, O'Connor E, DeBar LL, Kelleher C, et al. Overcoming depression on the Internet (ODIN): a randomized controlled trial of an Internet depression skills intervention program. J Med Internet Res 2002;4(3):E14. [doi: 10.2196/jmir.4.3.e14] [Medline: 12554545]
28. Clarke G, Reid E, Eubanks D, O'Connor E, DeBar LL, Kelleher C, et al. Overcoming depression on the Internet (ODIN) (2): a randomized trial of a self-help depression skills program with reminders. J Med Internet Res 2005;7(2):e16. [Medline: 15998607] [doi: 10.2196/jmir.7.2.e16]
29. Patten SB. Prevention of depressive symptoms through the use of distance technologies. Psychiatr Serv 2003 Mar;54(3):396-398 [FREE Full text] [Medline: 12610251] [doi: 10.1176/appi.ps.54.3.396]
30. Spek V, Nyklícek I, Smits N, Cuijpers P, Riper H, Keyzer J, et al. Internet-based cognitive behavioural therapy for subthreshold depression in people over 50 years old: a randomized controlled clinical trial. Psychol Med 2007 Dec;37(12):1797-1806. [Medline: 17466110] [doi: 10.1017/S0033291707000542]
31. Spek V, Cuijpers P, Nyklícek I, Smits N, Riper H, Keyzer J, et al. One-year follow-up results of a randomized controlled clinical trial on internet-based cognitive behavioural therapy for subthreshold depression in people over 50 years. Psychol Med 2008 May;38(5):635-639. [Medline: 18205965] [doi: 10.1017/S0033291707002590]
32. Warmerdam L, van Straten A, Twisk J, Riper H, Cuijpers P. Internet-based treatment for adults with depressive symptoms: randomized controlled trial. J Med Internet Res 2008;10(4):e44 [FREE Full text] [Medline: 19033149] [doi: 10.2196/jmir.1094]
33. van Straten A, Cuijpers P, Smits N. Effectiveness of a web-based self-help intervention for symptoms of depression, anxiety, and stress: randomized controlled trial. J Med Internet Res 2008;10(1):e7 [FREE Full text] [Medline: 18364344] [doi: 10.2196/jmir.954]
34. Kenardy J, McCafferty K, Rosa V. Internet-delivered indicated prevention for anxiety disorders: a randomized controlled trial. Behavioural and Cognitive Psychotherapy 2003;31(3):279-289. [doi: 10.1017/S1352465803003047]
35. Kenardy J, McCafferty K, Rosa V. Internet-delivered indicated prevention for anxiety disorders: six-month follow-up. Clin Psychol 2006;10(1):39-42. [doi: 10.1080/13284200500378746]
36. Carlbring P, Westling BE, Ljungstrand P, Ekselius L, Andersson G. Treatment of panic disorder via the Internet: a randomized trial of a self-help program. Behav Ther 2001;32:751-764. [doi: 10.1016/S0005-7916(03)00026-0]
37. Carlbring P, Bohman S, Brunt S, Buhrman M, Westling BE, Ekselius L, et al. Remote treatment of panic disorder: a randomized trial of internet-based cognitive behavior therapy supplemented with telephone calls. Am J Psychiatry 2006 Dec;163(12):2119-2125 [FREE Full text] [Medline: 17151163] [doi: 10.1176/appi.ajp.163.12.2119]
38. Klein B, Richards D. A brief Internet-based treatment for panic disorder. Behavioural and Cognitive Psychotherapy 2001;29(1):113-117. [doi: 10.1017/S1352465801001138]

39. Klein B, Richards JC, Austin DW. Efficacy of internet therapy for panic disorder. J Behav Ther Exp Psychiatry 2006 Sep;37(3):213-238. [Medline: 16126161] [doi: 10.1016/j.jbtep.2005.07.001]
40. Richards JC, Klein B, Austin DW. Internet cognitive behavioural therapy for panic disorder. Does the inclusion of stress management information improve end-state functioning? Clin Psychol 2006;10(1):2-15. [doi: 10.1080/13284200500378795]
41. Andersson G, Carlbring P, Holmström A, Sparthan E, Furmark T, Nilsson-Ihrfelt E, et al. Internet-based self-help with therapist feedback and in vivo group exposure for social phobia: a randomized controlled trial. J Consult Clin Psychol 2006 Aug;74(4):677-686. [Medline: 16881775] [doi: 10.1037/0022-006X.74.4.677]
42. Carlbring P, Gunnarsdóttir M, Hedensjö L, Andersson G, Ekselius L, Furmark T. Treatment of social phobia: randomised trial of internet-delivered cognitive-behavioural therapy with telephone support. Br J Psychiatry 2007 Feb;190(2):123-128 [FREE Full text] [Medline: 17267928] [doi: 10.1192/bjp.bp.105.020107]
43. Titov N, Andrews G, Schwencke G, Drobny J, Einstein D. Shyness 1: distance treatment of social phobia over the Internet. Aust N Z J Psychiatry 2008 Jul;42(7):585-594. [Medline: 18612862]
44. Titov N, Andrews G, Schwencke G. Shyness 2: treating social phobia online: replication and extension. Aust N Z J Psychiatry 2008 Jul;42(7):595-605. [Medline: 18612863]
45. Hirai M, Clum GA. An Internet-based self-change program for traumatic event related fear, distress, and maladaptive coping. J Trauma Stress 2005 Dec;18(6):631-636. [Medline: 16382433] [doi: 10.1002/jts.20071]
46. Knaevelsrud C, Maercker A. Internet-based treatment for PTSD reduces distress and facilitates the development of a strong therapeutic alliance: a randomized controlled clinical trial. BMC Psychiatry 2007;7(1):13 [FREE Full text] [Medline: 17442125] [doi: 10.1186/1471-244X-7-13]
47. Lange A, van de Ven JP, Schrieken B, Emmelkamp PM. Interapy, treatment of posttraumatic stress through the Internet: a controlled trial. J Behav Ther Exp Psychiatry 2001 Jun;32(2):73-90. [Medline: 11764063] [doi: 10.1016/S0005-7916(01)00023-4]
48. Lange A, Rietdijk D, Hudcovicova M, van de Ven JP, Schrieken B, Emmelkamp PMG. Interapy: a controlled randomized trial of the standardized treatment of posttraumatic stress through the internet. J Consult Clin Psychol 2003 Oct;71(5):901-909. [Medline: 14516238] [doi: 10.1037/0022-006X.71.5.901]
49. Houck PR, Mazumdar S, Koru-Sengul T, Tang G, Mulsant BH, Pollock BG, et al. Estimating treatment effects from longitudinal clinical trial data with missing values: comparative analyses using different methods. Psychiatry Res 2004 Dec 15;129(2):209-215. [Medline: 15590048] [doi: 10.1016/j.psychres.2004.08.001]
50. Schafer JL. Analysis of Incomplete Multivariate Data. London, UK: Chapman and Hall; 1997.
51. Hunot V, Churchill R, Silva de Lima M, Teixerira V. Psychological therapies for generalised anxiety disorder. Cochrane Database Syst Rev 2007;1 CD001848.
52. Meichenbaum D, Turk DC. Facilitating Treatment Adherence: A Practitioner’s Guidebook. New York, NY: Plenum Press; 1987.
53. Waller R, Gilbody S. Barriers to the uptake of computerized cognitive behavioural therapy: a systematic review of the quantitative and qualitative evidence. Psychol Med 2009 May;39(5):705-712. [Medline: 18812006] [doi: 10.1017/S0033291708004224]
54. Hunsley J, Mash EJ. Evidence-based assessment. Annu Rev Clin Psychol 2007;3(1):29-51. [Medline: 17716047] [doi: 10.1146/annurev.clinpsy.3.022806.091419]
55. Bower P, Gilbody S, Richards D, Fletcher J, Sutton A. Collaborative care for depression in primary care. Making sense of a complex intervention: systematic review and meta-regression. Br J Psychiatry 2006 Dec;189(6):484-493 [FREE Full text] [Medline: 17139031] [doi: 10.1192/bjp.bp.106.023655]
56. Robertson L, Smith M, Castle D, Tannenbaum D. Using the Internet to enhance the treatment of depression. Australas Psychiatry 2006 Dec;14(4):413-417. [Medline: 17116083] [doi: 10.1111/j.1440-1665.2006.02315.x]
57. Brawley LR, Culos-Reed SN. Studying adherence to therapeutic regimens: overview, theories, recommendations. Control Clin Trials 2000;21(5 Suppl):156S-163S.
58. Corritore CL, Kracher B, Wiedenbeck S. On-line trust: concepts, evolving themes, a model. Int J Hum Comput Stud 2003;58(6):737-758. [doi: 10.1016/S1071-5819(03)00041-7]
59. Sun PC, Cheng HK. The design of instructional multimedia in e-Learning: a media richness theory-based approach. Computers and Education 2007;49(3):662-667. [doi: 10.1016/j.compedu.2005.11.016]

Abbreviations

CBT: cognitive behavioural therapy
GAD: generalized anxiety disorder
ITT: intention to treat
LLM: linear mixed modelling
LOCF: last observation carried forward
MAR: missing at random
MI: multiple imputation

ML: maximum likelihood methods
NMAR: not missing at random
PD: panic disorder
PTSD: post-traumatic stress disorder
RCT: randomized controlled trials
REML: restricted maximum likelihood estimation
SP: social phobia
WHO: World Health Organization

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Review

A Survey of Health-Related Activities on Second Life

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Abstract

Background: Increasingly, governments, health care agencies, companies, and private groups have chosen Second Life as part of their Web 2.0 communication strategies. Second Life offers unique design features for disseminating health information, training health professionals, and enabling patient education for both academic and commercial health behavior research.

Objectives: This study aimed to survey and categorize the range of health-related activities on Second Life; to examine the design attributes of the most innovative and popular sites; and to assess the potential utility of Second Life for the dissemination of health information and for health behavior change.

Methods: We used three separate search strategies to identify health-related sites on Second Life. The first used the application's search engine, entering both generic and select illness-specific keywords, to seek out sites. The second identified sites through a comprehensive review of print, blog, and media sources discussing health activities on Second Life. We then visited each site and used a snowball method to identify other health sites until we reached saturation (no new health sites were identified). The content, user experience, and chief purpose of each site were tabulated as well as basic site information, including user traffic data and site size.

Results: We found a wide range of health-related activities on Second Life, and a diverse group of users, including organizations, groups, and individuals. For many users, Second Life activities are a part of their Web 2.0 communication strategy. The most common type of health-related site in our sample (n = 68) were those whose principle aim was patient education or to increase awareness about health issues. The second most common type of site were support sites, followed by training sites, and marketing sites. Finally, a few sites were purpose-built to conduct research in SL or to recruit participants for real-life research.

Conclusions: Studies show that behaviors from virtual worlds can translate to the real world. Our survey suggests that users are engaged in a range of health-related activities in Second Life which are potentially impacting real-life behaviors. Further research evaluating the impact of health-related activities on Second Life is warranted.

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KEYWORDS

User-computer interface; virtual systems; virtual worlds; Second Life; health education; social and behavioral research; behavioral research; health behavior; health behavior change

Introduction

Second Life, created by San Francisco based company Linden Labs in 2003, is an online virtual reality world where users, called residents, create their own virtual selves, called avatars, and interact within a simulated 3-D environment, literally living a virtual "Second Life". Users can register for a free basic account online at Second Life's website [1] and download the free software to run the program. Users can search for places to visit, people to meet, and groups to join, and they can even create their own objects and spaces using software provided by Second Life. The content in Second Life is all user-generated.

There are over 15 million registered users within the virtual world, and over 1 million active users. Statistics from December 18, 2008 indicate that 1,437,910 residents had logged in to Second Life within the previous sixty days [2]. The average age of a Second Life user is 32, and there are slightly more males than females using the platform [3]. Second Life has its own currency called the Linden dollar which is traded on the LindeX. Linden dollars can be traded for real world currency, based on fluctuating market values. At the time this article was written, the exchange rate was approximately LD $263 to US $1 [4]. Similar to the real world, there is a spatial geography to Second Life where users can freely interact. There are over 19,000 islands in Second Life [3] which users navigate by making their avatars walk, run, fly, or teleport directly from place to place. Users can also wander through the world; however, there are private spaces with restricted access.

The communication features in Second Life simulate real world communication. For example, sounds become louder as the avatar moves closer to the source. Avatars can publicly or privately chat with each other either through voice or text tools. When using text chat, avatars automatically become animated and type in the air as their user enters a message. Instant messaging and note cards — text files that users receive when entering certain spaces — are other ways that people can communicate with each other both online and offline. Avatars also come with a variety of common human gestures that can be activated by the user, allowing them to communicate with virtual body language

Second Life encourages anonymity and interactivity, and it can be accessed from any location with a high-speed Internet connection. This makes it a potentially effective tool for disseminating user-generated health information on a site where users can access, learn about, and discuss various health topics. Many different health care agencies, organizations, companies, and private groups have chosen Second Life as one of their Web 2.0 communication strategies.

There are few research articles describing or surveying the range of health-related activities on Second Life [5,6,7,8]. A notable exception is Kamel Boulos et al's (2007) overview of several health sites, "Second Life: an overview of the potential of 3-D virtual worlds in medical and health education" [7]. Kamel Boulous has also compiled a list of Second Life health resources on a website Health Cybermap [9]. Hansen (2008) described the potential of 3-D health care learning environments on Second Life in her review of existing literature [6]. Other Web 2.0 sites describe a range of health resources in Second Life, such as Meskó's blog, "Top 10 Medical Sites in Second Life" [10] and websites that provide direct links (SLurls — Second Life URLs) to sites in the program. SL Healthy is an online wiki where people can submit information about their health site in Second Life [11]. However, to our knowledge, this is the first comprehensive survey of health activities on Second Life. This article not only catalogues the kinds of health-related activities within Second Life, but also summarizes and compares the various strategies used to communicate health information in a virtual world setting.

Methods

To explore Second Life, we opened a free basic account and created an avatar, named Ellebee Helendale. We registered for a username and password, and then downloaded and installed the free software. The Second Life software contains an application-specific search engine; however, trial searches using a selection of generic and illness-specific keywords were disappointing (Table 1), yielding few relevant results. We focused on physical sites (called "Places" in the Second Life search engine), and identified several health sites. In addition to this search strategy, we identified several key Second Life locations through a comprehensive review of print, blog, and media sources discussing health activities on Second Life (using PubMed, Scholars Portal, Google, and Google Scholar). We then used a snowball method to identify other health sites until we reached saturation (no new health sites were identified). The search methods used to identify each site are coded in Table 2, Table 3, Table 4, Table 5, and Table 6 as follows: SLSRCH = Second Life Search Engine, CLR = Comprehensive Literature Review, SB = Snowball. We then visited sites with relevant descriptions and catalogued experiences from those with the most pertinent content. The first point of identification for each site is listed in bold in Table 2, Table 3, Table 4, Table 5, and Table 6. We described and analyzed our experiences and developed categories to group sites based on their primary purpose, and the primary purpose is listed in bold (Tables 2 - 6; Multimedia Appendix 1).

Table 1. Search results using a variety of test keywords in the Second Life search engine

Keywords	Relevant Hits (13 relevant of 68 total returns)
health[a], hospital, American Cancer Society, Autism[a], Autistic[a], CDC Island[a], vaccine[a], vaccination, immunization, depression[a], sexual health[a], AIDs, HIV	American Cancer Society, Autism Parents' Connection – SOS; Biomedicine Research Organization; Coordinated School Health for Teachers; Healthinfo Island; UIS/ CSU/ Basuah Welcome; University of Wisconsin-Milwaukee, Health Science, Virtual Cancer Institute; The Walk of Life Natural Health Education Center; CDC Island; Iowa Wellness and Spinal Tuning Center; NewWays – Counselling & Support; Palomar West Hospital; SL-Labs Psychology at University of Derby.

[a] Indicates a hit with this keyword.

We tabulated all sites that either disseminated health information or provided a health experience to users with some English content. Excluded were sites that did not directly disseminate health information or provide a health experience to users; for example, sites that served solely as memorials for victims of specific diseases but contained no information on the disease itself. We recorded how the site was found, including those found through a snowball (SB), through the Second Life search engine (SLSRCH), or through comprehensive literature review (CLR). Our searches often identified specially formatted hyperlinks, or SLurls, or the precise keywords that, once inputted into the Second Life search engine, provided a direct link to the Second Life site. We also summarized the features of the identified sites, traffic information, region size, and region name. Traffic is defined as the number of minutes a unique avatar spends on an area of land [12] and is ultimately a rough measure of site popularity. Measuring site usage, or popularity, by tracking user traffic is inexact; however, other measures such as the user "count statistics" are even more unreliable due to user gaming and manipulation (eg, installing dummy avatars or "bots" permanently in the site, or paying users to keep their avatar at the site, a practice also known as "camping"). To compare the traffic between different health sites, we recorded the traffic for each site on the day of December 18, 2008 in a randomized order. This measure is only a snapshot of the popularity of each site when we visited it and does not reflect fluctuations in traffic based on Second Life events and meetings nor different times of the day.

The region information recorded includes the region name (the host of the site) and the size. Region size is measured in square meters and can be used to compare the geographical size of each site. Multiple unique sites can exist in a single region [13]. The region size can also fluctuate if more real estate is purchased. As with traffic, we recorded the region size and name for each site on the day of December 18, 2008.

We found five distinct types of health-related activities on Second Life and classified them as follows:

Education & Awareness

These sites focused primarily on offering information about various health issues, redirecting users to other websites and real-life information centers. Many of these sites also included discussion groups, lectures, classrooms, and events for communicating information about specific topics.

Support

Sites in this category often offered one-on-one discussion with real-life doctors, therapists, nurses, librarians, and other health care professionals. Some sites also facilitate peer support groups, both moderated and not, with specific topics, group membership, events, and meeting places.

Training

Training sites focus on educating people in the health care industry. Some sites are specific to the type of training they provide, and offer classrooms, discussions, lectures, simulations of health experiences, and patient interactions. Training sites that are linked to schools sometimes offer real-life academic credit for training completed within the Second Life site.

Marketing & Promotion of Health Services

These sites exist primarily to promote new or future health services, organizations, fundraising efforts, and real-life health care initiatives. Some sites offer users an experiential simulation of an organization's future plans for health care, while others recruit real-life volunteers for fund raising projects.

Research

These sites are actively engaged in recruiting participants and conducting health research in both Second Life and real world settings.

While these categories reflect what we found to be the primary motivations for these Second Life sites, many sites fall into multiple categories, offering multiple experiences.

Results

We found 68 relevant health sites that we included in our sample. In our experience, the application's search engine failed to return many relevant sites with generic keywords (13 relevant sites/68 total sites sampled). The most successful way of identifying sites was through a comprehensive literature review. This was the first point of identification for 47 relevant sites out of 68 total sites we sampled. This method brought to our attention the existence of new sites, thereby giving us specific keywords to use in the Second Life search engine, or provided direct links to the sites themselves. This suggests that the Second Life search engine is more effective when specific keywords are entered or when the user is already familiar with the name of the organization hosting the site. It also suggests that there are barriers to finding health-related information on Second Life using typical Internet strategies, such as search engines. More likely, users are drawn to these sites through Second Life advertising, Second Life special events, referrals from other sites, or networking with other users who recommend visiting the site.

We found a considerable number of Second Life sites (34) whose primary purpose is to disseminate health information. There are many features of Second Life that make it an ideal tool to do so. The interactivity, online accessibility, dynamic visual displays, and communication capabilities are key components in many of the health sites we surveyed. As mentioned previously, we tracked the popularity of the size of the sites on the day of December 18, 2008. We did not find a particular correlation between the size of the site and its popularity; in fact, some sites that are smaller geographically had a higher traffic rating than larger sites. It is interesting to note that although there are some government sponsored sites, they are not necessarily the most popular. Our sample indicates that sites in the Support category and Education & Awareness category are notably popular.

The following is a summary of our findings supported by specific examples from sites we found to be compelling and particularly innovative.

Education & Awareness

Of the 68 relevant health sites we surveyed in Second Life, 34 focused primarily on education and awareness. Educational activities include real-world health communication tools such as prepared messages disseminated through interactive information kiosks, poster and bulletin boards, broadcast multi-media productions such as health videos, slideshows, and presentations, and links to Web pages. Other sites provide Web interfaces for interactive health information seeking, such as search engines, database portals, and townhall style meetings. There are other interactive features such as games, simulations with user-participation, virtual labs and classrooms, and vicarious avatar experiences.

Table 2. Selection of health education and awareness sites (top 15 sites — ranked by traffic and, in addition, the University of Plymouth (Sexual Health Sim) which is discussed in article). See Appendix 1 for the complete results for this category

Name	Identified	First Accessed	Features	Traffic	Region Size (m^2)	Region Name
CF University (Cystic Fibrosis University)	CLR	Oct 30 2008	Several social areas and meeting places, library, memorial, Art Gallery, Medical Center, theatre.	2205	57264	Boomer Island
Contact a Family – For Families with Disabled Children	CLR	Nov 26 2008	Information for parents about raising children with disabilities. Site visitors can send questions to the site's parent advisor.	608	784	Aloft Nonprofit Commons
Venus Ventures (Hottie Hospital)[a]	CLR[b] & SLSRCH	Sept 2008	Mature site. Information about reproductive systems mostly presented in a pornographic way.	564	2784	Waved
Karuna	CLR[b] & SB	Dec 1 2008	Grand opening Dec 1 2008 to commemorate the 20th anniversary of World Aids Day. AIDS education and awareness, classroom, auditorium, links to other sites, social settings.	502	57920	Karuna
Healthinfo Island	SLSRCH	Sept 2008	Features a medical library (aka Second Life Medical Library) and consumer library, AIDS/HIV center, games, interactive displays, videos and more. Site run by RL librarians.	232	28528	Healthinfo Island
CDC Island	CLR[b] & SLSRCH	Sept 2008	Information about various public health issues, links to external websites, virtual microbiology labs, conference rooms, information about the CDC.	224	63296	CDC Island
Virtual Hallucinations	CLR[b] & SLSRCH	Sept 2008	Simulation of common hallucinations experienced by people with schizophrenia; focus on keywords, hearing voices, self-deprecating feelings, and more.	211	2560	Sedig
Ohio University Second Life Campus (Nutrition Game)[a]	CLR	Nov 4 2008	The Nutrition Game is one component of the Island (Featured Game). Interactive game teaches healthy food choices and nutrition.	179	53664	Ohio University
Autistic Liberation Front	CLR	Oct 30 2008	Hosted by an autism self-advocacy group. Meeting areas, memorial for autistic children who have been murdered, library/museum, interactive displays, store with SL items.	177	9360	Porcupine

Name	Identified	First Accessed	Features	Traffic	Region Size (m^2)	Region Name
Preferred Family Healthcare Island	CLR	Nov 4 2008	Real-life prevention and treatment provider for mental health issues and substance use. Online staff members, education, presentation areas, fitness center, conference rooms, game area.	175	62416	Preferred Family HC
Genome Island	CLR	Sept 2008	Scientific exploration of genetics. Scavenger hunt, many interactive features, free t-shirt of “your favourite chromosome” for avatars.	164	61264	Genome
Occupational Therapy Center at Thomas Jefferson University	SB	Nov 17 2008	Information about the role of occupational therapists. Interactive house display explains accessibility for physical and cognitive disabilities.	161	1120	Eduisland II
Tox Town at Virtual NLM	SB	Nov 17 2008	Includes a town, city, farm, port, and US-Mexico border, to help users identify toxic substances in their environment.	109	65536	Virtual NLM
Alliance for Consumer Education (ACE)	CLR[b] & SLSRCH	Nov 20 2008	Information center for disease prevention and inhalant abuse prevention. Interactive “Stop Germs” House.	101	65536	ConsumerEd Island
Coordinated School Health for Teachers	SLSRCH	Nov 24 2008	Information for teachers on implementing health programs into education. (Also for general public.)	49	8192	Eduisland 5
University of Plymouth (Sexual Health Sim)	CLR[b] & SLSRCH	Sept 2008	Information specific to sexual health; pictures of STD symptoms, interactive AIDS map, virtual condom, chatbot, quizzes, links, 3-D Tour of the Testes.	3	1536	Education UK

[a] Indicates that traffic and area size are bundled by the host, and include unrelated activities.

[b] Represents the first point of identification for the site.

Healthinfo Island

Healthinfo Island is funded by a $40,000 grant [7] from the Greater Midwest Region of the National Networks/National Library of Medicine. The site is run by real-life health librarians and medical experts [7] and aims to provide users with education and awareness of and access to health information. The island features a Medical Library, a Consumer Health Library, PubMed search capability, the iVinnie Accessibility Center, and various other displays and meeting spots. There is a broad range of health information conveyed by kiosks in the Information Outreach Lab, from posters that redirect users to an HIV awareness website to ToxTown, an interactive area that explains the health risks from environmental agents.

According to van den Breckel (2007), Healthinfo Island aims to become the “central point in (Second Life) for health and medical information” [14] (page 1) by acting in cooperation with other health and medical agencies to “reach out to all Support Groups in Second Life” [14] (page 1). Healthinfo Island’s Pathway of Support serves as a clearinghouse for support group activity, providing users with information about various health-related support groups in the virtual world. Healthinfo Island is also committed to encouraging the development of support groups in Second Life, offering free land for six months to select non-profit health groups and organizations [14].

University of Plymouth Sexual Health Sim

The Sexual Health Sim, run by the University of Plymouth (UK) contains public health information about sexually transmitted diseases. The site was made possible by a land grant from Education UK in July 2007 [15] and contains several interactive features, such as photographs of symptoms of various sexually transmitted diseases and a 3-D tour of the testes. Users can read about condoms and safe sex practices, and receive a virtual condom for their avatars to use. Avatars can also simulate the experience of illness by literally donning a “skin” (similar to clothing but acts like a second skin) that, in this case, visually displays the lesions of AIDS-related Kaposi Sarcoma on the avatar. Furthermore, the Sim provides information about both active sexuality and abstinence groups. The Sexual Health Sim employs unique features of Second Life in order to communicate health information to users.

CDC Island

CDC Island is a 3-D virtual representation of the US Centers for Disease Control and Prevention. The island, which neighbors Healthinfo Island, contains many displays that link users to different websites and, at times, allows them to participate in discussion and focus groups. The buildings are interactive and contain meeting rooms, reception areas, and even microbiology labs where users can interact with microscopes to examine different bacteria and diseases. John Anderton, one of the creators of CDC Island, stated that he wanted the island to be a place for information, education, and dialogue [16]. The site includes several outreach activities, including CDC robots that ask for comments and site suggestions, a bracelet for avatars that automatically informs users of health awareness initiatives, live RSS feeds of health stories, and occasionally a live CDC representative is available in-world.

The National Institutes of Health (NIH) Second Life White Paper noted the benefit of anonymity for users in seeking health information and the opportunity to speak directly with a CDC representative [17]. Anderton notes that these representatives direct people to the information they need and are not “a surrogate for doctor-patient information” [18].

Women’s Health Center at the Ann Myers Medical Center

The Ann Myers Medical Center, founded by Dr. Ann Buchanan in honor of her mother, Ann Myers, is run entirely by real-life nurses and physicians who donate their time. Much of the site is off limits to non-members. For its members, the site offers education through classrooms, resources, and simulations and is noted as being the first Second Life community to have adopted medical simulations in 2007 [19].

A few areas are open to all visitors, including the Women’s Health Center (WHC), where we received note cards explaining the importance of self-breast examinations. A room in the WHC shows female users how to perform their own breast exams. Another area shows what a mammogram machine looks like. As our avatar received a virtual mammogram (Figure 1), we were urged by our tour guide (a member of the AMMC) to take these lessons from SL (Second Life) to RL (Real life).

Figure 1. Our avatar Ellebee Helendale receiving a mammogram at the Ann Myers Medical Center

Virtual Hallucinations

Virtual Hallucinations, a project originally launched by Peter Yellowlees and collaborators at the School of Medicine at the University of California at Davis, aims to educate people about the perceptual abnormalities experienced by schizophrenics by simulating common hallucination experiences. Auditory and visual hallucinations are simulated as the avatar enters the space and begins interacting with objects in the room. As our avatar entered the room, we were presented with a note card warning us not to proceed with the simulation if there was any history of mental illness in our family, indicating that the site managers are concerned about the real-life effects this site could have on users.

There are several interactive components within the simulation that aim to educate the user about this illness and the challenges faced by people with schizophrenia. In the pilot project, Yellowlees (2006) and his team surveyed 579 users who toured the site. Respondents were slightly more positive about the effects of the auditory hallucinations but indicated that the site improved their understanding of both auditory and visual hallucinations [20], and 82% of respondents said they would recommend the site to others [20]. Yellowlees thus shows that the virtual simulation was a successful education tool in promoting a deeper understanding of the experiences of those with mental illness.

The majority of health sites in Second Life offer some level of education and awareness. Our survey of health sites shows that Second Life offers unique and interactive ways to facilitate health education. The sites we found the most compelling are ones that took full advantage of experiential features.

Support

Of the 68 relevant health sites in Second Life, 14 focused primarily on offering illness-specific patient or peer support. Many sites that aim to educate and promote awareness about specific illnesses also offer some level of individual and group support. Groups in Second Life offer support for everything from weight loss to living with AIDS. While these groups may not own virtual land or have their own spaces, they often will meet at other sites for discussions and will even host virtual events. Other sites offer personal consultations with health care providers and therapy sessions. Gorini stated that “3-D virtual worlds may convey greater feelings of presence, facilitate the clinical communication process, positively influence group processes and cohesiveness in group-based therapies, and foster higher levels of interpersonal trust between therapists and patients” [21] (page 1549). The interactivity and anonymity of Second Life make it an interesting platform for medical consultation, therapy, and peer support. Individual consultations and support groups are appropriate for Second Life largely due to the anonymity the platform encourages and by the many communication tools it provides. Some sites offer one-on-one appointments with doctors, nurses, medical librarians, therapists, and other health care professionals. Others provide virtual meeting places for groups to assemble and discuss the support group topic, moderated discussion groups, themed support group meetings, and group membership.

Table 3. Support sites (ranked by traffic)

Name	Identified	First Accessed	Features	Traffic	Region Size (m^2)	Region Name
Transgender Resource Center – Peer Support & Social Activism	SB[a]& SLSRCH	Nov 17 2008	Offers support for transgendered individuals, regular meetings, peer support groups, online forums.	2313	1296	Aloft Nonprofit Commons
Wellness Island (Counseling Center – Homes and Offices)	CLR	Nov 5 2008	Library and support/education materials on mental health, relationships, etc. Counselling services available for a fee. Workshops also available. Community Outreach area provides links and direct teleports to other health sites in SL.	327	6528	Wellness Island
Live2Give	CLR	Nov 4 2008	Designed for people with severe physical limitations, to provide education, support, and a barrier-free environment.	192	65536	Live2Give
GimpGirl Community	CLR	Nov 18 2008	Meeting place for women with disabilities. Weekly support groups, presentations, and social gatherings.	66	15104	3DE
The Center for Positive Mental Health	CLR	Sept 2008	Provides support for various mental health issues. Managed by a psychologist. Book reviews and link to fee-based psychology appointments within SL. Meeting space for discussions.	43	5632	Kkotsam
Breast Cancer Network of Strength	CLR	Oct 30 2008	Site offers links and contact information for support groups, and meeting areas for people to discuss health issues.	29	4096	Association Works
NewWays – Counselling & Support	SLSRCH	Nov 17 2008	Offers free counselling and support to SL users by certified psychotherapists. Donations accepted. Confidentiality ensured, appointments available every Tuesday from 10:30am - 1:30pm PDT.	26	560	Hauwai
Meeting Circle	CLR[a]& SLSRCH	Nov 24 2008	Peer support groups with diverse health related talks; facilitated meetings several times per week. Notecards with some information about depression and medication, and suicide prevention.	24	1584	Support for Healing
12 Step Recovery Meeting Hall	SB[a]& SLSRCH	Nov 17 2008	Designed for any user going through a 12 step program (any addiction).	21	512	Idunn
Light Bearer Grief Center	CLR	Nov 4 2008	Room setting with links to support groups, grief resources, grief organizations, poems, music, other sites.	2	64	Imagination Island
Aspies for Freedom resource center	SB[a]& SLSRCH	Nov 17 2008	A meeting place for those diagnosed with Asperger's syndrome. Note card links user to the website which holds forums, chatrooms, wikis and more.	2	960	Coders Cove
Autism Parent's Connection–SOS	SLSRCH	Nov 27 2008	Site for parents of children with autism. Weekly meetings on Saturdays.	0	384	Amiaguas Avalon
The Counselling Center Annex Office	SB	Nov 17 2008	Information about individual health counselling. Users can make an appointment with a counsellor through the site. Description on "About" tab says it is the mainland satellite office for Wellness Island.	0	512	Boncarus
The Heron Sanctuary	CLR	N/A[b]	Meeting place for people with disabilities. Restricted access.	N/A	N/A	N/A

[a] Represents the first point of identification for the site.

[b] N/A indicates that the site was not available at time of sampling, or access was restricted (members only).

Sexual Health Sim

The Sexual Health Sim offers links to outside support groups for people who have sexually transmitted diseases, AIDS, and HIV or questions about sexual health, as well as links to a Christian abstinence group and others. The site also holds its own discussion groups periodically, and one recent discussion group about disability and sexuality sparked quite a lot of interest in the Second Life community and was attended by more than 40 avatars [22].

Transgender Resource Center — Peer Support & Social Activism

The Transgender Resource Center is a site that primarily offers support for transgendered individuals. The site is a room with chairs, a screen showing trailers for movies related to the subject (for example, "Transamerica"), and health information resources. The Center also holds regular meetings, peer support groups, and online forums for discussion. The popularity of the site should be noted. On almost every one of the authors' visits to the site, they were greeted by other avatars using the space. On one visit, we met a group of avatars who were meeting socially in the site and were discussing transgendered issues outside of a discussion group. This site also had one of the highest traffic ratings of the sites we visited. The high traffic rating, coupled with the noted interactions in the space, suggest a popular and successful peer support group.

Training

Of the 68 relevant health sites we discovered in Second Life, 11 focused primarily on training. The use of Second Life to provide specialized staff training is growing rapidly. IBM, Dell,and others are using the platform to their train staff, and several health care organizations have initiated training programs in Second Life. Several universities are training medical students in Second Life [23]. Stott (2007) noted that some universities have found that having a Second Life presence can affect the brand of the school and attract future students [23].

Typically, virtual training simulations provide users with an interactive and safe way to engage in a situation. Skiba (2007) quoted the Second Life Education Wiki in describing the benefits of using the platform for training and education: "Second Life provides an opportunity to use simulation in a safe environment to enhance experiential learning, allowing individuals to practice skills, try new ideas, and learn from their mistakes" [8] (page 156). Hansen (2008) argued that there are many gaps, unanswered questions, and potential issues with providing health care education in Second Life because very little empirical research has been conducted to suggest its efficacy [6]. However, the author felt that medical education in Second Life is something that should be pursued, and that research should be conducted to evaluate the value of the strategy and the effect of the experience of the users [6]. Training sites differ in their delivery of education, but most offer some level of simulation in which the users can participate. Many offer classes, classrooms, discussions, assignments, lectures, slideshows, videos, quizzes, and tests. Some users can even qualify for real-life credit for completing training scenarios in certain sites.

Table 4. Training sites (ranked by traffic)

Name	Identified	First Accessed	Features	Traffic	Region Size (m^2)	Region Name
Ann Myers Medical Center	CLR[a]& SLSRCH	Sept 2008	Primarily used to train medical students. Public users can watch presentations, learn about health issues, and tour some of the virtual facilities with a member. Private areas include training resources for students, classrooms, presentations, conference rooms.	989	64192	Hospital
EMS Island	CLR	Dec 4 2008	Interactive quiz about medicine and health care, information about fractures, sprains, ailments, and diagnoses, links to external websites.	166	6656	Immaculate
Medical Examiner's Office – Forensic Pathology	CLR	Nov 18 2008	Information about pathology, graphic images from dissections and autopsies. Area for virtual autopsy sim (not functioning at time of visit).	164	4096	San Miguel
University of Wisconsin-Milwaukee, Health Science	SLSRCH	Nov 24 2008	Classroom with instructions for a medical setting Scenario for avatars. Slideshow on ethics in health care.	124	8192	Arts and Letters
RL Education – Heart Murmur Sim	CLR	Nov 4 2008	"Cardiac Auscultation Training Concept". Interactive activities with virtual patients.	101	1280	Waterhead
Evergreen Island	CLR	Dec 4 2008	Hosted by Washington State Community and Technical Colleges.Training area for nurses. MRI machine with explanation of it's function. NHS signs. Patient rooms complete with bathrooms, classrooms with bed for avatar CPR, nurses station. Poster with a list of outcomes for SL class.	90	62400	Evergreen Island
CSCE – Healthcare Projects	CLR[a]& SLSRCH	Dec 11 2008	Designed as a hospital with Pharmacy, Patient Care area, Diagnostics, etc. Most interactive features not functioning at time of visit, but apparent that it is set up for training purposes.	88	24576	University of Arkansas
Imperial College London (Virtual Hospital)	CLR	Nov 5 2008	Virtual Respiratory Ward offers activities and simulated patient experiences. Students registered can receive course credit.	65	50784	Imperial College London
Medical Visualisation Network	CLR	Nov 18 2008	Aim is to produce new and innovative teaching solutions. Wall with pictures and bios of the Board Members of the MVN. Poster about virtual reality and anatomy training.	8	6832	Vue
SL Institute for Clinician Education (SLICE)	CLR	Nov 18 2008	University of Illinois virtual clinic for training medical students, physicians, and standardized patients.	0	512	Aido Wedo
Play2Train	CLR	Sept 2008	Emergency preparedness training simulation. Access restricted to members (invitation only). Designed in part to teach users how to manage patients and dispense drugs in emergency situations.	N/A[b]	N/A	N/A

[a] Represents the first point of identification for the site.

[b] N/A indicates that the site was not available at time of sampling, or access was restricted (members only).

Imperial College London (Virtual Hospital)

Upon entry to the site we received an automated message saying our avatar had to register to be granted permission to enter the virtual hospital and treat patients. The Virtual Respiratory Ward offers activities and simulated patient experiences for which registered students can receive credit. Guests who have registered can participate but must pay for each diagnostic test they order for their virtual patient. The diagnostic simulation includes patient interviews, ordering diagnostic tests, arriving at a diagnosis, and providing treatment. This simulated environment allows students to go through the motions of visiting with a patient and the sequence of events that follows their treatment.

Play2Train

Play2Train is a simulation sponsored by the United States Department of Health and Human Services [24] and supported by the Idaho Bioterrorism Awareness and Preparedness Program. The simulation trains users for emergency preparedness and features a virtual town and hospital where the training sessions take place [24]. Unlike other simulations, Play2Train forces participants to communicate with each other during sessions in a realistic fashion. The audio features of Second Life enhance the realism of the communication, as voice volume is dependent on the users' proximity to one another [24]. The people behind Play2Train plan to compare the results of this training method to real-world simulations [24].

Medical Examiner's Office — Forensic Path

The Medical Examiner's Office provides information about pathology and how autopsies are performed. Graphic images from dissections and autopsies are the backdrop for an autopsy simulation in which the user's avatar is the coroner. Although it was not fully functional at the time of our visit, our avatar was given tools to perform an autopsy on a virtual corpse. The simulation opportunities in Second Life are virtually limitless and can be built to provide training scenarios for many different purposes. Other features that allow lectures, virtual classrooms and assignments, videos, and slideshows also enable training within the platform.

Marketing/Promotion of Health Services and Institutions

Of the 68 relevant health sites in Second Life, 6 focus primarily on marketing and the promotion of health services. The use of Second Life as a means of promoting business and emerging technologies is not exclusive to companies like IBM and Apple. Health care institutions are now using the platform as a way of promoting specific hospitals, services, health system reform, and even fundraising. It also provides a global showcase for best practices in medicine. The simulation capabilities in Second Life allow for organizations to provide users with first-hand virtual experiences of their initiatives and thereby garner public support. They can also recruit membership among Second Life users for real-life projects and promote upcoming fundraising initiatives.

Table 5. Marketing sites (ranked by traffic)

Name	Identified	First Accessed	Features	Traffic	Region Size (m^2)	Region Name
American Cancer Society (Office and Lobby)[a]	CLR[b] & SLSRCH	Oct 30 2008	Office area includes information on Relay for Life office, and several executive offices and conference rooms. Volunteer recruitment.	358	16416	American Cancer Society
Palomar West Hospital	SLSRCH	Sept 2008	PWH is a virtual replica of the new hospital being built in San Diego in 2011. It features a simulation of the future patient experience.	222	64112	Palomar West Hospital
Second Health (by Imperial College London)	CLR[b]& SLSRCH	Sept 2008	SH is affiliated with the NHS and has many different areas, including a Polyclinic Tour, auditorium, hospital, a training facility, and a private medical school.	49	64064	Second Health London
Diabetes UK	CLR	Nov 18 2008	Information about the organization (research charity), donation recruitment, "Diabetes Info Centre", meeting areas, work stations, support phone number provided (RL).	18	5136	21CC
AICR (Association for International Cancer Research)	CLR	Oct 30 2008	Virtual auditorium, FAQ's about different types of cancer, fundraising activities for cancer research (fashion shows, SL items)	3	22192	AICR
Faster Cures	CLR	Nov 26 2008	Information about the organization, curing diseases, innovations in treatment, and clinical trials.	3	640	Aloft Nonprofit Commons

[a] Region contains multiple health-related areas specific to the region; only one area was sampled and recorded.

[b] Represents the first point of identification for the site.

Second Health (UK)

Second Health showcases recent efforts to implement the polyclinic model, a single point of access for both insured hospital and clinic medical services by simulating a London polyclinic. The region is set up like a town with several different areas to which users can teleport, such as a training area, a hospital, a polyclinic, and the Second Health Auditorium which hosted the first meeting for the international Virtual Association of Surgeons (iVAS) in April 2008. iVAS was attended by forty-seven avatars from five different countries [25]. Second Health has an extensive website which states that “The future of healthcare communication” [26]. Another part of their current outreach includes videos on YouTube that show various scenarios of the Second Life simulation, still allowing those who are not Second Life members to learn about Second Health.

Palomar West Hospital

Palomar West Hospital (PWH) is a virtual simulation of a hospital which will be opened by Palomar Pomerado Health (PPH) in 2011 [27]. The Cisco-powered site, which is based on the blueprints for the future physical building [28] also showcases Cisco technologies that will be used within the hospital [29]. From the moment our avatar stepped into PWH, an automated yet interactive simulation began. When we entered, we were greeted by a woman on a large screen near the reception desk. She advised us that we would be wearing a hospital ID bracelet, equipped with an electronic identification tag, which assigned us to a health scenario: our avatar was informed that she required gall bladder surgery and that she must proceed to the elevator which will take her directly to her patient room. From this point on, our avatar was led through an extensive simulation and explanation of the design and experience of the patient room, diagnostic testing, robotic surgery procedures, and recovery. Orlando Portale, the Chief Innovation Officer of PPH, stated that the primary goal of creating PWH “was to allow our constituents to experience, rather than just to see the entire project” [30].

American Cancer Society (ACS)

The ACS site in Second Life features entertainment areas, donations from visitors, a multi-level building with office space and meeting rooms, and information about the ACS and Relay for Life of Second Life. Relay For Life of Second Life, launched by the ACS in 2005, is a virtual walk-a-thon to raise money for the American Cancer Society. The event has grown substantially since its inception in 2005, when it raised nearly US $5,000. In 2007 it raised nearly US $120,000 [31], and the 2008 event, which was held on July 19, raised over US $200,000 [32]. Attendance for the event has also grown astronomically. In 2005, the event was attended by a few hundred avatars [31], while the 2008 event was attended by 2300 [32]. The office areas in the ACS site provide information about volunteering for Relay for Life of Second Life, complete with a bulletin board with job opportunities.

Second Life offers many features that can enhance an organization’s marketing initiatives. Traditional advertising is replicated in Second Life with billboard ads and product placement. Real-life current and future initiatives can also be replicated in the platform as simulations and user experiences. The variety of communication tools and interactivity provide organizations with new and innovative ways to reach out and gain buy-in from their clientele.

Research

In our survey of health sites, we found few that focused primarily on conducting health research within Second Life (3 of 68 relevant health sites). Second Life offers the potential for health research to be conducted directly and indirectly within the platform. Bainbridge (2007) discusses the value of conducting research in virtual worlds, stating that they can create laboratories, experiments, and settings that simulate the real-world experience at a very low cost [33]. Furthermore, researchers could have access to a large population of subjects given the growing demographics of Second Life [33].

HHP at UH (Health & Human Performance at the University of Houston) in Second Life focuses on promoting healthy lifestyles. The site includes a large auditorium with video screen, presentations, and many buildings, including the Exercise Science building and the Texas Obesity Research building, it and offers visitors payment in Linden dollars to participate in surveys, studies, and activities. One of these studies is a 28-day health challenge for which avatars can enrol to participate.

Many sites give users note cards that contain voluntary surveys, asking questions about their experience, while others offer the user note cards to recruit participants for other studies. For example, the SL-Labs Psychology at University of Derby site offers users the chance to enrol in psychological studies.

Despite the lack of direct health research being conducted via avatar studies in Second Life, there are many other indirect ways that health care organizations are conducting research within the application. Second Life is also a viable resource for collecting passive research data and surveillance on various health topics, including what health issues users are researching, the geographical location of those searches, discussion topics, and health concerns. The CDC has been conducting in-world focus groups with avatars to collect data about the design and content of the virtual space [34]. Land owners can also keep track of site “traffic” (ie, the number of minutes avatars spend on the site) [12].

Second Life can also be used to survey the effectiveness of the information being displayed within the platform by tracking site referrals, visits to linked websites, and repeat visits from avatars. Van den Breckel (2007) states that one of the grant purposes of Healthinfo Island is to research the benefits and efficacy of disseminating health information within Second Life, stating, “All resources, areas and informational displays are being ‘monitored’ to evaluate effectiveness based on gathered statistics. Information on navigation, length of stay, items ‘touched’ will be used as input for this research” [14] (page 4).

Table 6. Health research sites (ranked by traffic)

Name	Identified	First Accessed	Features	Traffic	Region Size (m^2)	Region Name
Stanford University Libraries[a]	SLSRCH	Nov 27 2008	Virtual Stanford Psychology Department where users can register to participate in experiments. Not functioning at time of visit.	2360	65536	Stanford University Libraries
Biomedicine Research Organization	SLSRCH	Nov 27 2008	Lecture area with slides on Chlamydia, research labs (purpose unknown), classrooms, board rooms, interactive display, virtual hospital. Links to information about the organization.	38	65536	Biomedicine Research Labs
HHP at UH (Health & Human Performance at the University of Houston)	CLR	Nov 5 2008	Offers visitors payment (in $Linden) to participate in surveys and activities, including a 28 day health challenge.	23	32224	HHP at UH

[a] Indicates that traffic and area size are bundled by the host, and include unrelated activities.

Discussion

Our survey of health sites on Second Life indicates that virtual worlds have significant potential to improve health communication and patient experiences in the real world. Second Life is being used to educate users about important public health issues, train health care providers, market and promote health services, allow individuals to seek out individual or group support for diverse health issues, and, finally, to facilitate research. The steady rise in Internet use for seeking health information has converged with increased popularity of a range of Web 2.0 applications. These applications are increasingly returned when users perform keyword searches on health issues of interest. For example, a typical Google search of keywords from popular health topics will direct users not only to traditional websites, but also to YouTube videos, health blogs, and even to virtual worlds like Second Life. The Gartner Group consultancy claims that by 2011, 80% of active Internet users will use virtual realities [35]. In 2008, the McKinsey Group consultancy expressed the validity of Second Life and warned: “Ignore Second Life at your peril”[36].

Virtual worlds, like Second Life, offer unique didactic experiences to users seeking health information, skill building and health care training, group support, and, finally, individual consultation. Second Life venues for training can remove the travel and overhead costs that traditional health care training requires, and 3-D simulations can increase the utility of online training in areas where one-on-one inter-personal communication is an issue, as in the classic physical exam. While training programs on Second Life have a demonstrable utility, it is unclear how the communication of health information or virtual health experiences may impact individual health behavior. Research examining the impact of patient expectations and anxiety over health procedures suggests that this “priming” of patients with a Second Life experience may improve clinical outcomes by giving patients a better understanding of the health care system and its procedures before they come to the hospital or the clinic [3]. Having a virtual experience may give patients an increased sense of control over health experiences and should improve both knowledge and confidence, since the patient can navigate the health care system from the comfort of their own home. Patients can literally practice being patients or making healthy choices: they can formulate and ask questions in a simulated health experience and receive reinforcement from a variety of virtual experiences.

How experiences from Second Life might translate into real life is unclear and requires further research. Would having a trim, fit avatar have any impact on a person’s real self-image? Might it motivate people to engage in healthier behaviors? Second Life offers researchers unique opportunities to monitor user behavior and to study the impact of health communication, interventions, and training. Simulating a typical health experience scenario can make the logic of medical advice more comprehensible and concrete, for example by personalizing the long-term risks of certain health behaviors like smoking. Users can have their avatar experience the outcome of certain risk behaviors as a variety of illnesses, and their trust and responsiveness to public health recommendations may be bolstered by Second Life experiences. Thus, Second Life experiences have the potential to improve user trust in, and compliance to, public health messaging.

The Real-life Implications of Second Life

Studies show that Second Life has real-life behavior implications. One study indicates that the behavior of users even correlates to the physical appearance of their avatars. Researchers at Stanford University’s Virtual Human Interaction Lab coined the term “Proteus Effect” to describe this phenomenon, as they found that the height of the avatar affected the users’ assertiveness and behavior within the virtual setting [3]. The appearance of the avatar alone can thus indicate some of the behaviors of the user.

National Institutes of Health (NIH) states that the Second Life platform enables public outreach initiatives and that it can be used by global health organizations as a new usability model for collaboration and to explore new ways to communicate health information [17]. Huang et al (2008) suggest that professional collaboration within Second Life may lead to real-life collaboration and exploration [37]. Many outreach initiatives for health care are being explored by various organizations, companies, and individuals in an effort to impact real-life behaviors.

Simulations that teach users about a specific topic can leave a lasting impact that transfers to the real world. In the Virtual Hallucinations pilot project, Yellowlees found that users reported a greater understanding of hallucinations and schizophrenia as a result of the simulation [20]. Web 2.0 applications such as Second Life have been credited for reducing the stigma of Autism and Asperger's, as they promote awareness and stimulate empathy [38]. These are examples of knowledge transfer that will most likely follow users from Second Life to real life as they encounter health topics like schizophrenia and autism in the real world, they will have an awareness and understanding that was previously lacking and respond to situations differently as a result.

While some sites provide awareness about external topics, others look to provide the user with information that can be applied to their own real lives. Hoch, a neurologist at Massachusetts General Hospital, developed a pilot project to determine the effects of virtual meditation and relaxation on reducing real-life stress [39]. Hoch found that the virtual group displayed the same type of interactions as the real-life groups [30]. Bignell, a psychology lecturer at the University of Derby, England, is using Second Life to study how the platform can improve real-life communication skills among users with autistic spectrum disorders [40]. Gustafson (2008) stated that Second Life could potentially improve the results of substance abuse treatments, in part because the exposure to health information in Second Life may influence users to seek real-world information, advice, and treatment [3]. There is even a case report of a woman combating alcoholism within the platform. "Shelly", and approximately 100 other alcoholics, underwent a therapy program through Accelerated Recovery Centers in Atlanta that existed solely in Second Life, where they were taught real-life techniques for avoiding alcohol [41]. Gustafson suggested that therapy for substance abuse in virtual reality, particularly virtual role-playing exercises, could have real-life benefits because users are able to practice new behaviors in a safe, simulated environment [3].

Some studies suggest that Second Life is a powerful research tool because it allows researchers to predict real-life behavior in a simulated setting [3,42,43]. Slater reproduced Stanley Milgram's controversial shock therapy experiment where participants displayed a strong obedience to authority despite their own sentiments. Slater's virtual reproduction of the experiment was not conducted in Second Life, but in a similar virtual setting using an avatar as a subject. Although the participants inducing the shocks to the avatar knew the experiment was not connected to a real person, they were still uncomfortable shocking the avatar. Despite their discomfort with the experiment, the users continued to shock the avatar, just as Milgram's subjects had continued to shock their subject. Slater stated that virtual realities can thus be used as predictors for real-life human behavior [43].

Some agencies are building their sites specifically in an effort to change real-world behaviors. The CDC hopes that visitors to their site will apply what they learned in real life. Erin Edgerton, the content lead for interactive media at the National Center for Health Marketing for the CDC stated, "Today, the focus is less on the CDC as an agency and much more on specific health-related issues and on engaging visitors in virtual behaviors that might influence real-world health decisions" [30].

The transfer of Second Life to real-life behaviors has implications for health care. The experiential qualities of Second Life can be leveraged to promote the transfer of behaviors in Second Life to real-life. Edgerton stated that "when people practice health behaviors in a virtual world, they are more apt to perform them in the real world" [44]. Disseminating health information in the virtual reality could thus offer more effective health communication, reach a substantial number of people at once, and, in turn, produce real-life health results at low cost and with high impact.

The realism and social interaction within Second Life make it a viable venue for developing and testing new technologies that have implications outside of the Second Life platform. As more users embrace virtual worlds and the technology continues to evolve, issues over the ethics of virtual world research, user privacy, avatar informed consent [33], and intellectual property will have to be addressed.

Conclusions

Second Life offers various interactive and innovative ways of communicating health information to a growing population of users. We developed five categories to describe the range of health-related activities online. The most common category was those sites whose primary purpose was to disseminate health information, followed by sites for peer-support, training of health care professionals, sites marketing and promoting health institutions and products, and, finally, sites dedicated to both virtual and real-world health research. The ability for individual users, health care institutions, and companies to create their own content presents opportunities for greater access to information and access to real-world health resources.

The design attributes of successful Second Life health sites suggest that both anonymity and interactivity are paramount. Second Life offers users the ability to interact with and speak to real people in real time while preserving their anonymity. They can consult with experts and other individuals with shared experiences, either privately or publicly in a group setting. Even when engaged in public discourse, there is still an element of privacy that does not exist in real-world interactions. This makes Second Life a potentially powerful tool for enabling discourse about personal and private issues, particularly those concerning health.

The number of health sites within Second Life indicates a need for this type of interaction in health care. Health care and communications professionals can learn why people are attracted to these virtual settings to engage in health discourse and potentially apply these lessons to real-world health communication strategies. Users are encouraged to expand their understanding of illnesses and to practice health promotion and prevention strategies through their avatar's experiences. To be able to ask questions and pursue health information and experiences in an interactive 3-D setting, with inter-personal but anonymous contact, is singular to virtual worlds and opens up a range of exciting new possibilities for both patients and health care professionals.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Full list of all identified sites.

[PDF(Adobe PDF File), 50 KB - jmir_v11i2e17_app1.pdf]

References

1. ; Linden Research, Inc. http://secondlife.com. 2009. Second Life URL: http://secondlife.com/ [accessed 2009 Apr 16] [WebCite Cache ID 5g5kWLjLV]
2. ; Linden Research, Inc. http://secondlife.com. 2009. Economic Statistics. URL: http://secondlife.com/whatis/economy_stats.php [accessed 2009 Apr 16] [WebCite Cache ID 5dAmiJbz1]
3. Gustafson D, Shaw B, Isham A, Dillon D, Spartz J. Robert Wood Johnson Foundation. 2008. Exploring the Potential of the Web-based Virtual World of Second Life to Improve Substance Abuse Treatment Outcomes. URL: http://www.rwjf.org/pr/product.jsp?id=34428 [accessed 2009 Apr 17] [WebCite Cache ID 5dAlzIqme]
4. ; Linden Research, Inc. http://secondlife.com. 2009. LindeX™ Exchange: Market Data. URL: http://secondlife.com/whatis/economy-market.php [accessed 2009 Apr 17] [WebCite Cache ID 5dbmw2Awk]
5. Gorini A, Gaggioli A, Vigna C, Riva G. A second life for eHealth: prospects for the use of 3-D virtual worlds in clinical psychology. J Med Internet Res 2008;10(3):e21 [FREE Full text] [Medline: 18678557] [doi: 10.2196/jmir.1029]
6. Hansen MM. Versatile, immersive, creative and dynamic virtual 3-D healthcare learning environments: a review of the literature. J Med Internet Res 2008;10(3):e26 [FREE Full text] [Medline: 18762473] [doi: 10.2196/jmir.1051]
7. Boulos MNK, Hetherington L, Wheeler S. Second Life: an overview of the potential of 3-D virtual worlds in medical and health education. Health Info Libr J 2007 Dec;24(4):233-245. [Medline: 18005298] [doi: 10.1111/j.1471-1842.2007.00733.x]
8. Skiba DJ. Nursing education 2.0: second life. Nurs Educ Perspect 2007;28(3):156-157. [Medline: 17557638]
9. Boulos MNK. HealthyCyberMap.org. 2008. Web 2.0 and the 3D Web (Virtual Worlds and Second Life®). HealthCyberMap. URL: http://healthcybermap.org/sl.htm [accessed 2009 Apr 17] [WebCite Cache ID 5dAmAMKk8]
10. Meskó B. ScienceRoll.com. 2007. Top 10: Virtual Medical Sites in Second Life! URL: http://scienceroll.com/2007/06/17/top-10-virtual-medical-sites-in-second-life [accessed 2009 Apr 17] [WebCite Cache ID 5dAn812aS]
11. SLHealthy. SL Healthy. SL Healthy File Cabinet URL: http://slhealthy.wetpaint.com/page/SL%20Healthy%20File%20Cabinet?t=anon [accessed 2009 Apr 17] [WebCite Cache ID 5dAl2d1f7]
12. ; Linden Research, Inc. Second Life Wiki. About Traffic URL: http://wiki.secondlife.com/wiki/Traffic [accessed 2009 Apr 17] [WebCite Cache ID 5dAmVum6r]
13. ; Linden Research, Inc. Second Life Wiki - Land. Region URL: http://wiki.secondlife.com/wiki/Region [accessed 2009 Apr 17] [WebCite Cache ID 5dAn2o8yS]
14. van den Brekel AJP. Get your Consumer Health Information from an Avatar!: Health and Medical Related Activities in a Virtual Environment URL: http://www.eahil.net/conferences/krakow_2007/www.bm.cm-uj.krakow.pl/eahil/proceedings/oral/vanBrekel.pdf [accessed 2009 Apr 17] [WebCite Cache ID 5gQRl2sBg]
15. Boulos MNK. HealthCyberMap. The University of Plymouth Sexual Health Sim in Second Life URL: http://healthcybermap.org/publications/BoulosMNK_UOPSHSIM_CELDA2007_Dec9_Carvoeiro.pdf [accessed 2009 Apr 17] [WebCite Cache ID 5dAmHAOr2]
16. Weinreich N. Spare Change. The CDC's Second Life. URL: http://www.social-marketing.com/blog/2006/11/cdcs-second-life.html [accessed 2009 Apr 17] [WebCite Cache ID 5dAoP7EoT]
17. ; National Institutes of Health (NIH). National Institutes of Health (NIH). "NIH Second Life White Paper Networked Virtual Environments and the NIH Mission: How Second Life and other Virtual Systems Can Assist with Collaboration and Citizen Outreach." URL: http://healthcybermap.org/NIH_cached_version.mht [WebCite Cache ID 5dBfqJe6Y]
18. Woodford P. Medicine's not-so-secret Second Life. National Review of Medicine 2007;4(6):12-18.

19. Rosen KR. The history of medical simulation. J Crit Care 2008 Jun;23(2):157-166. [Medline: 18538206] [doi: 10.1016/j.jcrc.2007.12.004]
20. Yellowlees PM, Cook JN. Education about hallucinations using an internet virtual reality system: a qualitative survey. Acad Psychiatry 2006;30(6):534-539. [Medline: 17139026] [doi: 10.1176/appi.ap.30.6.534]
21. Gorini A, Gaggioli A, Riva G. Virtual worlds, real healing. Science 2007 Dec 7;318(5856):1549 [FREE Full text] [Medline: 18063769] [doi: 10.1126/science.318.5856.1549b]
22. Boulos MNK, Toth-Cohen S. A Sexual Health SIM in Second Life®. 2008. Sex and disability seminar: another great success! (University of Plymouth) URL: http://sl-sexualhealth.org.uk/ [accessed 2009 Apr 17] [WebCite Cache ID 5dAmQNsMf]
23. Stott D. Attending medical school in virtual reality. Student BMJ 2007;15:427-470.
24. Kenter P. Training to make it real: What’s on Second (Life)? OHS Canada 2008;24(3):17-18.
25. Leong JJ, Kinross J, Taylor D, Purkayastha S. Surgeons have held conferences in Second Life. BMJ 2008;337:a683. [Medline: 18614495] [doi: 10.1136/bmj.a683]
26. ; Second Health. National Physical Laboratory (NPL UK). Second Health - The future of healthcare communication. URL: http://secondhealth.wordpress.com/ [accessed 2009 Apr 18] [WebCite Cache ID 5dAnapyFe]
27. Brown S. Hospitals & Health Networks. Research, Surveys and Solutions from the World of Information Technology URL: http://www.hhnmag.com/hhnmag_app/jsp/articledisplay.jsp?dcrpath=HHNMOSTWIRED/Article/data/Spring2008/08Spring_DEPT_SolutionSet&domain=HHNMOSTWIRED [accessed 2009 Apr 18] [WebCite Cache ID 5dbmS7zts]
28. Lee J. PPH to Showcase Hospital of the Future. San Diego Business Journal 2008;29(7):1 ProQuest ID:1449253681.
29. ; Palomar Pomerado Health. Virtual Palomar West / Powered by Cisco Technology. Palomar West: Hospital of the Future URL: http://virtualpalomarwest.org/index.php [accessed 2009 Apr 18] [WebCite Cache ID 5dAng6d9t]
30. Brunk L. GSPay Solutions. Health care for Avatars? Medicine in the Metaverse. URL: http://www.gspaysolutions.com/news/E-commerce/4993/Healthcare_for_Avatars?_Medicine_in_the_Metaverse/ [WebCite Cache ID 5gQSCIRFT]
31. ; American Cancer Society. American Cancer Society. Relay For Life® in Second Life® URL: http://www.cancer.org/docroot/GI/content/GI_1_8_Second_Life_Relay.asp [accessed 2009 Apr 18] [WebCite Cache ID 5dAl8xlJs]
32. ; Relay for Life of Second Life. Relay for Life of Second Life. Relay for Life of Second Life’s 2008 Awards URL: http://www.rflofsl.org/?p=281 [accessed 2009 Apr 18] [WebCite Cache ID 5dAnrBAm4]
33. Bainbridge WS. The scientific research potential of virtual worlds. Science 2007 Jul 27;317(5837):472-476 [FREE Full text] [Medline: 17656715] [doi: 10.1126/science.1146930]
34. Casanova A. Centers for Disease Control and Prevention. CDC Island in Second Life. URL: http://www.ndu.edu/IRMC/CDC_SecondLife.pdf [accessed 2009 Apr 18] [WebCite Cache ID 5dAlpsEFD]
35. Hendaoui A, Limayem M, Thompson CW. 3D social virtual worlds: research issues and challenges. IEEE Internet Computing 2008 Jan/Feb; 1089. -7801:88-92.
36. Richards J. Times Online. 2008. McKinsey: ignore Second Life at your peril. URL: http://technology.timesonline.co.uk/tol/news/tech_and_web/article3803056.ece [accessed 2009 Apr 18] [WebCite Cache ID 5dAnwPPhI]
37. Huang ST, Kamel Boulos MN, Dellavalle RP. Scientific discourse 2.0. Will your next poster session be in Second Life? EMBO Rep 2008 Jun;9(6):496-499. [Medline: 18516082] [doi: 10.1038/embor.2008.86]
38. Biever C. Let’s meet tomorrow in Second Life. New Scientist Magazine 2007;194(2610):26-27.
39. Baard M. Boston Globe. 2008. MD to fight stress in Second Life: relaxation response program will be tested in the virtual world. URL: http://www.boston.com/business/technology/articles/2008/03/03/md_to_fight_stress_in_second_life/ [accessed 2009 Apr 18] [WebCite Cache ID 5dI4RYaDD]
40. Parsons C. San Francisco Chronicle. 2008. Second Life offers healing, therapeutic options for users. URL: http://www.sfgate.com/cgi-bin/article.cgi?f=c/a/2008/07/13/LVL211GP5C.DTL [accessed 2009 Apr 18] [WebCite Cache ID 5dAnlCSaj]
41. Schultz S. Spiegel Online. 2008. Virtual rehab: how Shelly in ‘Second Life’ resists vodka. URL: http://www.spiegel.de/international/world/0,1518,druck-562493,00.html [accessed 2009 Apr 18] [WebCite Cache ID 5dAo2rHs0]
42. Miller G. Living in societies. The promise of parallel universes. Science 2007 Sep 7;317(5843):1341-1343. [Medline: 17823341] [doi: 10.1126/science.317.5843.1341]
43. Slater M, Antley A, Davison A. A virtual reprise of the Stanley Milgram obedience experiments. PLoS ONE 2006;1(1):e39. [Medline: 17183667] [doi: 10.1371/journal.pone.0000039]
44. ; AIS Health. AIS Health. Presence in virtual worlds could help health plans achieve real-world behavior change. 2008 URL: http://www.aishealth.com/Bnow/hbd082808.html [WebCite Cache ID 5dC66f0oC]

Abbreviations

AMMC: Ann Myers Medical Cente
CDC: Center for Disease Control
CLR: comprehensive literature review
HHP: Health & Human Performance
NIH: National Institutes of Health

RL: real life
SB: snowball
SL: Second Life
SLSRCH: Second Life Search Engine
UH: University of Houston
WHC: Women’s Health Center

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Review

Measuring the Impact of a Moving Target: Towards a Dynamic Framework for Evaluating Collaborative Adaptive Interactive Technologies

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Abstract

Background: Website evaluation is a key issue for researchers, organizations, and others responsible for designing, maintaining, endorsing, approving, and/or assessing the use and impact of interventions designed to influence health and health services. Traditionally, these evaluations have included elements such as content credibility, interface usability, and overall design aesthetics. With the emergence of collaborative, adaptive, and interactive ("Web 2.0") technologies such as wikis and other forms of social networking applications, these metrics may no longer be sufficient to adequately assess the quality, use or impact of a health website. Collaborative, adaptive, interactive applications support different ways for people to interact with health information on the Web, including the potential for increased user participation in the design, creation, and maintenance of such sites.

Objective: We propose a framework that addresses how to evaluate collaborative, adaptive, and interactive applications.

Methods: In this paper, we conducted a comprehensive review of a variety of databases using terminology related to this area.

Results: We present a review of evaluation frameworks and also propose a framework that incorporates collaborative, adaptive, and interactive technologies, grounded in evaluation theory.

Conclusion: This framework can be applied by researchers who wish to compare Web-based interventions, non-profit organizations, and clinical groups who aim to provide health information and support about a particular health concern via the Web, and decisions about funding grants by agencies interested in the role of social networks and collaborative, adaptive, and interactive technologies technologies to improve health and the health system.

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KEYWORDS

Evaluation; framework; Internet; eHealth; consumer health information

Introduction

Most of the publications on the evaluation of Web-based health applications focus on sites designed to provide health information to patients, their caregivers, or health professionals [1-3]. As technology changes, new challenges related to its evaluation emerge [1]. This is particularly relevant to collaborative, adaptive, and interactive technologies. We define collaborative, adaptive, and interactive technologies as technologies that (1) facilitate collaboration among users in traditional or novel ways, (2) support adaptation of form, function, and content according to user needs or preferences, and (3) enable users to interact with the technology via mechanisms of explicit interaction, such as purposefully sending data back and forth, and implicit interaction, such as exchange of data via sensors [4]. Collaborative, adaptive, and interactive technologies encompass many Web 2.0 applications, which have been described within a framework of (1) community, which relates to collaboration, and (2) information (re)organization, which necessarily draws on adaptation and interaction [5]. We view the concept of collaborative, adaptive, and interactive technologies as an umbrella definition and term that also encompasses the five major aspects of Web 2.0 health applications recently summarized by Eysenbach [6], namely: (1) social networking (collaborative and interactive), (2) participation (collaborative and adaptive), (3) apomediation (collaborative), (4) collaboration (collaborative), and (5) openness (adaptive and interactive). In this article we provide background information on evaluation designs for health-related websites, describe frameworks associated with evaluating them, and suggest a dynamic approach that could match the challenges associated with the evaluation of collaborative, adaptive, and interactive technologies.

Methods

Eligible articles were identified through a search of (1) MEDLINE (1990 - Nov 2007), CINAHL (1990 - December 2007), Cochrane, PsycINFO (1990 - Nov 2007), Social Science Abstracts and Citation Index (1990 - 2008), and ERIC (1990 - Nov 2007); (2) personal collections of the authors; and (3) reference lists of relevant publications. The search strategy, developed in consultation with a medical librarian, included a string of Internet-related terms cross-matched with an evaluation framework string using Boolean operators. For example, the MEDLINE search used terms related to technology (Internet, World Wide Web, informatics, online), Web 2.0 terms (blog, wiki, podcast, tag), terms related to patients (some include consumer participation, education/non professional, consumer participation), and evaluation concepts (these include outcome, process, quantitative, for example). Please see Multimedia Appendix 1 for a complete list of the strategies and search terms used for each database. These searches were run again one year later when the article was accepted for publication (please see Multimedia Appendix 2).

Articles published in English in a peer-reviewed journal were deemed potentially eligible for inclusion in the review:

1. If they described a generic evaluation framework applicable to a wide range of Web-based health applications for lay members of the public; or
2. For health-specific websites, if they provided a full description of the process followed for the evaluation of such a framework that met criteria point 1.

By "generic" we meant frameworks that are applicable to sites that provide information or tools to promote decision support, social support, self-management, or self-care support.

Articles concerning evaluation of websites that provided some form of therapy or treatment such as cognitive behavioral therapy or communication with health care professionals were excluded because these sites serve a purpose that is distinctly different from the sites described above. Such sites are, in effect, a form of treatment or an extension of the clinical encounter per se, rather than a means to access information and support. As such, they have important evaluation criteria that extend beyond the website itself. We also considered out of scope those articles describing evaluation of a single formal decision aid, of diagnostic aids, or of sites designed for education of or use by medical professionals.

Three investigators (LOG, HW, JB) independently reviewed a random selection of 100 titles and abstracts from the articles that were identified through the literature search. A Single Measures Intraclass Correlation Coefficient (ICC) of 0.89 (95% CI 0.85 - 0.95) was calculated using SPSS v15.0 with a two-way mixed effects model. In the repeated search one year later, the same procedure was followed. Two of the raters had zero variance in their assessments, rendering ICC calculation not applicable. In this case, of the 100 randomly selected articles, there was agreement for 98. In both instances, the level of agreement was deemed sufficient to support independent evaluation of one-third of the total yield of the search. During independent evaluation, if the eligibility of a particular citation was judged to be questionable, the investigator included it in this initial filtering step in order to allow the other investigators to make an assessment as to whether or not it satisfied the inclusion criteria. Investigators met to review and confirm each other's findings. Two authors (HW, JB) then reviewed the full text of all of the potentially eligible articles.

Articles were selected for inclusion in the final analysis if they described an evaluation framework applicable to Web-based, consumer-oriented health applications that could be categorized under at least two of the three core evaluation phases: (1) formative evaluation, (2) summative evaluation, and (3) outcome assessment. Within each category, parameters were organized according to these temporal phases. In order to clarify the practical differences between the phases, we describe formative evaluation as a stage of development and laboratory testing, summative evaluation as a stage of field-testing, and outcome evaluation as a stage of overall impact assessment.

For each of the 12 articles, we generated a complete list of evaluation parameters. The parameters were pooled and organized via a multidimensional card sort [7]. Using a cross-comparative analysis method we explored common themes that spanned each of the three evaluation phases.

Results

The initial literature search yielded a total of 3304 citations, of which 41 were deemed to be potentially eligible for inclusion in the review. After reviewing the full reports, 13 articles that described evaluation frameworks met all of the inclusion criteria. Seven articles were identified from the literature search; and six were identified in personal libraries and reference lists. Two articles [8,9] were regarded as one as they discussed the same evaluation framework, producing an analysis set of 12. Of the 12 included articles, 4 described evaluation frameworks designed for Web-based, consumer-oriented health websites specifically, while 8 described evaluation frameworks designed for eHealth applications in general. Overall, 11 included elements of formative evaluation, all 12 included elements of summative evaluation, and 10 included elements of outcome evaluation. None of the articles addressed all three evaluation phases comprehensively. Flow diagrams depicting this process are available in Multimedia Appendix 3. The same steps were repeated for the second search and the flow diagram representing this process can be found in Multimedia Appendix 4.

We identified five themes that cut across the three core evaluation phases. These included an emphasis on: (1) the People affected by the website, (2) the Content of the website, (3) the Technology of the website, (4) Human-Computer Interaction between the person and the website, and (5) effects on the greater health care community, or Health Systems Integration. These themes reflect the core attributes, user-centric, context-centric, and functionality-centric, that Currie [10] advocates should be addressed in any eHealth evaluation framework.

In constructing this framework, we observed and filled in gaps relevant to collaborative, adaptive, interactive applications. For example, when evaluating applications that promote collaboration among users, we must consider interactions not only between humans and computers, but also between humans, mediated by computers. Accordingly, we refer to this theme as “Computer-Mediated Interaction” to encompass this larger scope. Articles within the review contained few to no elements corresponding to the “Content”, “Technology” and “Computer-Mediated Interaction” categories within the outcome assessment column, reflecting perhaps that general information websites, whose static content was governed mainly by webmasters, did not need to address these parameters during the outcome phases of the evaluation. However, the nature of collaborative, adaptive, interactive applications necessitates that evaluators consider and assess these parameters during the outcome phase of a project.

It has been suggested that applications that are “...interactive, user-centred, dynamic and evolving...” should have measures appropriate to these aspects [27] (page S124). Collectively, the evaluation frameworks to date demonstrated an increasing trend towards flexible, iterative evaluation designs that are user-, context-, and functionality-centric and that address multiple questions using multiple methods at each stage of the process. Similar trends in eHealth evaluation have been observed and reported by others [9,27,28]. These characteristics will be considered an issue when evaluating health sites that employ collaborative, adaptive, interactive technologies, which are considerably more fluid, dynamic, and interactive than their predecessors.

Discussion

A Proposed Dynamic Framework for the Evaluation of Collaborative, Adaptive, and Interactive Technologies

None of the identified frameworks matched the evaluation needs of collaborative, adaptive, and interactive technologies; therefore, we propose a new, dynamic framework in Table 1 which is described in detail below. This evaluation framework builds on our review and synthesis of existing evaluation frameworks for consumer health sites and recent descriptions of adaptive, Web-based technologies [29]. The incorporation of evaluation criteria relevant to new Web technologies addresses the gaps identified in our review and addresses the technological changes associated with collaborative, adaptive, interactive technologies, stressing their inherent social and dynamic qualities. Elements identified in the articles in our review are cited accordingly, while elements added, expanded, or adapted to reflect new areas of evaluation specific to collaborative, adaptive, and interactive technologies appear in *italics* font.

Table 1. Evaluation schema: collaborative, adaptive and interactive technology. Elements which were not identified in the authors' review of the literature are printed in *italics*.

	Formative	Summative	Outcome
	Development & laboratory testing	Efficacy and goal achievement	Impact assessment

People	• Identification of Stakeholder Characteristics and Needs [2,7,10,11,13,14,16,17,19]
	• *Assessment of Stakeholder Interests*
		• User Traits [14]
		  • Computer Proficiency [14,15],*eHealth Literacy*
		  • *Health Literacy*
		  • *Cognitive Style*
		  • *Affective Traits*
		• User Perspectives [12,13]
		  • Intentions to Use [15]
		  • Satisfaction [7,12,13,15]
		  • *Motivation for Use[13]*
			• Patient Outcomes [2,10,12,13,14,15,16,18,19]
			• Impact on Interpersonal Relationships [2,18]
			  • Patient-physician [14]
			  • *Caregiver-patient*

Content	• Quality and Credibility [2,7,10,11,13,15]
	• Utility [2,12,15]
	  • Completeness [12,15]
	  • Understandability [2,12,15]
	  • Relevance [12,15]
		• *Quality and Credibility[7]*
		• Subjective Utility [16]
		• *Level of Personalization[12]*
			• *Content Produced*
			  • *Form*
			  • *Nature*
			• *Positioning of User-Generated Content*

Technology	• System Robustness [18]
	  • Performance [12,15,16]
	  • Functionality and Features [7,11,12,15,16]
	  • *Security[12,15]*
	  • *Privacy*
	• *System Interoperability*
	• *Platforms/Portability*
		• Usage Statistics: Hits; Visitors; Browsers; Errors [2,10,13,14,15,16]
		• System Reliability [7,15,18]
		• Speed [12,18]
		• *Positioning within Current Technology*
		• *Standards Compliance*
			• *Dynamic Evolution*
			• *Collaborative Development Models*
			  • *Open Source*

Computer-Mediated Interaction	• Usability [2,7,10,12,13,16,17] • Accessibility [11,16] • *Sociability*[17] • *Interactivity* • Information Architecture [10,13]	• User Perspectives on Usability[7,12,14,15,18] • User Perspectives on Accessibility[15,16] • Demonstrated Sociability[17] • *Demonstrated Interactivity* • *Collaboration* • Findability [2]	• *Community Development* • *Evolution of Collaboration*

Health Systems Integration	• Definition of Evaluation Metrics and Process [10,11]
	• Ethics/Liability [10]
		• Administration [2,18,19]
		  • Service Utilization [2]
		  • Care Coordination [15,18]
		  • Patient Safety [15]
			• Public Impact (may include community-defined outcomes) [17,18]
			• Cost-Effectiveness [2,7,10,12,15,16,18]
			• Intended Effect [7]
			  • Appropriateness [15,18]
			  • Effectiveness [12,15]

People

The category "People" contains parameters related to the individuals who are involved in using or developing the site, or who may be affected by the implementation of the site. Within this category, evaluation parameters in the formative phase consist of *Identification of Stakeholders and Stakeholder Needs* [2,8,11,12,14,15,17,18,20]. Stakeholders will necessarily include end users and may also include health care providers, funding agencies, advocacy groups, family caregivers, and people responsible for the design, development, and approval of the site. Evaluation tasks associated with this category include formal needs assessments, identification of key characteristics of potential users, and consultations with relevant stakeholders. In the summative phase, parameters within this category include: (1) *User Traits* [15], which refers to user characteristics such as computer proficiency [15,16] and demographic or disease characteristics that may affect use [2,11,14]; and (2) *User Perspectives* [13,14], which includes feedback from users or potential users regarding their *Intentions to Use* the site [16], their *Satisfaction* with the website [8,13,14,16] and their *Motivations for Use* of the site [14]. Outcome assessments for this category involve investigating the impact of the application on *Patient Outcomes*, including the psychosocial well-being, health behaviors, and physiologic outcomes of people who use the site or people for whom the site was designed [2,11,13-17,19,20]. The *Impact on Interpersonal Relationships* component [2,19] includes assessments of any change or lack of change within patient-provider relationships [15].

People: Focus on Collaborative, Adaptive, Interactive Elements

At the formative stage, the category "People" must assess not only the informational needs of the stakeholders, but also the broader interests that will transform them from users of the site to contributors and collaborators of a dynamic enterprise transferring or generating new knowledge. We refer to this as "*Assessment of Stakeholder Interests*". In the summative phase, the evaluative scope must expand to reflect the transition from passive learning to active participation. *Motivations for Use* of a particular site may no longer be inferred through the single or small set of purposes of a site, and may need to be evaluated more thoroughly. *User Traits* should include health literacy, health numeracy [30,31], and *eHealth Literacy* [21], which refers to how well people are able to make effective use of health information online. User traits should also include the parameter *Affective Traits* to allow for the evaluation of factors that influence social interaction such as motivation, frustration, engagement, and disengagement [29]. Previous generations of health websites could be considered as stand-alone Web destinations visited for a small range of particular purposes, such as viewing the information contained on the site or obtaining referrals to other information sites or sources. Although elements of communication (for example, Web-based message forums, newsgroups, and mailing lists) were previously available, the incorporation of collaborative, adaptive, interactive applications and features introduces a new level of complexity to health websites by expanding the functions and tasks that a user may perform at a site and by creating or reinforcing ties to other locations on the Web. Therefore, users' *Cognitive Style* may also have an important role to play in the design of the site, given that whether or not individuals are impulsive or reflective, conceptual or inferential, thematic, or rational etc [29] will have an impact on how they experience a computer mediated-interaction. Finally, we suggest that outcome evaluations may usefully include impacts on the *Caregiver-patient* relationship, especially in cases where the application is designed to address health and life conditions involving a caregiver.

Content

The category "Content" describes parameters related to all content on a website, including text, images, and multimedia components. In the formative phase, evaluation of content may include appraisal of content *Quality and Credibility*, such as evaluations of how accurately content represents available evidence and how well the quality is depicted [2,8,11,12,14,16]; *Utility* [2,13,16], which includes attributes such as the *Completeness* of content within the context and goals of the website program [13,16]; *Understandability*, which refers to aspects of the content such as readability statistics of text, plain language and options for translation, explanations of medical language and acronyms, choice of display formats for numerical or graphical information and clarity of images [2,13,16]; and *Relevance*, which refers to the applicability of each item of content to potential users' health situations [13,16]. These parameters may be assessed with standardized metrics or judgment by experts and/or members of the target user population. In the summative phase, parameters within this category include *Quality and Credibility* [8], which in this phase refer to users' perceptions of these attributes, such as whether they find the content trustworthy and believable, and *Subjective Utility* [17], or how actual users evaluate the elements of utility described in the formative phase and users' overall assessments of the usefulness of the information on the site. Evaluation methods consist primarily of direct consultation with users via feedback mechanisms such as surveys. Finally, *Level of Personalization* [13] refers to users' access to information that is applicable and useful to them as individuals and represents the parameter *Relevance* from the formative phase, implemented in practice.

Content: Focus on Collaborative, Adaptive, Interactive Elements

In collaborative, adaptive, interactive applications, the potential fluidity of content presents new challenges to evaluation. The shift towards dynamic, user-generated content necessitates a change in how credibility is depicted and its subsequent assessment [33]. In this new framework there is a renewed focus on content *Quality and Credibility* (individually as in a single-author blog, or collectively as in a wiki.) With increased user-generated content, readers must be prepared to evaluate each entry, rather than each site, for its credibility. Analysis of content produced by users therefore becomes an important component of the evaluation, and the scope of *Qualityand Credibility* evaluation expands beyond source credibility to include foci on message credibility and credibility of apomediaries [34]. In addition, adaptive and interactive features enable increases in *Level of Personalization*, expanding the scope of analysis on this element to include more detailed assessments of how personalized site content is to each user.

Outcome evaluations of collaborative, adaptive, interactive applications create entirely new requirements and avenues for evaluation. For sites that support user-generated content, *Content Produced* becomes an important output that should be investigated. Evaluations of user-generated content could involve assessment of its *Form* (narrative, numerical, and aggregated) and *Nature* (advice, opinion, personal information, and emotional support). *Positioning of User-Generated Content* may also be assessed by examining how the content provided by users is framed within the site. For example, is the user-generated content central to the site or peripheral? Is there any mechanism for feedback or dialogue between users of the site and communities of clinicians and researchers? [35].

Technology

The category 'Technology' refers to the underlying technology used to create and run the site. The primary formative evaluation parameter discussed in the reviewed articles was *System Robustness*. This parameter includes various aspects related to performance and functionality of the technology [19]. *System Performance* refers to the quality of the infrastructure or architecture of the site including how quickly the website loads, how many concurrent users it can support, and how well the site can respond to increased requests [13,16,17]. *Functionality and Features* refer to what a user can technically do on the site and the extent to which the site's pages and external links load appropriately and without errors (eg, 404 Error indicating page not found) using a variety of different browser applications [8,12,13,16,17]. *Privacy* refers to protection of data, both stored data and data in transit, from unauthorized or unwanted disclosure, and *Security* refers to the ability to maintain control of the website and its content in the face of external threats [13,16]. In the summative phase, evaluation parameters include *Usage Statistics*, or measures of how the site is being used, such as: *Hits*, or the number of times each page is called; *Visitors*, which refers to the number of different users who visit a site and may include assessments of new and repeat visitors; *Browsers*, or the Web browsers in use by the people using the site; and incidence of *Errors*, in which visitors or software request files that do not exist or files that should exist but do not [2,11,14,15,16,17]. These metrics are commonly assessed using log file analysis [22]. Further parameters that may be evaluated at this phase include *System Reliability*, which refers to uptime and downtime, meaning the amount of time a site is available for use, as well as data corruption or loss [8,16,19], and *Speed*, which incorporates measures of performance reduction due to system load and, where appropriate, measures of database performance as a database grows [13,16]. Most of the evaluation parameters relevant to this cell may be assessed via log file analysis or Web analytics [21].

Technology: Focus on Collaborative, Adaptive, Interactive Elements

The incorporation of new technologies into health websites serves to shift the focus of several evaluation categories. Extensive formative evaluations of *Privacy* and *Security* measures will become particularly important for Web-based applications that enable data to be shared in new ways. Traditional information websites with little to no user-generated content do not have the same critical need to consider the security of such content or the boundaries of privacy that may be challenged by people sharing sensitive, personal and identifying health information. *System Interoperability and Platforms* must be considered as additional evaluation parameters where applicable. *System Interoperability* refers to how well the site communicates with other sites and, where appropriate, how well it can be used in concert with others. This may include application programming interface (API) compatibility and data portability that allow for site integration and interactions such as mashups and syndication feeds [5]. *Platforms/Portability* refers to how well the site can be viewed and used on other devices including small-screened mobile devices, such as personal digital assistants (PDAs) and mobile phones.

In the summative phase, the dynamic nature of collaborative, adaptive, and interactive technologies prompts evaluation of the application's *Positioning within Current Technology* and *Standards Compliance*. The former refers to the currency of the application's technology; the latter reflects how well or poorly the site complies with Web standards and health-specific standards such as HL7. These considerations lead to outcome assessments of the *Dynamic Evolution* of the site, meaning its ability to respond to new technological and social trends. *Collaborative Development Models* refers to how the ongoing nature of the site is envisioned at the conclusion of a project. This raises the question: do *Open Source* approaches ensure the dynamic growth of platforms?

Computer-Mediated Interaction

The category "Computer-Mediated Interaction" refers to assessments of user interactions with and via the interface. In the formative phase, evaluation parameters include *Usability* [2,8,11,13,14,17,18], which refers to how intuitive the site is for people to use [23]. In this phase, usability is typically assessed via heuristic evaluations and usability testing with sample populations of target users. Other parameters include *Accessibility* [12,17], or how well the interface is designed for people who may have barriers to use, such as vision, motor, or cognitive disabilities [24,25]; *Sociability* [18], the ability to support social interactions; and *Information Architecture* [11,14], or how well the content is organized within the site to support different information use behaviour [26]. In the summative phase, evaluation parameters within this category include user perspectives on many of the attributes assessed in the formative phase. These include: *User Perspectives on Usability* [8,13,15,16,19], which refers to actual users' feedback on how easily and intuitively they are able to use the website; *User Perspectives on Accessibility* [16,17], which refers to feedback on barriers and enablers to use; *Demonstrated Sociability* [18], which addresses the mechanisms to promote community among users and assesses whether it is actually a sociable site now that there is a functioning community; and *Findability* [2], which refers to how well visitors who are seeking information are able to find the site. Many of the parameters in this category may be evaluated through consultations with users such as online surveys. Some, such as findability and demonstrated sociability, may also be inferred through measures of user activity.

Computer-Mediated Interaction: Focus on Collaborative, Adaptive, Interactive Elements

At the formative stage, a shift to collaborative, adaptive, and interactive technologies expands the scope of interaction study. In the context of collaborative websites, this category is not only about interacting with the technology, but also focused on computer-assisted interactions with others. Within this category, therefore, we suggest additional focus on parameters in the formative phase such as *Sociability* [18], which refers to whether and how well the site is designed to support community interaction [36], and we propose an additional metric, *Interactivity*, or whether the interface supports adaptive, interactive human-computer behavior such as offering avenues for interface personalization.

In the summative phase, the shift to "Computer-Mediated Interaction" expands the scope of the evaluation and assessment.

Usability and *Accessibility* testing must incorporate assessments of user interactions with changing interfaces. User-generated content, user-initiated reorganization of information, and the principle of *perpetual beta* [32], in which interfaces are presumed to be frequently changing, may all contribute to changes to the interface as seen by the user. *Demonstrated Interactivity* refers to how and whether site visitors use the interactive features of the site. Preece and colleagues [18] have done extensive work on sociability heuristics which they have thus far determined are largely community-specific. Health sites that make use of CAI tools that explicitly promote *Collaboration* as a product of *Sociability* will require evaluation of the actual collaboration that results from user interactions.

"Computer-Mediated Interaction" should also be assessed during the outcome evaluation phase and on an ongoing basis for monitoring and quality-improvement purposes. *Community Development* refers to retrospective evaluation of whether and how well the evolving site has supported community interaction. The question of how the user community has responded over time to the site is referred to as *Evolution of Collaboration*. Assessment of this parameter involves summary statistics and longitudinal analysis of evidence of collaboration within sites that incorporate collaborative features. Sites that provide mechanisms for participants to exchange information may now include blogs that allow readers to provide feedback by posting comments. If the goal of the evaluation is to assess whether community members are using the site to collaborate with each other, analyses can be conducted by examining whether the participants are exchanging messages regularly [37]. For example, a blog may attract a few comments posted by readers daily, weekly, or even monthly, and such response rates may change over time. There must be some interaction for collaboration to take place. One way to measure this is to examine the number of posted messages and their associated responses [37]. Equally important in this analysis is to review the message content and tone. A series of messages threaded together may not necessarily be a sign of collaboration; rather, it may indicate an argument. However, measuring incidents of collaboration through message postings may not be enough to prove a community is functioning effectively. A community must meet the needs of its members in order for it to be sustained. Although there may be evidence of collaboration on a large scale, some members may be posting questions and not receiving responses to their queries.

Health Systems Integration

The category "Health Systems Integration" refers to the larger system, health processes, and society in which a health website for laypeople might be implemented. Formative evaluation parameters within this category include *Definition of Evaluation Metrics and Process* [11,12], which means whether and how well evaluation is incorporated into the design, development, and implementation of a site, and *Ethics/Liability* [11], which refers to how and whether ethical and liable issues of providing information online have been addressed within the larger health care system. Summative evaluation within this category involves assessments of how the site affects *Administration* [2,19,20], including *Service Utilization* [2], or usage rates for health care system and community services; *Care Coordination* [16,19], which refers to ways in which the site might be affecting delivery of health services; and *Patient Safety* [16], or assessments of how or whether the site is affecting patient safety indicators such as appropriate use of medications. Outcome assessment parameters within this category include *Public Impact* [18,19], which refers to any general effects that the website may have on the larger community and may include outcomes that are self-reported or defined by a particular community; *Cost-Effectiveness* [2,8,11,13,16,17,19], which refers to incremental health gain from use of the site and any associated resources; and *Intended Effect* [8], which is a context-specific assessment that will vary depending on the goals of the project and which includes *Appropriateness* [16,19], or overall observed suitability of the site as a means to achieve those goals, and *Effectiveness* [13,16], which refers to how well the site achieved its intended goals.

Health Systems Integration: Focus on Collaborative, Adaptive, Interactive Elements

Evaluation of the integration of information technologies and their processes into the larger health system has been well-covered in previous frameworks. It is worth noting, however, that due to their expanded capabilities, collaborative, adaptive, and interactive technologies may offer both greater benefit and greater unintended consequences in this area [38]. It remains to be seen whether these potentials are actualized.

Conclusion

We have presented an evaluation framework that proposes formative, summative, and outcome evaluation indicators for five themes of Collaborative, Adaptive, and Interactive applications: People, Content, Technology, Computer-Mediated Interaction, and Health Systems Integration. The increased use of collaborative, adaptive, and interactive technologies in health care and other fields underscores the importance of their evaluations. We need to determine whether something is effective before it can be of value. Collaborative, adaptive, interactive technologies are becoming pervasive and rapidly becoming an integral part of society. In record time, resources promoting collaboration such as Wikipedia, Facebook, MySpace, YouTube, and Orkut have joined the ranks of the most widely used online services in the world. With their vertiginous ascent, they have heralded an era in which the public can wield enormous power to create and share knowledge, to communicate with people and machines, and to find and evaluate services with unprecedented levels of freedom.

Although at a slightly slower pace, health-specific collaborative, adaptive, and interactive technologies are emerging, promising to transform the roles, workflows, rights, and responsibilities of all stakeholders within the system [38]. As any other set of interventions, however, collaborative, adaptive, and interactive technologies also carry the risk of causing more harm than good. It is a rare privilege to witness the emergence of a new set of powerful technologies that could have a profound and widespread effect on society. We should assume the responsibility that comes with such privilege "to look beyond the hype, and to dissect what works and what doesn't" [39]. Thus, it is essential to conduct thoughtful, careful evaluations.

We offer this framework as a means to structure evaluations across a wide range of applications and purposes. In some cases there may not be sufficient resources to conduct an evaluation that addresses all of the components listed in this framework. In these situations, we suggest that the evaluation focus on the particular aspect(s) (People, Content, Technology, Computer-Mediated Interaction, Health Systems Integration) that are the most relevant to the objective(s) of the evaluation. Tailoring an outcome evaluation to the specific requirements of the funding organization rather than attempting to address all of the various components in Table 1 within this phase would be another means to reduce the resources required to measure all of the elements in every phase. Each of the components presented in the framework may also have uses beyond those of evaluative measures within an established program. For example, the components listed as formative evaluations, in particular the People, Content, and Technology sections, could also be used to form the components of a needs assessment or as part of a funding application, and the framework could be used to troubleshoot an under-utilized application.

Evaluation plays a critical role in high-quality design, efficient development, and effective implementation of Collaborative, Adaptive, and Interactive applications. In an era of constrained resource allocation, the adoption of robust and appropriate evaluation frameworks will help to ensure that collaborative, adaptive, and interactive technologies live up to the expectations and that they contribute to the improvement of health for all.

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Conflicts of Interest

ARJ owns Foresight Links Corporation, a consultancy company which works in the area of systematic reviews and evaluation, which may indirectly benefit from publication of this article.

Multimedia Appendix 1

Search strings for 2007 and prior

[PDF (Adobe PDF File), 96 KB - jmir_v11i2e20_app1.pdf]

Multimedia Appendix 2

Search string for 2008 - 2009

[PDF (Adobe PDF File), 39 KB - jmir_v11i2e20_app2.pdf]

Multimedia Appendix 3

QUOROM statement flow diagram for Literature Search 2008 and prior

[PDF (Adobe PDF File), 32 KB - jmir_v11i2e20_app3.pdf]

Multimedia Appendix 4

QUOROM statement flow diagram for Literature Search 2008 and 2009

[PDF (Adobe PDF File), 9 KB - jmir_v11i2e20_app4.pdf]

References

1. Dansky KH, Thompson D, Sanner T. A framework for evaluating eHealth research. Eval Program Plann 2006 Nov;29(4):397-404. [Medline: 17950868] [doi: 10.1016/j.evalprogplan.2006.08.009]
2. Wyatt J. Commentary: measuring quality and impact of the World Wide Web. BMJ 1997;314(7098):1879-1881. [Medline: 9224137]

3. Eng TR, Gustafson DH, Henderson J, Jimison H, Patrick K. Introduction to evaluation of interactive health communication applications. Science Panel on Interactive Communication and Health. Am J Prev Med 1999 Jan;16(1):10-15. [Medline: 9894549] [doi: 10.1016/S0749-3797(98)00107-X]
4. Schmidt A. Implicit human computer interaction through context. Pers Ubiq Comput 2000;4(2-3):191-199.
5. Witteman H, O’Grady L. eHealth in the Era of Web 2.0. Working Papers for Virtually Informed: The Internet as (New) Health Information Source, Final Conference of the Project, Virtually Informed: The Internet in the Medical Field.. Vienna, Austria; 2008 Jan. p. 13-40 URL: http://www.univie.ac.at/virusss/documents/737266552.pdf [accessed 2009 May 21] [WebCite Cache ID 5emv3F4fp]
6. Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. J Med Internet Res 2008;10(3):e22 [FREE Full text] [Medline: 18725354] [doi: 10.2196/jmir.1030]
7. Cooke N. Varieties of knowledge elicitation techniques. Int J Human-Comput St 1994;41(6):801-849. [doi: 10.1006/ijhc.1994.1083]
8. Eng TR, Maxfield A, Patrick K, Deering MJ, Ratzan SC, Gustafson DH. Access to health information and support: a public highway or a private road? JAMA 1998 Oct 21;280(15):1371-1375 [FREE Full text] [Medline: 9794322] [doi: 10.1001/jama.280.15.1371]
9. Robinson TN, Patrick K, Eng TR, Gustafson D. An evidence-based approach to interactive health communication: a challenge to medicine in the information age. Science Panel on Interactive Communication and Health. JAMA 1998 Oct 14;280(14):1264-1269 [FREE Full text] [Medline: 9786378] [doi: 10.1001/jama.280.14.1264]
10. Currie LM. Evaluation frameworks for nursing informatics. Int J Med Inform 2005 Dec;74(11-12):908-916. [Medline: 16099711] [doi: 10.1016/j.ijmedinf.2005.07.007]
11. Beale IL. An evaluation model for psychoeducational interventions using interactive multimedia. Cyberpsychol Behav 2002 Dec;5(6):565-580. [Medline: 12556120] [doi: 10.1089/109493102321018213]
12. Cummins C, Prochaska J, Driskell M. Development of review criteria to evaluate health behavior change websites. J Health Psychol 2003;8(1):55-62. [doi: 10.1177/1359105303008001434]
13. Delone WH, McLean ER. The DeLone and McLean Model of Information Systems Success: A Ten-Year Update.. J Manage Inf Syst 2003;19(4):9-30.
14. Escoffery C, McCormick L, Bateman K. Development and process evaluation of a web-based smoking cessation program for college smokers: innovative tool for education. Patient Educ Couns 2004 May;53(2):217-225. [Medline: 15140462] [doi: 10.1016/S0738-3991(03)00163-0]
15. Kushniruk AW, Patel C, Patel VL, Cimino JJ. 'Televaluation' of clinical information systems: an integrative approach to assessing Web-based systems. Int J Med Inform 2001 Apr;61(1):45-70. [Medline: 11248603] [doi: 10.1016/S1386-5056(00)00133-7]
16. Lau F, Hagens S, Muttitt S. A proposed benefits evaluation framework for health information systems in Canada. Healthc Q 2007;10(1):112-6-11118. [Medline: 17326376]
17. Pagliari C. Design and evaluation in eHealth: challenges and implications for an interdisciplinary field. J Med Internet Res 2007;9(2):e15 [FREE Full text] [Medline: 17537718] [doi: 10.2196/jmir.9.2.e15]
18. Preece J, Abras C, Maloney-Krichmar D. Designing and evaluating online communities: research speaks to emerging practice. Intl J Web Based Communities 2004;1(1):2-18.
19. Shaw NT. 'CHEATS': a generic information communication technology (ICT) evaluation framework. Comput Biol Med 2002 May;32(3):209-220. [Medline: 11922936] [doi: 10.1016/S0010-4825(02)00016-1]
20. Stamm BH, Perednia DA. Evaluating psychosocial aspects of telemedicine and telehealth systems. Prof Psychol-Res PR 2000;31(2):184-189. [doi: 10.1037/0735-7028.31.2.184]
21. Norman CD, Skinner HA. eHealth Literacy: Essential Skills for Consumer Health in a Networked World. J Med Internet Res 2006;8(2):e9 [FREE Full text] [Medline: 16867972] [doi: 10.2196/jmir.8.2.e9]
22. Stout R. Web Site Stats: Tracking Hits and Analyzing Traffic. Berkeley, CA: Osborne McGraw-Hill; 1997.
23. Nielsen J. Designing Web Usability. Indianapolis, IN: New Riders; 2000.
24. Eysenbach G. Designing and evaluation of consumer health information Web sites. In: Lewis D, Eysenbach G, Kukafka R, Stavri PZ, Jimison HB, editors. Consumer Health Informatics: Informing Consumers and Improving Health Care. New York, NY: Springer; 2005:34-61.
25. Thatcher J. Constructing Accessible Web Sites. New York, NY: Glasshaus; 2002.
26. Rosenfeld L, Morville P. Information Architecture for the World Wide Web. 1st ed. Sebastopol, CA: O’Reilly; 1998.
27. Glasgow RE. eHealth evaluation and dissemination research. Am J Prev Med 2007 May;32(5 Suppl):S119-S126. [Medline: 17466816] [doi: 10.1016/j.amepre.2007.01.023]
28. Kaplan B. Evaluating informatics applications--some alternative approaches: theory, social interactionism, and call for methodological pluralism. Int J Med Inform 2001 Nov;64(1):39-56. [Medline: 11673101] [doi: 10.1016/S1386-5056(01)00184-8]
29. Brusilovsky P, Kobsa A, Wolfgang N. The Adaptive Web: Methods and Strategies of Web Personalization. Berlin, Germany: Springer-Verlag; 2007.

30. Baker DW. The meaning and the measure of health literacy. J Gen Intern Med 2006 Aug;21(8):878-883 [FREE Full text] [Medline: 16881951] [doi: 10.1111/j.1525-1497.2006.00540.x]
31. Ancker JS, Kaufman D. Rethinking health numeracy: a multidisciplinary literature review. J Am Med Inform Assoc 2007;14(6):713-721 [FREE Full text] [Medline: 17712082] [doi: 10.1197/jamia.M2464]
32. Musser J, O’Reilly T. O’Reilly Radar Report: Web 2.0 Principles and Best Practices. Sebastopol, CA: O’Reilly Media; 2006.
33. Witteman H, Chandrashekar S, Betel L, O’Grady L. Sense-making and credibility of health information on the social Web: a multi-method study accessing tagging and tag clouds. 2007 Presented at: World Conference on e-Learning in Corporate, Government, Healthcare & Higher Education; October 15-19 2007; Quebec City, QC, Canada.
34. Eysenbach G. Credibility of health information and digital media: new perspectives and implications for youth. In: Metzger MJ, Flanagin AJ, editors. Digital Media, Youth, and Credibility. Cambridge, MA: The MIT Press; 2008:123-154. [doi: 10.1162/dmal.9780262562324.123]
35. Akrich M, Méadel C, Rémy C. Building Collectives Via the Web? Information and Mobilization on Cancer Websites. Working Papers for Virtually Informed: The Internet as (New) Health Information Source, Final Conference of the Project, Virtually Informed: The Internet in the Medical Field.. Vienna, Austria; 2008 Jan. p. 104-120 URL: http://www.univie.ac.at/virusss/documents/737266552.pdf [accessed 2009 May 21] [WebCite Cache ID 5emv3F4fp]
36. Preece J. Online Communities: Designing Usability, Supporting Sociability. New York, NY: John Wiley; 2000.
37. Collison G. Facilitating Online Learning: Effective Strategies for Moderators. Madison, WI: Atwood Pub; 2000.
38. Deshpande A, Jadad A. Web 2.0: Could it help move the health care system in the 21st century? J Men's Health Gender 2006;3(4):332-336. [doi: 10.1016/j.jmhg.2006.09.004]
39. Eysenbach G. Call for Papers: Medicine 2.0. 2008. Journal of Medical Internet Research. URL: http://www.jmir.org/announcement/view/12 [accessed 2009 May 11] [WebCite Cache ID 5W1zt5JZB]

Abbreviations

API: application programming interface
HL7: health level 7
ICC: Intraclass Correlation Coefficient
PDA: personal digital assistant

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Review

Periodic Prompts and Reminders in Health Promotion and Health Behavior Interventions: Systematic Review

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Abstract

Background: Health behavior interventions using periodic prompts have utilized technology, such as the Internet, that allows messages to be sent to participants in cost-effective ways. To our knowledge, no comprehensive evidence review has been performed specifically to evaluate the effectiveness of communicating regular messages and to examine how characteristics of the prompts change the effectiveness of programs aimed at reminding people to adopt healthy behaviors, maintain those they already practice, and cease unhealthy behaviors.

Objective: A systematic literature review was performed to investigate the effectiveness of limited contact interventions targeting weight loss, physical activity, and/or diet that provided periodic prompts regarding behavior change for health promotion. The review sought to identify specific characteristics of these interventions that may be associated with superior results.

Methods: Electronic literature searches were performed between February and April, 2008. Articles were included if periodic prompts were used as an intervention or a component of an intervention, a behavioral or biological outcome measure was used, and an ongoing health promotion behavior was targeted. A rating system was applied to each study to provide a quantitative representation of the quality of the evidence provided by each article.

Results: There were 19 articles with a combined sample size of 15,655 that met the inclusion criteria, and 11 studies reported positive findings regarding the utility of periodic prompts. Several articles showed enhanced effectiveness when prompts were frequent and personal contact with a counselor was included. Long-term behavior change and health improvements were not examined by this review because of a lack of long-term follow-up in the literature.

Conclusions: In light of promising results of most studies, additional research on limited contact interventions targeting health behaviors including weight loss, physical activity, and/or diet is merited that utilizes rigorous methods including control groups; follow-up data collection; and testing of prompt frequencies, specific intervention components, or prompt characteristics. Future research would be especially valuable if it improves understanding of the most effective types of periodic prompts for fostering long-term behavior change in order to maximize use of this tool in limited contact health promotion programs. Specifically, various types of communication technology should be used and evaluated to expand and refine their use.

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KEYWORDS

Prompt; limited contact intervention; eHealth; behavior change

Introduction

Periodic prompts that encourage healthy behaviors are a way to remind and help motivate people to change their health behaviors. We define periodic prompts as messages, reminders, or brief feedback communicated to participants multiple times over the duration of an intervention. Prompts can be delivered at various intervals such as daily, weekly, or monthly, and can be sent using email, telephone, and mail. Health promotion professionals use periodic prompts both as standalone interventions and also as components of interventions [1]. Some interventions use personalization and tailoring in an attempt to increase prompts' relevance to recipients [2]. Some programs also utilize counselors to communicate periodic messages, although this type of intervention requires more resources than interventions that are automated [3]. Although it might make intuitive sense to some that it is valuable to communicate regular messages to remind people to initiate or maintain healthy behaviors, to our knowledge no comprehensive evidence review has been done specifically to evaluate the effectiveness of using periodic prompts and examine which characteristics of prompts work best in health promotion interventions. A review article published in 2001 examined interventions that used one or more computer-generated messages aimed at increasing medication adherence or immunization uptake and improving chronic disease management, as well as other health behaviors [4]. This review builds upon that work by examining interventions targeting other health behaviors, evaluating the effect of periodic health prompts within health promotion interventions, and updating the literature.

A systematic literature review was performed to investigate the effectiveness of periodic prompts regarding behavior change and to identify specific characteristics of prompts that may be associated with superior results. The literature review was feasible because of the increasing use of limited contact interventions due to widespread access to the Internet and other media that are used to communicate prompts. Data from a Pew Internet and American Life Project survey in May 2008 revealed that 73% of US adults go online, and 78% have cellular phones [5]. The potential impact that increased access to technology can have on an individual's health is great, and many organizations are recognizing the potential value of eHealth, which refers to "health services and information delivered or enhanced through the Internet and related technologies" [6]. Finding ways to implement behavior change interventions with large audiences in cost-effective ways is important due to the overwhelming challenges facing public health agencies and the limited resources available to meet them.

Health promotion studies using emerging technology are becoming more common, and researchers are tasked with balancing cost and personalization, and measuring the effects those two competing characteristics have on effectiveness of interventions. E-Health is a rapidly growing field [7,8] with advantages regarding cost and reach, and it is our hope that this review will serve to inform program development of eHealth interventions using periodic prompt messaging.

Methods

To identify peer-reviewed articles examining the use of periodic prompts for health promotion interventions, electronic literature searches were performed between February and April of 2008. Databases and search tools accessed, with the number of articles found in initial searching, included: PubMed (1119), PsycINFO (394), Google Scholar (142), CINAHL (148), and Web of Science (444). No publication date parameter was used to exclude older articles, and all searches included articles published up to the date of the search. Searches utilized the following terms in various combinations: prompt, weekly, reminder, email, Internet, Web-based, limited contact, intervention, health, and promotion. In addition, references of articles that were identified through searching were reviewed. Twenty-four additional articles were identified through this process.

Articles were included if periodic prompts were used as a standalone intervention or were part of a larger program; a biological or behavioral outcome measure was used; and ongoing health promotion behaviors such as weight loss, physical activity, and diet were targeted. Studies aiming to change compliance with immunization or health screening guidelines were not included because of the intermittent nature of those activities. After reviewing titles and abstracts to identify relevant articles, reviewing references to locate additional articles, and applying the inclusion criteria, 19 articles were included. A meta-analysis was not feasible due to the varying data collection methods and outcome measures.

A rating system was used to represent quantitatively the quality of the evidence provided by each article included in the review. The rating system was adapted from a review article that examined studies that used one or more computer-generated patient contacts aimed at increasing medication adherence or immunization uptake and improving chronic disease management, as well as other health behaviors [4]. The authors of that review created the rating based on recommendations from the literature [9,10]. The rating system is described in Table 1, which is a modified version of a table in the review article [4]. Articles were rated by the lead author, and the range of possible scores is 0 to 10. No minimum score was used to exclude studies from the review.

Table 1. Rating system

Factor	Description	Possible Points
Randomization	Assignment to different interventions by chance	2
Control Group	Comparison made to group of subjects not given the health behavior intervention	2
Sampling	Sampling method described Sample composition clearly described Sample of adequate size Number and ratio of withdrawals described	3
Analysis of Main Effect Variables	Clear definitions for each variable Clear description of methods and results Numeric table presented for each effect variable	1
Follow-up	Follow-up data collection to measure effects beyond immediate findings	1
Content	Intervention clearly described and replicable Discussion of withdrawals Discussion of study limitations	1

Results

This section describes the interventions, study designs, and main findings. The main findings are broken down into the following sections: prompt frequency, medium used, intervention components, tailoring, and level of interaction with intervention. Table 2 and Table 3 present descriptive information, main findings, and a quality score for each article.

Descriptive Findings

The 19 articles were published between 1988 and 2008, with 17 of the studies published after the year 2000. Study sample sizes ranged from 43 to 7743, with a median sample size of 190 participants. There were a total of 15,655 participants in all 19 of the studies described in the journal articles, of which 12,697 (81%) participated in the four largest studies. These four studies had sample sizes ranging from 1032 to 7743 and an average sample size of 3174. Approximately 65% of all the subjects were women. While the largest study had 60% women, 14 of the 19 articles had over 70% women, including 4 that included only women.

Randomized controlled trials made up 13 of the 19 studies (articles 2, 3, 5, 6, 7, 8, 10, 12, 14, 15, 16, 17, 18 in Table 2 and Table 3 [hereafter, article numbers refer to Table 2 and Table 3]). Six conducted follow-up data collection between 3 and 12 months post-intervention (articles 6, 8, 11, 13, 17, 18). Two studies used randomization for group assignment but did not include control groups (articles 3 and 9). Four studies were observational with only one group in each study (articles 1, 4, 11, 19). The range of the quality score scale is 0 to 10, and assigned scores for the 19 articles in this review range in value from 4 to 9. The four studies with scores of 4 or 5 (articles 1, 4, 11, and 19 in Table 2 and Table 3) did not include a control group, and therefore no randomization could take place (reducing the total possible points to 6). These studies are less informative because of their study designs, but they are included in this review because the interventions used periodic prompts and outcome measures were included.

Eight of the interventions aimed to increase physical activity, seven focused on weight loss as the outcome, one was aimed at weight loss maintenance, two sought to improve dietary habits, and one focused on both physical activity and nutrition.

In terms of periodicity, 12 out of 19 studies sent prompts every week, and two studies sent prompts every 2 weeks. One program sent 5 prompts over 8 weeks, and one sent them every 5 weeks. One study sent prompts at variable time periods, allowing participants to pace themselves and providing prompts as lessons were completed. Two interventions compared weekly prompts to prompts sent less frequently (eg, every 3 weeks and monthly).

The type of periodic prompts, and the ways they were integrated with other intervention components, varied. The following are methods utilized in the most studies. In terms of mode of prompt administration, 13 interventions sent only email prompts to participants, and two studies used only telephone prompts. Seven studies used only online tools in addition to prompts, and three articles used pedometers and step logs. Two studies used in-person sessions and online tools along with prompts. Some type of tailoring was used in 14 of the 19 studies to provide personalized information to participants as part of periodic prompts. Contact with a counselor was used in 9 articles. Six studies reported on associations between the level of interaction participants had with the intervention and outcomes. Level of interaction with an intervention was measured as weeks a participant took part in the intervention, number of log ins to the intervention website, or amount of use of the online tools on an intervention website.

Intervention length ranged from 6 weeks to 30 months. The median and mode intervention time-span was 3 months (or 12 weeks), with five studies implementing interventions of this duration.

Table 2. Study characteristics

	Article	N	Health Behavior	Intervention Duration	Study Design	Control Group	Follow-up	Additional Intervention Components
1	Block 2004 [11]	84	nutrition	12 weeks	observational, single group, pretest-posttest; set up to test effect of weekly emails and online tools in moving people forward in stage of change, decreasing fat intake, and increasing fruit and vegetable consumption	no	no	online tools: goal setting and bulletin board
2	Conn 2003 [12]	190	physical activity	3 months	randomized, four groups (2 x 2 design), pretest-posttest; set up to test effect of motivational interviewing and weekly prompts aiming to increase exercise; groups: (1) motivational interviewing and prompts, (2) motivational interviewing only, (3) prompts only, (4) control	yes	no	motivational interviewing
3	Dinger 2007 [13]	74	physical activity	6 weeks	randomized, two groups, pretest-posttest; set up to test effect of e-mails based on the transtheoretical model (TTM) on walking; second group wore pedometers, submitted step logs, and received weekly reminder emails, first group also received emails based on the TTM	no	no	pedometers and step logs
4	Dinger 2005 [14]	43	physical activity	6 weeks	observational, one group, pretest-posttest; set up to test effect of intervention including pedometers, a brochure, and emails targeting TTM constructs on walking behavior and changes in TTM constructs	no	no	pedometers, step logs and brochures
5	Hunter 2008 [15]	446	weight	6 months	randomized, two groups, pretest-posttest; set up to test effect of a behavioral Internet intervention using online tools, two brief motivational interviewing phone calls, and personalized feedback compared to usual care	yes	no	online tools: self-monitoring tools for food and exercise, weight tracking chart, weekly lessons; two brief motivational interviewing phone calls
6	Jeffery 2003 [16]	1801	weight	self-paced	randomized, three groups, pretest & two posttests; set up to test effect of an interactive 10-lesson intervention on weight loss where feedback was delivered by mail or telephone, compared to usual care	yes	yes	ten paper-and-pencil lessons
7	King 1988 [17]	52	physical activity	6 months	randomized, two groups, pretest-posttest; set up to test effect of periodic phone calls on amount of exercise and level of oxygen consumption	yes	no	baseline exercise instruction session
8	Lombard 1995 [18]	135	physical activity	12 weeks	randomized, five groups (2 x 2 plus a control group), repeated measures; set up to test effect of prompting frequency (weekly versus every 3 weeks) and prompt structure (high versus low); five groups: (1) weekly prompts with high structure, (2) less frequent prompts with high structure, (3) weekly prompts with low structure, (4) less frequent prompts with low structure, (5) no prompts	yes	yes	walking logs and instruction on how to start walking groups

	Article	N	Health Behavior	Intervention Duration	Study Design	Control Group	Follow-up	Additional Intervention Components
9	Marshall 2003 [19]	655	physical activity	8 weeks	randomized, two groups, pretest-posttest; set up to test effect of (1) booklet with reinforcement letters and (2) a website with reinforcement emails to affect stage of change and increase physical activity	no	no	booklet or online tools: quizzes, goal setting, activity planning, and target heart rate guide
10	Napolitano 2003 [20]	65	physical activity	12 weeks	randomized, two groups, pretest & two posttests; set up to test effect of an intervention website based on the social cognitive theory with weekly emails on moving people forward in stage of change and increasing physical activity	yes	no	website based on the Social Cognitive Theory
11	Petersen 2008 [21]	7743	weight	self-paced	observational, one group, pretest & two posttests; set up to test effect of a multi-component online intervention on changing stage of change, dietary habits, exercise, and weight	no	yes	online tools: food and weight tracking tools, progress reports, weekly newsletters, community support, expert assistance, “SparkPoints”
12	Plotnikoff 2005 [22]	2121	physical activity & nutrition	12 weeks	randomized, two groups, pretest-posttest; set up to test effect of email messages based on the social cognitive theory on physical activity, dietary changes, and social cognitive theory constructs	yes	no	weekly prompts only
13	Spittaels 2007 [23]	379	physical activity	8 weeks	randomized, three groups, pretest-posttest; set up to compare the effect of (1) computer-tailored online advice with 5 emails based on the stage of change theory, (2) tailored online advice with no emails, and (3) online advice only	no	yes	online physical activity advice
14	Svetkey 2008 [24]	1032	weight loss maintenance	30 months	randomized, three groups, pretest & five posttests; set up to compare effect of three conditions on weight loss maintenance: (1) monthly personal contact, (2) interactive technology-based intervention, (3) self-directed control group	yes	no	technology-based intervention: online tools-social support, self-monitoring, check-in accountability, problem solving and relapse prevention training; personal contact: met or spoke with interventionist monthly; control: pamphlet and one brief meeting with interventionist
15	Tate 2006 [25]	192	weight	6 months	randomized, three groups, pretest & two posttests; set up to compare effect of free weight loss website with no counseling to two counseling groups who had access to a more comprehensive weight loss website; the two counseling groups were (1) automated counseling and (2) feedback from a weight loss counselor	yes	no	online tools: weekly reporting and graphs, tips, recipes, e-buddy system, diary, message board, and behavioral lessons

	Article	N	Health Behavior	Intervention Duration	Study Design	Control Group	Follow-up	Additional Intervention Components
16	Tate 2003 [26]	92	weight	12 months	randomized, two groups, pretest-posttest; set up to compare effect of weight loss programs: (1) Internet only (2) Internet plus behavioral e-counseling (regular email communication with a counselor)	yes	no	one in-person counseling session, weekly weight, calorie and exercise reporting
17	Tate 2001 [27]	91	weight	3 months	randomized, two groups, pretest & two posttests; set up to compare effect of weight loss programs: internet education (had access to website with weight loss links) and Internet behavioral therapy (access to website plus weekly lessons, online diaries, bulletin board, and individualized therapist feedback)	yes	yes	one in-person group session; online tools: weight loss links, weekly lessons, online submission of self-monitoring diaries, and a bulletin board
18	Williamson 2006 [28]	80	weight	12 months	randomized, two groups, pretest & four posttests; set up to compare the effect of a passive health education program (a few educational sessions and access to an informational website) and an interactive behavior therapy program (nutrition education and internet counseling)	yes	yes	four in-person sessions, weekly lessons with quizzes, regular email communication with counselor, weight and activity graphs, and food intake monitoring tool
19	Woodall 2007 [29]	380	nutrition	4 months	observational, one group, pretest-posttest; set up to determine effect of an intervention consisting of an informational website and reminder emails alerting participants of new content on website	no	no	online tools: health benefit information, recipes, community directory, links related to fruit and vegetable intake

Table 3. Prompt characteristics, research questions, and findings

		Prompt Characteristics			Findings		
	Article	Prompt Frequency	Medium Used for Prompt	Tailoring	Level of Interaction	Summary of Results	Score (on a scale of 0 to 10)
1	Block 2004 [11]	weekly	email	yes, by lifestyle factors and chosen dietary behavior	positive association found between number of weeks a participant interacted and stage of change	• responders not in action or maintenance stages at baseline: 65% progressed for fat reduction and 74% progressed in stage for fruit and vegetable consumption • weeks a participant interacted with program related to change in stage • decrease in dietary fat and increase in fruits and vegetables observed	5
2	Conn 2003 [12]	weekly	telephone and mail	none	n/a	• prompted participants significantly increased their exercise compared to those not prompted • motivational interviewing did not have a significant effect on amount of exercise	9
3	Dinger 2007 [13]	weekly	email	yes, by stage of change for intervention group (second group received non-tailored reminders)	n/a	• both groups significantly increased amount of walking • no difference between groups' amount of walking or stage movement.	6
4	Dinger 2005 [14]	weekly	email	none	n/a	• total walking minutes significantly increased • six of the TTM constructs measured improved, but self-efficacy was not effected	4
5	Hunter 2008 [15]	weekly	email	yes, a counselor provided weekly feedback by email	positive association found between use of intervention website and weight loss	• intervention group lost more weight than usual care group, had significant BMI reduction, percent body fat reduction, and waist circumference reduction • more weight loss was associated with more use of intervention website	9
6	Jeffery 2003 [16]	varied (self-paced)	telephone or mail	yes, personalized feedback from counselor by mail or telephone	n/a	• telephone group lost significantly more weight than usual care group at 6 months • 12 month differences were not significant for either treatment group • more agreed to take part in the intervention if in the mail group • higher percentage in phone group completed all lessons	9
7	King 1988 [17]	every 2 weeks	telephone	yes, counselor provided further instruction and support through telephone calls	n/a	• oxygen consumption (VO_2 Max) significantly better in intervention group • no difference in number of exercise sessions or duration between groups	7

		Prompt Characteristics			Findings		
	Article	Prompt Frequency	Medium Used for Prompt	Tailoring	Level of Interaction	Summary of Results	Score (on a scale of 0 to 10)
8	Lombard 1995 [18]	weekly or every 3 weeks	telephone	yes, counselor conducted a high structure prompt or low structure prompt	n/a	• groups that received weekly prompts walked significantly more than those prompted every 3 weeks (even after the intervention ended) • prompt structure had no significant effect on amount of walking	8
9	Marshall 2003 [19]	every 2 weeks	mail or email	yes, messages were tailored to stage of change	n/a	• no significant difference in amount of physical activity found between groups • participants inactive at baseline: both groups showed a positive change in total physical activity, but only significant for print group • decreased time sitting on a weekday observed for both groups, only significant for Web group • quarter of participants in both groups moved forward at least one stage	6
10	Napolitano 2003 [20]	weekly	email	none	n/a	• at one month, intervention group more likely to have moved forward in stage of change, had more moderate intensity minutes of exercise, and more walking minutes • at 3 months, only minutes spent walking remained significant between intervention and control groups	8
11	Petersen 2008 [21]	weekly	email	yes, individualized messages were sent to help participants stay on course	positive association found between use of intervention website and weight loss	• small, but statistically significant, positive changes in most dietary measures • higher percentage of participants in normal weight category compared to non-participants, but no difference in average weight change • increased website usage associated with more weight loss and stage of change improvement	5
12	Plotnikoff 2005 [22]	weekly	email	none	n/a	• intervention group found to be more active, have higher self-efficacy, perceive not being active as more of a threat to health, perceive more advantages and less disadvantages to being active, and have favorable changes in the dietary variables • effect sizes were small	9

		Prompt Characteristics			Findings		
	Article	Prompt Frequency	Medium Used for Prompt	Tailoring	Level of Interaction	Summary of Results	Score (on a scale of 0 to 10)
13	Spittaels 2007 [23]	five messages over 8 weeks	email	yes, one group received messages tailored to stage of change	n/a	• all groups increased their activity levels, but no differences were found between groups • subgroup of participants who went through more thorough data collection: body fat significantly decreased in tailored plus email group • tailored advice reported to be remembered, printed out, and discussed more with others • more in tailored group reported to have changed their activity behavior after reading advice.	9
14	Svetkey 2008 [24]	weekly or monthly	email and/or telephone	yes, the personal contact group spoke or met with an interventionist monthly	n/a	• first 24 months: both the intervention groups gained significantly less weight than the control group • at 30 months: personal contact group regained significantly less weight than the other two groups • interactive technology-based group was not statistically different than control group at 30 months	9
15	Tate 2006 [25]	weekly	email	yes, study compared groups that received no feedback, automated tailored counseling, or feedback from a counselor	positive association found between use of free website (among control group) and number of diary submissions (intervention group) and weight loss	• at 3 months: two counseling groups did not differ from each other and had lost significantly more weight than website only group • at 6 months: human counseling group lost more weight than website only group, and automated counseling group not significantly different than the other two groups • greater use of free site associated with greater weight loss in the website only group • more diary submissions were associated with more weight loss in two counseling groups	8
16	Tate 2003 [26]	weekly	email	yes, counseling group received personalized feedback	n/a	• at 12 months: internet plus e-counseling group lost more weight than the internet only group	7
17	Tate 2001 [27]	weekly	email	yes, counseling group received personalized feedback	n/a	• behavioral therapy group lost more weight than Internet only group at three and 6 months	8
18	Williamson 2006 [28]	weekly	email	yes, counselor provided feedback on participant's progress with the program components	n/a	• at 6 months: interactive behavior therapy group lost more body fat than passive education group • at 24 months: no difference in weight between groups (the interactive group regained the lost weight)	8

	Article	Prompt Characteristics			Findings		
		Prompt Frequency	Medium Used for Prompt	Tailoring	Level of Interaction	Summary of Results	Score (on a scale of 0 to 10)
19	Woodall 2007 [29]	every 5 weeks	email	none	positive association found between responding to reminder emails and positive dietary change	• participants were more likely to visit the site on the day a reminder e-mail was sent • responding to reminder emails associated with positive dietary change including increased fruit and vegetable intake	4

Main Findings

Out of the 19 articles included in this review, 11 reported generally positive results regarding the use of periodic prompts (articles 1, 2, 3, 4, 5, 8, 12, 14, 15, 16, 17 in Table 2 and Table 3). This classification of study results as generally positive is based on whether periodic prompts themselves appeared to be supported, and not on whether the specific research questions the studies aimed to address were supported by the results.

The following section describes the articles' main findings regarding prompt characteristics. Results from studies that compared specific aspects of interventions between groups are described in each section. First, we discuss the findings regarding prompt frequency and how weekly prompts compare with other periodicities. Then, to supplement that analysis and understand the conditions under which periodic prompts may be more or less effective, we examine medium used for prompt, intervention components, tailoring, and level of interaction with intervention. As appropriate, some studies are described more than once. Table 2 and Table 3 provide information on the research questions the studies were designed to answer and the main findings reported.

Frequency of Prompt

In examining the effectiveness of periodic prompts, the first question is what prompt frequency might be most effective. Only two studies specifically compared timing intervals for sending prompts. One intervention aimed at increasing walking sent prompts weekly to one group and every 3 weeks to another treatment group (article 8). Participants who were prompted every week walked for significantly more weeks than the participants who were prompted less often (based on survival analysis), and this statistically significant difference was maintained over a 3-month time frame post-intervention [18].

In the second study examining periodicity, a weight-loss maintenance intervention used weekly and monthly prompts with two different treatment groups, but it is difficult to draw conclusions regarding frequency of communication from this study because the weekly messages were automated emails and the monthly contact was with a weight gain prevention counselor mostly by telephone (article 14). At 24 months, the two intervention groups did not differ by weight regained, and the participants in the treatment groups regained significantly less weight than the no-treatment control group (data not available to calculate effect sizes) [24]. At 30 months, only the monthly personal contact group remained significantly better than the control group [24]. At 30 months the difference between the group that received weekly automated prompts and the control group was not statistically significant, and the difference between the two treatment groups was not statistically significant.

Medium Used for Prompt

The medium used to deliver periodic prompts may affect the outcome of a behavior change intervention. In a weight-loss intervention, the telephone group lost significantly more weight than the mail group at 6 months (0.12 kg difference [$P < .01$]), but at 12 months differences were not significant (article 6) [16].

The effect of a booklet with mailed reinforcements and a website with emailed messages on physical activity levels were compared (article 9). Both groups increased their activity and there was no significant difference in amount of physical activity between the groups [19]. Another study evaluated groups receiving telephone prompts, email prompts, and no prompts (article 14). One group received monthly personal contact mostly by telephone, the second intervention group had access to an interactive website and had to check in weekly, and the control group received no prompts [24]. The two interventions were significantly better at preventing weight regain than the control through 24 months of data collection (data necessary to calculate effect size not reported). At 30 months the personal contact group had regained less weight than the interactive website group (0.21 kg difference [$P < .01$]) and the control group (0.27 kg difference [$P = .001$]), and the interactive website group was not significantly different from the control group [24]. This result is hard to interpret, though, because the telephone group was receiving personal contacts and the email group's prompts were automated.

Intervention Components

Most of the interventions described in the articles used multifaceted approaches to change participants' behavior. Unfortunately, it is difficult to draw conclusions regarding effectiveness of prompts when additional components are used because no studies compared prompts alone to prompts with additional intervention tools.

Eight interventions included periodic prompts in association with online tools. Examples of tools used include quizzes, weight-tracking charts, goal setting, and bulletin boards. One study reported that participants with access to online tools, including periodic lessons and feedback, lost more weight than a group with access to only weight loss links at 3 months (0.84 kg difference [*P* = .001]) and 6 months (0.63 kg difference [*P* < .05]) (article 17) [27]. A similar study found that two groups assigned to a website with online tools, including periodic automated or counselor feedback, lost more weight at 3 months than a group assigned to a less comprehensive, free weight-loss site with periodic non-tailored email prompts (counseling group vs online tools only group 0.89 kg difference [*P* = .001] and automated feedback group vs online tools only group 0.65 kg difference [*P* < .01]) (article 15) [25]. The difference between the periodic automated feedback and non-tailored email prompt group was not significant at 6 months, and only the group with periodic feedback from a counselor in addition to online tools had better weight loss results than the email prompt control group at 6 months (0.79 kg difference [*P* < .001]) [25]. Finally, an intervention involving the extensive use of online tools and periodic personal feedback was compared to passive online education regarding weight loss (article 18). The periodic feedback and online tools group lost more body fat than the passive education group at 6 months (0.74 percent body fat difference [*P* < .05]), but the weight lost was gained back, and there was no significant difference between the groups at 24 months [28].

Tailoring

Health promotion researchers hypothesize that sending participants personalized prompts relevant to their own situation or interest is more effective at changing behavior than generic reminders, and have tested this idea [30]. This section focuses on the results of studies that tested the effects of tailoring prompts in conjunction with periodicity of prompts. Prompts were tailored by personal contact with a counselor or automated online information personalized using information provided by participants.

An intervention aimed at increasing physical activity tested the effect of highly structured prompts compared to non-structured prompts (article 8). High-structure prompts consisted of a research staff member providing specific feedback to the participant based on the walking behavior information they submitted the week prior, and the staff member and participant together setting a specific walking goal for the next week. Low-structure prompts consisted of a research staff member asking the participants how their walking was going. The final survival analysis showed that the structure of the prompt had no significant effect on walking behavior, and that all prompted groups increased their walking [18].

Monthly personal prompts, mostly by telephone, were compared to an online intervention with required weekly check ins and no tailoring (article 14). Both were aimed at preventing weight regain, and a control group was included. At 24 months, both treatment groups gained significantly less weight than the control group (data needed to calculate effect size not reported), but at 30 months the personal contact group had regained significantly less than the control group (0.27 kg difference [*P* < .01]) and the online group was not significantly different from the control group [24].

A weight-loss intervention compared three groups: one received no feedback and only had access to a basic website; one received automated, tailored periodic prompts and had access to a comprehensive website; and a third group received periodic feedback from a counselor and had access to the comprehensive website (article 15). At 3 months the two groups receiving feedback did not differ, and both had lost significantly more weight than the no feedback group (counseling group vs online tools only group 0.89 kg difference[*P* = .001]; automated feedback group vs online tools only group 0.65 kg difference [*P* < .01]) [25]. At 6 months, the counselor feedback group had lost significantly more weight than the no feedback group (0.79 kg difference [*P* < .001]), and the automated feedback group was not significantly different from either of the other two groups [25].

Level of Interaction with Intervention

Several studies reported differences in results in the frequency with which the participants responded to the periodic prompts or otherwise interacted with the intervention. Interaction can be measured by the number of emails opened, number of log ins to the intervention website, or number of weeks a participant remained in a program. Interpreting these findings is difficult because of the possibility that participants who were already motivated to change their behavior interacted with the intervention tools more than other participants.

In a nutrition intervention the number of weeks a participant interacted with the program was significantly related to forward progression in stage of change (article 1). Two weight loss studies that used periodic prompts reported that more weight loss was associated with more use of an intervention website (articles 5 and 11), which may have been increased because of prompting. In another study, greater use of a free website among a control group, and more diary submissions by two counseling groups, were found to be associated with greater weight loss (article 15). Finally, responding to periodic email prompts by visiting an intervention website was associated with positive dietary change in a nutrition intervention (article 19).

Discussion

Findings

As evidenced by 11 articles reporting generally positive effects of periodic prompts and 8 articles reporting mixed results, the evidence that periodic prompts can effectively enhance diet, weight loss, and exercise behaviors appears to be positive, but is not entirely consistent. The few studies that looked at prompt frequency did show that it affected intervention effectiveness, with one study in particular demonstrating that weekly prompts were significantly more useful than prompts given every 3 weeks (article 8). Questions remain regarding how prompts issued more than once a week, or even every day, would affect behavior change because these frequencies were not tested in any of the studies. The medium used to communicate prompts did not affect results (if personal feedback was not added to the intervention) in the two studies testing different media for delivering prompts; both found no differences in effectiveness (articles 6 and 9).

It is difficult to evaluate findings regarding the effectiveness of prompts within multi-component interventions because prompts, and other elements, were not often explicitly tested. In addition, components included in multi-component programs varied widely. Therefore, it is unknown if websites with more comprehensive sets of online tools are more effective at changing behavior than less comprehensive sites. When intervention components were implemented with one group and not another, often that was not the only difference between the groups. For example, if periodic prompts were also not communicated to the control group, then the effect of the intervention components was not tested. This makes it difficult to assess the value of individual intervention elements.

Tailoring periodic prompts through regular contact with a counselor produced positive results (articles 10, 16, 17, 19, 20, 23), especially when compared over time to groups not receiving personal contact (articles 14, 15, 17). Significant limitations regarding tailoring exist in the literature because often groups provided with personalized periodic prompts were compared to groups that were not given any prompts (articles 7, 17, 18). Contact with a counselor over the phone or by email is an important form of periodic prompting to consider because health behavior counselors can serve many more clients by using methods other than face-to-face contact. This finding poses a challenge, though, to those who are designing limited contact interventions to be automated for cost-effectiveness and other reasons. Comparing automated prompts to regular counselor contact is important because programs using automated prompts that are implemented to save resources need to know which prompt characteristics produce effects as close to those using prompts given by counselors. Cost benefit analyses would be beneficial for further understanding optimal program choices.

More interaction by participants with the periodic prompt intervention program was associated with better outcomes in several studies (articles 1, 5, 11, 15, 19). The association found between more interaction with intervention components and better results could be a reflection of self-selection among the most motivated participants, or it could be that certain people were more engaged because of the intervention itself, and that resulted in better outcomes, or both.

Long-term, sustainable behavior change and health benefits are not shown by this review because of the lack of follow-up data collection and results in the literature. Two of the six studies that incorporated follow-up data collection showed non-significant or inconclusive results (articles 11 and 18). In addition, the articles that did collect follow-up data used heterogeneous methods in terms of cessation of prompts, outcome measures, and time period following the intervention, and were therefore difficult to compare.

All of the studies reviewed, except one, had participants who were recruited and volunteered to participate in the interventions. It is possible that those who volunteer for health interventions are already motivated to change their behavior and are open to the information being sent to them. If this is true, then results of limited contact interventions with prompts implemented broadly may have less positive outcomes than the ones included in this review. From an alternative perspective, providing interventions with prompts to facilitate behavior change among those who are motivated to improve their health would be a valuable service.

Related to the self-selection issue is the non-equivalent participation by males and females in the studies reviewed. Women may be more likely to volunteer for these types of studies, as is illustrated by the high proportion of participants who were female in the combined sample of all the studies in this review. Little is known about how effective these interventions would be at changing the behaviors of men. Most studies did not report on differences in results among men in their sample, and the men who volunteer for these studies may produce different results than men in the general population.

Finally, to prove effectiveness of an emerging type of intervention, data must be collected to evaluate the results. Many of the studies included in this review required participants to visit study staff for the data to be collected. It is possible that behavior change may be partially attributed to the fact that participants know they will need to return to a study site for data collection. If this is the case, and this type of contact is not part of the program when implemented on a large scale, then the results of the intervention could be weaker than the results from the initial study.

Limitations and Strengths of Studies

Multiple issues make it difficult to draw strong, generalizable conclusions about the effectiveness of limited contact interventions with prompts, including: (1) a lack of follow-up; (2) self-selected samples; (3) a higher proportion of female participants; (4) a lack of rigorous testing of intervention factors; and (5) data collection methods that might differ when an intervention is implemented on a broad scale. The body of literature on periodic prompt interventions also has strengths. It has produced relatively consistent results, which show promise for this type of behavior change program. Control groups, randomization, and follow-up data collection were used in several studies, and those findings were therefore strengthened. In addition, several of the studies had large sample sizes.

Limitations and Strengths of Review

Despite using a thorough search strategy, there may be some literature on interventions using prompts that were not identified for this review. Specifically, we did not examine the grey literature (unpublished documents and reports) on this topic, focusing instead on data that had been through the peer-review process. A meta-analysis was not possible due to the various data collection methods and outcomes in the studies. Also, the variability in limited contact interventions regarding targeted behavior and methods utilized makes it difficult to develop generalized conclusions about their effectiveness.

Despite these limitations, this is the first literature review, to our knowledge, that examines the effectiveness of periodic prompts for changing diet, activity, and weight-loss behaviors. Insights regarding effectiveness of prompts and possible ways to make them more effective are presented in an organized manner, and future research directions in this area are recommended based on this review.

Conclusions

In light of promising results from some studies, additional research on limited contact interventions is warranted. It would be valuable for future studies to use no-treatment control groups, include long-term follow-up data collection, and test specific intervention components or prompt characteristics instead of entire programs. In particular, further investigation into the effectiveness of different time intervals between prompts would be highly valuable. It would also be informative if researchers were able to include a more representative proportion of men in studies to see if they respond differently to these types of interventions.

New media has the potential to reach people in fresh and exciting ways. Examples of such media include text messages on cellular phones [31], and messages which could appear on social networking sites. Further research comparing reach and effectiveness of various types of communication technology is recommended.

This review shows that the use of periodic prompts can be effective in behavior change interventions. Effectiveness is enhanced if prompts are frequent and personal contact with a counselor is included. These findings can be used to improve interventions that use periodic prompts and will hopefully result in increased effectiveness, positive behavior change, and improved health.

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Conflicts of Interest

None declared.

References

1. Maibach E, Holtgrave DR. Advances in public health communication. Annu Rev Public Health 1995;16(1):219-238. [Medline: 7639871] [doi: 10.1146/annurev.pu.16.050195.001251]
2. Kreuter MW, Strecher VJ, Glassman B. One size does not fit all: the case for tailoring print materials. Ann Behav Med 1999;21(4):276-283. [Medline: 10721433] [doi: 10.1007/BF02895958]
3. Saywell RM, Champion VL, Skinner CS, McQuillen D, Martin D, Maraj M. Cost-effectiveness comparison of five interventions to increase mammography screening. Prev Med 1999 Nov;29(5):374-382. [Medline: 10564629] [doi: 10.1006/pmed.1999.0568]
4. Revere D, Dunbar PJ. Review of computer-generated outpatient health behavior interventions: clinical encounters "in absentia". J Am Med Inform Assoc 2001;8(1):62-79 [FREE Full text] [Medline: 11141513]
5. Fox S, Vitak J. Degrees of access (May 2008 data). Washington, DC: Pew Internet & American Life Project; 2008. URL: http://www.pewinternet.org/PPF/r/251/presentation_display.asp [WebCite Cache ID 5glOX5J2G]
6. Eysenbach G. What is e-health? J Med Internet Res 2001;3(2):E20 [FREE Full text] [Medline: 11720962] [doi: 10.2196/jmir.3.2.e20]
7. About Health e-Technologies Initiative. Health e-Technologies Initiative. 2009. URL: http://www.hetinitiative.org/ [accessed Mar 11] [WebCite Cache ID 5alRCjHyt]
8. World Health Organization Regional Office for Europe. World Health Assembly Resolution on eHealth. 2005 URL: http://www.euro.who.int/telemed/20060713_1 [WebCite Cache ID 5alRFq0bE]
9. Moher D, Jadad AR, Tugwell P. Assessing the quality of randomized controlled trials. Current issues and future directions. Int J Technol Assess Health Care 1996;12(2):195-208. [Medline: 8707495] [doi: 10.1017/S0266462300009570]
10. Balas EA, Austin SM, Brown GD, Mitchell JA. Quality evaluation of controlled clinical information service trials. Proc Annu Symp Comput Appl Med Care 1993:586-590. [Medline: 8130541]
11. Block G, Block T, Wakimoto P, Block CH. Demonstration of an E-mailed worksite nutrition intervention program. Prev Chronic Dis 2004 Sep 15;1(4):A06 [FREE Full text] [Medline: 15670437]
12. Conn VS, Burks KJ, Minor MA, Mehr DR. Randomized trial of 2 interventions to increase older women's exercise. Am J Health Behav 2003;27(4):380-388. [Medline: 12882432]
13. Dinger MK, Heesch KC, Cipriani G, Qualls M. Comparison of two email-delivered, pedometer-based interventions to promote walking among insufficiently active women. J Sci Med Sport 2007 Oct;10(5):297-302. [Medline: 16950654] [doi: 10.1016/j.jsams.2006.07.011]
14. Dinger MK, Heesch KC, McClary KR. Feasibility of a minimal contact intervention to promote walking among insufficiently active women. Am J Health Promot 2005;20(1):2-6. [Medline: 16171154]
15. Hunter CM, Peterson AL, Alvarez LM, Poston WC, Brundige AR, Haddock CK, et al. Weight management using the internet a randomized controlled trial. Am J Prev Med 2008 Feb;34(2):119-126. [Medline: 18201641] [doi: 10.1016/j.amepre.2007.09.026]

16. Jeffery RW, Sherwood NE, Brelje K, Pronk NP, Boyle R, Boucher JL, et al. Mail and phone interventions for weight loss in a managed-care setting: Weigh-To-Be one-year outcomes. Int J Obes Relat Metab Disord 2003 Dec;27(12):1584-1592. [Medline: 14517547] [doi: 10.1038/sj.ijo.0802473]
17. King AC, Taylor CB, Haskell WL, Debusk RF. Strategies for increasing early adherence to and long-term maintenance of home-based exercise training in healthy middle-aged men and women. Am J Cardiol 1988 Mar 1;61(8):628-632. [Medline: 3344690] [doi: 10.1016/0002-9149(88)90778-3]
18. Lombard DN, Lombard TN, Winett RA. Walking to meet health guidelines: the effect of prompting frequency and prompt structure. Health Psychol 1995 Mar;14(2):164-170. [Medline: 7789352] [doi: 10.1037/0278-6133.14.2.164]
19. Marshall AL, Leslie ER, Bauman AE, Marcus BH, Owen N. Print versus website physical activity programs: a randomized trial. Am J Prev Med 2003 Aug;25(2):88-94. [Medline: 12880874] [doi: 10.1016/S0749-3797(03)00111-9]
20. Napolitano MA, Fotheringham M, Tate D, Sciamanna C, Leslie E, Owen N, et al. Evaluation of an internet-based physical activity intervention: a preliminary investigation. Ann Behav Med 2003;25(2):92-99. [Medline: 12704010] [doi: 10.1207/S15324796ABM2502_04]
21. Petersen R, Sill S, Lu C, Young J, Edington DW. Effectiveness of employee internet-based weight management program. J Occup Environ Med 2008 Feb;50(2):163-171 [FREE Full text] [Medline: 18301173] [doi: 10.1097/JOM.0b013e31815c6cf6]
22. Plotnikoff RC, McCargar LJ, Wilson PM, Loucaides CA. Efficacy of an E-mail intervention for the promotion of physical activity and nutrition behavior in the workplace context. Am J Health Promot 2005;19(6):422-429. [Medline: 16022206]
23. Spittaels H, De Bourdeaudhuij I, Brug J, Vandelanotte C. Effectiveness of an online computer-tailored physical activity intervention in a real-life setting. Health Educ Res 2007 Jun;22(3):385-396 [FREE Full text] [Medline: 16971674] [doi: 10.1093/her/cyl096]
24. Svetkey LP, Stevens VJ, Brantley PJ, Appel LJ, Hollis JF, Loria CM, et al; Weight Loss Maintenance Collaborative Research Group. Comparison of strategies for sustaining weight loss: the weight loss maintenance randomized controlled trial. JAMA 2008 Mar 12;299(10):1139-1148 [FREE Full text] [Medline: 18334689] [doi: 10.1001/jama.299.10.1139]
25. Tate DF, Jackvony EH, Wing RR. A randomized trial comparing human e-mail counseling, computer-automated tailored counseling, and no counseling in an Internet weight loss program. Arch Intern Med 2006;166(15):1620-1625 [FREE Full text] [Medline: 16908795] [doi: 10.1001/archinte.166.15.1620]
26. Tate DF, Jackvony EH, Wing RR. Effects of Internet behavioral counseling on weight loss in adults at risk for type 2 diabetes: a randomized trial. JAMA 2003 Apr 9;289(14):1833-1836 [FREE Full text] [Medline: 12684363] [doi: 10.1001/jama.289.14.1833]
27. Tate DF, Wing RR, Winett RA. Using Internet technology to deliver a behavioral weight loss program. JAMA 2001 Mar 7;285(9):1172-1177 [FREE Full text] [Medline: 11231746] [doi: 10.1001/jama.285.9.1172]
28. Williamson DA, Walden HM, White MA, York-Crowe E, Newton RL, Alfonso A, et al. Two-year internet-based randomized controlled trial for weight loss in African-American girls. Obesity (Silver Spring) 2006 Jul;14(7):1231-1243. [Medline: 16899804] [doi: 10.1038/oby.2006.140]
29. Woodall WG, Buller DB, Saba L, Zimmerman D, Waters E, Hines JM, et al. Effect of emailed messages on return use of a nutrition education website and subsequent changes in dietary behavior. J Med Internet Res 2007;9(3):e27 [FREE Full text] [Medline: 17942389] [doi: 10.2196/jmir.9.3.e27]
30. Kreuter MW, Wray RJ. Tailored and targeted health communication: strategies for enhancing information relevance. Am J Health Behav 2003;27 Suppl 3(s3):S227-S232. [Medline: 14672383]
31. Patrick K, Raab F, Adams MA, Dillon L, Zabinski M, Rock CL, et al. A text message-based intervention for weight loss: randomized controlled trial. J Med Internet Res 2009;11(1):e1 [FREE Full text] [Medline: 19141433] [doi: 10.2196/jmir.1100]

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Tutorial

Methodological Challenges in Online Trials

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Abstract

Health care and health care services are increasingly being delivered over the Internet. There is a strong argument that interventions delivered online should also be evaluated online to maximize the trial’s external validity. Conducting a trial online can help reduce research costs and improve some aspects of internal validity. To date, there are relatively few trials of health interventions that have been conducted entirely online. In this paper we describe the major methodological issues that arise in trials (recruitment, randomization, fidelity of the intervention, retention, and data quality), consider how the online context affects these issues, and use our experience of one online trial evaluating an intervention to help hazardous drinkers drink less (DownYourDrink) to illustrate potential solutions. Further work is needed to develop online trial methodology.

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KEYWORDS

Internet; randomized controlled trial; research design; alcohol drinking

Introduction

The Internet is widely used for health-related services [1-5]. These range from simple health information sites to complex self-management programs incorporating interactive components such as decision support, social support, behavior change support [6-8], and computerized cognitive behavioral therapy [9,10]. Advantages of delivering health care over the Internet include convenience (can be used at any time of day or night), anonymity (valued by people with stigmatized conditions), and low cost.

To date, much of the research into such Internet interventions [11] has used conventional face-to-face methods of patient recruitment, randomization, and outcome assessment [12]. However, there are grounds for exploring methods of evaluation that rely totally on the Internet [13]. For example, if one of the potential advantages of an Internet intervention is that users can self-refer to it, without going through a health professional, it should also be possible for users to participate in the evaluation without going through an intermediary, thus enhancing external validity [14].

One example is the evaluation of an online intervention to help hazardous drinkers drink less (DownYourDrink, DYD) [15,16]. Data from an early cohort study of the intervention had made it clear that users appreciated the anonymity and convenience of the online environment [17]. This provided a strong rationale for ensuring that the evaluation of this intervention was also done online. In preparation for a phase 3 randomized controlled trial of DYD (DYD-RCT) [18], we undertook a phase 2 pilot trial to optimize the trial parameters [19,20]. During the pilot we undertook a number of substudies to provide empirical data to inform the final trial protocol. It was our experience that the change in trial environment, or context, from a traditional face-to-face environment to an entirely online environment had considerable impact on aspects such as recruitment, randomization, fidelity of the intervention, retention, and data quality. We also experienced two problems that are unique to undertaking research online: spamming and cybersquatting.

In this paper we use our experience from this pilot work (Textbox 1) to explore the methodological challenges that may arise in online trials of online interventions with a view to informing future research. First we address the main issues that arise in all trials (recruitment, randomization, fidelity of the intervention, retention, and data quality) and describe how the change in context impacts these, and then we touch briefly on the challenges unique to online research (Table 1).

Textbox 1. Case study: piloting the DYD-RCT

Background

In preparation for a phase 3 randomized controlled trial of an online intervention to help hazardous drinkers drink less (DownYourDrink, DYD), we undertook a pilot phase 2 trial. The aim of the pilot was to optimize the trial parameters of recruitment, randomization, retention, and data quality. As part of our optimization procedures, we undertook various substudies within the pilot.

Methods

Design: Two-armed randomized controlled trial with substudies. Ethical approval was obtained from the University College London ethics committee.

Setting: The World Wide Web

Participants: Internet surfers aged 18 or over who found DYD on the Web.

Intervention: Theoretically informed interactive website aimed at helping hazardous drinkers reduce their alcohol consumption. The website contained three phases: Phase 1 applied the principles of motivational interviewing to help users reach a high-quality decision about whether and how to change their drinking. Phase 2 used behavioral self-control and computerized cognitive behavioral therapy techniques to enable the user to make the planned change, while phase 3 focused on relapse prevention. For the duration of the pilot and subsequent phase 3 trial, both intervention and comparator sites were only available to people who consented to participate in a trial.

Comparator: Text-based website containing high-quality information on the harms associated with excess alcohol consumption, but with minimal interactivity and no theoretically informed components.

Procedures: Recruitment, consent, baseline data collection, randomization, and follow-up were all undertaken entirely online using a secure site, with no offline contact between the research team and participants.

Optimization of trial parameters:

1. Recruitment
    - Focus groups of users provided feedback on the trial Web pages, including advertising, participant information, consent, and data collection.
2. Randomization and identity verification
    - User feedback on the high value users ascribed to the anonymity of the DYD site.
    - Trial of requesting voluntary provision of offline contact details (address and/or phone number): less than one-third of participants provided such details.
    - Monitoring IP addresses to look for evidence of re-registration.
    - Requiring email address validation.
3. Retention
    - Three email requests for data.
    - Emailed newsletters to participants: appeals to altruism, encouraging participants to feel part of an important endeavour.
    - Trial of offline follow-up of nonresponders (up to three letters and/or two phone calls to those who provided contact details).
    - Trial of financial incentives.
4. Data quality
    - User feedback on design of questionnaires.
    - Close collaboration between Web designers and statisticians.
    - Use of radio buttons and drop-down text, minimized use of free text, and inability to proceed until all mandatory questions answered.

Table 1. Summary of challenges that may arise in online trials and their possible solutions

Challenge	Possible Solutions
Recruitment	
Online recruitment can allow rapid recruitment of large numbers of participants, but some researchers have had difficulty in achieving target sample size.	Develop a recruitment strategy, and pilot it to determine likely recruitment rates. Achieve high visibility (eg, by including link to trial on highly visited and well-trusted websites—the host organization should have records of visitor numbers). Use mixed recruitment methods, including email, targeted online advertisements, lurking in discussion groups, and offline recruitment.
Randomization	
It is easy to ensure that researchers cannot subvert the randomization process and that randomization occurs after collection of baseline data; it is more difficult to ensure that participants do not register more than once, using multiple identities.	Consider the issue. Avoid building in incentives to re-register (such as advertising financial incentives for participation). Consider undertaking identity verification procedures, such as email address verification or verification of offline contact details. Monitor potential re-registration.
Fidelity of the Intervention	
Although the researcher has very tight control over what goes into the intervention, the user has a great deal of freedom to determine how he or she uses the intervention and, hence, to determine both “how much” of the intervention (dose) is received as well as which bits (active components) are used.	Develop a clear theoretical pathway of how the intervention is likely to work, and ensure primary and secondary outcome measures reflect this proposed pathway of action. Pilot use of the intervention to determine the relationship between how the researchers plan users to use it and how they actually use it. Monitor use of the intervention (number of log-ins, pages visited) during the trial.
Retention	
This is a major challenge for online trials, with very low retention rates (10%-25%) reported.	Some researchers have improved retention rates by using offline (letter or telephone) follow-up or financial incentives. These solutions all have resource implications that need considering before applying for funding.
Data Quality	
There are three issues to consider here: validity; alteration of psychometric properties by change of mode from paper-and-pencil to online administration; and item nonresponse.	Researchers need to determine the impact of change of mode to online administration on well-established outcome measures as part of preparation for a trial. Item nonresponse can be avoided by preventing participants from moving on to the next page until all questions are answered.
Spamming	
	Ensure requests for follow-up data include instructions on how to withdraw from the trial if desired.
Cybersquatting	
	Buy related domain names prior to starting a program of research.

Methodological Challenges

Recruitment

Conventional Trials

Recruitment is often a major challenge in conventional trials, with a recent review finding that one third of trials failed to reach the desired sample size [21]. Although there are few empirical studies of different strategies for improving recruitment [22], there are factors that are recognized as likely to enhance recruitment, including asking a clinically important question at a timely point, embedding trials in existing clinical practices, generating results that are likely to impact future practice, meeting patient needs, and having excellent organizational and communication structures [21]. A perception of equipoise among potential participants may also be important [23], as may altruism and a desire to “give something back” [24], particularly where health care is free at the point of delivery as it is in the United Kingdom.

Online Trials

Experience of recruitment online is varied. Recruitment to “one-off” surveys appears relatively straightforward [25], but participation in a trial requires greater commitment, both in terms of using the proffered intervention and in completing follow-up questionnaires. While some researchers report good recruitment and follow-up [26,27], others do not [28,29]. Additional problems with online recruitment include a potentially unrepresentative sample [30]. Online recruitment methods have included email invitations [28], online advertising with banner advertisements [31], invitations posted in discussion forums or user groups [28], “lurking” in discussion groups [31], and advertising on websites that specifically list trials currently looking for participants (such as ClinicalTrials.gov) [12,32].

Other researchers have opted to use more traditional offline recruitment methods [29].

The DYD Experience

The DYD experience was that online recruitment was very successful. In the pilot phase (8 months), there were just over 50,000 unique visitors to the DYD home page. Of these, 3734 completed all the stages leading to study entry (consent, provision of demographic data, email validation, completion of baseline outcome measures, and randomization).

The factors that we believe contributed to this good recruitment included exclusivity, user-centered design, findability, and media awareness:

1. *Exclusivity*: DYD was not freely available during the pilot and main trial; people who wished to use it were informed that it was only available as part of a research study.
2. *User-centered design*: The trial recruitment pages were developed in close collaboration with a user group, who provided detailed feedback on initial drafts of participant information and consent pages. The main message from the user group was to keep these pages brief and provide hyperlinks for those who wanted to know more about the research team, privacy policy, and other sensitive issues.
3. *Findability*: The DYD front page, with its invitation to take part in the DYD-RCT, could be reached from the home page of Alcohol Concern, the premier charity in the United Kingdom for people concerned about their alcohol consumption. There were also links to DYD from several other well-respected sites, such as those of the British Broadcasting Corporation (BBC) and UK National Health Service (NHS). We had no control over these links, which tended to come and go according to the priorities of the host organization. DYD was usually the first page of any Google search for help with alcohol problems, although again, this varied from month to month.
4. *Media awareness*: Excessive alcohol consumption and the potential hazards of drinking too much were near the top of the public health agenda during the study period. There were a series of major media stories about the harm of alcohol, with lead stories in major newspapers and the BBC. Many of these stories provided information about Alcohol Concern and/or DYD.

Implications for Other Researchers

The main implication for researchers planning an online trial is that a well-planned recruitment strategy is needed. Piloting can establish the likely number of visitors to a site and what proportion of visitors convert into participants. Advertising the study on the home page of a well-known and trusted charity can help ensure large numbers of visitors, and charitable endorsement is likely to have a positive impact on trust and, hence, the conversion rate of visitors to participants. Having links from numerous respected and well-visited sites is likely to be beneficial. We found it essential to have a user group to critique the trial recruitment materials. It is important to strike a balance between making the recruitment procedures easy for the participants (to enhance recruitment) and placing sufficient hurdles to ensure the participants are fully aware of what they are agreeing to and will not be surprised by subsequent requests for follow-up data (to enhance retention).

Randomization

Conventional Trials

Effective randomization is the defining feature of a randomized controlled trial, with concealment of allocation being a significant component of most quality assessment measures for trials [33]. If the randomization procedure can be subverted in some way, the entire trial is jeopardized. Concealment of allocation has received a great deal of attention, with acceptable and unacceptable methods clearly defined [34].

Online Trials

Online trials have some advantages over conventional trials; for example, there is no way for the researchers to subvert a randomization process that is fully automated and based on computer-generated random numbers. Equally, it is easy to ensure that randomization occurs after collection of baseline data. However, online trials do have a unique problem, namely, the relative ease with which a potential participant can re-register using different identities, either to obtain access to all arms of the trial, or, if incentives for participation are on offer, to obtain multiple incentive payments. If a significant proportion of participants were to adopt this strategy, it would fatally undermine the entire trial. That this is a real, rather than hypothetical, challenge was demonstrated in a Web-based survey in which 11% of total responses were repeat submissions from existing participants. One respondent generated no fewer than 65 submissions [35]. This is part of a larger issue of identity verification—trials that are conducted entirely online have no way of independently verifying participants' identity. Some researchers have avoided this difficulty by requiring participants to sign and return a paper consent form, sent to the participant's home address [32].

The DYD Experience

User feedback from the earlier, cohort study had made it clear that DYD users valued the anonymity of the intervention [17]. We were concerned that inserting an offline consent procedure would have two negative impacts on our trial: first, it could result in the trial recruiting a population that differed systematically from our target population for whom anonymity was an important feature, and, second, sending a consent form through the post and awaiting its return would have introduced a significant time delay to the recruitment procedures, which we considered would have a negative impact on recruitment overall.

As we could not undertake an offline identify verification process, we introduced a number of processes aimed at minimizing participant re-registration:

1. We included an email validation step, to prevent people re-registering with the same email address or registering people other than themselves. However, as many people have multiple email addresses, and obtaining new email addresses is straightforward, we adopted a variety of additional strategies.

2. We tried to remove any incentive to re-register. The participant information stressed that the information provided in the two arms of the trial was the same, and it was only the format that differed. We tried to make the comparator site highly credible, with the same look and feel as the active site but with none of the psychologically enhanced interactive tools that we hypothesized were the active ingredients. We appealed to user altruism by explaining that the results of the trial would be used to inform policy and service provision within the NHS. There were no financial incentives offered at the recruitment stage for participation.
3. We attempted to monitor potential re-registrations. We did this firstly by requesting voluntary provision of offline contact details, such as address and phone number. Only one third of our participants provided either an address or a phone number, and in our subsequent substudy of offline follow-up, described below, it transpired that not all the information provided was valid. We also monitored potential re-registrations by looking at IP (Internet Protocol) addresses of users. Each IP address is unique and acts to allow electronic devices to locate and communicate with each other on an electronic network. Some computers have fixed (static) IP addresses (the computer keeps the same IP address for all time), but dynamic IP addresses (each computer is given a new IP address by the network each time it is switched on and connects to the network) are increasingly common. Moreover, re-registrations from the same IP address could be legitimate, for example, two people using the same computer, either if they cohabit or are using a publicly accessible computer. Despite these caveats, we considered that comparing the proportion of multiple registrations from the same IP address prior to the start of the trial (when there was open access to DYD) and during the trial period would give us some indication of whether re-registration was a significant problem. Before the pilot, 97% (2521/2597) of IP addresses used for registration were used to register one user only. During the pilot, this figure increased to 99% (3357/3396) of IP addresses. However, about 50% of users had a different IP address on their second log-in, reflecting use of different computers or dynamic IP addresses. These findings suggested firstly that re-registration was not increased by randomization, and secondly that re-registration amounted to no more than a few percent of registrations.

Implications for Other Researchers

This is an area that clearly needs considerable further work. In our experience, neither requesting optional provision of offline contact details, nor monitoring IP addresses satisfactorily addressed the issue. Equally, neither exercise provided data to suggest that this was a significant problem in reality, as well as in theory. Researchers might choose to require online participants to provide offline contact details and then use these details to contact each participant and check their identity. This approach has significant disadvantages, including deterring participants who value the anonymity of the Internet—a real issue in many areas, including alcohol consumption, drug use, sexual health, and mental health.

Fidelity of the Intervention

Conventional Trials

Fidelity of the intervention is an important issue in trials of complex interventions, initially defined as interventions that consist of a number of components that may act independently or interdependently [19]. More recent thinking on what makes an intervention complex includes the number of interacting components within the experimental and control interventions, the number and difficulty of behaviors required by those delivering or receiving the intervention, the number of groups or organizational levels targeted by the intervention, the number and variability of outcomes, and the permitted degree of flexibility or tailoring of the intervention [36]. An important component of evaluations of complex interventions is a proposed mechanism of action, which predicts how, and why, the intervention works. Outcome measures can then be selected to measure change in the proposed intermediate outcomes along the pathway of action, as well as the final outcomes. Adequate interpretation of the trial findings also requires a detailed description of the intervention [20].

An additional issue is the proportion of participants who actually receive the intervention under trial. Bias is avoided by an “intention to treat” analysis, where all participants’ results are analyzed according to the treatment to which they were assigned [37], but if a substantial proportion do not receive the intervention, then power is lost and the true effect of the intervention is underestimated [38].

Online Trials

Internet interventions are complex interventions. One way that an Internet intervention may differ from an offline intervention is that the researcher (or intervention developer) has absolute control over what goes into the intervention. In contrast, a researcher evaluating an intervention delivered by multiple different therapists cannot be certain that each therapist is delivering the same intervention. However, with an Internet intervention, the user has a great deal of freedom in how they use the intervention, in terms of number, frequency, and duration of visits; pages used; and active participation in online interactive tools. Non-use of an intervention is a noted feature of online evaluations (the Law of Attrition [39]). Again, this differs from a therapist-delivered intervention, where the number and duration of sessions is usually standardized.

For these reasons, it is particularly important that trials of online interventions include a clear proposed mechanism of action, preferably underpinned by relevant theoretical approaches. A full description of the intervention should be provided, including any theoretical basis to its development [36]. Use of the intervention by trial participants must be carefully monitored, allowing determination of whether exposure to certain parts of the intervention is associated with change in specific intermediate outcomes.

The DYD Experience

The DYD intervention was based on theoretical and empirical data on effective face-to-face interventions for people at risk from their alcohol consumption [40]. A detailed description of the development of the intervention, and its format for use in the trial, has been published [16]. Automatic monitoring of each participant's use of the intervention has been undertaken.

Implications for Other Researchers

As with all complex intervention trials, online trials require considerable preparatory work, including gaining a clear theoretical understanding of how, and why, the proposed intervention is likely to work [20]. This allows the researchers to identify appropriate primary outcomes and also secondary or intermediate measures.

Retention

Conventional Trials

Retention in a trial, or the proportion of participants who provide follow-up data, is an important safeguard against bias. The lower the follow-up rate, the greater the risk of bias and imprecision of the estimated effect of the intervention. There is enhanced potential for bias where there are differential follow-up rates between the intervention and comparator groups.

Online Trials

High drop-out rates are another noted feature of online evaluations (the Law of Attrition [39]), with follow-up rates being often markedly lower in online trials than in conventional trials [30,31,41,42]. The Bull et al trial involving an online sample for an HIV prevention intervention targeting men who have sex with men reported a 15% follow-up rate at 3 months [31], while Verheijden et al had an 11% follow-up rate at 3 months in their study of a Web-based health promotion program [41]. Both these studies used email reminders only for follow-up. Studies that have used mixed methods, including postal or telephone reminders, have achieved higher follow-up rates. Glasgow et al found that a postal reminder combined with a cash incentive (US$10) more than doubled 12-month follow-up rates from 22% for email reminder only to 48% in a trial of an online weight loss program [30]. Similarly, when Couper et al in their trial of an online weight management program had only a 15% retention rate, they were able to boost follow-up among a subsample of nonresponders to 59% with telephone follow-up and to 55% with postal follow-up [42].

The DYD Experience

Like Bull et al, our study involved stigmatized behavior and, as described above, a population that valued their anonymity. Hence, our primary method of follow-up was by email. Participants were sent an email containing a link to follow-up questionnaires at 1 and 3 months. Nonresponders were sent up to two further email reminders at 7-day intervals with links to the full battery of outcome measures, and a final (4th) email requesting completion of the primary outcome measure only. In order to determine whether our response rate could be boosted by using additional postal or telephone reminders, we studied a subsample of 499 nonresponders at 3 months (defined as not having provided a response 40 days after the first request). Of these, 146 (29%) had provided an address, phone number, or both. Twenty-eight of these were excluded as the address or phone number proved false or incomplete (n = 8), or they responded after having been identified as nonresponders (n = 10). A further 10 were excluded as the address or phone number was non-UK based. Of the remaining 118, 17 had provided a phone number only, 22 an address only, and 79 had provided both phone number and address. Up to two postal reminders were sent to those providing an address, with an additional phone call to those providing an address and a phone number. Participants who had only provided a phone number were contacted by phone. This extensive additional follow-up yielded a total of 15 additional responses (15/499, 3%). We concluded that this was not a good use of researcher time in the context of our study.

Implications for Other Researchers

Poor follow-up rates are a significant challenge to online trials, particularly where all follow-up is done online. Studies of online weight loss programs have successfully boosted follow-up rates by using postal and telephone reminders for participants who did not respond to email reminders. This was not our experience with DYD, possibly reflecting the stigmatized nature of excessive alcohol consumption and our participants' desire for anonymity, as well as our recruitment model. This issue clearly requires careful consideration, as a clear threat to valid inference in online trials. Offline follow-up is considerably more expensive and time consuming than online follow-up, so researchers planning to use mixed methods should budget accordingly.

Data Quality

Conventional Trials

Researchers traditionally have two concerns about data quality. One is the validity of the data—to what extent is the information provided by participants "true"? Objective data (eg, data obtained through blood or other laboratory tests) are considered less prone to bias than self-reported, or subjective, data. However, data obtained from self-report may better reflect the intended outcome of a given intervention; for example, the effectiveness of an intervention aimed at reducing pain is best judged by patient reports of perceived pain. Using well-established, validated outcome measures enhances the external validity of a trial and can also facilitate comparing or combining data from different studies.

A second concern is the amount of missing data, in terms of item nonresponse. There has been considerable debate about how to avoid introducing bias into a study where there is missing data [43,44].

Online Trials

Conducting a trial entirely online has several implications for data quality. There are two implications for the validity of the data—the first is that even demographic data, such as age and gender, cannot be independently verified. The important issue here is bias, and collecting baseline data prior to randomization protects against bias in the baseline data. Systematic bias may be introduced after randomization if there is something about either the intervention or comparator that encourages differential responses to the follow-up questionnaires.

A second issue is that standard patient-completed outcome measures have usually been designed for paper-and-pencil completion. Any change in the mode of delivery of an outcome measure may change its psychometric properties [45,46].

Item nonresponse can be easily prevented in online trials by using software that does not allow participants to move on until all (mandatory) questions are answered.

The DYD Experience

For the reasons described above (see Randomization), we decided against offline identity verification. We focused instead on minimizing the potential for bias, by collecting baseline data prior to randomization and maximizing the credibility of the comparator intervention. Our primary outcome measure was developed specifically for online use, and we undertook a preliminary study to determine its reliability and validity [47].

All questionnaires were designed to maximize data quality by minimizing the use of free text and using drop-down menus or forced-choice options. The Web software required participants to complete all mandatory questions, and it was designed so that participants could not provide unusable data (eg, we used radio buttons, which only allowed the user to mark one answer per question). All questionnaires were piloted with a user group. At baseline, all those who entered the trial had usable data, and at follow-up, all those who completed follow-up generated data of adequate quality for analysis.

Implications for Other Researchers

Two collaborations were essential for high-quality data collection. The first was an active user group, who provided feedback on the draft data collection instruments. The second was the collaboration between the statisticians and the programmers, to ensure that the data collected was stored in a usable format. The great advantage of online data collection is that it obviates data entry from paper-and-pencil forms into statistical databases, thus saving a considerable amount of researcher time and money.

Analysis

Some of the challenges inherent in online trials can best be addressed during analysis. For example, measuring levels of exposure to an Internet intervention is important for the interpretation of trial results. Since participants who never used the intervention are likely to differ systematically from those who did, they must be included in the analysis in their randomized group (the intention-to-treat principle [38]). However, there may be interest in understanding the benefit of the intervention in those who did use it. This should be explored by methods such as estimating the “complier average causal effect” (CACE), which effectively deduces the benefit of the intervention in those who did use it from the intention-to-treat results and the proportion of intervention users [48].

Analysis plans should address the potential for bias created by low follow-up rates. In the DYD trial, we have planned a series of sensitivity analyses, for example, by imputing missing outcomes, using baseline characteristics as predictors of nonresponse, and utilizing the trend in outcome across number of email reminders [18].

Challenges Unique to Online Trials

The challenges described above demonstrate how methodological issues common to all trials are altered by the change in context from face-to-face to entirely online. In addition, we encountered two problems that were unique to online trials, namely spamming and cybersquatting.

Spamming

Spamming is illegal in many countries, including the European Union. One software company defines an email to be spam if “(1) the recipient’s personal identity and context are irrelevant because the message is equally applicable to many other potential recipients; and (2) the recipient has not verifiably granted deliberate, explicit, and still-revocable permission for it to be sent; and (3) the transmission and reception of the message appears to the recipient to give a disproportionate benefit to the sender” [49]. Hence, for mass mailings to be legal, they should have an “unsubscribe” option easily visible. One of our participants suggested that our repeated emails requesting follow-up verged on being spam as there was no obvious way to revoke the permission to be sent emails originally granted in the consent form. As a result of this suggestion, emails requesting follow-up data were amended to include a reminder that participants could withdraw from the study at any time by following a link within the email or by sending an email to the research team (email address provided).

Cybersquatting

Cybersquatting is “registering, trafficking in, or using a domain name with bad-faith intent to profit from the goodwill of a trademark belonging to someone else” [50]. DownYourDrink.org.uk was initially launched in September 2001, and all offline advertising ceased at the end of 2001. However, the site was increasingly accessed as its reputation grew [17]. By the end of the pilot study described here (October 2007), there were at least three cybersquatters (downyourdrink.org, downyourdrink.com, and downyourdrink.co.uk) benefiting from the DownYourDrink name. All three were sites that made money by advertising other websites. Users who visited these sites were presented with home pages that looked as if they offered appropriate alcohol services (such as information about alcohol or how to calculate units drunk), but clicking on these links took the user to a page of Web adverts. Visiting these sites also unleashed a torrent of pop-ups advertising various services. We were concerned that people who visited one of these sites while searching for the “real” DYD might think they had found the original site and be put off from further searching. We have no way of determining whether this affected a significant number of people or whether this had an adverse effect on recruitment or the reputation of DYD. However, prevention is better than cure, and our advice to other researchers would be to buy all related domain names (or at least the top-level ones like .org and .com) prior to starting a research program.

Conclusion

Online trials are a recent development. There are strong methodological reasons for using such a design in terms of maximizing the trial's external validity. Other benefits include easy access to large numbers of people and automated data collection, which greatly reduces the costs of the research and has the potential to improve internal validity. In our experience, the main challenges are the risks of participants subverting randomization by re-registering with multiple identities, the difficulties of collecting any objectively measured data, and the high rate of attrition, all of which challenge the internal validity of the trial. We think further methodological work addressing these challenges is needed, to enable the research community to benefit from the potential advantages of online trials.

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Conflicts of Interest

None declared.

References

1. Fox S. The online health care revolution: how the Web helps Americans take better care of themselves. Washington, DC: Pew Internet & American Life Project; 2002.
2. Fox S. Health information online. Washington, DC: Pew Internet & American Life Project; 2005. URL: http://www.pewinternet.org/~/media//Files/Reports/2005/PIP_Healthtopics_May05.pdf.pdf [WebCite Cache ID OvT]
3. Dutton WH, di Gennaro C, Hargrave AM. The Oxford Internet Survey (OxIS) Report 2005: The Internet in Britain. Oxford, UK: Oxford Internet Institute, University of Oxford; 2005. p. 1-60 URL: http://www.oii.ox.ac.uk/research/oxis/oxis2005_report.pdf [WebCite Cache ID 5flNcu2aE]
4. Dutton WH, Helsper E. The Internet in Britain: 2007. Oxford, UK: Oxford Internet Institute, University of Oxford; 2007. p. 1-83 URL: http://www.oii.ox.ac.uk/research/oxis/OxIS2007_Report.pdf [WebCite Cache ID 5flNgC9vX]
5. Kummervold PE, Chronaki CE, Lausen B, Prokosch HU, Rasmussen J, Santana S, et al. eHealth trends in Europe 2005-2007: a population-based survey. J Med Internet Res 2008;10(4):e42 [FREE Full text] [Medline: 19017584] [doi: 10.2196/jmir.1023]
6. Murray E, Burns J, See Tai S, Lai R, Nazareth I. Interactive Health Communication Applications for people with chronic disease. Cochrane Database Syst Rev 2005(4):CD004274.
7. Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. BMJ 2004 May 15;328(7449):1166 [FREE Full text] [Medline: 15142921] [doi: 10.1136/bmj.328.7449.1166]
8. Wantland DJ, Portillo CJ, Holzemer WL, Slaughter R, McGhee EM. The effectiveness of Web-based vs. non-Web-based interventions: a meta-analysis of behavioral change outcomes. J Med Internet Res 2004 Nov 10;6(4):e40 [FREE Full text] [Medline: 15631964] [doi: 10.2196/jmir.6.4.e40]
9. Kaltenthaler E, Shackley P, Stevens K, Beverley C, Parry G, Chilcott J. A systematic review and economic evaluation of computerised cognitive behaviour therapy for depression and anxiety. Health Technol Assess 2002;6(22):1-89 [FREE Full text] [Medline: 12433315]
10. Spek V, Cuijpers P, Nyklícek I, Riper H, Keyzer J, Pop V. Internet-based cognitive behaviour therapy for symptoms of depression and anxiety: a meta-analysis. Psychol Med 2007 Mar;37(3):319-328. [Medline: 17112400] [doi: 10.1017/S0033291706008944]
11. Ritterband L, Gonder-Frederick LA, Cox DJ, Clifton AD, West RW, Borowitz S. Internet Interventions: In Review, In Use, and Into the Future. Prof Psychol Res Pr 2003;34(5):527-534. [doi: 10.1037/0735-7028.34.5.527]
12. Paul J, Seib R, Prescott T. The Internet and clinical trials: background, online resources, examples and issues. J Med Internet Res 2005;7(1):e5 [FREE Full text] [Medline: 15829477] [doi: 10.2196/jmir.7.1.e5]
13. Eysenbach G. Issues in evaluating health websites in an Internet-based randomized controlled trial. J Med Internet Res 2002 Dec 23;4(3):E17 [FREE Full text] [Medline: 12554548] [doi: 10.2196/jmir.4.3.e17]
14. Rothwell PM. External validity of randomised controlled trials: "to whom do the results of this trial apply?". Lancet 2005;365(9453):82-93. [Medline: 15639683] [doi: 10.1016/S0140-6736(04)17670-8]

15. Linke S, Brown A, Wallace P. Down your drink: a web-based intervention for people with excessive alcohol consumption. Alcohol Alcohol 2004;39(1):29-32 [FREE Full text] [Medline: 14691071]
16. Linke S, McCambridge J, Khadjesari Z, Wallace P, Murray E. Development of a psychologically enhanced interactive online intervention for hazardous drinking. Alcohol Alcohol 2008;43(6):669-674 [FREE Full text] [Medline: 18693217] [doi: 10.1093/alcalc/agn066]
17. Linke S, Murray E, Butler C, Wallace P. Internet-based interactive health intervention for the promotion of sensible drinking: patterns of use and potential impact on members of the general public. J Med Internet Res 2007;9(2):e10 [FREE Full text] [Medline: 17513281] [doi: 10.2196/jmir.9.2.e10]
18. Murray E, McCambridge J, Khadjesari Z, White IR, Thompson SG, Godfrey C, et al. The DYD-RCT protocol: an on-line randomised controlled trial of an interactive computer-based intervention compared with a standard information website to reduce alcohol consumption among hazardous drinkers. BMC Public Health 2007;7(1):306 [FREE Full text] [Medline: 17963483] [doi: 10.1186/1471-2458-7-306]
19. ; MRC Health Services and Public Health Research Board. A Framework for Development and Evaluation of RCTs for Complex Interventions to Improve Health. London, UK: Medical Research Council; 2000:1-18.
20. Campbell NC, Murray E, Darbyshire J, Emery J, Farmer A, Griffiths F, et al. Designing and evaluating complex interventions to improve health care. BMJ 2007 Mar 3;334(7591):455-459 [FREE Full text] [Medline: 17332585] [doi: 10.1136/bmj.39108.379965.BE]
21. Campbell MK, Snowdon C, Francis D, Elbourne D, McDonald AM, Knight R, et al. Recruitment to randomised trials: strategies for trial enrolment and participation study. The STEPS study. Health Technol Assess 2007;11:1-126.
22. Mapstone J, Elbourne D, Roberts I. Strategies to improve recruitment to research studies. Cochrane Database Syst Rev 2007:MR000013.
23. Mills N, Donovan JL, Smith M, Jacoby A, Neal DE, Hamdy FC. Perceptions of equipoise are crucial to trial participation: a qualitative study of men in the ProtecT study. Control Clin Trials 2003 Jun;24(3):272-282. [Medline: 12757993] [doi: 10.1016/S0197-2456(03)00020-5]
24. Coleman K, Murray E. Patients' views and feelings on the community-based teaching of undergraduate medical students: a qualitative study. Fam Pract 2002 Apr;19(2):183-188 [FREE Full text] [Medline: 11906985] [doi: 10.1093/fampra/19.2.183]
25. Eysenbach G, Wyatt J. Using the Internet for surveys and health research. J Med Internet Res 2002 Nov 22;4(2):E13 [FREE Full text] [Medline: 12554560] [doi: 10.2196/jmir.4.2.e13]
26. McAlindon T, Formica M, Kabbara K, LaValley M, Lehmer M. Conducting clinical trials over the internet: feasibility study. BMJ 2003 Aug 30;327(7413):484-487 [FREE Full text] [Medline: 12946971] [doi: 10.1136/bmj.327.7413.484]
27. Formica M, Kabbara K, Clark R, McAlindon T. Can clinical trials requiring frequent participant contact be conducted over the Internet? Results from an online randomized controlled trial evaluating a topical ointment for herpes labialis. J Med Internet Res 2004 Feb 17;6(1):e6 [FREE Full text] [Medline: 15111272] [doi: 10.2196/jmir.6.1.e6]
28. Koo M, Skinner H. Challenges of internet recruitment: a case study with disappointing results. J Med Internet Res 2005;7(1):e6 [FREE Full text] [Medline: 15829478] [doi: 10.2196/jmir.7.1.e6]
29. Thompson D, Canada A, Bhatt R, Davis J, Plesko L, Baranowski T, et al. eHealth recruitment challenges. Eval Program Plann 2006 Nov;29(4):433-440. [Medline: 17950873] [doi: 10.1016/j.evalprogplan.2006.08.004]
30. Glasgow RE, Nelson CC, Kearney KA, Reid R, Ritzwoller DP, Strecher VJ, et al. Reach, engagement, and retention in an Internet-based weight loss program in a multi-site randomized controlled trial. J Med Internet Res 2007;9(2):e11 [FREE Full text] [Medline: 17513282] [doi: 10.2196/jmir.9.2.e11]
31. Bull SS, Lloyd L, Rietmeijer C, McFarlane M. Recruitment and retention of an online sample for an HIV prevention intervention targeting men who have sex with men: the Smart Sex Quest Project. AIDS Care 2004 Nov;16(8):931-943. [Medline: 15511725] [doi: 10.1080/09540120412331292507]
32. Riper H, Kramer J, Smit F, Conijn B, Schippers G, Cuijpers P. Web-based self-help for problem drinkers: a pragmatic randomized trial. Addiction 2008 Feb;103(2):218-227. [Medline: 18199300] [doi: 10.1111/j.1360-0443.2007.02063.x]
33. Schulz KF, Chalmers I, Hayes RJ, Altman DG. Empirical evidence of bias. Dimensions of methodological quality associated with estimates of treatment effects in controlled trials. JAMA 1995 Feb 1;273(5):408-412. [Medline: 7823387] [doi: 10.1001/jama.273.5.408]
34. Hewitt C, Hahn S, Torgerson DJ, Watson J, Bland JM. Adequacy and reporting of allocation concealment: review of recent trials published in four general medical journals. BMJ 2005 May 7;330(7499):1057-1058 [FREE Full text] [Medline: 15760970] [doi: 10.1136/bmj.38413.576713.AE]
35. Konstan J, Rosser BR, Ross MW, Stanton J, Edwards WM. The Story of Subject Naught: A Cautionary but Optimistic Tale of Internet Survey Research. J Comput Mediated Commun 2005;10 article 11.
36. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and Evaluating Complex Interventions: New Guidance. London, UK: Medical Research Council; 2008:1-39.
37. Pocock SJ. Clinical Trials: A Practical Approach. Chichester, UK: Wiley; 1983.
38. Heritier SR, Gebski VJ, Keech AC. Inclusion of patients in clinical trial analysis: the intention-to-treat principle. Med J Aust 2003 Oct 20;179(8):438-440 [FREE Full text] [Medline: 14558871]

39. Eysenbach G. The law of attrition. J Med Internet Res 2005;7(1):e11 [FREE Full text] [Medline: 15829473] [doi: 10.2196/jmir.7.1.e11]
40. Raistrick D, Heather N, Godfrey C. Review of the effectiveness of treatment for alcohol problems. London, UK: National Treatment Agency for Substance Misuse; 2006:1-210.
41. Verheijden MW, Jans MP, Hildebrandt VH, Hopman-Rock M. Rates and determinants of repeated participation in a web-based behavior change program for healthy body weight and healthy lifestyle. J Med Internet Res 2007;9(1):e1 [FREE Full text] [Medline: 17478410] [doi: 10.2196/jmir.9.1.e1]
42. Couper MP, Peytchev A, Strecher VJ, Rothert K, Anderson J. Following up nonrespondents to an online weight management intervention: randomized trial comparing mail versus telephone. J Med Internet Res 2007;9(2):e16 [FREE Full text] [Medline: 17567564] [doi: 10.2196/jmir.9.2.e16]
43. Altman DG, Bland JM. Missing data. BMJ 2007 Feb 24;334(7590):424 [FREE Full text] [Medline: 17322261] [doi: 10.1136/bmj.38977.682025.2C]
44. Wood AM, White IR, Thompson SG. Are missing outcome data adequately handled? A review of published randomized controlled trials in major medical journals. Clin Trials 2004;1(4):368-376. [Medline: 16279275] [doi: 10.1191/1740774504cn032oa]
45. Buchanan T, Ali T, Heffernan TM, Ling J, Parrott AC, Rodgers J, et al. Nonequivalence of on-line and paper-and-pencil psychological tests: the case of the prospective memory questionnaire. Behav Res Methods 2005 Feb;37(1):148-154 [FREE Full text] [Medline: 16097355]
46. Thomas BA, McCambridge J. Comparative psychometric study of a range of hazardous drinking measures administered online in a youth population. Drug Alcohol Depend 2008 Jul 1;96(1-2):121-127. [Medline: 18406079] [doi: 10.1016/j.drugalcdep.2008.02.010]
47. Khadjesari Z, Murray E, Kalaitzaki E, White IR, McCambridge J, Godfrey C, et al. Test-retest reliability of an online measure of past week alcohol consumption (the TOT-AL), and comparison with face-to-face interview. Addict Behav 2009 Apr;34(4):337-342. [Medline: 19097705] [doi: 10.1016/j.addbeh.2008.11.010]
48. White IR. Uses and limitations of randomization-based efficacy estimators. Stat Methods Med Res 2005 Aug;14(4):327-347. [Medline: 16178136] [doi: 10.1191/0962280205sm406oa]
49. Ixis Research Ltd. Antispam Policy. URL: http://www.emailarms.com/spam_policy.html [WebCite Cache ID 5VD7eZMbC]
50. Wikipedia. Cybersquatting. URL: http://en.wikipedia.org/wiki/Cybersquatting [WebCite Cache ID 5VElaIGhd]

Abbreviations

BBC: British Broadcasting Corporation
DYD: DownYourDrink
DYD-RCT: randomized controlled trial of DYD
IP: Internet Protocol
NHS: UK National Health Service

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Original Paper

Effectiveness of a Novel Integrative Online Treatment for Depression (Deprexis): Randomized Controlled Trial

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Abstract

Background: Depression is associated with immense suffering and costs, and many patients receive inadequate care, often because of the limited availability of treatment. Web-based treatments may play an increasingly important role in closing this gap between demand and supply. We developed the integrative, Web-based program *Deprexis,* which covers therapeutic approaches such as behavioral activation, cognitive restructuring, mindfulness/acceptance exercises, and social skills training.

Objective: To evaluate the effectiveness of the Web-based intervention in a randomized controlled trial.

Methods: There were 396 adults recruited via Internet depression forums in Germany, and they were randomly assigned in an 80:20 weighted randomization sequence to either 9 weeks of immediate-program-access as an add-on to treatment-as-usual (N = 320), or to a 9-week delayed-access plus treatment-as-usual condition (N = 76). At pre- and post-treatment and 6-month follow-up, we measured depression (Beck Depression Inventory) as the primary outcome measure and social functioning (Work and Social Adjustment Scale) as the secondary outcome measure. Completer analyses and intention-to-treat analyses were performed.

Results: Of 396 participants, 216 (55%) completed the post-measurement 9 weeks later. Available case analyses revealed a significant reduction in depression severity (BDI), Cohen's d = .64 (CI 95% = 0.33 - 0.94), and significant improvement in social functioning (WSA), Cohen's d = .64, 95% (CI 95% = 0.33 - 0.95). These improvements were maintained at 6-month follow-up. Intention-to-treat analyses confirmed significant effects on depression and social functioning improvements (BDI: Cohen's d = .30, CI 95% = 0.05 - 0.55; WSA: Cohen's d = .36, CI 95% = 0.10 - 0.61). Moreover, a much higher percentage of patients in the intervention group experienced a significant reduction of depression symptoms (BDI: odds ratio [OR] = 6.8, CI 95% = 2.90 - 18.19) and recovered more often (OR = 17.3, 95% CI 2.3 - 130). More than 80% of the users felt subjectively that the program had been helpful.

Conclusions: This integrative, Web-based intervention was effective in reducing symptoms of depression and in improving social functioning. Findings suggest that the program could serve as an adjunctive or stand-alone treatment tool for patients suffering from symptoms of depression.

Trial Registration: International Standard Randomized Controlled Trial Number (ISRCTN): 64953693; http://www.controlled-trials.com/ISRCTN64953693/64953693 (Archived by WebCite at http://www.webcitation.org/5ggzvTJPD)

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Introduction

Depression is associated with immense personal suffering and—due to treatment expenses and lost productivity—with high costs to the individual and society [1-3]. Despite the enormous burden imposed by depression, and even though depression is clearly treatable [4], many sufferers still receive inadequate treatment or no treatment at all [5-8]. For example, it has been estimated that only 10% of the 4 million people who suffer annually from depression are treated adequately in a well developed health care system such as the one established in Germany [9]. In other countries, similar problems are evident. For example, in the early 2000s, fewer than 25% of adults with major depressive disorders in the US received the recommended appropriate treatment [10]. The World Health Organization has estimated that during a 12-month period, about 14 million depressed individuals in Europe and 20 million in North and South America (combined) went untreated [11].

Many depressed patients who could benefit from treatment also remain on waiting lists for a long time or do not engage with treatment due to geographical inaccessibility, prohibitive costs, or other reasons, such as a preference for self-help [8]. The evidence shows that depressed patients who remain on waiting lists continue to report high levels of distress, even over many months [12].

What can be done to help more of these patients quickly and efficiently? In the UK, experts have recommended the training of 10,000 new therapists and the creation of new treatment delivery systems [13]. Similarly, a workgroup commissioned by the US National Institute of Mental Health [14] has recommended the development of innovative treatments that can be delivered at low costs to large populations. Specifically, the workgroup noted that “the Internet affords the opportunity to make psychosocial interventions available to large segments of the public. Interventions can be delivered programmatically and reliably, greatly extending the numbers and types of people who can be reached with services” [14] (page 623). In recent years, Web-based approaches have been increasingly used and it has been repeatedly shown that Internet-delivered treatments may be an effective and inexpensive alternative to traditional treatments [15-17]. Most of the existing Internet-based depression treatments are based on cognitive-behavioral principles, although other modalities, such as problem-solving therapy, appear promising as well [18].

The purpose of the project described here was to develop a novel, integrative program that could be delivered via the Internet to reduce symptoms of depression. The name *Deprexis* was chosen because it expresses which symptoms are targeted (ie, depression), and it conveys the idea that active practice is an inherent part of the treatment. The word is a combination of depression and *praxis*—a word of Greek and Latin origin denoting *deed* or *action*. The aim of this paper is to describe an initial study of its effectiveness.

Methods

Recruitment of Participants

The study was conducted between February of 2007 and June of 2008. Participants were recruited via advertisements posted on the Internet (eg, by posting brief notices on depression-related Internet forums in Germany, given the permission of the forum administrators). Upon establishing contact via email, potential participants received a detailed response email describing the project and inviting them to complete a set of online questionnaires. The email also informed potential participants that the program was not intended to replace psychotherapy or medical treatment and did not entail personal interactions with any treatment provider. Additionally, it explained that participants would be randomly assigned to one of two conditions: 9 weeks of access to an online self-help program or 9 weeks in a waitlist/delayed-access condition. Only those who provided consent, were above the age of 18, and completed at least half of the baseline depression questionnaire were included in the study. Similar to some previous studies in this area (eg, Warmerdam et al [19]) no other inclusion or exclusion criteria were used. The study was approved by an internal review board (IRB) in Frankfurt/Main (Hesse Ministry of Health, Germany).

Intervention

The Web-based intervention consists of 10 content modules representing different psychotherapeutic approaches, plus one introductory and one summary module, each of which can be completed in 10 to 60 minutes, depending on the user’s reading speed, interest, motivation, and individual path through the program (see Figure 1 and Multimedia Appendix 1 for screenshots). Modules are organized as simulated dialogues in which the program explains and illustrates concepts and techniques, engages the user in exercises, and continuously asks users to respond by selecting from response options. Subsequent content is then tailored to the users’ responses, resulting in a simulated conversational flow. All modules are accompanied by illustrations (eg, drawings, photographs, flash animations). The program version that was evaluated in this study did not include audio or video features in order to increase accessibility by reducing the requirements for broad bandwidth and specialized hardware or software.

Figure 1. Example screenshot (see Multimedia Appendix 1 for additional examples)

Dienstag, der 05.05.2009

Das freut mich! Dann werde ich mir weiterhin Mühe geben, damit es auch interessant bleibt!

Sie haben jetzt ja ziemlich viele Fragen beantwortet und sich viel durchgelesen. Dadurch habe ich Sie ein wenig kennengelernt. Das wird für unsere weiteren "Gespräche" sehr gut sein!

Ich schlage vor, dass es für heute erst einmal genug mit den vielen Fragen ist. Aber jetzt habe ich noch eine kleine Übung für Sie - etwas Entspannendes, recht Schönes...

Eine Entspannungsübung kann ich jetzt gut gebrauchen!

● Na, dann zeigen Sie mir mal Ihre Übung.

○ Mir ist noch nicht ganz klar, warum Sie mir eigentlich all diese Fragen gestellt haben. Können Sie das nochmal erklären?

○ Ich bin schon ziemlich entspannt...

The modules cover a variety of therapeutic content that is broadly consistent with a cognitive-behavioral perspective, although the program is not restricted to one CBT manual. Instead, an effort was made to design the program as an integrative treatment tool that provides a variety of relevant therapeutic approaches and fits within the broad array of contemporary CBT. The modules' theoretical rationale and content draws from theories like (1) Behavioral Activation, (2) Cognitive Modification, (3) Mindfulness and Acceptance, (4) Interpersonal Skills, (5) Relaxation, Physical Exercise and Lifestyle Modification, (6) Problem Solving, (7) Childhood Experiences and Early Schemas, (8) Positive Psychology Interventions, (9) Dreamwork and Emotion-Focused Interventions, and (10) Psychoeducation. Each is explained in turn below.

Behavioral Activation and Cognitive Modification

There is strong evidence that CBT techniques such as cognitive restructuring (eg, identifying and refuting unhelpful automatic thoughts, recognizing cognitive distortions, etc) and behavioral activation (eg, scheduling potentially enjoyable activities) are effective in the treatment of depression [4,20,21], so their inclusion in Web-based programs appears justified. Some controversy remains, however, with regard to the necessity of the cognitive elements of CBT packages. In some studies, behavioral activation alone has been as effective as, or even outperformed, the more cognitive CBT interventions [22-24]. In line with most CBT packages for depression, one *Deprexis* module was designed with a focus on behavioral activation (BA) and another with a focus on cognitive restructuring.

The BA module incorporates standard BA principles and procedures, as described in existing manuals (eg, Lejuez et al [25] and Martell et al [26]), but also contains modifications. For instance, users are encouraged to schedule activities that have the potential to satisfy basic psychological needs: the needs for social relatedness, autonomy, competence, self-esteem, and hedonic enjoyment. This need-satisfaction aspect is not a traditional element of BA but is a key feature of other treatments that have garnered empirical support, such as Grawe's integrative therapy (a treatment that is well-known and widely used in German-speaking countries) [27,28].

The cognitive restructuring module incorporates standard cognitive intervention elements, as described in existing manuals [29-31], but it also contains modifications to adapt these approaches to the format and style of the program. A main emphasis in the cognitive modification module is on the mood-determining role of automatic thoughts; on the interaction between thoughts, emotions, overt behavior, and environmental events (ie, reciprocal determinism [32]; and on simple techniques that can be used to challenge or refute unhelpful automatic thoughts or to develop a more distanced and accepting attitude towards unhelpful thoughts.

Mindfulness and Acceptance

One of the most notable trends in psychotherapy research over the past decade has been the development of mindfulness- and acceptance-based interventions for depression, anxiety, and related syndromes and disorders [33-35]. Treatments such as acceptance and commitment therapy (ACT) [35] and mindfulness-based cognitive therapy for depression (MBCT) [36] have demonstrated their merit in terms of enhancing the effectiveness of traditional treatments [34,37]. In the *Deprexis* program, an acceptance/mindfulness module was designed to engage patients with key principles of such approaches. Brief exercises illustrate the difficulty of suppressing unwanted thoughts and feelings, and the idea that unwelcome experiences can be calmly observed and willingly accepted is presented via stories, metaphors, images, and texts.

Interpersonal Skills

Problems in interpersonal adjustment are well-known antecedents and concomitants of depression [38,39], and interpersonal psychotherapy for depression (IPT) [40,41] is a strongly empirically supported treatment [4,20]. Therefore, the inclusion of an interpersonally-focused module appeared justified. In this module, the role of social and interpersonal adjustment in the etiology and maintenance of depression is explained, and a variety of suggestions are provided to help users improve their interpersonal functioning and satisfaction. Such suggestions include, for example, tips for improved verbal and nonverbal communication as well as guidelines for relationship-enhancing behavior (eg, responding to good news conveyed by partners with enthusiasm rather than passive disinterest or active hostility) [42].

Relaxation, Physical Exercise and Lifestyle Modification

Physical exercise and healthy lifestyle behavior (eg, consuming healthy foods) are regarded as useful elements of integrative depression treatments [43,44,45]. Relaxation exercises, such as imagery and repeated tension exercises (eg, Suinn [46]) may also play a useful role in depression treatments, particularly for patients suffering from anxiety symptoms, which are exceedingly common in depression [47]. Given this evidence, a module was developed with a focus on relaxation exercises and healthy lifestyle tips. For example, users are guided through imagery and breathing exercises to help reduce tension and increase relaxation.

Problem Solving

Evidence indicates that problem-solving interventions are effective in the treatment of depression (eg, Mynors-Wallis et al [48], Mynors-Wallis et al [49], and Nezu [50]). In such treatments, patients learn how to define problems in concrete rather than vague terms, set achievable goals, generate potential solutions, evaluate different solution options, implement the chosen solution, and evaluate outcomes with respect to the original problem. Such algorithms are typically practiced repeatedly so that patients can generalize them to a variety of life problems and improve their overall problem-solving skills. One module is devoted to teaching and demonstrating this problem-solving approach to cope with a variety of depression-related problems.

Childhood Experiences and Early Schemas

Many depressed patients attribute their depression to problematic childhood experiences [51], and those who do regard childhood adversity as causally related to their depression tend to be specifically motivated to address unresolved childhood issues in psychotherapy [52]. Moreover, there is evidence that adversity in childhood predisposes to depression in later life [53], which further points to the importance of including interventions that target memories and other sequelae of difficult childhood experiences. Such interventions have shown empirical promise; for example, Young and colleagues' schema therapy places "much greater emphasis on exploring the childhood and adolescent origins of psychological problems" than traditional CBT [54]. In the *Deprexis* program, one module focuses on difficult childhood memories. For example, the program explains techniques such as expressive writing [55-57], forgiveness [58], and acceptance of difficult memories [35].

Positive Psychology Interventions

Positive psychology focuses on the scientific study of positive experiences such as happiness, well-being, life satisfaction, and optimal functioning. From its inception in the late 1990s, the movement has become an increasingly dynamic force within psychology, with regular conferences, a journal, and various handbooks testifying to its momentum [59]. In recent years, the application of positive psychology to depression treatment has also been explored. Seligman and colleagues [60], for example, reported that positive psychology interventions such as encouraging people to cultivate strengths, expressing gratitude, and savoring positive experiences can lead to lasting reductions in depressive symptoms. In the *Deprexis* program, one module focuses on positive psychology interventions, including savoring positive experiences and memories, satisfying basic needs [61], and cultivating strengths and talents.

Dreamwork and Emotion-Focused Interventions

Although working with dreams is not a standard ingredient of empirically supported depression therapies such as CBT, there is evidence that therapeutic work with dreams can be a useful and productive therapeutic element, especially for patients who hold positive attitudes towards such approaches [62,63]. Rather than offering interpretations regarding the symbolic meaning of dreams, modern approaches to dreamwork use dreams as vehicles for creative problem solving [62]. In the *Deprexis* program, a dream and emotion-focused module is included and offered to users who indicate that they hold positive attitudes towards such content. The dialogue explains basic techniques such as keeping a dream journal, rewriting problem-laden dreams with positive endings, brainstorming about the relationships between dream contents and real-life problems, and others (cf Morris [64]).

Psychoeducation

Psychoeducation is an important aspect of many empirically supported depression interventions (eg, CBT) [30,65]. Therefore, the *Deprexis* program also includes a module that explains basic descriptive aspects of depression. This includes, for example, a review of the diagnosis of major depression (as a brief, jargon-free summary), an overview of diathesis-stress models of depression (emphasizing the interaction between personal and environmental factors in depression), a section on biological and medical aspects of depression, and a synopsis of cultural aspects. This module is offered optionally, although psychoeducational elements are included throughout other modules as well. Furthermore, a review module is offered in which key ideas of other modules are briefly reviewed. Users are encouraged to repeat all modules as often as they wish after they have passed once through the module sequence.

Design

In order to examine the effectiveness of the *Deprexis* program, a randomized controlled trial was conducted with help-seeking adults who reported symptoms of depression. It was hypothesized that, over the course of 9 weeks, program users would achieve greater reductions of depression symptoms than comparison participants in a delayed-access, treatment-as-usual (TAU) condition. Additionally, we hypothesized that the majority of users would evaluate the *Deprexis* program favorably and report that they benefitted from using it.

For the main hypothesis, a 2 x 2 (pre vs post by treatment vs waitlist-control condition) design was used. Participants completed baseline (T0) self-reports of depression severity and other variables online and were then assigned either to the immediate-treatment condition (9 weeks of access to the program) or to a waitlist/delayed-treatment condition, in which they received access to the program after waiting for 9 weeks. At the 9-week time-point (T1), participants were invited to complete online questionnaires to determine whether the immediate-treatment group had, indeed, improved to a greater degree than the waitlist/delayed access group.

For exploratory purposes, we also gathered follow-up data, beyond T1. The delayed-access group completed post-treatment questionnaires, which coincided with the 9-week follow-up data collection time-point of the immediate-treatment group (T2). This design enabled us to test whether any treatment effect that might be observed in the immediate-treatment group could be replicated among those in the delayed-treatment condition. The delayed-treatment group was also asked to complete 9-week follow-up questionnaires (T3), and both groups were invited to complete follow-up questionnaires 6 months after treatment termination (T4). The outcome variable of primary interest was depression severity, as measured by the Beck Depression Inventory (BDI). However, given the exploratory, open nature of this study, we did not limit our focus on patients with a bona fide diagnosis of a depressive disorder, and we regard the BDI as a measure of general distress, which correlates highly with depression as well as with other forms of emotional distress [12].

Randomization

We used a weighted randomization procedure in which 80% were assigned to the immediate-treatment condition and 20% to the delayed-treatment condition. The purpose of this weighting was to ensure that a sufficiently large number of participants would take part in the treatment and would be able to provide feedback that could be used for further program development. An a priori power analysis indicated that, given this 4:1 weighted randomization strategy, at least 200 participants (immediate-treatment group: 160; delayed-treatment condition: 40) would be required to achieve a power level of > .80, assuming a medium effect size, (Cohen’s d = .50), with alpha set at .05 (two-tailed). The goal was to retain this number of participants at the T1 time-point, after those in the immediate-treatment condition had completed 9 weeks of program access, and those in the delayed-treatment condition had waited for program access for an equal duration.

Randomization was performed via a computer generated list of random numbers. After generating a list of 500 random numbers and sorting them by size, the highest 20% were marked to indicate that they referred to the control condition. The list was then resorted to its original order and newly enrolled participants were consecutively placed onto this list. If a new participant received a marked number, he or she was assigned to the control condition; otherwise, the new participant was assigned to the immediate-access condition. This procedure ensured that an 80:20 chance—but no predictable sequence—existed with regard to whether a new participant would be assigned to the immediate-access or the delayed-access condition.

Measures

Beck Depression Inventory (BDI)

The BDI [66,67] is one of the most commonly used self-report measures of depression severity and has well established validity and reliability [68]. The German version of the BDI [67], which was used in this study, includes 21 items measuring symptoms such as hopelessness, irritability, guilt, feelings of being punished, fatigue, weight loss, and lack of interest. Cronbach alpha of .84 (T0) indicated good internal consistency of the BDI in this study. Because of ethical concerns, the suicidality item was dropped from the BDI, but this missing item-score was imputed from the remaining 20 items so that the sum scores are comparable to established 21-item BDI norms. The BDI was administered at each of the assessment time-points.

Work and Social Adjustment Scale

This 5-item questionnaire measures the extent to which the respondent’s depression interferes with his or her ability to perform various tasks of daily living, such as household chores, hobbies, or private leisure-time activities [69]. In the present study, internal consistency was excellent (Cronbach alpha = .83, T0). The WSA was scored on a 1-9 Likert-type response scale. The use of this questionnaire was exploratory in the present study because a translated (German) version was employed, which has not been validated in Germany so far. Given the face-valid nature of these items and high internal consistency, however, it seems likely that the translated WSA would still yield a useful estimate of depression-related psychosocial impairment. The WSA was also administered at all time-points.

Additional Questions: Program Acceptability and Subjective Benefit

A series of questions was administered to evaluate the extent to which participants felt they benefited personally from the program, liked or disliked the program, and would recommend the program to others. These questions are described in detail in the results section.

Statistical Analyses

Preliminary descriptive statistics and correlational analyses were conducted to illuminate the associations between program usage (number of sessions completed) and changes in depression over time. To test the hypotheses that depression and social dysfunction scores would decrease as a consequence of program usage versus scores for those assigned to the control group, both intention-to-treat (ITT) and available-cases analyses were conducted. For the intention-to-treat analysis, we conducted mixed-model repeated measures ANOVA with time (pre-post) as a within-groups factor and treatment condition as a between-groups factor. Mixed-model repeated measures ANOVA uses all available data on each subject and does not involve the substitution of missing values. In addition, and as a comparison, a 2 x 2 repeated measures ANOVA was applied to a dataset in which pre-treatment data were carried forward for non-completers to replace missing values. A repeated-measures ANOVA with time as a within-subjects and group (immediate *Deprexis* use vs waitlist control) as a between-subjects independent variable was also used to analyze the available-cases. In addition to tests of statistical significance and computation of effect sizes, we also computed the clinical significance of the observed effects, using standardized procedures as described in detail below.

Results

Demographics, Response Rates, and Attrition

As summarized in Table 1, a total of 396 individuals was included in the study, of which 81% were assigned to the immediate-treatment condition and 19% to the delayed-treatment condition. Table 1 shows that the average age was around 35, with a range from 18 to 72. About ¾ of the sample were women, consistent with the well-documented predominance of women among depression sufferers. Many of the participants in this study were quite incapacitated in terms of symptom severity and social dysfunction. For example, slightly over half of the sample was currently unemployed, more than half reported currently being in treatment (medication and/or psychotherapy), and 85% stated they had been feeling depressed for several months (29%) or even several years (56%). There was no significant difference between the intervention and control group on any of the baseline variables, including baseline depression and social functioning (Table 2).

Table 1. Sample characteristics

	Immediate treatment group	Delayed treatment group	Total (combined) sample	*P* Value
Time 0 (Baseline)				
N (%)	320 (80.81%)	76 (19.19%)	396 (100%)	
Age (M, SD)	34.58 (11.53)	35.47 (11.98)	34.76 (11.60)	.55
Gender (% Female : % Male)	77 : 23	71 : 29	76 : 24	.30
% married or partnered	51%	58%	53%	.37
% completed univ degree	18%	20%	18%	.61
% currently unemployed	51%	56%	52%	.44
% previously treated for depression	66%	70%	67%	.54
% in current treatment for depression	58%	64%	59%	.32
% currently receiving psychotherapy-only vs medication-only vs both	13% vs 20% vs 23%	11% vs 31% vs 20%	13% vs 22% vs 22%	.14
Time 1 (9 weeks)				
N (%)	159 (74%)	57 (26%)	216 (100%)	
Age (M, SD)	34.89 (11.40)	35.25 (11.79)	34.99 (11.48)	.84
Gender (% Female : % Male)	78 : 22	70 : 30	76 : 24	.24
% married or partnered	54%	64%	57%	.16
% completed univ. degree	18%	20%	18%	.84
% currently unemployed	46%	57%	49%	.16
% previously treated for depression	67%	72%	70%	.50
% in current treatment for depression	60%	68%	62%	.34
% currently receiving psychotherapy-only vs medication-only vs both	16% vs 20% vs 22%	12% vs 31% vs 21%	15% vs 23% vs 22%	.36

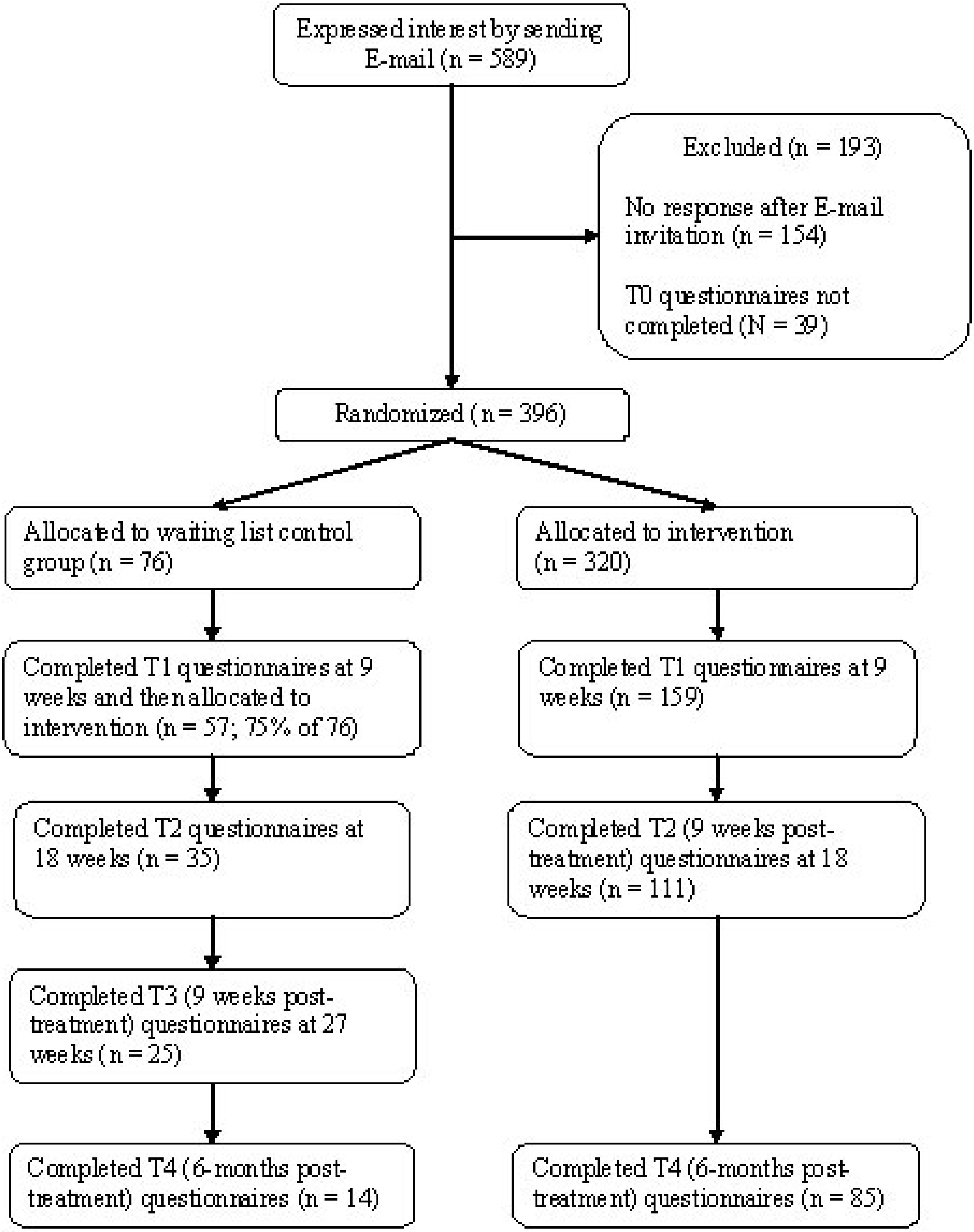
Table 2. Descriptive statistics: depression and social functioning

	Immediate-treatment group M (SD), N	Delayed-treatment group M (SD), N	Mean comparisons and effect size (between-groups Cohen's *d*)
Depression (BDI)			
T0 (baseline)	26.72 (9.86), 320	27.11 (8.98), 76	*t* (394) = .31, *P* = .76 (*d* = .04)
T1 (9 weeks)	19.87 (11.85), 159	27.15 (10.01), 57	*t* (214) = 4.14, *P* < .001 (*d* = .64)
T2 (18 weeks)	17.23 (11.85), 111	20.39 (12.92), 35	*t* (144) = 1.34, *P* = .18 (*d* = .25)
T3 (27 weeks)[a]		19.07 (15.32), 25	
T4 (6-months follow-up)	16.50 (12.93), 85	15.25 (14.80), 14	*t* (97) = -.33, *P* = .74 (*d* = .09)
Social Dysfunction (WSA)			
T0 (baseline)	5.66 (1.66), 315	5.89 (1.50), 75	*t* (388) = 1.10, *P* = .27 (*d* = .15)
T1 (9 weeks)	4.80 (2.14), 154	6.06 (1.42), 57	*t* (209) = 4.11, *P* < .001 (*d* = .64)
T2 (18 weeks)	4.48 (2.26), 109	4.65 (1.92), 34	*t* (141) = .40, *P* = .69 (*d* = .08)
T3 (27 weeks)[a]		4.86 (2.30), 24	
T4 (6-months follow-up)	4.10 (2.41), 83	4.07 (2.74), 12	*t* (93) = -.04, *P* = .97 (*d* = .01)

[a] At the T3 data-collection time-point, questionnaires were administered only to the delayed-treatment group, given that this constituted the 9-week post-treatment follow-up for that group.

In terms of attrition, between one-third and half of the sample was lost from the study at each time-point (Figure 2). That is, from 396 participants who were initially randomized at T0, 216 (55%) completed the depression questionnaire 9 weeks later (T1). Similarly, of these 216 T1 participants, 146 (68%) completed the depression questionnaires at the 18-week time-point (T2). Of these participants, 99 (68%) were available for the 6-month follow-up data collection time-point (T4).

Figure 2. Participant flow



With regard to the post-assessment (T1), the response rate was higher in the control group (75%; n = 57) than in the intervention group (50%; n = 159; $P < .001$). However, there was no difference at post-assessment (T1) between the intervention and control group on any of the assessed client characteristics (Table 1).

Figure 3 presents a graphic overview of program usage. These descriptive statistics are based on the entire sample, collapsing across the immediate-access and delayed-access groups. Comparisons between these groups are presented further below. Of the 396 participants who completed the initial T0 questionnaire and were randomized to conditions, 19 (4.8%)

never logged on to the program again and can be considered pre-treatment drop-outs. Another 67 (16.9%) never completed a single session of at least 10 minutes duration and can be considered early drop-outs. The 86 drop-outs did not differ from the 310 actual program users in terms of baseline depression severity, social functioning, age, gender, self-reported depression chronicity, and current as well as past depression treatment (eg, medication, psychotherapy, or both).

Figure 3 shows that 310 users completed at least 1 session of more than 10 minutes over the course of the entire study. Of these 310 users, 249 (80.3%) completed at least 2 sessions of more than 10 minutes duration, 183 (59.0%) completed at least 3 such sessions, and only 2 users (0.6%) completed more than 13 sessions. It was possible to complete more than 12 sessions because each module could be repeated once or several times, depending on the user's preference. Thus, there was no upper limit to the number of sessions a user could do. In practice though, as shown in Figure 3, the upper limit was 23—the number of sessions completed by a single user.

Figure 3. Program usage over time: comparison between Deprexis participants and similar studies (data from Eysenbach)

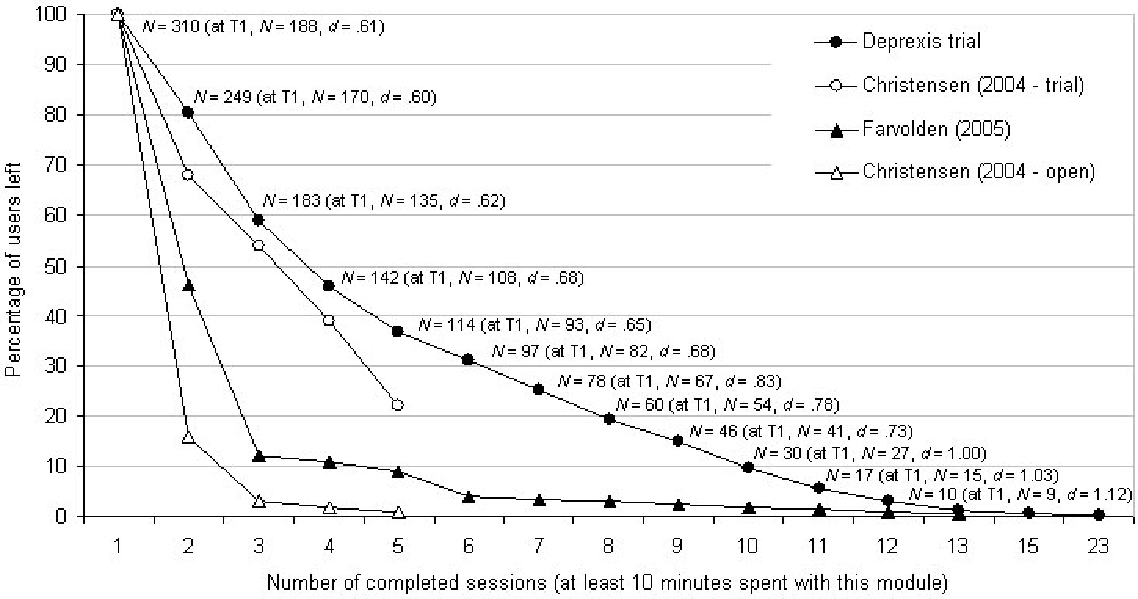


Figure 3 also presents comparison data from similar studies, as discussed in Eysenbach's "Law of Attrition" article [70]. The figure shows that the attrition rate in the current study appeared favorable compared to previous studies in which no therapist support has been included.

Figure 3 also shows the number of users who were available for the post-treatment assessment time-point, grouped by the number of sessions completed. For example, of the 310 participants who completed at least 1 session, 188 (61%) completed the post-treatment assessment. Of the 60 who completed at least 8 sessions, though, 54 (90%) completed the post-treatment assessment. As one might expect, the more sessions users completed, the more likely they were to complete the post-treatment assessment. A very high correlation confirmed the impression of such a strong linear association between program usage and study compliance (r = .91, P < .001, N = 12, completion percentages derived from the values shown in Figure 3 were correlated with the number of sessions, from 1 to 12, shown on the x-axis).

Figure 3 also shows the pre-post treatment effect sizes (Cohen's *d*) of depression improvement, as measured by the BDI, for users who completed different numbers of sessions. For example, the pre-post effect size for those 188 users who completed at least one session was .61. The pre-post effect size of those 78 users who completed at least 7 sessions, by contrast, was .83. Indeed, the correlation between number of sessions completed and effect size was also extremely high (r = .91, P < .001, N = 12). For this analysis, the effect sizes shown in Figure 3 were correlated with number of sessions shown on the x-axis, from session 1 to 12.

These strong associations suggested that users who engaged more often and intensively with the program were more likely to complete the follow-up assessment and to benefit from the program. These preliminary analyses do not answer the question, though, of whether differences exist in symptomatic and functional improvement between those in the treatment versus the waitlist group. The next section presents the relevant comparisons.

Symptoms of Depression and Social Functioning

Intention-to-Treat Analyses

As shown in Table 1, Figure 2, and Figure 3, and as discussed above, attrition was a considerable problem in this study: between 30% and 50% of participants were lost between any two assessment time-points, and fewer than 50% of the users completed more than 3 sessions. Several questions arise, therefore: what happened to those who chose not to continue the program and not to complete the post-treatment and follow-up questionnaires? Would analyses based on the completer sample exaggerate true effect sizes?

To respond to these concerns, we conducted intention-to-treat (ITT) analyses in two ways. First, we analyzed the data by using mixed-model repeated measures ANOVA with time (pre-post) as a within-groups factor and treatment condition as a between-groups factor. Mixed-model repeated measures ANOVA uses all available data on each subject and does not involve the substitution of missing values [71,72]. Second, and as a comparison, analyses were undertaken using a dataset in which the missing T1 data for those participants who did not complete the T1 questionnaires was set at their baseline (T0) level. This last observation carried forward (LOCF) approach assumes that, of the 320 participants who were assigned to immediate treatment at T0, the 161 who did not complete T1 questionnaires did not improve at all. The LOCF-dataset was analyzed with a 2 x 2 repeated measures ANOVA with time as the within-group factor and treatment as the between-group factor.

In the mixed-model repeated measures procedure, relationships between the observations at pre- and post-assessment were modeled as an unstructured covariance matrix. With regard to the BDI, a significant interaction between treatment condition and time (T0 vs T1) was found ($F_{1,219.7} = 19.2$, $P < .001$). Based on estimated marginal means, the immediate-treatment group improved 5.4 BDI points (from 26.72 to 21.30), which corresponded to a pre-post effect size of $d = 0.58$. By using the estimates from the mixed-model, the between-groups effect size was at $d = 0.65$.

Using the LOCF-dataset, the 2 x 2 repeated measures ANOVA showed a significant interaction between treatment condition and time (T0 vs T1) in the prediction of BDI-scores, $F_{1,394} = 10.12$, $P = .002$. In this sample, there was a reduction of 3.11 BDI points between T0 and T1 among the 320 participants assigned to the immediate-treatment group (from 26.72 to 23.61, pre-post Cohen's $d = .29$). This change was significant, paired-$t_{319} = 7.20$, $P < .001$. Among the 76 participants assigned to the delayed-treatment group, which did not have access to the program at this time, depression levels remained unchanged in this ITT sample (27.11 to 27.07, pre-post Cohen's $d = .00$, paired-$t = .05$, $P = .96$). The between-groups effect size at T1, using this ITT sample, was Cohen's $d = .30$.

Similar analyses were performed with the WSA. The mixed-model repeated measures ANOVA revealed a significant interaction between treatment condition and time ($F_{1,402.1} = 7.7$, $P = .006$). The within-groups effect size based on the estimated marginal means was at $d = .47$, the between-groups effect size at $d = .63$. Using the LOCF-dataset, the 2 x 2 repeated measures ANOVA showed a significant interaction, $F_{1,388} = 6.98$, $P = .009$. Whereas social dysfunction decreased slightly in the immediate-treatment group, paired-$t_{314} = 4.15$, $P < .001$, there was no significant change in the delayed-treatment group between T0 and T1, paired-$t_{74} = -1.02$, $P = .31$. The pre-post effect size in the immediate-treatment group was Cohen's $d = .17$, and the between-group effect size at T1 was Cohen's $d = .36$.

Overall, both analyses revealed clear evidence of reductions in depression and social dysfunction in response to the treatment. Results obtained using LOCF were less pronounced, suggesting that the LOCF-procedure produces more conservative estimates of effectiveness. However, mixed-model repeated measures ANOVA is more and more recognized as the preferred choice for the analysis of repeated measures data [71].

Available Case Analyses

Descriptive statistics for the BDI and the WSA at all time-points are shown in Table 2. The mean comparisons shown in the table are based on data from participants who actually completed the questionnaires at each time-point. Statistics for the intention-to-treat sample are discussed above.

Table 2 shows that, as predicted, using the program was associated with improvements in depression severity and social dysfunction, whereas not using the program was associated with no improvement. Consistent with the hypotheses, the immediate-treatment group scored significantly lower on depression and social dysfunction at T1, compared to the delayed-access group, but the respective values did not differ at any of the other time-points.

The between-group differences in depression and social dysfunction at T1 correspond to effect sizes of $d = .64$ on both measures.

A 2 x 2 repeated measures ANOVA with the BDI as dependent variable, time-point as a within-subjects independent variable (T0 vs T1), and treatment condition as a between-subjects independent variable was conducted. Only participants who completed questionnaires at both T0 and T1 were included in this analysis. This ANOVA showed a significant interaction and confirmed the main hypothesis, that depression levels would decrease more among those in the immediate-treatment rather than the delayed-treatment condition, $F_{1,214} = 17.81$, $P < .001$. There was a significant reduction in BDI-scores between T0 and T1 among those in the immediate-treatment group, paired-$t_{158} = 7.87$, $P < .001$ (pre-post Cohen's $d = .58$), but no change in depression between T0 and T1 among those in the delayed-treatment group, paired-$t_{56} = .05$, $P = .96$ (pre-post Cohen's $d = .01$).

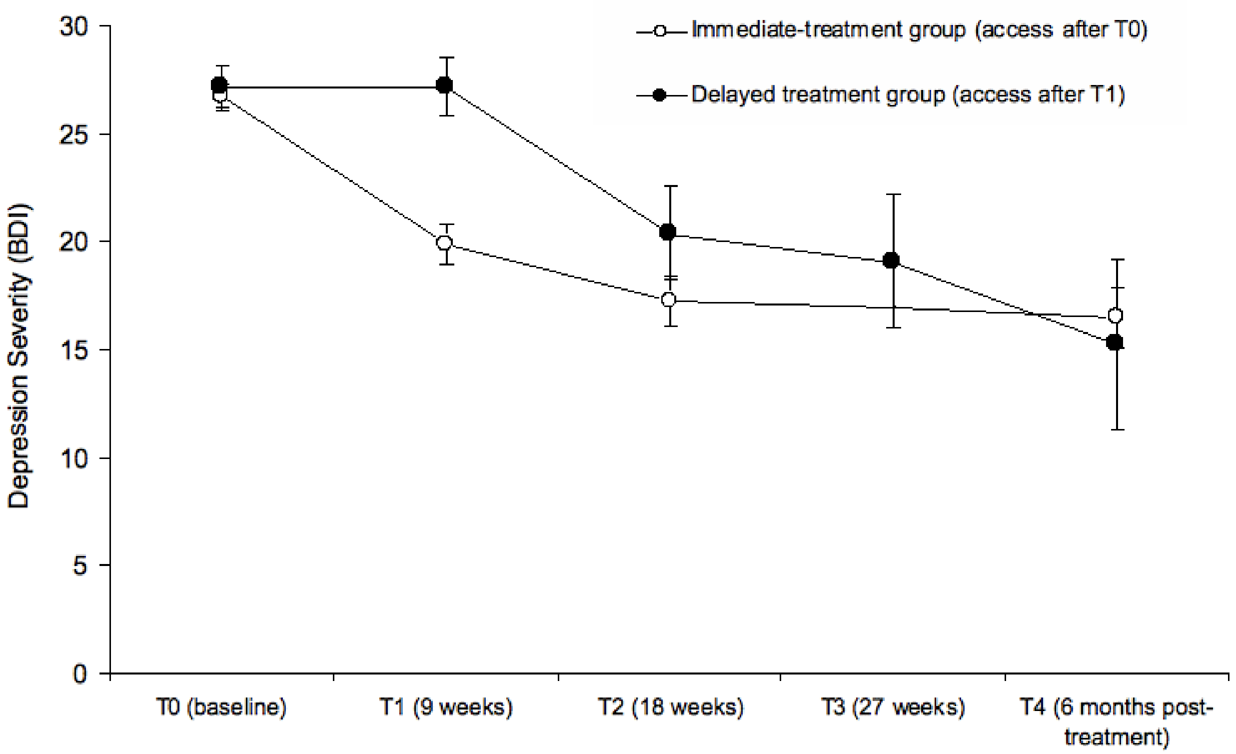
Similarly, a significant interaction was found with the WSA as the dependent variable, $F_{1,206} = 9.17$, $P = .004$. Again, social dysfunction improved significantly between T0 and T1 among those in the immediate-treatment group, paired-$t_{151} = 4.27$, $P < .001$ (pre-post Cohen's $d = .33$), but not among those in the delayed-treatment group, paired-$t_{55} = -1.02$, $P = .31$ (pre-post Cohen's $d = .12$).

The course of depression symptoms is graphically depicted in Figure 4, which shows that, at baseline, depression severity was in the moderate-to-severe range in both groups. Note that the data points in Figure 4 are based on all participants who completed questionnaires at each respective time-point (eg, in the immediate-treatment group, N = 320 at T0, N = 159 at T1, et cetera, Table 2).

Once the treatment was received, there was a marked reduction of around 6 BDI-points in both the immediate-treatment (reduction by 6.26 points, on average, among those 159 participants in the immediate-treatment group who completed both the T0 and T1 BDI) and the delayed-treatment (reduction by 5.94 points, on average, among those 34 participants in the delayed-treatment group who completed both the T1 and T2 BDI) groups.

Among those in the immediate-treatment group, the reduction in depression severity in the 9 weeks following the treatment, between T1 and T2, was also significant, paired-t_{88} = 3.16, P = .002. After this, depression levels remained stable in the mild-to-moderate range, around 17, with no significant change between T2 and T4, paired-t_{52} = .40, P = .69. Among those in the delayed-treatment condition, there were no significant symptom changes after completion of the treatment (Ps > .30). In this group, the marked change in depression also occurred in response to the treatment, and symptoms remained in the mild-to-moderate range at the 6-months follow-up time-point (Figure 4). The pre-post effect size for those 85 participants who completed the BDI at both T0 and at the 6-month follow-up (T4) was d = .74. For those 14 in the delayed-access group, the T0 - T4 effect size was d = .96.

Figure 4. Depression severity over time: comparison between the immediate-treatment versus delayed treatment groups (data points are based on all participants who completed questionnaires at each respective time-point)



Clinical Significance of Depression Changes

Data on clinically significant improvement as defined by Jacobson and Truax [73] are presented in Table 3. Following the recommendations of Seggar, Lambert, and Hasen [74], reliable change was defined as a move of at least 8.46 points on the BDI from pre-test to post-test (ie, from T0 to T1). Furthermore, a post-test score of below 14.29 needed to be achieved in order for the improvement to be considered clinically significant [74]. For these analyses, dropouts were not included. Also, only participants who exceeded the cut-off score of 14.29 at the T0 pre-test time-point were included in order to have a chance to move from a dysfunctional to a functional range.

Table 3. Data for the proportion of participants reaching the criteria of clinical significant improvement (recovered) or of reliable change (improved but not recovered)

	Immediate treatment (n = 138)		Control (n = 52)		
	%	n	%	n	$\chi^2(1)$
Recovered	25.4	35	1.9	1	19.08 (P < .001)
Improved but not recovered	16.7	23	7.7	4	
No reliable change	53.6	74	82.7	43	
Deteriorated	4.3	6	7.7	4	

As can be seen in Table 3, there were significant differences in terms of clinically significant improvement between the immediate-treatment and the waitlist/control group. About one-quarter of those assigned to the immediate-treatment condition showed large improvements in depression severity with post-treatment scores more in line with non-clinical than clinically depressed populations. Such improvements were extremely rare among those assigned to the waitlist/control group (occurring in only 1 out of 52 cases). Whereas 42.1% of those assigned to the immediate-treatment condition showed reliable improvement or recovery, this was true for less than 10% of those in the waitlist/control group.

The proportions of clinically significant improvement shown in Table 3 compare the immediate-treatment with the waitlist/control group. But what were the rates of improvement among those in the control group after they also received the treatment? Of the 31 participants with complete T2 data, 7 (22.6%) could be classified as recovered, 5 (16.1%) as improved but not recovered, 17 (54.8%) as not reliably changed, and 2 (6.5%) as deteriorated. Thus, even though the sample size was considerably smaller for this delayed-treatment group, the rates of improvement shown in Table 3 were closely replicated. It appears that about 40 of 100 program users will clearly benefit, with up to 25 of those achieving post-test scores in the recovered range. Of the 55 - 60 who do not benefit, the vast majority will simply show no clear change in either direction, and fewer than 5 of 100 can be expected to deteriorate.

Subjective Benefit and Acceptance of the Program

Table 4 provides an overview of the questions that were asked to estimate participants' subjective satisfaction with the program. Approximately 80% of the users were generally satisfied. For example, 83% gave the program a grade between 1 and 3 on a 1 - 6 scale (with 58% assigning a score of 1 or 2); 82% had the sense that the program had helped at least a little bit; 78% reported that the program had met or exceeded their expectations; 74% felt that the program's tips and suggestions were as good or better than those given by human therapists; and 95% would recommend it to others suffering from mild depression (79% would recommend it to others with moderately severe depression and 42% to those with severe depression). Table 4 also shows that none of the participants felt that the program had harmed rather than helped them.

Table 4. Subjective benefit and user impressions

	Number and percentage of participants
Overall impression: How did you like the program, all in all? (1 - 6 scale, 1 = very good, 6 = seriously flawed)	
Liked the program (1-3)	164 (83%)
Did not like the program (4-6)	34 (17%)
Subjective benefit: Do you have the sense that the program helped you?	
Helped me a lot	28 (14%)
Helped me a little	139 (68%)
Did not help	36 (18%)
Did more harm than help	0 (0%)
User satisfaction: Did the program meet your expectations?	
Positively surprised: The program exceeded my expectations	36 (18%)
Satisfied: The program met my expectations	119 (60%)
Disappointed: The program did not meet my expectations	42 (21%)
Quality of content: How would you rate the program’s tips and suggestions compared to a “real” (human) psychotherapist?	
Content was better than human therapist	31 (16%)
Content was about as good as human therapist	111 (58%)
Content was worse than human therapist	48 (25%)
Recommendations: Would you recommend the program to others...	
...who are suffering from mild depression?	
- would definitely not recommend it	5 (3%)
- would probably not recommend it	4 (2%)
- would recommend it with reservations	32 (16%)
- would definitely recommend it	156 (79%)
...who are suffering from moderately severe depression?	
- would definitely not recommend it	9 (5%)
- would probably not recommend it	31 (16%)
- would recommend it with reservations	92 (47%)
- would definitely recommend it	63 (32%)
...who are suffering from severe depression?	
- would definitely not recommend it	56 (29%)
- would probably not recommend it	57 (29%)
- would recommend it with reservations	60 (31%)
- would definitely recommend it	21 (11%)

Discussion

In the randomized controlled trial described here, adults who used the *Deprexis* program improved, on average, by about 6 BDI points, whereas those in a delayed-access control condition did not improve at all during the waiting period. On average, participants initially reported being moderately to severely depressed, but by the end of treatment, only mildly to moderately depressed. Among those who completed the pre- and post-treatment questionnaires, the treatment effect corresponded to an effect size of .64 (post-treatment between-groups comparison) and was replicated when the waitlist control group also received access to the program. In the ITT analyses, significant treatment effects were also observed, although the effect sizes were weaker (eg, d = 30 for the between-groups effect at T1).

The gains in depression improvement were maintained over a follow-up period of 6 months, and positive changes were also demonstrated in terms of social functioning. About one-quarter of the participants experienced clinically significant rates of depression improvement, such that they no longer reported being depressed after the treatment. Half of the participants did not report such improvements, although about 80% of the users subjectively felt that the program had been helpful. In sum, these findings strongly suggest that the *Deprexis* program can be a useful and effective treatment for help-seeking Internet users suffering from depression.

The findings from the study suggest that online programs for depression can work even in the absence of therapist support. These findings are consistent with previous evidence, which demonstrated the effectiveness of other online depression programs, such as the Australian MoodGym program or the US-American ODIN program [75-78]. Overall, then, a clear effect of online support for depression has been established [17], although unguided online depression programs tend to achieve relatively low effect sizes [15-17]. The present study tentatively suggests that online programs might work better if interactivity is emphasized and a wide range of treatment ingredients are included. Compliance and dropout still remain problematic, but it may be possible to increase adherence by providing participants with a clear deadline and scheduled follow-up appointments, even if these are automated.

A surprising observation in this study was that a large proportion of participants showed lasting positive effects even though they received only a small dosage of the treatment (ie, 4 sessions or fewer). This finding is actually consistent with previous research showing that many psychotherapy clients experience the majority of therapeutic gains within the first few sessions. Howard et al [79], for example, found that 41% of therapeutic gains typically occur within the first 4 sessions. Similarly, Kopta et al [80], found that 50% of patients achieve symptomatic recovery from depression after only 5 sessions. Barkham et al [81] as well as Stiles et al [82] also recently found that more than 70% of patients in routine psychotherapy who only attended fewer than 4 sessions achieved reliable and clinically significant improvement. Once they achieve a personal "good enough" level, many of these patients terminate treatment because the most pressing treatment goals have been achieved. In open-access Internet treatments, this possibility also seems plausible: many of those who dropped out after only a few sessions in this study may have done so because they felt that they had reached a "good enough" level or had received an adequate amount of help from the program. An alternative possibility is, of course, that many of these participants dropped out early because they did not find the program useful. Future research will be needed to disentangle and further understand these possibilities.

Limitations

The results of the current study must be interpreted in light of several limitations. A major caveat in interpreting these results concerns the high attrition rate. Only about half of those who had completed the baseline questionnaires and entered the study also completed questionnaires 9 weeks later, at the post-treatment time-point for the immediate-access group. Furthermore, only about half of the users completed more than 3 sessions (Figure 3). Nevertheless, ITT analyses revealed significant treatment effects even when one assumes that all dropouts remained at their initial level of depression severity. Thus, it seems unlikely that the observed effects are spurious or due to the fact that non-improvers dropped out.

In this context, Eysenbach [70] also highlighted the finding that high attrition rates are actually expected when conducting open Internet trials without any therapist support (see also Andersson [83]). When participants can easily discontinue without adverse consequences, many of them will regularly do so. Future efforts in this area would be well advised to explore new methods to increase treatment engagement and adherence. For example, brief telephone-delivered interventions that are based on motivational interviewing might improve engagement and reduce attrition among depressed patients [84,85].

A second limitation of the study concerns the heterogeneous sample of users. Future investigations would benefit from studying more narrowly defined user groups, such as depressed inpatients or outpatients with stringently confirmed diagnoses, in order to establish with precision how the program operates among different user groups. A third and related limitation is that the depressed participants in this study may have differed from other depressed adults in that they were more comfortable with computer technology. That is, these participants were recruited in online depression discussion/support groups, so they were presumably relatively experienced computer/Internet users. It remains to be seen whether the effects reported for this group generalize to less computer-literate populations. A fourth potential limitation concerns the program's lack of multimedia components. Conceivably, the effectiveness of *Deprexis* could be enhanced further by integrating audio or video clips. The downside, though, would be the need for more sophisticated computers and high-speed Internet connections. Follow-up studies are required, then, to examine the processes and components that might further enhance the program's effectiveness, to delineate the contextual moderators defining the program's optimal conditions of use, and to understand the mediators explaining how the program's effects unfold in different user groups (see also Caspar [86] for a discussion of future research directions in this area).

Conclusion

The present study showed that an integrative online treatment program—*Deprexis*—was effective in improving symptoms of depression among many of its users. On average, program users experienced lasting symptom reductions and improvements in functioning, whereas those who did not use the program remained at their original level of distress and dysfunction. Future studies could examine how the program can best be deployed to reach those who might benefit from its use, how large-scale adoption of the program could help address unmet treatment needs, and how the therapeutic effects achieved by the program unfold on changes at the behavioral, cognitive, interpersonal, and other levels of analysis.

Conflicts of Interest

Dr. Weiss is chief executive officer of the GAIA AG, which is developing products related to the research described in this paper. Björn Meyer was employed by the GAIA AG at the time this research was conducted.

Multimedia Appendix 1

Deprexis screenshots

[PDF(Adobe PDF File), 2,400 KB - jmir_v11i2e15_app1.pdf]

References

1. Leslie DL, Rosenheck R. Shifting to outpatient care? Mental health care use and cost under private insurance. Am J Psychiatry 1999 Aug;156(8):1250-1257 [FREE Full text] [Medline: 10450268]
2. Luppa M, Heinrich S, Angermeyer MC, König HH, Riedel-Heller SG. Cost-of-illness studies of depression: a systematic review. J Affect Disord 2007 Feb;98(1-2):29-43. [Medline: 16952399] [doi: 10.1016/j.jad.2006.07.017]
3. Wang PS, Simon G, Kessler RC. The economic burden of depression and the cost-effectiveness of treatment. Int J Methods Psychiatr Res 2003;12(1):22-33. [Medline: 1283030] [doi: 10.1002/mpr.139]
4. Hollon SD, Thase ME, Markowitz JC. Treatment and prevention of depression. Psych. Science in the Public Int 2002;3(2):39-77. [doi: 10.1111/1529-1006.00008]
5. Andrews GA, Henderson AS. Unmet Need in Psychiatry: Problems, Resources, Responses. Cambridge, UK: Cambridge University Press; 1999.
6. Bebbington P, Brugha T, Meltzer H, Jenkins R, Ceresa C, Farrell M, et al. Neurotic disorders and the receipt of psychiatric treatment. Int Rev Psychiatry 2003;15(1-2):108-114. [Medline: 12745317] [doi: 10.1080/0954026021000046010]
7. Frank RG, Glied SA. Better but Not Well: Mental Health Policy in the United States since 1950. Baltimore, MD: The Johns Hopkins University Press; 2006.
8. Kessler RC, Berglund PA, Bruce ML. The prevalence and correlates of untreated serious mental illness. Health Serv Res 2001;36(6 Pt 1):987-1007. [Medline: 1177567]
9. Wittchen HU, Müller N, Pfister H, Winter S, Schmidtkunz B. Erscheinungsformen, Häufigkeit und Versorgung von Depressionen. Ergebnisse des bundesweiten Gesundheitssurveys “Psychische Störungen”. Fortschritte der Medizin 2000;118(Suppl. 1):4-10.
10. Kessler RC, Berglund P, Demler O, Jin R, Koretz D, Merikangas KR, et al; National Comorbidity Survey Replication. The epidemiology of major depressive disorder: results from the National Comorbidity Survey Replication (NCS-R). JAMA 2003 Jun 18;289(23):3095-3105 [FREE Full text] [Medline: 12813115] [doi: 10.1001/jama.289.23.3095]
11. Kohn R, Saxena S, Levav I, Saraceno B. The treatment gap in mental health care. Bull World Health Organ 2004 Nov;82(11):858-866 [FREE Full text] [Medline: 15640922] [doi: /S0042-96862004001100011]
12. Barkham M, Mullin T, Leach C, Stiles WB, Lucock M. Stability of the CORE-OM and the BDI-I prior to therapy: evidence from routine practice. Psychol Psychother 2007 Jun;80(Pt 2):269-278. [Medline: 17535599] [doi: 10.1348/147608306X148048]
13. Layard R. The depression report: a new deal for depression and anxiety disorder. London, UK: Centre for Economic Performance Mental Health Policy Group; 2006.
14. Hollon SD, Muñoz RF, Barlow DH, Beardslee WR, Bell CC, Bernal G, et al. Psychosocial intervention development for the prevention and treatment of depression: promoting innovation and increasing access. Biol Psychiatry 2002 Sep 15;52(6):610-630. [Medline: 12361671] [doi: 10.1016/S0006-3223(02)01384-7]
15. Spek V, Cuijpers P, Nyklícek I, Riper H, Keyzer J, Pop V. Internet-based cognitive behaviour therapy for symptoms of depression and anxiety: a meta-analysis. Psychol Med 2007;37(3):319-328. [Medline: 1711240] [doi: 10.1017/S0033291706008944]
16. Andersson G, Cuijpers P, Carlbring P, Lindefors N. Effects of Internet-delivered cognitive behaviour therapy for anxiety and mood disorders. Review Series Psychiatry 2007;9:9-14.
17. Barak A, Hen L, Boniel-Nissim M, Shapira N. A comprehensive review and a meta-analysis of the effectiveness of Internet-based psychotherapeutic interventions. Journal of Technology in Human Services 2008;26(2/4):109-160. [doi: 10.1080/15228830802094429]
18. van Straten A, Cuijpers P, Smits N. Effectiveness of a Web-based self-help intervention for symptoms of depression, anxiety, and stress: randomized controlled trial. J Med Internet Res 2008;10(1):e7. [Medline: 1836434] [doi: 10.2196/jmir.954]
19. Warmerdam L, van Straten A, Twisk J, Riper H, Cuijpers P. Internet-based treatment for adults with depressive symptoms: randomized controlled trial. J Med Internet Res 2008;10(4):e44 [FREE Full text] [Medline: 19033149] [doi: 10.2196/jmir.1094]
20. Craighead WE, Craighead LW, Ilardi SS. Psychosocial treatments for major depressive disorder. In: Nathan PE, Gorman JM, editors. A Guide to Treatments that Work. 2nd edition. New York, NY: Oxford University Press; 2002:245-261.

21. Cuijpers P, van Straten A, Warmerdam L. Behavioral activation treatments of depression: a meta-analysis. Clin Psychol Rev 2007 Apr;27(3):318-326. [Medline: 17184887] [doi: 10.1016/j.cpr.2006.11.001]
22. Dimidjian S, Hollon SD, Dobson KS, Schmaling KB, Kohlenberg RJ, Addis ME, et al. Randomized trial of behavioral activation, cognitive therapy, and antidepressant medication in the acute treatment of adults with major depression. J Consult Clin Psychol 2006 Aug;74(4):658-670 [FREE Full text] [Medline: 16881773] [doi: 10.1037/0022-006X.74.4.658]
23. Jacobson NS, Dobson KS, Truax PA, Addis ME, Koerner K, Gollan JK, et al. A component analysis of cognitive-behavioral treatment for depression. J Consult Clin Psychol 1996 Apr;64(2):295-304. [Medline: 8871414] [doi: 10.1037/0022-006X.64.2.295]
24. Gortner ET, Gollan JK, Dobson KS, Jacobson NS. Cognitive-behavioral treatment for depression: relapse prevention. J Consult Clin Psychol 1998 Apr;66(2):377-384. [Medline: 9583341] [doi: 10.1037/0022-006X.66.2.377]
25. Lejuez CW, Hopko DR, Hopko SD. A brief behavioral activation treatment for depression. Treatment manual. Behav Modif 2001;25(2):255-286. [Medline: 1131763] [doi: 10.1177/0145445501252005]
26. Martell CR, Addis ME, Jacobson NS. Depression in Context: Strategies for Guided Action. New York, NY: Norton; 2001.
27. Grawe K. Neuropsychotherapy: How the Neurosciences Inform Effective Psychotherapy. Mahwah, NJ: Lawrence Erlbaum; 2006.
28. Grawe K. Psychological Therapy. Ashland, OH: Hogrefe & Huber Publishers; 2004.
29. Beck JS. Cognitive Therapy: Basics and Beyond. New York, NY: The Guilford Press; 1995.
30. Beck AT, Rush AJ, Shaw BF, Emery G. Cognitive Therapy of Depression. New York, NY: Guilford Press; 1979.
31. Hautzinger M. Kognitive Verhaltenstherapie bei Depressionen (Cognitive behavioural therapy of depression). Weinheim, Germany: Verlagsgruppe Beltz; 2003.
32. Bandura A. Human agency in social cognitive theory. Am Psychol 1989 Sep;44(9):1175-1184. [Medline: 2782727] [doi: 10.1037/0003-066X.44.9.1175]
33. Baer RA. Mindfulness training as a clinical intervention: a conceptual and empirical review. Clinical Psychology: Science and Practice 2003;10(2):125-143. [doi: 10.1093/clipsy/bpg015]
34. Hayes SC, Luoma JB, Bond FW, Masuda A, Lillis J. Acceptance and commitment therapy: model, processes and outcomes. Behav Res Ther 2006 Jan;44(1):1-25. [Medline: 16300724] [doi: 10.1016/j.brat.2005.06.006]
35. Hayes SC, Strosahl K, Wilson KG. Acceptance and Commitment Therapy: An Experiential Approach to Behavior Change. New York, NY: Guilford Press; 1999.
36. Segal ZV, Williams S, Teasdale J. Mindfulness-Based Cognitive Therapy for Depression: A New Approach to Preventing Relapse. New York, NY: Guilford; 2002.
37. Kenny MA, Williams JMG. Treatment-resistant depressed patients show a good response to Mindfulness-based Cognitive Therapy. Behav Res Ther 2007 Mar;45(3):617-625. [Medline: 16797486] [doi: 10.1016/j.brat.2006.04.008]
38. Coyne JC. Toward an interactional description of depression. Psychiatry 1976 Feb;39(1):28-40. [Medline: 1257353]
39. Joiner TE. Depression's vicious scree: self-propagating and erosive processes in depression chronicity. Clinical Psychology: Science and Practice 2000;7:203-218. [doi: 10.1093/clipsy.7.2.20]
40. Klerman G, Weissman M, Rounseville B. Interpersonal Psychotherapy of Depression. New York, NY: Basic Books; 1984.
41. Weissman MM, Markowitz JC, Klerman GL. Comprehensive Guide to Interpersonal Psychotherapy. New York, NY: Basic Books; 2000.
42. Gable SL, Reis HT, Impett EA, Asher ER. What do you do when things go right? The intrapersonal and interpersonal benefits of sharing positive events. J Pers Soc Psychol 2004 Aug;87(2):228-245. [Medline: 15301629] [doi: 10.1037/0022-3514.87.2.228]
43. Dunn AL, Trivedi MH, Kampert JB, Clark CG, Chambliss HO. Exercise treatment for depression: efficacy and dose response. Am J Prev Med 2005 Jan;28(1):1-8. [Medline: 15626549] [doi: 10.1016/j.amepre.2004.09.003]
44. Pollock KM. Exercise in treating depression: broadening the psychotherapist's role. J Clin Psychol 2001 Nov;57(11):1289-1300. [Medline: 11590615] [doi: 10.1002/jclp.1097]
45. Richardson CR, Avripas SA, Neal DL, Marcus SM. Increasing lifestyle physical activity in patients with depression or other serious mental illness. J Psychiatr Pract 2005 Nov;11(6):379-388. [Medline: 16304506] [doi: 10.1097/00131746-200511000-00004]
46. Suinn RM. Anxiety Management Training: A Behavior Therapy. New York, NY: Plenum Press; 1990.
47. Mineka S, Watson D, Clark LA. Comorbidity of anxiety and unipolar mood disorders. Annu Rev Psychol 1998;49(1):377-412. [Medline: 949662] [doi: 10.1146/annurev.psych.49.1.377]
48. Mynors-Wallis LM, Gath DH, Lloyd-Thomas AR, Tomlinson D. Randomised controlled trial comparing problem solving treatment with amitriptyline and placebo for major depression in primary care. BMJ 1995 Feb 18;310(6977):441-445 [FREE Full text] [Medline: 7873952]
49. Mynors-Wallis LM, Gath DH, Day A, Baker F. Randomised controlled trial of problem solving treatment, antidepressant medication, and combined treatment for major depression in primary care. BMJ 2000 Jan 1;320(7226):26-30 [FREE Full text] [Medline: 10617523] [doi: 10.1136/bmj.320.7226.26]
50. Nezu AM. Efficacy of a social problem-solving therapy approach for unipolar depression. J Consult Clin Psychol 1986 Apr;54(2):196-202. [Medline: 3700806] [doi: 10.1037/0022-006X.54.2.196]

51. Addis ME, Truax P, Jacobson NS. Why do people think they are depressed? The Reasons For Depression Questionnaire. Psychotherapy: Theory, Research, Practice, Training 1995;32(3):476-483.
52. Meyer B, Garcia-Roberts L. Congruence between reasons for depression and motivations for specific interventions. Psychol Psychother 2007 Dec;80(Pt 4):525-542. [Medline: 17999783] [doi: 10.1348/147608306X169982]
53. Harkness KL, Monroe SM. Childhood adversity and the endogenous versus nonendogenous distinction in women with major depression. Am J Psychiatry 2002;159(3):387-393. [Medline: 1187000] [doi: 10.1176/appi.ajp.159.3.387]
54. Young JE, Klosko JS, Weishaar ME. Schema Therapy: A Practitioner's Guide. New York, NY: Guilford Press; 2003.
55. Esterling BA, L'Abate L, Murray EJ, Pennebaker JW. Empirical foundations for writing in prevention and psychotherapy: mental and physical health outcomes. Clin Psychol Rev 1999 Jan;19(1):79-96. [Medline: 9987585] [doi: 10.1016/S0272-7358(98)00015-4]
56. Pennebaker JW. Writing to Heal. Oakland, CA: New Harbinger; 2004.
57. Pennebaker JW. Opening Up: The Healing Power of Expressing Emotions. New York, NY: Guilford Press; 1990.
58. Bono G, McCullough ME. Positive responses to benefit and harm: bringing forgiveness and gratitude into cognitive psychotherapy. Journal of Cognitive Psychotherapy 2006;20(2):147-158. [doi: 10.1891/088983906780639835]
59. Seligman ME, Csikszentmihalyi M. Positive psychology. An introduction. Am Psychol 2000 Jan;55(1):5-14. [Medline: 11392865] [doi: 10.1037/0003-066X.55.1.5]
60. Seligman MEP, Rashid T, Parks AC. Positive psychotherapy. Am Psychol 2006 Nov;61(8):774-788. [Medline: 17115810] [doi: 10.1037/0003-066X.61.8.774]
61. Deci EL, Ryan RM. The "what" and "why" of goal pursuits: human needs and the self-determination of behavior. Psychological Inquiry 2000;11:227-268.
62. Hill CE. Dreams and therapy. Psychotherapy Research 1996;6(1):1-15. [doi: 10.1080/10503309612331331538]
63. Hill CE, Crook-Lyon RE, Hess SA. Prediction of session process and outcome in the Hill dream model: contributions of client characteristics and the process of the three stages. Dreaming 2006;16(3):159-185. [doi: 10.1037/1053-0797.16.3.159]
64. Morris J. The Dream Workbook: Discover the Knowledge and Power Hidden in your Dreams. New York, NY: Fawcett Crest; 1985.
65. Schotte CKW, Van Den Bossche B, De Doncker D, Claes S, Cosyns P. A biopsychosocial model as a guide for psychoeducation and treatment of depression. Depress Anxiety 2006;23(5):312-324. [Medline: 16688730] [doi: 10.1002/da.20177]
66. Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh J. An inventory for measuring depression. Arch Gen Psychiatry 1961 Jun;4:561-571. [Medline: 13688369]
67. Hautzinger M, Bailer M, Worall H, Keller F. BDI: Beck-Depressions-Inventar, Testhandbuch, 2. überarbeitete Auflage. Bern, Switzerland: Verlag Hans Huber; 1995.
68. Beck AT, Steer RA, Garbin MG. Psychometric properties of the Beck Depression Inventory: twenty-five years of evaluation. Clin Psych Rev 1988;8:77-100.
69. Mundt JC, Marks IM, Shear MK, Greist JH. The Work and Social Adjustment Scale: a simple measure of impairment in functioning. Br J Psychiatry 2002 May;180(5):461-464 [FREE Full text] [Medline: 11983645] [doi: 10.1192/bjp.180.5.461]
70. Eysenbach G. The law of attrition. J Med Internet Res 2005;7(1):e11 [FREE Full text] [Medline: 15829473] [doi: 10.2196/jmir.7.1.e11]
71. Gueorguieva R, Krystal JH. Move over ANOVA: progress in analyzing repeated-measures data and its reflection in papers published in the Archives of General Psychiatry. Arch Gen Psychiatry 2004 Mar;61(3):310-317. [Medline: 14993119] [doi: 10.1001/archpsyc.61.3.310]
72. Mackinnon A, Griffiths KM, Christensen H. Comparative randomised trial of online cognitive-behavioural therapy and an information website for depression: 12-month outcomes. Br J Psychiatry 2008 Feb;192(2):130-134 [FREE Full text] [Medline: 18245031] [doi: 10.1192/bjp.bp.106.032078]
73. Jacobson NS, Truax P. Clinical significance: a statistical approach to defining meaningful change in psychotherapy research. J Consult Clin Psychol 1991 Feb;59(1):12-19. [Medline: 2002127] [doi: 10.1037/0022-006X.59.1.12]
74. Seggar LB, Lambert MJ, Hansen NB. Assessing clinical significance: application to the Beck Depression Inventory. Behav Therapy 2002;33:253-269. [doi: 10.1016/S0005-7894(02)80028-4]
75. Christensen H, Griffiths KM, Korten A. Web-based cognitive behavior therapy: analysis of site usage and changes in depression and anxiety scores. J Med Internet Res 2002 Feb 15;4(1):e3 [FREE Full text] [Medline: 11956035] [doi: 10.2196/jmir.4.1.e3]
76. Griffiths KM, Christensen H. Internet-based mental health programs: a powerful tool in the rural medical kit. Aust J Rural Health 2007 Apr;15(2):81-87. [Medline: 17441815] [doi: 10.1111/j.1440-1584.2007.00859.x]
77. Christensen H, Griffiths KM, Jorm AF. Delivering interventions for depression by using the Internet: randomised controlled trial. BMJ 2004;328(7434):265. [doi: 10.1136/bmj.37945.566632.EE]
78. Clarke G, Eubanks D, Reid E, Kelleher C, O'Connor E, DeBar LL, et al. Overcoming Depression on the Internet (ODIN) (2): a randomized trial of a self-help depression skills program with reminders. J Med Internet Res 2005;7(2):e16 [FREE Full text] [Medline: 15998607] [doi: 10.2196/jmir.7.2.e16]

79. Howard KI, Kopta SM, Krause MS, Orlinsky DE. The dose-effect relationship in psychotherapy. Am Psychol 1986 Feb;41(2):159-164. [Medline: 3516036] [doi: 10.1037/0003-066X.41.2.159]
80. Kopta SM, Howard KI, Lowry JL, Beutler LE. Patterns of symptomatic recovery in psychotherapy. J Consult Clin Psychol 1994 Oct;62(5):1009-1016. [Medline: 7806709] [doi: 10.1037/0022-006X.62.5.1009]
81. Barkham M, Connell J, Stiles WB, Miles JNV, Margison F, Evans C, et al. Dose-effect relations and responsive regulation of treatment duration: the good enough level. J Consult Clin Psychol 2006 Feb;74(1):160-167. [Medline: 16551153] [doi: 10.1037/0022-006X.74.1.160]
82. Stiles WB, Barkham M, Connell J, Mellor-Clark J. Responsive regulation of treatment duration in routine practice in United Kingdom primary care settings: replication in a larger sample. J Consult Clin Psychol 2008 Apr;76(2):298-305. [Medline: 18377125] [doi: 10.1037/0022-006X.76.2.298]
83. Andersson G. Internet-based cognitive behavioral self help for depression. Exp Rev of Neurotherapeutics 2006;6:1137-1642. [doi: 10.1586/14737175.6.11.1637]
84. Swartz H, Zuckoff A, Grote NK. Engaging depressed patients in psychotherapy: integrating techniques from motivational interviewing and ethnographic interviewing to improve treatment participation. Professional Psychology: Res and Pract 2007;38(4):430-439. [doi: 10.1037/0735-7028.38.4.430]
85. Simon GE, Ludman EJ, Tutty S, Operskalski B, Von Korff M. Telephone psychotherapy and telephone care management for primary care patients starting antidepressant treatment: a randomized controlled trial. JAMA 2004;292(8):935-942. [Medline: 16271654] [doi: 10.1001/jama.292.8.935]
86. Caspar F. Technological developments and applications in clinical psychology and psychotherapy: summar and outlook. J Clin Psychol 2004;60:347-349. [doi: 10.1002/jclp.10268]

Abbreviations

ACT: acceptance and commitment therapy
ANOVA: analysis of variance
BA: behavioral activation
BDI: Beck Depression Inventory
CBT: cognitive behavioral therapy
IPT: interpersonal psychotherapy
IRB: internal review board
ITT: intention-to-treat
LOCF: last observation carried forward
MBCT: mindfulness-based cognitive therapy
TAU: treatment-as-usual
WSA: work and social adjustment scale

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Original Paper

Use of Non-Assigned Smoking Cessation Programs Among Participants of a Web-Based Randomized Controlled Trial

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Abstract

Background: Concurrent with their enrollment in Web-based Randomized Controlled Trials (RCTs), participants can easily choose to use treatment programs that are not assigned in the study. The prevalence of using non-assigned treatments is largely unknown although it is likely to be related to the extent to which non-assigned treatments are: (a) easy to find and use, (b) low in cost, (c) well publicized, and (d) available from trusted sources. The impact of using other programs—both beneficial and detrimental—warrants additional research investigation.

Objective: The aim of this report is to explore the extent to which participants enrolled in a Web-based intervention for smoking cessation used treatment methods that were not explicitly assigned (“non-assigned treatment”). In addition to describing the relation between using non-assigned treatments and smoking cessation outcomes, we also explore the broader issue of non-assigned program use by RCT participants in Web-based behavioral interventions, generally.

Methods: We describe the use of other programs (as measured by self-report at the 3-month follow-up assessment) by 1028 participants who were randomized to the Web-based SHIP (Smokers’ Health Improvement Program) RCT which compared the Quit Smoking Network (QSN) treatment program and the Active Lives control condition. We examine the extent to which pharmacotherapy products were used by participants in the QSN condition (which explicitly recommended their use) and the Active Lives condition (which purposefully omitted mention of the use of pharmacotherapy). We also test for any between-condition impact of using non-assigned treatments and pharmacotherapy products on smoking cessation outcomes.

Results: A total of 24.1% (248/1028) participants reported using one or more smoking cessation treatment programs that were not explicitly recommended or assigned in their treatment protocol. Types of non-assigned treatments used in this manner included individual counseling (1.7%), group counseling (2.3%), hypnotherapy/acupuncture (4.5%), pamphlets/books (12.6%), and other Web-based smoking cessation programs (9.0%). Participants who used non-assigned treatments were more likely to be female and have at least a high school education. Use of non-assigned Web programs was related to greater levels of self-reported smoking cessation measured at the 3-month assessment (OR = 2.63, CI = 1.67 - 4.14, $P < .001$) as well as the combined 3- and 6-month assessments (OR = 2.09, CI = 1.11 - 3.91, $P = .022$). In terms of reported medication use, there were no differences between conditions in the number of pharmacotherapy products used. However, more participants in the QSN condition used at least one pharmacotherapy product: 50.0% (262/524) vs 43.8% (221/504); χ^2 (1, N = 1028) = 3.90, $P = .048$. The use of pharmacotherapy and non-assigned treatment types showed a small but marginally significant correlation: $r_{1028} = .061$, $P = .05$.

Conclusions: A noteworthy proportion of individuals recruited via the Internet to participate in a Web-based intervention used treatment programs and tools not formally assigned as a part of their research protocol. We consider factors likely to influence using non-assigned treatments and suggest ways that future research can begin to study more fully this important phenomenon which is likely to be found in any type of research, but may be particularly pronounced in minimal contact, Web-based intervention trials.

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KEYWORDS

Non-assigned treatments; treatment integrity; treatment fidelity; Web-based interventions; Internet; tobacco cessation

Introduction

Research interest in Web-based health behavior change interventions is growing rapidly [1-3]. The power and convenience of current Internet search engines make it likely that online recruitment will reach many prospective participants for randomized controlled trials (RCTs). Consider, for example, data from NCI's Health Information National Trends Survey [4] indicating that 58.4% of respondents looked for personally relevant health or medical information on the Internet. Similarly, the Pew Internet & American Life Project reported that 9% of all Internet users searched for quit-smoking advice [5]. The same computer skills that enable Web users to reach online health behavior change programs can easily be used by study participants to find—and use—other treatment programs concurrent with being enrolled in an RCT. In some cases, Web interventions encourage participants to explore the use of additional treatment resources [6].

In many other instances, researchers have not acknowledged or even reported upon the prevalence and impact of RCT participant use of non-assigned treatments in this manner. Literature germane to this topic includes treatment debriefing (eg, [7]), treatment integrity and fidelity (eg, [8]), and quality assurance of clinical trials (eg, [9]). In this paper we describe the extent to which participants enrolled in the Smokers' Health Improvement Program (SHIP) project—a Web-based smoking cessation trial—reported that they used various treatment methods that had not been explicitly included in their assigned protocol.

Methods

The SHIP RCT

The SHIP smoking cessation RCT used online recruitment methods (ie, ad placement on Google and Yahoo search engines and links to affiliated sites) to enroll 2318 smokers from the US and Canada to participate in a randomized controlled trial. The trial was not registered, because enrollment started in spring 2005, before trial registration became mandatory. Prospective participants visited the recruitment website where they completed an online screening survey that included the 8-item Physical Activity Readiness Questionnaire (PAR-Q) [10]. Prospective participants had to be current smokers, at least 18 years of age, interested in quitting within the next 30 days, willing to engage in moderate physical activity, and have access to the Internet. Exclusion criteria included any positive answers on the PAR-Q used to identify individuals for whom physical activity might be inappropriate or individuals who should have medical advice concerning the type of activity most suitable for them. A more complete description of recruitment procedures and eligibility criteria has been reported in our outcome results paper [11].

Smokers who completed the screening and consent stages were randomized using a computer-based vector method to one of two Web-based programs: (a) the Quit Smoking Network (QSN) condition (N = 1159) or (b) the Active Lives control condition (N = 1159). Baseline data of 2318 study participants showed that most were women (70.5%), White (86.6%), urban (80.3%), married (61.6%), had at least some college education (68.2%), and smoked 1 - 2 packs of cigarettes each day (78.5%).

The QSN Intervention Condition

When study participants first used the Web-based QSN program, they were required to move through a series of Web pages that introduced key concepts and strategies of a combined behavioral-pharmacologic program for quitting smoking. Thereafter—and during subsequent visits—participants were free to choose any of a broad array of additional content on quitting and maintaining nonsmoking. The behavioral intervention was based on Social Cognitive Theory [12,13], and it provided modules (each having multiple Web pages) focused on getting ready to quit, developing a personal quitting plan, setting a personal quit date, avoiding and altering trigger situations, using substitutes, managing thoughts, and using strategies to manage mood. Tailored recommendations were provided to participants based on their baseline characteristics, and online videos of ex-smokers and a program expert were used on many Web pages to reinforce and model the use of program content and recommendations. The QSN program also provided access to a peer-to-peer Web forum, a moderated "Ask an Expert" forum, and an extensive library of additional content. Because participants were required to log in to the website using their unique usernames and passwords, it was possible to tailor portions of the program content to each participant's smoking/nonsmoking status (checked at the start of each session) and to display online prompts recommending the review of program content that a participant had not yet explored.

The QSN program strongly advocated the use of pharmacological adjuncts and it contained a number of Web pages devoted to the use of Nicotine Replacement Therapy (NRT) and Zyban®. These Web pages provided an explanation of how to use these products, photos of representative products, supportive videos of smokers, interactive questions designed to elicit participant commitment to use these products, and agreement to see a doctor in order to obtain a prescription. NRT products included nicotine gum, patch, lozenge, spray, and inhaler.

The Active Lives Control Condition

The Web-based Active Lives control condition was a content-rich, multiple-module Web-based program that encouraged smokers to develop a personal physical activity program in order to become more fit which, in turn, would help them to quit smoking. The program guided each participant through a multi-step plan that included a motivational component (exploration of the benefits of physical activity and a clarification of personal goals and barriers), a behavioral action plan with extensive tracking features (eg, weekly activity schedules personalized to each participant's schedule and types of activities), additional online resources (articles and "tip" sheets), and access to a Web Forum for peer support (distinct from the aforementioned peer forum in the QSN program). In contrast to the QSN condition, the Active Lives control condition purposefully omitted any reference to the use of pharmacotherapy (NRT or Zyban®).

Recommendations Regarding Use of Non-assigned Treatment/Resources for Smoking Cessation

Both the QSN and Active Lives programs encouraged participants to use the smoking cessation approaches featured in each website. However, participants were not explicitly cautioned against using other treatment programs or resources during and/or following their involvement with this study.

Measures

Assessments

Assessment data were collected at screening, baseline, and at 3- and 6-month follow-up assessments. Assessments were completed either online or via phone.

Use of Other Treatment Programs

Non-assigned treatment use was measured by two items on the 3-month follow-up assessment. The first item asked: Which of the following products or methods have you tried in the last 3 months? (check all that apply). Answer options included treatment methods assigned in the QSN intervention condition but not in the Active Lives control condition (nicotine gum, nicotine patch, nicotine lozenge, nicotine spray, nicotine inhaler, other nicotine replacement product, Zyban), treatment methods that were not assigned in either the treatment or control condition (group cessation program or class, individual counseling [including by telephone], hypnosis or acupuncture, pamphlets or books), or none of the above. A separate item asked: Have you used any other Internet smoking cessation programs since first using the QSN/Active Lives program?

We created two composite measures of non-assigned treatment usage: one measure was defined as the sum of non-assigned treatments reportedly used (score ranged from 0 - 5; treatments included individual counseling, group counseling, hypnotherapy/acupuncture, other Web programs, and pamphlets/books), and the other composite was defined as the yes/no dichotomy describing whether any of these non-assigned treatments had been used.

Use of Pharmacotherapy Products

As noted above, participants were asked (yes/no) whether they had used any pharmacotherapy products (nicotine gum, patch, lozenge, spray, and inhaler) or Zyban® since the start of their involvement in the SHIP study. Use of NRT products was explained and strongly recommended in the QSN condition, but the topic was purposefully omitted in the Active Lives control condition. We created two composite measures of using pharmacotherapy: one measure was defined as the sum of non-assigned treatments reportedly used (nicotine gum, patch, lozenge, spray, inhaler, and Zyban®), and the score ranged from 0 - 6; and the other measure was defined as the yes/no dichotomy describing whether any of these pharmacotherapy programs had been used.

Participant Exposure

The extent to which participants accessed their assigned Web-based program was measured unobtrusively using a combination of database tracking and Web-server log analysis [14] to determine both number and duration of visits (sessions). A composite measure of participant exposure was defined as the mean of standard scores for the number of visits and total time spent across all visits.

Smoking Cessation Outcomes

Participant 7-day point prevalence smoking abstinence was assessed both at 3 and 6 months by asking: Have you smoked any cigarettes in the last week, even a puff? The more rigorous repeated point prevalence of self-reported smoking cessation at both the 3- and 6-month assessments was also used. As with other Web-based programs and large-scale self-help interventions for tobacco cessation (eg, [15,16,17,18,19]), we did not collect biochemical measures to verify self-reported tobacco abstinence. Outcomes are reported using both Intent-to-Treat (ITT) analyses (missing cases imputed as smokers) and complete case analyses (based only on cases that completed assessments).

We also measured putative predictors of smoking cessation. Baseline assessment included an item about friends' smoking (Most of my friends and acquaintances smoke [1 = Not true of me at all, 7 = Extremely true of me]), two items on nicotine dependence (I usually want to smoke right after I wake up [1 = Not true of me at all, 7 = Extremely true of me]; How strong are your urges when you first wake up in the morning? [1 = Not strong at all, 7 = Extremely strong]), and five self-efficacy items. The self-efficacy items all used the same 7-point rating scale (1 = Not at all confident, 7 = Very confident), and they included a global item (If you decided to quit smoking, how confident are you that you could quit) and four items that asked about specific settings/circumstances (How confident are you that you can resist smoking when you are feeling bored or restless?; How confident are you that you can resist smoking when you are angry, frustrated, or tense?; How confident are you that you can resist smoking when you drink alcohol?; How confident are you that you can resist smoking when you are around others who are using it?).

Statistical Analyses

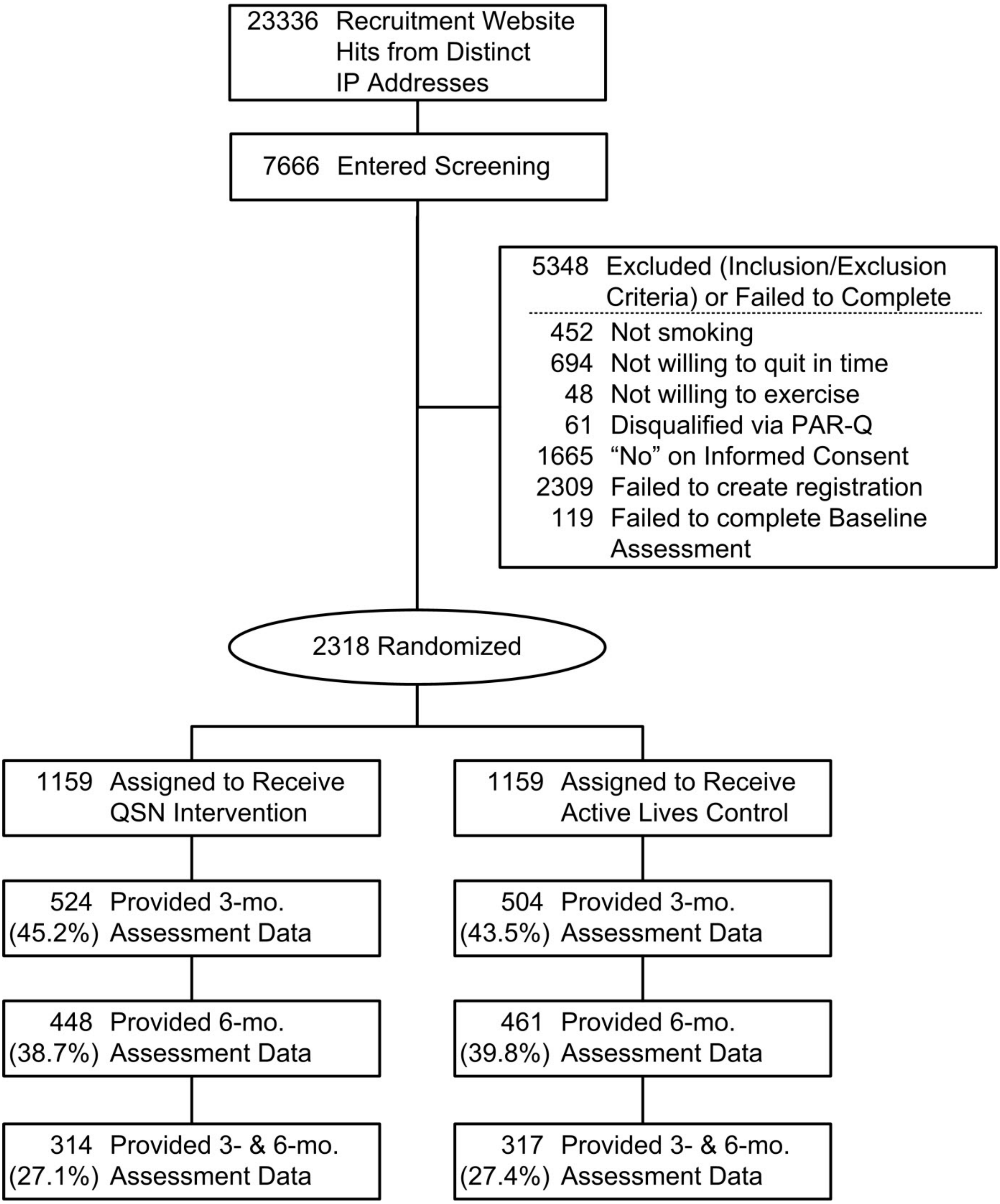
Logistic and standard regression tests were used to test the relation between participant characteristics and reported use of non-assigned treatments. Similar analyses were used to test the relation of non-assigned treatment use, controlling for treatment condition, on point prevalence smoking cessation at 3 months, at 6 months, and for repeated point prevalence that considered smoking status at both 3- and 6-month follow-up assessments.

Results

Assessment Completion and Participant Attrition

Consistent with many Web-based tobacco cessation interventions, the SHIP trial experienced significant attrition over the follow-up interval. Of the 2318 participants initially randomized, 44.3% (N = 1028) completed the 3-month assessment, 32.8% (N = 909) completed the 6-month assessment, and 27.2% (N = 631) completed both assessments. No between-group differences in attrition were found.

Figure 1. CONSORT diagram for SHIP RCT



Use of Non-assigned Treatments

A total of 24.1% (248/1028) of participants reported that they had used some other smoking cessation program during the first 3 months they were enrolled in the SHIP trial. The types of non-assigned treatments used depicted in Table 1 show that a small proportion of participants used group counseling (2.3%) and individual counseling (1.7%), and substantially more participants reported using hypnotherapy/acupuncture (4.5%). More striking was the reported use of pamphlets/books (12.6%) and other Web-based smoking cessation programs (9.0%). Differences between the QSN and Active Lives conditions were not significant in terms of the number of non-assigned treatments used (Mean = 0.29, SD = 0.60 vs Mean = 0.31, SD = 0.59; unequal variance $t_{1025.5}$ = 0.63, P = .530) or in terms of any non-assigned treatment use: 23.1% (121/524) vs 25.2% (127/504); χ^2 (1, N = 1028) = 0.62, P = .43). As a result, we hereafter describe non-assigned treatment usage patterns for the total sample of participants (collapsed across condition) for whom assessment data were available.

Table 1. Participant use of non-assigned treatments: reported at the 3-month follow-up

	QSN Intervention	Active Lives Control	Total
Non-assigned treatment	N = 524	N = 504	N = 1028
Individual counseling	7 (1.3%)	10 (2.0%)	17 (1.7%)
Group counseling	15 (2.9%)	9 (1.8%)	24 (2.3%)
Hypnotherapy/acupuncture	22 (4.2%)	24 (4.8%)	46 (4.5%)
Other Web-based programs	43 (8.2%)	50 (9.9%)	93 (9.0%)
Pamphlets/books	65 (12.4%)	65 (12.9%)	130 (12.6%)

The QSN intervention condition explained and recommended the use of pharmacotherapy products whereas the Active Lives control condition did not. As can be seen in Table 2, the two conditions did not differ in terms of the number of pharmacotherapy products used as reported at the 3-month assessment (QSN: Mean = 0.68, SD = 0.86; Active Lives: Mean = 0.60, SD = 0.83; unequal variance $t_{1026.97}$ = -1.54, P = .062). However, significantly more participants in the QSN condition were found to have used at least one pharmacotherapy product: 50.0% (262/524) vs 43.8% (221/504); χ^2 (1, N = 1028) = 3.90, P = .048. Participants made greatest use of nicotine patches and Zyban®. The use of pharmacotherapy and non-assigned treatments types showed a small but marginally significant correlation: r_{1028} = .061, P = .05.

Table 2. Participant use of pharmacotherapy products: reported at the 3-month follow-up

	QSN Intervention	Active Lives Control	Total
	N = 524	N = 504	N = 1028
Nicotine gum	65 (12.4%)	65 (12.9%)	130 (12.6%)
Nicotine patch	143 (27.3%)	124 (24.6%)	267 (26.0%)
Nicotine lozenge	40 (7.6%)	25 (5.0%)	65 (6.3%)
Nicotine spray	5 (1.0%)	5 (1.0%)	10 (1.0%)
Nicotine inhaler	22 (4.2%)	14 (2.8%)	36 (3.5%)
Zyban®	71 (13.5%)	56 (11.1%)	127 (12.4%)

Non-assigned Treatment Use and Participant Characteristics

Each of six participant baseline characteristics (age, gender, marital status, education, rurality, cigarettes smoked/day) was tested using univariate logistic regression for its relation to any non-assigned treatment use. Non-assigned treatment use (composite dichotomous yes/no measure) was found to be positively related to being female (OR = 1.90, 95% CI = 1.34 - 2.69, P < .001) but negatively related to lower levels of education (no high school degree: OR = 0.38, CI = 0.16 - 0.88, P < .023; high school graduate: OR = 0.53, CI = 0.36 - 0.78, P = .001). The same findings obtained when we tested gender and education together using a multivariate logistic regression.

Non-assigned Treatment Use and Participant Exposure

A Pearson correlation was used to test the relation between participant exposure and the number of non-assigned treatment types used. The result indicated little relation between participant exposure to the assigned Web-based program and the use of non-assigned treatments: r_{1028} = .059, P = .06.

Non-assigned Treatment Use and Smoking Cessation

A total of 202 participants reported not smoking at 3 months: 19.6% complete case (202/1028) and 8.7% ITT (202/2318). At the 6-month assessment, 232 participants reported not smoking: 25.5% complete case (232/909) and 10.0% ITT (232/2318). A total of 89 participants who completed both the 3- and 6-month follow-up assessments indicated that they were not smoking on each occasion: 14.1% complete case (89/631) and 3.8% ITT (89/2318). No statistically significant between-group differences in smoking cessation were found at these assessment points [11].

We used univariate logistic regression to determine the relation of each of the five types of non-assigned treatment use and smoking cessation at 3 months, at 6 months, and the 3- and 6-month repeated point prevalence measure. Only use of other Web programs was found to be related to smoking cessation: it was positively related at the 3-month assessment (OR = 2.63, CI = 1.67 - 4.14, P < .001), at the combined 3- and 6-month assessments (OR = 2.09, CI = 1.11 - 3.91, P = .022), but not at the 6-month assessment (OR = 1.63, CI = .946 - 2.79, P = .079). The significant effect of using other Web programs on smoking cessation obtained even when gender was included in a multivariate logistic regression. The composite measure (sum of non-assigned treatment types used) was found to be unrelated to smoking cessation outcomes.

In addition, a test for the moderator effect of condition and non-assigned treatment usage on smoking cessation failed to find any noteworthy interaction effects at either the 3- or the 6-month outcome. Indeed, when we eliminated from the analysis data of participants who indicated that they had used non-assigned treatments, no effect for condition on smoking cessation outcome emerged at 3 months, 6 months, or the combined 3- and 6-month assessments.

Univariate logistic regression revealed four putative predictors of smoking cessation to be significantly related to non-assigned treatment use: self-efficacy to quit when using alcohol (OR = 1.09, CI = 1.00 - 1.18, P = .040), most friends and acquaintances smoke (OR = 0.91, CI = 0.85 - 0.97, P = .005), urges to smoke upon awaking (OR = 1.14, CI = 1.06 - 1.23, $P < .001$), and smoking upon awaking (OR = 1.15, CI = 1.07 - 1.25, $P < .001$). Since the two dependence items were highly correlated (r_{1028} = .770, $P < .001$), we included only the item that asked about smoking upon awaking with the other two variables in a multivariate logistic regression which essentially confirmed the univariate results just described.

Pharmacotherapy Use and Smoking Cessation

Univariate logistic regression revealed that the sum of pharmacotherapy products reported at 3 months used was unrelated to smoking cessation at 3 months (OR = 1.07, CI = .89 - 1.27, P = .475), but the dichotomous measure of any pharmacotherapy product use at 3 months was related to 3-month smoking cessation (OR = 1.42, CI = 1.04 - 1.93, P = .027). A similar pattern emerged when we considered smoking cessation at 6 months: the sum of pharmacotherapy products reported at 3 months was not related to 6-month smoking cessation (OR = 0.94, CI = .81 - 1.21, P = .944), but the dichotomous measure of any pharmacotherapy product use at 3 months was unrelated to 6-month smoking cessation (OR = 1.41, CI = .99 - 2.01, P = .059).

Discussion

Strengths & Limitations

Strengths of the current research include the successful use of online marketing strategies to recruit a large sample of 2318 participants and our use of a RCT methodology. Limitations include noteworthy participant attrition—an outcome that has been reported in other Web-based tobacco cessation studies [1,20]. Another possible limitation is the large proportion of women participants: 70.5% (1634/2318) of the full randomized sample in the SHIP RCT and 71.6% (736/1028) of the participants completing the 3-month assessment. Results from the current study indicated that a significantly greater proportion of women than men reported that they used non-assigned treatments. However, gender did not influence the positive relation we found between using non-assigned Web programs and smoking cessation outcomes. Future research is needed to explore in more detail the role of gender on the prevalence and helpfulness of using non-assigned treatments.

Additional debriefing questions were not included in the assessment that could have helped to illuminate reasons for using non-assigned treatments. For example, questions could have probed participants’ attitudes about, and reasons for, using other smoking cessation programs, and the extent that they thought non-assigned treatments were helpful and personally relevant. It would be interesting to know whether study participants felt that outside programs were relatively more or less helpful than the treatment methods that were assigned. In addition, we could have asked more specifically about the timing of when participants used non-assigned treatments.

Conclusions

The incidence of using non-assigned treatments is quite difficult to gauge given that most publications fail to report upon this phenomenon. An exception is Strecher and colleagues [16] who reported that 32.6% (461/1415) of participants in a Web-based smoking cessation trial reportedly used non-assigned smoking cessation programs or aids during the treatment and follow-up period. The use of non-assigned treatments will probably be related to the extent to which treatment options are well-publicized, thought to be effective, and readily available to use. In our study, the number of pharmacotherapy products used was equivalent in the two conditions, even though this use was explicitly emphasized in QSN and purposefully ignored in the Active Lives control. The observed high levels of pharmacotherapy in our control condition is consistent with population data showing that 32.2% of 29,537 US smokers surveyed indicated that they used medication to help them try to quit smoking in the past year [21].

The phenomenon of using non-assigned treatments may be particularly likely among participants of Web-based RCTs who demonstrated their Web foraging skills [22] when they were recruited online. Finding other credible and attractive online behavior-change resources and programs requires minimal work and effort. The use of non-assigned treatments may also be more likely during extended follow-up periods, when participants who have been unsuccessful in changing their behavior, but who remain motivated, may decide against waiting to complete a final follow-up assessment before they begin to explore new treatment options.

The frequency and timing of asking participants about their use of non-assigned treatments deserves careful consideration. Because of the substantial attrition found in many Web-based intervention trials [1], it would be helpful to ask participants about non-assigned treatment use in early assessments. This would make it possible to obtain data from more participants, and it could permit analysis of the possible role of non-assigned treatment use on attrition. Asking about non-assigned treatment use on multiple occasions during follow-up would permit a test of whether non-assigned treatment use mediated treatment outcomes. However, questioning participants about their use of non-assigned treatments could also have the significant—and potentially undesirable—reactive effect of encouraging participants to engage in non-assigned treatment use. We recommend that Web-based interventions should routinely debrief participants about their use of non-assigned treatments as part of the final follow-up assessment. Asking at earlier points in the assessment phase warrants careful scrutiny to determine the extent to which such questioning might be reactive.

It is impractical to require Web-based RCT participants to refrain from using alternative treatment programs or to avoid treatment-seeking from other sources. We recommend that the use of non-assigned treatments should not be grounds for participant exclusion from Web-based behavior change interventions. Instead, Web-based interventions should be evaluated as being part of a larger fabric of ongoing self-help and personal improvement programs that people engage in to accomplish important personal behavioral changes. Before they become study participants—and possibly during the time that they are study participants—individuals are likely to be seeking out available resources, including those readily available on the Internet, some of which they may use in making a serious attempt to change their behavior, as in trying to quit smoking [4,5]. Only through asking participants about non-assigned treatments they may have used and/or treatments they may have sought (eg, [6,23]) will it be possible to determine whether such activities might have a positive effect on achieving goals (as in the use of other Web-based smoking cessation programs) or have a more negative relation with outcome (as in the use of pamphlets/books in the current study).

Research may show that it is beneficial to encourage participants to use other treatment resources to complement what they learn about in the behavior change program presented in their RCT. However, engaging in multiple concurrent treatments—some of which might be contradictory—could be counterproductive [1]. A caution about not trying to do too much at one time seems prudent until research highlights beneficial combinations of treatments and/or it identifies treatment combinations that are contraindicated.

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Conflicts of Interest

None declared.

References

1. Danaher BG, Seeley JR. Methodological issues in research on Web-based behavioral interventions. Ann Behav Med. Forthcoming 2009 .
2. Strecher V. Internet methods for delivering behavioral and health-related interventions (eHealth). Annu Rev Clin Psychol 2007;3(1):53-76. [Medline: 17716048] [doi: 10.1146/annurev.clinpsy.3.022806.091428]
3. Bennett GG, Glasgow RE. The Delivery of Public Health Interventions via the Internet: Actualizing Their Potential. Annu Rev Public Health 2009;30(1):273-292. [Medline: 19296777] [doi: 10.1146/annurev.publhealth.031308.100235]
4. National Cancer Institute. HINTS: Health Information National Trends Survey. NCI. 2009. URL: http://hints.cancer.gov/ [accessed 2009 Apr 7] [WebCite Cache ID 5hXQzrCNx]
5. Fox S. Online health search 2006. Washington, DC: Pew Internet & American Life Project; 2006. URL: http://www.pewinternet.org/Reports/2006/Online-Health-Search-2006.aspx [accessed 2009 Apr 7]
6. Christensen H, Leach LS, Barney L, Mackinnon AJ, Griffiths KM. The effect of web based depression interventions on self reported help seeking: randomised controlled trial [ISRCTN77824516]. BMC Psychiatry 2006;6(1):13 [FREE Full text] [Medline: 16595018] [doi: 10.1186/1471-244X-6-13]
7. Di Blasi Z, Crawford F, Bradley C, Kleijnen J. Reactions to treatment debriefing among the participants of a placebo controlled trial. BMC Health Serv Res 2005 Apr 22;5(1):30 [FREE Full text] [Medline: 15847683] [doi: 10.1186/1472-6963-5-30]
8. Collins SE, Eck S, Kick E, Schröter M, Torchalla I, Batra A. Implementation of a smoking cessation treatment integrity protocol: treatment discriminability, potency and manual adherence. Addict Behav 2009 May;34(5):477-480. [Medline: 19162408] [doi: 10.1016/j.addbeh.2008.12.008]
9. Rosa C, Campbell A, Kleppinger C, Sampson R, Tyson C, Mamay-Gentilin S. Quality assurance of research protocols conducted in the community: the National Institute on Drug Abuse Clinical Trials Network experience. Clin Trials 2009 Apr;6(2):151-161. [Medline: 19342468] [doi: 10.1177/1740774509102560]
10. Shephard RJ. PAR-Q, Canadian Home Fitness Test and exercise screening alternatives. Sports Med 1988 Mar;5(3):185-195. [Medline: 3368685] [doi: 10.2165/00007256-198805030-00005]
11. McKay HG, Danaher BG, Seeley JR, Lichtenstein E, Gau JM. Comparing two web-based smoking cessation programs: randomized controlled trial. J Med Internet Res 2008;10(5):e40 [FREE Full text] [Medline: 19017582] [doi: 10.2196/jmir.993]
12. Bandura A. Self-efficacy: toward a unifying theory of behavioral change. Psychol Rev 1977 Mar;84(2):191-215. [Medline: 847061] [doi: 10.1037/0033-295X.84.2.191]

13. Bandura A. Health promotion by social cognitive means. Health Educ Behav 2004 Apr;31(2):143-164. [Medline: 15090118] [doi: 10.1177/1090198104263660]
14. Danaher BG, Boles SM, Akers L, Gordon JS, Severson HH. Defining participant exposure measures in Web-based health behavior change programs. J Med Internet Res 2006;8(3):e15 [FREE Full text] [Medline: 16954125] [doi: 10.2196/jmir.8.3.e15]
15. Strecher VJ, Shiffman S, West R. Randomized controlled trial of a web-based computer-tailored smoking cessation program as a supplement to nicotine patch therapy. Addiction 2005 May;100(5):682-688. [Medline: 15847626] [doi: 10.1111/j.1360-0443.2005.01093.x]
16. Strecher VJ, McClure JB, Alexander GL, Chakraborty B, Nair VN, Konkel JM, et al. Web-based smoking-cessation programs: results of a randomized trial. Am J Prev Med 2008;34(5):373-381. [Medline: 18407003] [doi: 10.1016/j.amepre.2007.12.024]
17. Etter JF, Perneger TV. A comparison of cigarette smokers recruited through the Internet or by mail. Int J Epidemiol 2001 Jun;30(3):521-525 [FREE Full text] [Medline: 11416075] [doi: 10.1093/ije/30.3.521]
18. Etter JF. Comparing the efficacy of two Internet-based, computer-tailored smoking cessation programs: a randomized trial. J Med Internet Res 2005;7(1):e2. [Medline: 1582947] [doi: 10.2196/jmir.7.1.e2]
19. Severson HH, Gordon JS, Danaher BG, Akers L. ChewFree.com: evaluation of a Web-based cessation program for smokeless tobacco users. Nicotine Tob Res 2008 Feb;10(2):381-391. [Medline: 18236303] [doi: 10.1080/14622200701824984]
20. Eysenbach G. The law of attrition. J Med Internet Res 2005;7(1):e11 [FREE Full text] [Medline: 15829473] [doi: 10.2196/jmir.7.1.e11]
21. Shiffman S, Brockwell SE, Pillitteri JL, Gitchell JG. Use of smoking-cessation treatments in the United States. Am J Prev Med 2008 Feb;34(2):102-111. [Medline: 18201639] [doi: 10.1016/j.amepre.2007.09.033]
22. Pirolli PLT. Information Foraging Theory: Adaptive Interaction with Information. New York, NY: Oxford University Press; 2007.
23. Rigotti NA, Park ER, Regan S, Chang Y, Perry K, Loudin B, et al. Efficacy of telephone counseling for pregnant smokers: a randomized controlled trial. Obstet Gynecol 2006 Jul;108(1):83-92. [Medline: 16816060]

Abbreviations

ITT: intent-to-treat
NRT: nicotine replacement therapy
PAR-Q: physical activity readiness questionnaire
QSN: quit smoking network
RCT: randomized controlled trial
SHIP: smokers' health improvement program

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Original Paper

Health Professionals' Attitudes Towards Using a Web 2.0 Portal for Child and Adolescent Diabetes Care: Qualitative Study

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Abstract

Background: The Internet, created and maintained in part by third-party apomediation, has become a dynamic resource for living with a chronic disease. Modern management of type 1 diabetes requires continuous support and problem-based learning, but few pediatric clinics offer Web 2.0 resources to patients as part of routine diabetes care.

Objectives: To explore pediatric practitioners' attitudes towards the introduction of a local Web portal for providing young type 1 diabetes patients with interactive pedagogic devices, social networking tools, and locally produced self-care and treatment information. Opportunities and barriers related to the introduction of such systems into clinical practice were sought.

Methods: Twenty clinicians (seven doctors, nine nurses, two dieticians, and two social welfare officers) from two pediatric diabetes teams participated in the user-centered design of a local Web 2.0 portal. After completion of the design, individual semi-structured interviews were performed and data were analyzed using phenomenological methods.

Results: The practitioners reported a range of positive attitudes towards the introduction of a local Web 2.0 portal to their clinical practice. Most interviewees were satisfied with how the portal turned out, and a sense of community emerged during the design process and development of the portal's contents. A complementary role was suggested for the portal within the context of health practice culture, where patients and their parents would be able to learn about the disease before, between, and after scheduled contacts with their health care team. Although some professionals expected that email communication with patients and online patient information would save time during routine care, others emphasized the importance of also maintaining face-to-face communication. Online peer-to-peer communication was regarded as a valuable function; however, most clinicians did not expect that the portal would be used extensively for social networking amongst their patients. There were no major differences in attitudes between different professions or clinics, but some differences appeared in relation to work tasks.

Conclusions: Experienced clinical practitioners working in diabetes teams exhibited positive attitudes towards a Web 2.0 portal tailored for young patients with type 1 diabetes and their parents. The portal included provision of third-party information, as well as practical and social means of support. The practitioners' early and active participation provides a possible explanation for these positive attitudes. The findings encourage close collaboration with all user groups when implementing Web 2.0 systems for the care of young patients with chronic diseases, particularly type 1 diabetes. The study also highlights the need for efforts to educate clinical practitioners in the use of Web publishing, social networking, and other Web 2.0 resources. Investigations of attitudes towards implementing similar systems in the care of adults with chronic diseases are warranted.

(J Med Internet Res 2009;11(2):e12) doi:10.2196/jmir.1152

KEYWORDS

Web 2.0; childhood chronic disease; health professionals; attitudes; type 1 diabetes

Introduction

For individuals with a chronic health problem, the Internet has evolved from being a source for medical information retrieval (Web 1.0) to being a dynamic resource for living with a chronic disease, one that is created and maintained in part by third-party apomediation (Web 2.0) [1-3]. The broadened scope of information in the Web 2.0 context has been followed by a parallel evolution of information practices (eg, the introduction of new types of quality criteria for evaluating the presentation and trustworthiness of medical advice) [4]. In many respects, the concurrent development of medical information on the Internet towards both openness and control reflects the present transformation of health services organizations, where quality surveillance has become more and more important, generating increased participation, collaboration, and inter-organizational networking [5,6].

The Web 2.0 and open health service organization perspectives are equally applicable to the modern management of type 1 diabetes, since both possess a common denominator of focus on continuous support and problem-based learning [7,8]. For many patients, adolescence is a period during which diabetes care constitutes a more or less daily struggle with undesirable blood glucose levels and the risk of complications [9,10]. Long-term evaluations of diabetes treatment programs emphasize the importance of metabolic control [7,11,12]. Finding the means to educate and support young patients and their families is therefore of the utmost importance. Recent research focusing on patient views suggests that pediatric diabetes care needs improvement regarding patient information and access to care [13]. Previous studies indicate that successful use of interactive telecare and Internet-based methods may increase access to health services, enhance patient education, and improve the quality of diabetes care [14,15]. Internet-based interventions have been reported to influence diabetic patients' health care utilization, behavior, attitudes, knowledge, skills, and to some extent even metabolic control [16-18].

The benefits of electronic communication used by patients with diabetes, their relatives/caregivers, and health professionals were recently reviewed [19]. Although such methods show promise regarding improved diabetes care, few significant long-term effects on main outcomes could be found. Nevertheless, patients with poor metabolic control, greater use of health care services, higher motivation, and/or less experience with diabetes treatment benefited more. A few studies even demonstrated improved quality of life, although in most studies there was little focus on the patient perspective.

In light of these findings, it could be questioned why there are only a few Web 2.0 systems in routine clinical use in diabetes care [2,19-25]. At least three reasons can be identified. The first is that the process of system introduction requires active contributions from clinical professionals with experience from the present care process in order for them to play an optimal role in the improvement of care. However, most health care professionals have had little computer training in either their basic education or their professional life [26]. A second explanation is that, while young patients may already be sharing personal health information online, few health professionals are presently familiar with the rapidly emerging social networking tools on the Internet. A third reason is that when patients access information by themselves, some practitioners may experience this as a source of irritation [27]. Accordingly, a need for close collaboration between health care professionals and system developers has been increasingly pointed out [25]. In particular, the significance of practitioners' attitudes towards computer use in nursing and in patient education has been emphasized [28,29]. Indeed, the integration of Web 2.0 resources into routine care may require iterative inclusion of the perspectives of both health professionals and patients [21]. This paper reports views and voices from a sample of experienced care providers in two Swedish units for pediatric diabetes care.

The specific aim of the study is to explore health care practitioners' attitudes towards the introduction of a local Web 2.0 system tailored to young type 1 diabetes patients and their parents, and to seek opportunities and barriers related to introduction of such systems into clinical practice.

Methods

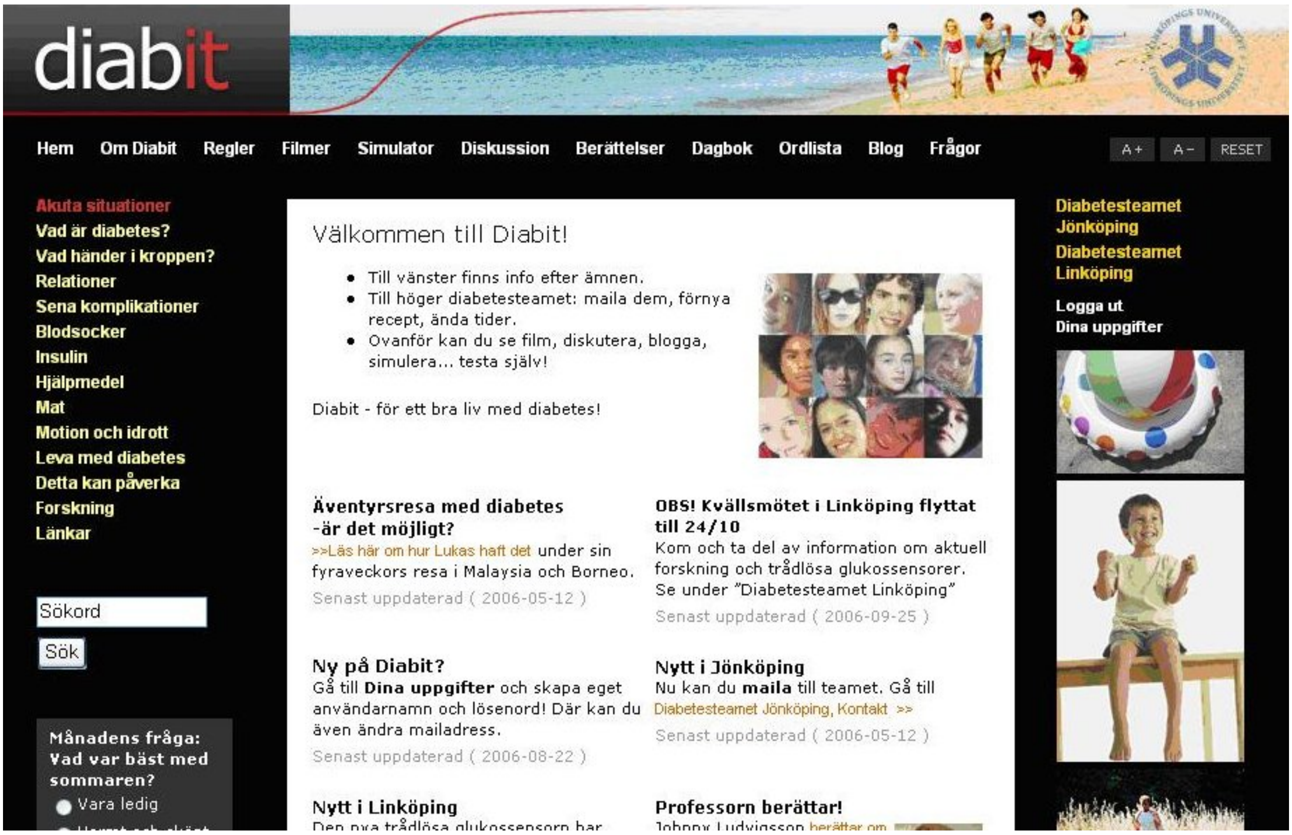
Process of Care

In Sweden, all children and adolescents with diabetes are treated by hospital-based pediatric diabetes teams consisting of nurses, nurse specialists, physicians, dieticians, social welfare officers, and/or clinical psychologists [30]. Clinicians meet their young patients and their parents at the onset of the disease when the patients are hospitalized, and continue to work with them as outpatients for many years. The process of care and the treatment policy have been described elsewhere [7,13,30]. Participants in the present study comprised two such diabetes teams at pediatric clinics situated in south-eastern Sweden which treat geographic populations of approximately 200 and 250 patients, respectively, below the age of 19 years.

Web 2.0 Portal

During the spring of 2006, the research group and the two participating diabetes teams launched an Internet portal with specific diabetes-related information and social networking functions for patients and parents (Figure 1). Social networking functions provided laypersons with the possibility of being guided to information by apomediaries (other users on the site), which meant that the role of staff members who acted as intermediaries between users and information became less involved [6]. Thus, the content was designed for use by children, parents, and clinicians who belonged to the local patient community of the two hospitals. It included some 200 Web pages of text, education videos, and online simulation software described elsewhere [21,31]. The portal also provided general information about the diabetes teams and their services, as well as a messaging service for medical prescription renewal, appointments, and open questions.

Figure 1. Screenshot of the portal displaying links for specific diabetes information (left); local diabetes team services, news, and personalized information (right); pedagogic devices and social networking functions (top)



Välkommen till Diabit!

- Till vänster finns info efter ämnen.
- Till höger diabetesteamet: maila dem, förnya recept, ända tider.
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Professorn berättar!
Johnny Ludvigsson berättar om

Månadens fråga: Vad var bäst med sommaren?
○ Vara ledig

Before launch, the portal gradually developed from a design model to the Web 2.0 prototype piloted in 2005 [32]. Thus, the user-centered design process for the portal and its contents included iterative sessions conducted over a long period of time with patients and parents, as well as the diabetes teams involved [21,32]. Specific diabetes-related information on 13 main topics, divided into 99 subtopics/Web pages, was written by an author group consisting of a nurse, a physician, and a dietician. Each section was revised by other multi-professional groups, signed by the professionals involved, and edited in a Web publishing system. In addition, each group of professionals summarized important basic information in plain speech and included their photo presentations, contact information, etc. Thus, all members of both diabetes teams participated in developing the content.

Study Population and Methods

Through participation in previous user meetings, elaboration work, and individual test use, the interviewees had been informed about the design and functions of the portal. The present study was conducted as a baseline measure before the clinicians started using the portal in their routine practice. The interviewees (with one exception) had not met any patients or parents whom they knew had used the portal.

Considering the explorative aim of the study, we used an inductive approach to construct an interview guide with questions we believed would provide information concerning the research issues. The guide asked questions about general attitudes towards using information technology in health care, related computer skills and use of computer aids at work, perceived possibilities and motivation to participate in the elaboration of the portal, and expected consequences for clinicians and patients, both pro and con.

Of the 23 active members of the two diabetes teams, 20 were interviewed, including seven doctors, eight nurse specialists in diabetes, one nurse, two dieticians, and two social welfare officers. Two members of the research group and one person who did not agree to the interview were excluded. The interviewees had been working at the clinic for eight years on average (ranging from 1-24 years), and the majority were female. After participants gave their informed verbal consent, audio-recorded qualitative telephone interviews were conducted in August and September 2006. The interviews were semi-structured. The interviewees could raise issues themselves, and they were given time to develop answers in response to their interviewer. Follow-up questions were asked in an attempt to receive more in-depth answers. On average the interviews lasted for 30 minutes.

Analysis

We analyzed the interviewees' experiences within the context of culture using a recent form of phenomenology developed in American nursing studies [33]. The interviewer, a sociologist with experience in interviewing health care staff but none working in health care, analyzed the data. She did not start studying the use of information technology (IT) in patient care until the analysis had been completed. The other members of the author group were two physicians/researchers and one nurse/PhD student. This group had extensive experience in clinical diabetes care, clinical research, and medical informatics. They commented on the results in discussions that took place during the analysis process. As one researcher conducted the analysis, quotations from the interviewees' statements were used throughout the process to facilitate validation of the findings by the other members of the research group.

In order to structure the data, the tapes were transcribed verbatim. The interviewer read the transcriptions while listening to the audio-recorded interviews and made a few corrections. Throughout the analysis, each of the staff categories, namely doctors, nurses, dieticians, and social welfare workers, was considered separately. First, the interviewer broadly categorized the issues that were discussed, which to a large extent comprised the research questions. Next, she coded all text in the categories line by line according to substantive content [34], and the codes were kept within their context. The codes were collected into themes which had emerged from the interviews, and these themes constitute the different sections in the results. Writing started early, using the first categorization for a horizontal analysis of the different themes in all interviews from the same staff category [35]. The line-by-line coding was intended as support for interpreting the meaning of the different comments.

Results

All interviewees reported previous computer and Internet use at home and at work. In most cases, the attitude toward extended use of computers was positive. Problems were attributed to becoming familiar with the portal, implying that interviewees thought they needed to learn more about the workings of the portal. No major differences in attitudes towards using computers, the Internet, or a Web 2.0 portal were found between the different staff categories or clinics, although some differences were observed concerning obstacles to, and opportunities for, using the portal as a means of support in their work. All interviewees participated in the collection of information materials for the portal, including the development of texts and the review of texts written by others. Limited time, lack of skills in Web design, and insufficient information about the writing process were reasons why some interviewees expressed dissatisfaction with their contributions. The respondents participated in accordance with their skills, and no one reported that the work overwhelmed them. Most interviewees were satisfied with the way the portal turned out, and one interviewee said, "I don't think we've ever done things this way and I think it was really nice that so many could be involved in it".

Thus, despite different experiences with the writing process, a sense of community was reported after working with the site. Moreover, the clinicians were confident that the portal's use in diabetes care would extend beyond the clinics, in addition to being a part of the internal routine of the clinics. Interestingly, most interviewees reported being prepared to keep working on the development of the portal and expected to maintain an active role, as expressed by the following participant:

> *Well, if it's something we're going to work with in the future, then of course I want to be involved and participate in it, of course, but ... in some way or another ... so that it seems practical to me too.*

Expectations of Web 2.0 Portal Use in Diabetes Families

Expectations varied regarding the impact a Web 2.0 portal would have on the everyday lives of patients and their families. Several interviewees offered optimistic comments:

> *I think it will probably be of great importance to patients to be able to gain access to information so easily .... And anyway, most children and adolescents are familiar with the Internet today ....*

Others were less hopeful concerning the use of Web 2.0 services. One reason for this was that parents and adolescents were presumed to have different needs, and it might therefore be difficult to design the portal so that it would appeal to all users. Another perceived risk was that only those who were already well informed would use the portal. In accordance with the low expectations of some of the interviewees, others felt that those who were not very interested in Web services in the first place would not become more interested just because of the introduction of new media. One interviewee said, "Many of our patients aren't very interested in reading at all ... and then when this reluctance is combined with something new, well I don't know, it's a problem".

Speculating on the prospects for success of the Web 2.0 portal, clinicians were of the opinion that simply providing information on a website might not be enough to enable all patients or their families to integrate the information available there and increase their self-efficacy. One interviewee explained it this way:

> *And I think there are so many different factors that make it possible for a person to take in information, and I mean ... how the person feels and what things are like in the family, and how easy it is for the person to understand and, well, there's a lot contributing to what support the person has from those around him.*

Accordingly, peer-to-peer communication online was specifically noted as being a key function of the portal, since contact between peer families could facilitate living with diabetes, as was suggested by one interviewee who commented that, "Maybe they ... will receive good suggestions from other patients, if they have an opportunity to discuss it".

A few interviewees emphasized the importance of maintaining some professional control over the site in order to reduce the risk of communicating harmful advice or passing along incorrect references concerning the management of diabetes. One interviewee expressed concern over the risk of young people revealing too much personal information about themselves and then regretting it later.

Despite the proposed benefits, most interviewees did not expect that the portal would initially be used very much for peer-to-peer contact. Some interviewees thought that social networking functions would probably be most appreciated by the parents of young children with problems, since they were expected to require more support. Others thought that adolescents would be the most frequent users, since they are the group most familiar with the media. One interviewee said that, “A young person may have a lot of questions he might not want to talk about with either his parents or the diabetes nurse, but he may be willing to talk with a friend who’s in the same situation”.

However, some interviewees thought that teenagers would ask for the ability to make peer-to-peer contact and then decide against doing so:

> *But even when you arrange something, they don’t always come anyway .... You have to catch adolescents on the run in some way.*

A common idea which emerged from the interviews was that access to a properly updated portal might encourage some patients to take an active role in learning more about their disease by searching for news and extending their search to other websites. One person said, “It can be a way to get information about things a person doesn’t get around to asking the doctor about, and I think that can be good”.

Another view expressed in the interviews was that, during face-to-face interaction and telephone contact with team members, patients received more complete information, since they could ask questions and receive their answers directly. Team members also provided information the patient did *not* ask for, and they took different circumstances into consideration. “You can hear how they feel from their voices and the like,” one interviewee said. Thus, direct contact helped staff to provide personalized advice that was adapted to the receiver’s needs at a particular point in time. A possible outcome of this is expressed in the following: “My idea would be maybe to add more information-based questions on this site [the portal] and answer questions about treatment over the telephone”.

Different complementary ways of providing information are described below:

> *They can read and take in information, and they can get it when they want it and at the pace they want, and if they wonder about something more, they can supplement that information by calling or asking questions at their next visit here. I think that’s good.*

Most interviewees presumed that all families had a computer and Internet access, and that it was natural for families to get and provide information about diabetes online. However, one interviewee stressed the following:

> *This can’t be the only method available ... so that if you need to get information, you have to do it yourself, and you have to do it on the Internet, period.*

If everyone does not have access to the information, the portal is not a common source of information, and if the portal should become the primary source of information, this might have negative consequences for those without Internet access.

Other reasons for caution that were mentioned by interviewees were the risk that patients would find information that frightened rather than motivated them; that they would develop false hopes about their chances of getting rid of their disease; or that some parents might “escape” into technical information on the Internet when they could not bear the fact that their child had a serious disease. Another risk identified was that patients could believe they were so well informed by the portal that they would not keep appointments with the diabetes team, or they would try their own treatment and fail.

Use in Clinical Diabetes Team Practice

According to most of the interviewees, one important function of the Web 2.0 portal was that it facilitated closer interaction between diabetes teams and families. In particular, it was expected that patients having long-term experience with diabetes would be more comfortable asking certain questions via the Internet and that the portal could even stimulate families to contact team members. According to the following interviewees:

> *If you feel uncertain and don’t even want to call and make contact to find out what a staff member can do to help, then you can log on to this site so that you can get information you may need. At the very least, you can make contact.*
>
> *It’s not only the case that there’s a child that has diabetes. There’s a mother and a father who have jobs and take part in leisure-time activities, and maybe there are siblings. They have a very full schedule. They might not be able to reach us during the day when we’re here, but when they come home in the evening and things have calmed down, maybe they can send a message or a question, or maybe say that they need some [diabetes] device.*

However, several interviewees also pointed out that it was unclear whether current legislation permitted email contact with patients, while others were uncertain about this but expected email communication to be safe. One interviewee stated, “I can do my banking online, so I certainly should be allowed to communicate with patients.

Other expected benefits of the portal were more traditional Web 1.0 functions (ie, providing information). Newly updated diabetes information would be available to families at any time (eg, when something unexpected happened or whenever information was needed during the regular three-month period between visits). Options for repeating information received in person at the clinic, as well as for updating old information, were also mentioned. For instance, children with early onset diabetes need to learn about their disease while growing up in order to become independent, since when they are young, their parents have more knowledge about the disease. The interviewees also emphasized, however, that the purpose of Web information was not to have families take on the responsibility of obtaining all information by themselves.

Since the information on the portal available from each respective diabetes team was identical to information provided at the clinic, it was described as “familiar”. Several interviewees expressed that a locally shared source of reliable information, such as references to verified websites, would be a great support to their work with patients, assuming that it was regularly updated. It could also be used by new team members or other staff, as commented on in the following: “I think this is a function the portal could provide to make it easier for those who don’t work much with diabetes. That function would be to provide advice that doesn't deviate too much from what they receive from the diabetes team".

Conformity of information could create a sense of security for families and also for relatives, friends, and school staff who want information. It was also thought that better informed patients would interact more often by asking more questions that would stimulate clinicians to keep up to date with news about diabetes care. Supplying patients with information about the responsibilities of the clinic was perceived as a challenge to the diabetes team: "For us it can also be a way to be a little more on the ball because it's out there in public view".

Another expected benefit of the Web 2.0 portal was its use in support of routine clinical checkups. The portal was described as a means of achieving a more informative and effective clinical encounter, which touches on the topic of time. Lack of time and how to deal with this problem was an issue often raised during the interviews. Several interviewees expected the portal to save time in the execution of some routine tasks and when providing general information. A few interviewees related the following:

> *I thought it sounded good because it could supplement what we don't have time for during visits to the clinic .... instead of having to call ....*

Most interviewees thought that extended use of email would save time and increase flexibility. Since patients need to be able to talk with a health care worker in acute situations, email was not perceived to be the best option in every situation. In addition, one interviewee stated that he did not want to be unexpectedly overwhelmed by email:

> *I want to know when my contact with patients will take place as I would if, for example, I had fixed email hours. Currently, we have fixed telephone times.*

Discussion

Main Findings

We found that pediatric practitioners reported a range of positive attitudes towards the introduction of a local Web 2.0 portal for young diabetes patients in their clinical practices. This is in contrast to attitudes of "resistant compliance" to computers in routine work reported in some other settings [28,36]. The findings are particularly interesting in light of the fact that the practitioners reported having been unfamiliar with Web 2.0 technology before the study and that all the legal aspects of Web 2.0 use at the clinics had not been settled (eg, the legal aspect of email communication with patients).

As diabetes treatment largely consists of daily self-care, enhanced patient education and support remain essential to pediatric practitioners' efforts to improve quality of care [8,13,30,31]. Thus, one explanation for their positive outlook is probably the interviewees' early participation in a collaborative design process. Their multi-professional development of information also seemed to ensure that a unified message about the treatment policy was provided by all members of the care team. Although some practitioners felt constrained by limited time and a lack of skills in Web design and publishing, participation may have produced a reciprocal learning process and a sense of community with respect to the portal. It may be that this approach led to a willingness to integrate the portal into routine care, as well as to engage in further developmental work. Our findings highlight the need for general efforts to enhance the education of clinical practitioners and others involved in the management of childhood chronic diseases regarding the use of Web publishing, social networking, and other Web 2.0 resources [26].

Constructive attitudes could also be attributed to the fact that a local Web 2.0 portal was perceived as potentially beneficial for both patients and staff. Other studies have indicated that two significant outcomes of using a Web 2.0 portal in routine care are the empowerment of patients and facilitation of work due to time-saving, simplified routines [37,38]. Confidentiality and patient integrity were also generally perceived to be managed satisfactorily by the system. Some practitioners suggested that patient trust could be enhanced by making certain that information supplied by the portal matched the information provided during personal visits to the clinic. It was furthermore inferred that the presence of local diabetes team members increased a patient's sense of security and stimulated greater interest in the portal. Quality and trust issues regarding online health resources have been the focus of much discussion [39]. In a chronic disease setting, it could be that a balance between information supplied during a personal meeting and information acquired via a local Web 2.0 portal may result in the optimization of efficiency, quality, and trust.

Practitioners expressed an open attitude and positive expectations towards the idea of more informed patients and parents, as well as the support of apomediation in online peer networks. However, they also expressed doubt concerning the progress and actual use of this section of the portal. Internet support groups have, however, reportedly improved parents' relationships with their children with special needs [40]. In addition, results from studies of diabetes-related Internet support groups seem encouraging, but few population studies have been conducted [41]. As of today, few real-world diabetes teams offer their patients online networking systems.

With regards to the issue of control, practitioners seemed to accept the loss of direct control over information when patients began to inform themselves by using apomediators online. Modern diabetes care involves teamwork which aims at developing empowered and well-informed patients. Participation in, openness to, and problem-based learning about the discipline of self-care have been regarded for many years as essential elements of pediatric diabetes care [8,30,31]. If social networking functions are actively used by families, one consequence might be their increased control over online information, since it is derived from peers in the community who have experienced similar treatment. Moreover, patients using the portal could be expected to benefit from increased knowledge about when to contact their diabetes team, when to seek information, and what to seek at any particular point in time.

Because it is difficult to design a website that will attract patients and parents with different proficiency and preferences, some interviewees feared that the site might be used primarily by those who were already well informed. This perceived risk seemed to stimulate the clinicians desire to “keep the site alive”, and they expected that this would result in new work tasks (eg, to add news and updates from the local practitioners). Importantly, some pointed out that the portal cannot replace personal contact. They emphasized that individualized telephone contact or face-to-face interaction, particularly in emotionally difficult situations and when complex issues are involved, will remain necessary. Finally, another source of anticipated loss of control was that, with the clinicians’ work routines available online, patients could more efficiently question the clinicians’ planning of services.

This study has some important limitations that need to be taken into account when interpreting the results. The study does not provide information about the attitudes of care teams, other than those involved during the design process. It is not possible, based on the data, to predict if the specific functions of the Web 2.0 portal will produce benefits during routine use, even though the practitioners in this study thought that the disadvantages, if any, would be outweighed by the advantages. In addition, because the study was performed using qualitative methods for data collection and analysis, it is not possible to quantify the attitudes observed. For instance, both generally positive attitudes and attitudes which expressed some doubt regarding the support of apomediation were recorded, but this study cannot quantify the proportions of these views. A strict, independent categorization of data by a second researcher might have further strengthened the validity of the results.

For future research, larger studies are warranted which would take into account the views of practitioners, as well as diabetes patients and their families, on the routine use of Web 2.0 portals, and such studies should include the collection of both qualitative and quantitative data. Investigation of attitudes towards implementing similar systems in the care of adults with chronic diseases are needed as well. Little is known regarding predictors for success (eg, comparisons with respect to benefits and pitfalls between patient-driven, peer-to-peer online networks and organization-driven networks monitored by professional “experts” have yet to be carried out). As every patient community has its own characteristics and needs, there is probably no such thing as a “one size fits all” model. Finally, the extent to which increasingly well-informed patients might stimulate creative dialogues remains to be explored, whether these take place between patients and care teams or within care teams themselves, with the aim of attaining coherent views and increased quality of care [13].

Conclusion

We found a range of positive attitudes towards the introduction of a local Web 2.0 portal and perceived benefits for patients of experienced clinical practitioners working with young diabetes patients. These findings contrast with previous reports and may hypothetically be associated with the early and active involvement of clinicians and their patients in the development work.

The implications of the results for future implementation of Web 2.0 systems in health care include the need for education of clinical practitioners in the use of Web 2.0 and the understanding that collaboration with all user groups is beneficial for developing the site. The findings are encouraging for the development and implementation of Web 2.0 resources as part of the care of young patients with chronic diseases, in particular those suffering from type 1 diabetes. There might also be important implications for the care of adult patients with diabetes and for other diagnosis groups as well.

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Conflicts of Interest

None declared.

References

1. Kim GR, Lehmann CU. The impact of the Internet on pediatric medicine. Paediatr Drugs 2003;5(7):433-441. [Medline: 12837116]
2. Nordfeldt S, Johansson C, Carlsson E, Hammersjö JA. Use of the Internet to search for information in type 1 diabetes children and adolescents: a cross-sectional study. Technol Health Care 2005;13(1):67-74. [Medline: 15706065]
3. Eysenbach G. From intermediation to disintermediation and apomediation: new models for consumers to access and assess the credibility of health information in the age of Web2.0. Stud Health Technol Inform 2007;129(Pt 1):162-166. [Medline: 17911699]
4. Kerr C, Murray E, Stevenson F, Gore C, Nazareth I. Internet interventions for long-term conditions: patient and caregiver quality criteria. J Med Internet Res 2006;8(3):e13 [FREE Full text] [Medline: 16954123] [doi: 10.2196/jmir.8.3.e13]
5. Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. J Med Internet Res 2008;10(3):e22 [FREE Full text] [Medline: 18725354] [doi: 10.2196/jmir.1030]

6. Delbanco T, Berwick DM, Boufford JI, Edgman-Levitan S, Ollenschläger G, Plamping D, et al. Healthcare in a land called PeoplePower: nothing about me without me. Health Expect 2001 Sep;4(3):144-150. [Medline: 11493320] [doi: 10.1046/j.1369-6513.2001.00145.x]
7. Ludvigsson J, Bolli GB. Intensive insulin treatment in diabetic children. Diabetes Nutr Metab 2001 Oct;14(5):292-304. [Medline: 11806471]
8. Wikblad KF. Patient perspectives of diabetes care and education. J Adv Nurs 1991 Jul;16(7):837-844. [Medline: 1918648] [doi: 10.1111/j.1365-2648.1991.tb01765.x]
9. Hoey H, Aanstoot HJ, Chiarelli F, Daneman D, Danne T, Dorchy H, et al. Good metabolic control is associated with better quality of life in 2,101 adolescents with type 1 diabetes. Diabetes Care 2001 Nov;24(11):1923-1928 [FREE Full text] [Medline: 11679458] [doi: 10.2337/diacare.24.11.1923]
10. Danne T, Mortensen HB, Hougaard P, Lynggaard H, Aanstoot HJ, Chiarelli F, et al; For the Hvidøre Study Group on Childhood Diabetes. Persistent differences among centers over 3 years in glycemic control and hypoglycemia in a study of 3,805 children and adolescents with type 1 diabetes from the Hvidøre Study Group. Diabetes Care 2001 Aug;24(8):1342-1347 [FREE Full text] [Medline: 11473067] [doi: 10.2337/diacare.24.8.1342]
11. ; The Diabetes Control and Complications Trial Research Group. The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. N Engl J Med 1993;329(14):977-986. [doi: 10.1056/NEJM199309303291401]
12. Nordwall M, Bojestig M, Arnqvist HJ, Ludvigsson J; Linköping Diabetes Complications Study. Declining incidence of severe retinopathy and persisting decrease of nephropathy in an unselected population of Type 1 diabetes-the Linköping Diabetes Complications Study. Diabetologia 2004 Jul;47(7):1266-1272. [Medline: 15235773] [doi: 10.1007/s00125-004-1431-6]
13. Hanberger L, Ludvigsson J, Nordfeldt S. Quality of care from the patient's perspective in pediatric diabetes care. Diabetes Res Clin Pract 2006 May;72(2):197-205. [Medline: 16300853] [doi: 10.1016/j.diabres.2005.10.009]
14. Jennett PA, Affleck Hall L, Hailey D, Ohinmaa A, Anderson C, Thomas R, et al. The socio-economic impact of telehealth: a systematic review. J Telemed Telecare 2003;9(6):311-320. [Medline: 14680514] [doi: 10.1258/135763303771005207]
15. Singh G, O'Donoghue J, Soon CK. Telemedicine: issues and implications. Technol Health Care 2002;10(1):1-10. [Medline: 11847443]
16. Jackson CL, Bolen S, Brancati FL, Batts-Turner ML, Gary TL. A systematic review of interactive computer-assisted technology in diabetes care. Interactive information technology in diabetes care. J Gen Intern Med 2006 Feb;21(2):105-110 [FREE Full text] [Medline: 16390512] [doi: 10.1111/j.1525-1497.2005.00310.x]
17. Harno K, Kauppinen-Mäkelin R, Syrjäläinen J. Managing diabetes care using an integrated regional e-health approach. J Telemed Telecare 2006;12 Suppl 1(Suppl 1):13-15. [Medline: 16884565] [doi: 10.1258/135763306777978380]
18. McMahon GT, Gomes HE, Hickson Hohne S, Hu TMJ, Levine BA, Conlin PR. Web-based care management in patients with poorly controlled diabetes. Diabetes Care 2005 Jul;28(7):1624-1629 [FREE Full text] [Medline: 15983311] [doi: 10.2337/diacare.28.7.1624]
19. Verhoeven F, van Gemert-Pijnen L, Dijkstra K, Nijland N, Seydel E, Steehouder M. The contribution of teleconsultation and videoconferencing to diabetes care: a systematic literature review. J Med Internet Res 2007;9(5):e37 [FREE Full text] [Medline: 18093904] [doi: 10.2196/jmir.9.5.e37]
20. Blonde L, Parkin CG. Internet resources to improve health care for patients with diabetes. Endocr Pract 2006;12 Suppl 1:131-137. [Medline: 16627397]
21. Nordfeldt S, Hanberger L, Malm F, Ludvigsson J. Development of a PC-based diabetes simulator in collaboration with teenagers with type 1 diabetes. Diabetes Technol Ther 2007 Feb;9(1):17-25. [Medline: 17316094] [doi: 10.1089/dia.2006.0053]
22. Franklin VL, Waller A, Pagliari C, Greene SA. A randomized controlled trial of Sweet Talk, a text-messaging system to support young people with diabetes. Diabet Med 2006 Dec;23(12):1332-1338. [Medline: 17116184] [doi: 10.1111/j.1464-5491.2006.01989.x]
23. Iafusco D, Ingenito N, Prisco F. The chatline as a communication and educational tool in adolescents with insulin-dependent diabetes: preliminary observations. Diabetes Care 2000 Dec;23(12):1853. [Medline: 11128367] [doi: 10.2337/diacare.23.12.1853b]
24. Hejlesen OK, Plougmann S, Cavan DA. DiasNet--an Internet tool for communication and education in diabetes. Stud Health Technol Inform 2000;77:563-567. [Medline: 11187615]
25. Pagliari C. Design and evaluation in eHealth: challenges and implications for an interdisciplinary field. J Med Internet Res 2007;9(2):e15 [FREE Full text] [Medline: 17537718] [doi: 10.2196/jmir.9.2.e15]
26. Booth RG. Educating the future eHealth professional nurse. Int J Nurs Educ Scholarsh 2006 Feb 27;3 [FREE Full text] [Medline: 16646940] [doi: 10.2202/1548-923X.1187]
27. Taub SJ. The Internet's role in patient/physician interaction: bringing our understanding in line with online reality. Compr Ophthalmol Update 2006;7(1):25-30. [Medline: 16630413]
28. Timmons S. Nurses resisting information technology. Nurs Inq 2003 Dec;10(4):257-269. [Medline: 14622372] [doi: 10.1046/j.1440-1800.2003.00177.x]

29. Ward R, Stevens C, Brentnall P, Briddon J. The attitudes of health care staff to information technology: a comprehensive review of the research literature. Health Info Libr J 2008 Jun;25(2):81-97. [Medline: 18494643] [doi: 10.1111/j.1471-1842.2008.00777.x]
30. Nordfeldt S, Ludvigsson J. Adverse events in intensively treated children and adolescents with type 1 diabetes. Acta Paediatr 1999 Nov;88(11):1184-1193. [Medline: 10591418] [doi: 10.1080/080352599750030275]
31. Nordfeldt S, Johansson C, Carlsson E, Hammersjö JA. Prevention of severe hypoglycaemia in type I diabetes: a randomised controlled population study. Arch Dis Child 2003 Mar;88(3):240-245 [FREE Full text] [Medline: 12598392] [doi: 10.1136/adc.88.3.240]
32. Timpka T, Eriksson H, Ludvigsson J, Ekberg J, Nordfeldt S, Hanberger L. Web 2.0 systems supporting childhood chronic disease management: a pattern language representation of a general architecture. BMC Med Inform Decis Mak 2008;8(1):54 [FREE Full text] [Medline: 19040738] [doi: 10.1186/1472-6947-8-54]
33. Caelli K. The changing face of phenomenological research: traditional and American phenomenology in nursing. Qual Health Res 2000 May;10(3):366-377. [Medline: 10947482] [doi: 10.1177/104973200129118507]
34. Kidd PS, Parshall MB. Getting the focus and the group: enhancing analytical rigor in focus group research. Qual Health Res 2000 May;10(3):293-308. [Medline: 10947477] [doi: 10.1177/104973200129118453]
35. Becker H. Sociological Work: Method and Substance. Chicago, IL: Adline; 1972.
36. Lester WT, Zai AH, Grant RW, Chueh HC. Designing healthcare information technology to catalyse change in clinical care. Inform Prim Care 2008;16(1):9-19. [Medline: 18534073]
37. Moody LE. E-health web portals: delivering holistic healthcare and making home the point of care. Holist Nurs Pract 2005;19(4):156-160. [Medline: 16006829]
38. Liederman EM, Lee JC, Baquero VH, Seites PG. Patient-physician web messaging. The impact on message volume and satisfaction. J Gen Intern Med 2005 Jan;20(1):52-57 [FREE Full text] [Medline: 15693928] [doi: 10.1111/j.1525-1497.2005.40009.x]
39. Lampe K, Doupi P, van den Hoven MJ. Internet health resources: from quality to trust. Methods Inf Med 2003;42(2):134-142. [Medline: 12743649]
40. Baum LS. Internet parent support groups for primary caregivers of a child with special health care needs. Pediatr Nurs 2004;30(5):381-388 401. [Medline: 15587531]
41. Zrebiec JF. Internet communities: do they improve coping with diabetes? Diabetes Educ 2005;31(6):825-828 , 830-822, 834, 836. [doi: 10.1177/0145721705282162] [Medline: 16288090]

Abbreviations

IT: information technology

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Original Paper

Rural eHealth Nutrition Education for Limited-Income Families: An Iterative and User-Centered Design Approach

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Abstract

Background: Adult women living in rural areas have high rates of obesity. Although rural populations have been deemed hard to reach, Internet-based programming is becoming a viable strategy as rural Internet access increases. However, when people are able to get online, they may not find information designed for them and their needs, especially harder to reach populations. This results in a “content gap” for many users.

Objective: User-centered design is a methodology that can be used to create appropriate online materials. This research was conducted to apply a user-centered approach to the design and development of a health promotion website for low-income mothers living in rural Maryland.

Methods: Three iterative rounds of concept testing were conducted to (1) identify the name and content needs of the site and assess concerns about registering on a health-related website; (2) determine the tone and look of the website and confirm content and functionality; and (3) determine usability and acceptability. The first two rounds involved focus group and small group discussions, and the third round involved usability testing with individual women as they used the prototype system.

Results: The formative research revealed that women with limited incomes were enthusiastic about a website providing nutrition and physical activity information targeted to their incomes and tailored to their personal goals and needs. Other priority content areas identified were budgeting, local resources and information, and content that could be used with their children. Women were able to use the prototype system effectively.

Conclusions: This research demonstrated that user-centered design strategies can help close the “content gap” for at-risk audiences.

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KEYWORDS

Qualitative research; website design; rural health; nutrition management; exercise; obesity

Introduction

Obesity is a national priority health issue [1], and the problem is particularly severe among rural populations, with the highest rate of obesity in adult women living in rural areas [2]. People living in rural areas experience several nutrition-related health disparities, including heart disease and diabetes [3]. Compounding this situation is the high rate of poverty among rural residents [4]. Rural populations have been deemed hard to reach with general communication methods [5] and with technology-based media [6].

More recently, Internet-based programming has been used to reach difficult-to-reach populations, including those in rural areas [7]. The purpose of this study was to conduct formative research to design and develop an Internet-based health education intervention promoting nutrition and physical activity among rural mothers with limited resources using an iterative user-centered approach.

Internet Access

In the past, rural populations have been shown to have lower rates of Internet use [8]. Recently, however, rural populations have had rates of Internet use similar to those of people living in other geographic locations [9]. Concerns have shifted to focus on whether rural Internet users will be susceptible to a new access barrier, having low-speed, dial-up connections rather than broadband [9]. Despite this concern, the rate of broadband adoption among rural Americans has been increasing. Between 2007 and 2008, broadband rates increased from 31% to 38%, an increase of 23% in one year [10].

Rural populations have different barriers to access than the general public. The main reason people in the general public do not go online is lack of interest [9], but most rural, limited-income mothers who were not yet online intended to use the Internet in the future [11]. The main barrier preventing use has been the expense of the hardware and software.

Rural populations have similar reasons as others for wanting to use the Internet, including searching for health information. Among Internet users in 2006, four out of five adults reported using the Internet to locate health information [12]. A recent study with rural, limited-income mothers (n = 146) also found that a large majority of those who used the Internet (86%) reported searching for medical information online, and two thirds reported viewing health-related websites [11]. Similarly, people living in rural areas have demonstrated no differences in their online searches for Medicaid and Medicare compared to people living in urban areas [14].

Content Divide

Access to the Internet is only part of the digital divide. Once individuals get online, information and tools they want and need may not be available [13]. More than 50 million Americans cannot find or use needed online materials and services [13]. Even if materials are available, they are often complex and require advanced literacy skills [15]. This "content gap" leaves the promise of the Internet unfulfilled for many, including those with low incomes, low literacy, limited English, and disabilities [13]. This gap affects online health information and tools, which have been found to have, on average, a tenth grade reading level [16]. Therefore, recommendations have been made to improve the reach of health websites by working to meet the needs of underserved populations [13].

User-Centered Design

Given increases in access and high rates of interest in Internet use in general and for health promotion specifically, technology-based interventions offer a potential means to reach rural populations [11]. With proper design and dissemination, eHealth programs could be a critical tool in the elimination of health disparities [16]. An important methodology to create appropriate online content is user-centered design [17]. In user-centered design, the target audience is involved in all stages of the development process in order to create a website that best meets users' needs [17]. According to the evidence-based guidelines, "The current research suggests that the best way to begin the construction of a Web site is to have many different people propose design solutions (i.e., parallel design), and then to follow up using an iterative design approach" [17].

Some of the more promising Internet-based interventions include tailored communication, which is a strategy that can improve the relevance and appeal of health messages [18]. However, tailored communication is based on demographic and other personal information provided by the individual. Technology has been implicated in various privacy issues because of its role in facilitating the gathering, aggregating, and disseminating of information [19]. The development of Internet-delivered interventions must therefore assess the audience's concerns about trust and privacy [15,20]. Most Internet users (84%) are concerned about others gaining access to their personal information, and about half (54%) are concerned about getting online medical information from unqualified sources [20]. Despite these concerns, over half (54%) have given personal information so that they can use a specific website, and another tenth report that they would provide personal information under certain circumstances [20]. Privacy may be less of a concern for those individuals who are actively engaged in seeking and sharing health information [21]. When asked the three most important ways that digital communication has changed how they share or receive health information, health-engaged individuals identified having access to more up-to-date health information (42%), access to new information (40%), and more immediate access to information (38%); however, only 10% felt that digital health communication made them more concerned about the privacy of their health information [21]. Understanding the kinds of information people would share is important in the development of a website providing tailored health information.

Purpose

The purpose of this study was to conduct three rounds of a user-centered design process to guide the development of a website to support and extend the goals of the Food Stamp Nutrition Education Program (FSNEP) in Maryland. The priority audience of this online program was mothers with limited incomes living in the state's rural counties because of their key role in guiding nutrition and health choices for their families.

The iterative process was designed to answer the following research questions:

- Round 1: (1) How acceptable is the idea of the proposed website to the priority population? (2) What are the preferences for the proposed website name and content? (3) How will limited-income mothers react to the idea of providing information about themselves during registration and log-in procedures proposed for the website?
- Round 2: (1) What design components will be most appealing and understandable? (2) What content and features would the priority audience want and expect in a website about nutrition, physical activity, and food budgeting?
- Round 3: (1) How acceptable is the prototype website? (2) Is the prototype website easy to navigate and use?

Methods

Sample

The priority population for the concept testing was limited-income adult females (age 18 or older and having an income < 185% of the federal poverty level) living in five counties in Maryland. Another selection criterion was having at least one child enrolled in school (preschool to eighth grade) in order to obtain feedback on making health choices in the context of a family. If potential participants were not currently receiving food stamps, eligibility for the concept and message testing was based on household income and household size.

Recruitment

Recruitment was conducted using multiple methods. Flyers were posted in key locations and distributed by community service providers (eg, Department of Social Services personnel, extension educators) to their eligible clients. In the second round, faith-based leaders also assisted in distributing flyers. Updated lists of food stamp recipients were obtained from the Maryland Department of Human Resources to recruit persons directly via telephone. Reminder calls were made to registered participants prior to the focus groups and interviews in an effort to increase attendance. In the first two rounds, a free meal was offered as an incentive. No incentives were offered in the third round; however, the participants in one county were given the opportunity to sign up for free Internet accounts, which may have provided some incentive.

Instrumentation

The focus groups and interviews were conducted with structured guides that built upon the findings of each previous round as the intervention was drafted and developed. See Table 1 for the topics and questions covered in the three rounds. Building upon the needs assessment findings of the previous year, the main purposes of the first round were to test the overall concept of the website, its name, and the idea of having people register. Based on these findings, three conceptual designs and a draft content outline were developed, and the interview guide was developed to be consistent with the designs and content. In the second round, participants were asked to evaluate the potential designs for the home page, identify which design they preferred, and recommend what content areas the site should include. Based on the second round, a functional prototype was developed with the recommended subsections and draft content pages.

In the third round of testing, individual interviews and usability testing protocols were used to assess acceptability and ease of use. The interviewee was asked to explore the website using a mouse as an interviewer observed and asked questions about the website. The interview began with general questions about the home page and purpose of the site. Next, home page features were described and pointed out to the interviewee, who was then asked to choose which features to look at in greater detail. Allowing the user to click on the features by order of interest allowed us to assess which features were the most interesting and compelling while getting more specific information about each feature. We also observed how well users were able to navigate back and forth between the features and the home page. This strategy was also used to explore the secondary pages—Feed Your Mind, Cooking Class, Stay Connected, Activities—in that a brief tour was given, then the user was able to pick which pages to visit and explore while answering questions about each. The ability to navigate between secondary content areas and their features was also observed to determine how well users could find information within the program. The interview ended with overall questions about website acceptability and suggestions for how to improve it.

The interview guides were developed with input from the Maryland Cooperative Extension. All three protocols were submitted to the Institutional Review Board at the University of Maryland and received approval prior to the initiation of each phase of the study.

Table 1. User-centered research questions by round of research process

Round	Section	Illustrative Questions
Round 1	Introduction	Who [here] has ever used the Internet? We want to create a website for low-income families with information to address food and physical activity needs. *Reaction to mock website (see Figure 1)* What are your feelings and thoughts about this idea?
	Input on Name	What are your ideas about what to name a website with this kind of information? If you wanted to find information about healthy eating or how to exercise for yourself or for your kids, what phrase or words would you enter into the computer? *Reactions to four draft concepts*
	Input on Registering	Has anyone [here] ever been on a website and had to create a log-in name and password? How would you feel about having to type in your name and password into a website each time you use it? How would you feel about registering on a website so you could get information on your specific interests and needs? What kind of personal information would you be most/least comfortable sharing when registering on a website? *Reactions to 27 types of information*
Round 2	Introduction	How many people here have ever used the Internet? What are some of your favorite websites? What do you like about these sites? Dislike?
	Reactions to Three Draft Websites	*Show three different examples of the website, one at a time (see Appendix 1)* What is the first thing that strikes your eye about this website? What do you like/dislike about this website? Is there anything confusing about this website? Who do you think this website is for? What do you think about the design of this website? How could we improve this website?
	Reactions to Proposed Content: • Reading Room • Cooking Class • Community Center • Tool Box	When you hear the name of this area, what is the first thing that comes to your mind? What kind of information would you expect to see here? If you visited this menu, which of these choices interest you the most/least? Overall, which one of these areas would interest you most/least?
Round 3	Introduction	Have you used the Internet before?
	Responding to Pilot Website Home Page	*Show the home page of the website.* What do you think the purpose of the website is? What is your reaction to how it looks?
	Responding to Home Page Features	*Provide brief tour of weekly poll, tip of the day, suggestion box, and ask the coach.* Which of these do you want to look at first? How well do you think this section accomplishes its purpose? Do you like or dislike it? Why? *Repeat with other three home page items in order of interest.*How could it be improved?
	Responding to Content	*Provide them with a brief tour/overview of each area (Feed Your Mind, Cooking Class, Stay Connected, Activities).* Which of these do you want to look at first? What do you think of this section? Do you like or dislike it? Why? How could it be improved? *Repeat with other three content areas in order of interest.*
	General Website Review	What did you like about this website? What was your favorite part? What did you dislike about this website? Is there anything confusing about this website? How could we improve this website? Would you recommend the website to others?

Data Collection

Round 1

Focus groups (n = 5) were held in five counties in February and March 2004. Groups ranged in size from 1-9, for a total of 28 participants. A trained moderator led all focus groups, which lasted approximately 90 minutes and were audiotaped; a second staff member took notes.

Round 2

Round 2 focus groups (n = 3) were held in May and June 2004 in three counties that would be piloting the website. Due to low recruitment rates in one county, three individual interviews were also conducted at an adult literacy program center in addition to the focus group. There were 4-5 participants in each group and three interviews, for a total of 16 participants. A moderator and note taker conducted the 90-minute groups, which were also audiotaped.

Round 3

Individual interviews were conducted in each of the three intervention counties. Researchers staffed several common areas where low-income mothers frequented, for approximately 7 hours at a time. These included sites such as an adult learning center and residential community center. Participants were asked to attend at a time that was convenient for them for a period of approximately 30-45 minutes. A trained moderator led all eight interviews, and, when possible, a second staff member took notes on a structured participant observation review form to capture both comments and actions as the individual moved through the pilot website.

Data Analysis

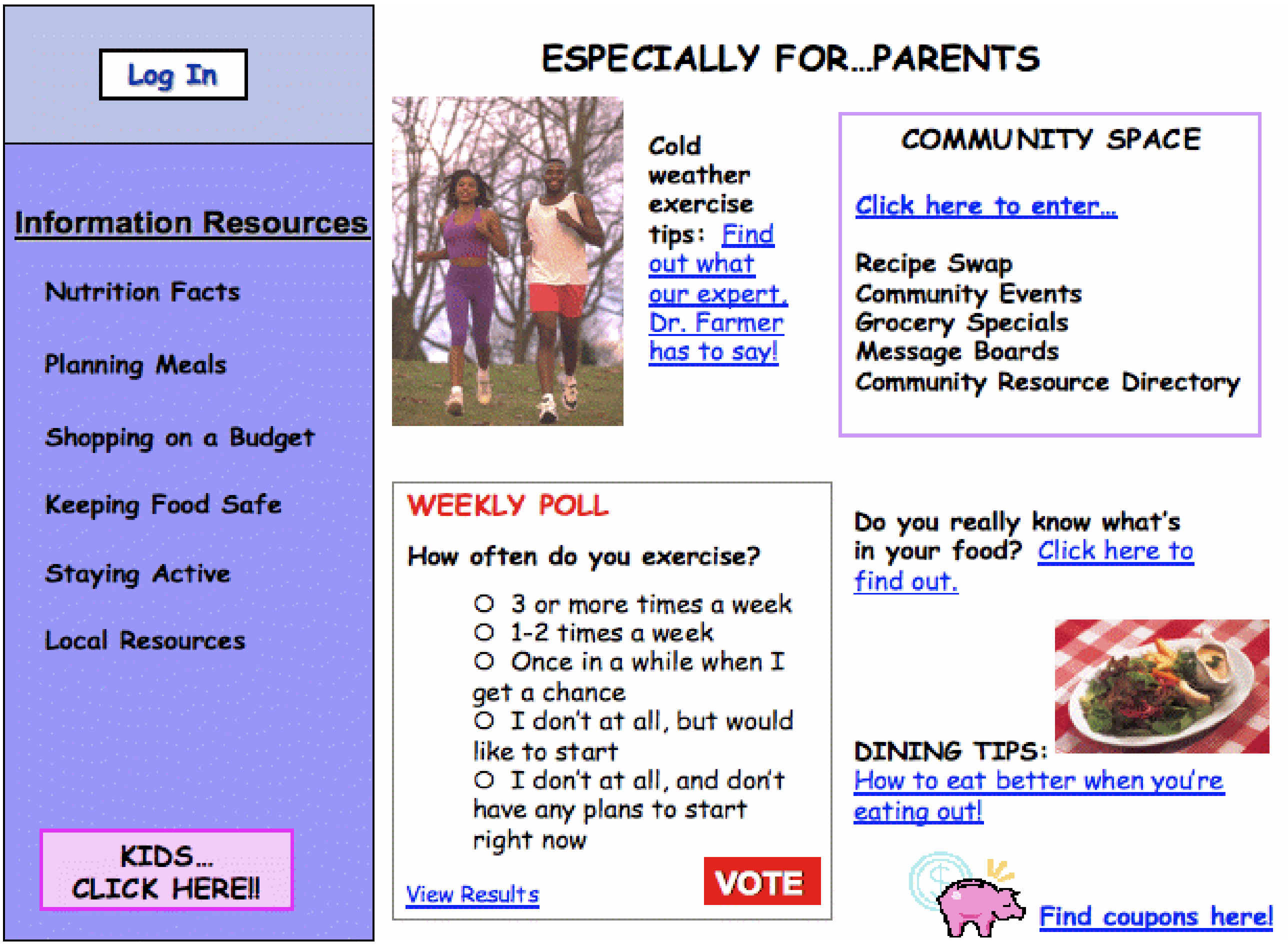
Data from the focus groups and interviews were analyzed using note-based analysis. This technique involves analyzing the notes taken during the sessions and any summary notes made by the moderator and note-takers immediately after the session, with the audiotapes used as needed for verification of findings [22]. The notes were analyzed to identify key issues and common themes by question and by area of the website. A grid was constructed to provide an overview summarizing the content of the discussions. Multiple reviewers (n = 3) were used to verify the emergent themes and issues.

Results

Round 1: Reaction to Proposed Intervention, Names, and Registration

When asked whether they had ever used the Internet, 22 of 28 participants reported that they were either current or past Internet users. When presented with a mock home page with proposed website content (Figure 1), overall reactions were positive.

Figure 1. Mock website home page



ESPECIALLY FOR...PARENTS

Cold weather exercise tips: Find out what our expert, Dr. Farmer has to say!

COMMUNITY SPACE

Click here to enter...

Recipe Swap
Community Events
Grocery Specials
Message Boards
Community Resource Directory

WEEKLY POLL

How often do you exercise?

○ 3 or more times a week
○ 1-2 times a week
○ Once in a while when I get a chance
○ I don't at all, but would like to start
○ I don't at all, and don't have any plans to start right now

Do you really know what's in your food? Click here to find out.

DINING TIPS: How to eat better when you're eating out!

Find coupons here!

Participants were interested in the website, especially the “community space” area that would allow them to access local information about their communities. Participants also expressed interest in content related to food budgeting, or “smart shopping,” and nutrition and physical activity information related to their children. They wanted content tailored to limited-income families that would take their monetary resources into account when providing budgeting information and recipe ideas. They provided several suggestions for topics to include in the website:

- Nutrition: How to pack a healthy meal; Cooking for picky eaters; Nutritional values of different foods; Interactive activities and tools (ie, nutrition assessments); Meal planning, budgeting, shopping on a budget, coupons
- Physical Activity: How to track exercise levels for kids and adults; Ideas for staying active, particularly in-home exercise options; Ways to stay motivated for exercise; Cooking; Weekly recipes that use low-cost, healthy ingredients; Ways to use different kinds of foods in recipes; Nutrition facts in recipes
- Content for Children: Healthy snack ideas for children; Cooking with children; How to deal with childhood obesity; Age-specific information about helping children be active; Printable coloring pages and age-specific games
- Local Resources: Message boards for community groups/events; Nutrition resources that provide low-cost food items; Low-cost recreational options, especially during the cold seasons

Participants were asked to react to four potential website names. The names were ranked in the following order: (1) Eat Smart, Be Fit; (2) Families Fit for Life; (3) HealthPath – The Path to Healthy Living; and (4) Healthy Community, Healthy Family, Healthy Me. The vast majority preferred the name “Eat Smart, Be Fit,” describing it as “catchy” and “straight to the point.” This name would give the user a good sense of what would be presented on the website and would appeal to families, particularly women and children, and to people who wanted to diet, eat healthfully, or exercise. Those who disliked it felt that the name was not representative of all the information on the website. The other names were less preferable because they did not give the user a clear, comprehensive idea of what the website was about. The last two suggested names listed above were considered long, confusing, and hard to remember.

With respect to registration, most participants had previously logged in to websites and were familiar with this practice. Remembering names and passwords was considered difficult for some participants. Some were concerned about the security of personal information entered during the log-in procedure. Others were not concerned, finding the process of logging in to a website to be routine and enjoying the personalized content they received. They preferred not to have to do it each time they accessed a website.

Each group was presented with 27 different types of information that could be gathered in a registration process. Groups were willing to provide information about health, nutrition, and physical activity goals and practices in order to get tailored advice. However, several items were considered sensitive: personal contact information (address, phone, email), household information (number of children in household, number of adults in household, income), personal health information (health problems, weight), and demographics (employment status, education level, food stamp status). See Table 2 with findings by topic.

Table 2. Comfort with giving personal information during website registration

Log-In Item	Proportion Comfortable	Favorable Findings	Unfavorable Findings
First/last name	4/5	Used to giving this information out	Don’t want to give last name
Gender	4/5		
Street address	2/5	Acceptable if site is secure	
Zip code	5/5		
Telephone number	5/5		Make optional
Email address	4/5	Interested in receiving a newsletter	Make optional
Age	5/5	Use age ranges	
Number of children in household	3/5		Too personal
Number of adults in household	3/5		
Topics of interest	5/5		
Health status	4/5		Some uncomfortable
Health goals	5/5		
Personal health problems	4/5		Should not ask about sensitive health problems
Family health problems	5/5		
Eating habits	5/5		
Food buying habits	5/5		
Food budgeting habits	5/5		
Exercise habits	5/5		
Computer habits	4/5		Unnecessary
Internet habits	4/5		Too personal
Height	4/5		Make optional
Weight	2/5	Use weight ranges	Sensitive
Employment status	3/5	Use categories; kind of personal but okay	Make optional
Education level	4/5		Unnecessary, make optional
Household income	4/5	Use ranges	Not relevant
Food stamp status	4/5		Unnecessary, determine from income and household size
How heard about website	5/5		

Round 2: Design and Content Preferences

When presented with three different websites (see Multimedia Appendix), participants identified what they liked and disliked about each. With respect to graphics and pictures, participants recommended that photographs include people representing a mix of ethnic backgrounds, body types, and ages. People should be shown in active poses and wearing comfortable, but not sloppy, exercise clothes. They also liked graphics that helped explain website content. In particular, they liked the graphic on the first website that depicted a large family having a barbecue. “Everybody can join in,” one person said. Others noted that the children in the picture were “probably talking about food” and that the picture showed children “being taught what’s good for them and what’s not.” The first website also used vegetables to create graphics in the header, and they appreciated how this linked the site to nutrition.

Participants liked the layout of the second website, saying that having the links divided by boxes made it easier to see what was on the page and where to click. All favored the idea of having drop-down menus rather than menus that required them to click to the next page before being able to view the submenus. They also expressed interest in the use of colorful graphics for website links. The third website was considered inappropriate and boring, mainly for its photo (“looks like a homeowner’s page”) and color scheme. The prominent display of the acronym FSNEP (Food Stamp Nutrition Education Program) was confusing because most participants were unfamiliar with it. Finally, the menu buttons on this website design were unclear.

Participants were asked to respond to the individual menu items and related content, and they appeared somewhat confused regarding the names of the menu options. They recommended changing the names of several menus to promote both clarity and interest among users. Participants preferred names that were "fun and catchy," that were inclusive of many users, and that would help the user anticipate the content.

The proposed content areas were received positively (Table 3). Participants seemed most interested in ensuring that content would appeal to a broad audience, including children. Participants offered suggestions for content, focusing on materials that could be used to ease a mother's daily tasks, such as planning meals on a budget. They wanted access to information on how to make healthier meals and be more active. Both information and interactive tools were of interest to the priority audience to help them accomplish these goals. They also stated an interest in local resources that could help them save money on food and provide low-cost exercise options.

Table 3. Reactions to and recommended new content for website sections during Round 2 focus groups and interviews

Section of Website	Reactions	Recommendations for New Content
Reading Room	Expected material pertaining to nutrition and exercise; Concerned about the amount of reading that might be involved; Wanted a name that was fun and catchy	Planning meals and menus; How to get kids to eat nutritiously; Eating on a budget; Assistance with counting calories; Ways to exercise and stay active; Links to other websites
Cooking Class	Was the area of greatest interest; Thought this section would be of interest to children; Thought people who do not like to cook would not be interested	Healthy recipes; Cooking with children; Menus for children; Proper kitchen skills; Low-fat cooking techniques
Community Center	Expected information about activities in the community; Confused initially about what kind of information the "Ask the Expert" feature would provide	Local activities and events; Grocery specials; Community centers; Recreational facilities; Access to legal and medical advice
Tool Box	Thought the name made the purpose of the section unclear; Expected to find information to help them use the website; Overweight people less interested in using a body mass index (BMI) calculator	Exercise and activity logs; Food journal and calorie counter; Quizzes

Participants were next asked to review sample messages representing website content to assess their appropriateness. These messages were previously determined through readability testing to be at a sixth grade or lower reading level. Participants were asked to use their own words to describe the meaning of the paragraph and what they learned from it. They were able to read and understand these messages with relative ease, and they were enthusiastic about the content they reviewed. As a result, we concluded that a sixth grade or lower reading level was appropriate.

Round 3: Acceptability and Ease of Use

Two of the eight participants in Round 3 had no Internet experience; however, even these respondents required very little direction on how to use a mouse and navigate the pages. When asked their impression of the intended purpose of the website, participants thought the purpose was to promote healthier eating and cooking habits, an interest in one's health, and spending their food stamps or money wisely on products that would further a healthier lifestyle. They also felt that the site was trying to get people to engage in physical activity. They thought the pictures suggested a family-oriented site, promoting togetherness and healthy eating habits.

Participants liked the visual appearance of the home page and found it "eye catching," colorful, and easy to use and understand. Suggestions for improving the home page included posting photos of diverse family configurations, including single-parent families, and people exercising and grocery shopping. Also, several participants felt that more colors and graphics should be added.

Next, participants reviewed and reacted to the prototype content and materials in each section (see Table 4 for their specific suggestions). Among the home page features, half the participants selected to view the tip of the day first; the "Ask the Coach" feature ranked second in interest. In terms of the content areas, users appeared most interested in areas that related to raising children and cooking with children. They were interested in the interactive features so that they could be more proactive in terms of meal planning, accessing local resources, and getting motivated to manage their weight. Of least interest were the suggestion box feature on the home page and the section on food safety in the cooking area.

Table 4. Suggestions for improvement of website sections/features during Round 3 interviews

Section/Feature	Suggestions for Improvement
General Website	Add brighter pictures and color to the background. Add humor to the content. Highlight key information into bullets, so text is less dense. Increase font size to make it easier to read. Simplify text, or provide access to a dictionary of terms. Make links more prominent. Provide more content targeted toward children.
Content Areas	
Planning Meals	Provide sample meals plans and meal planner tools.
Eating on a Budget	Add information on the food groups and recommended amounts. Provide food budgeting recommendations and worksheets.
Raising Healthy Kids	Add topics (eg, staying fit and eating right during and after pregnancy). Include links to local parks and recreation areas.
Keeping Food Safe	Add information on importance of using paper versus cloth towels. Provide information on the health effects of food additives.
Keep It in Season	Remove the section on canning.
Healthy Cooking	Add more information on healthy cooking. Provide nutrition information for people with illnesses (eg, diabetes).
Cooking with Kids	Provide lunch and recipe ideas for kids. Provide brown bag lunch ideas that won’t spoil.
Interactive Features	
Tip of the Day	Place in the box a link to related information about the tip. Provide ideas on implementing the tip in the context of a busy lifestyle.
Ask the Coach	Be clear that users can ask questions. Provide background information on “coaches.” Give time estimate for posting answers. Provide more visual aids, graphics next to questions and answers.
Community Events	Give instructions for expanding events on the calendar into full view. Provide wider range and greater number of events. Create a form letting community members post events on the website.
Grocery Specials	Provide recipes that can be used to shop for food items. Provide information on how to select foods at the grocery store. Create a grocery list builder or printable form to plan grocery lists. Create a shopping game.
Community Directory	Rename the food resources section to clarify the content found there. Add resources (eg, free/low-cost exercise classes, community pools).
My Activity Log	Stress the importance of checking with a physician before exercising. Provide field for recording specific upper and lower body exercises. List options for types of exercise. Give guidelines for weekly exercise and exercise intensity. Create online logging so that you don’t have to print out a log.
My Food Log	Provide daily caloric, fat, fiber, etc. guidelines. Provide information on servings (serving size, number of servings). Provide information on the importance of eating regular meals.
My Pledge	Include a timeline/calendar function to plan health behavior changes.
Bean Game	Use a more appealing graphic than a bean for the game, such as apples. Provide feedback telling the person how well they did at the game.

When asked to identify their favorite areas, participants generally selected the interactive components, such as Time Management, Ask the Coach, and the Activity and Food Logs. A few participants preferred the content areas, including Staying Active, Cooking Class, and Feed Your Mind. When asked what they disliked, participants identified specific components, such as individual graphics and tips, rather than large sections or areas of the website. For example, one person wanted to change the bean graphic to an apple graphic in the bean game because people might not like to eat beans. Another person recommended removing information on canning.

Overall, participants felt that the website would be helpful to them, they would like using it, and they would recommend it to others. Many wanted more information on the website that could be used with children, and several wanted to see a specific children's area.

While reviewing the website, users were asked to comment on how easy the website was to use. In particular, participants noted that the menu system was easy to navigate. Other website features on the home page, the Suggestion Box and Ask the Coach, were found to be easy to use. Some participants offered specific suggestions to help improve user interaction with the site (see Table 3). Some participants stated that they were visual learners and preferred more graphics to text. These participants felt too much reading was required and would have preferred more activities. Many participants thought the font size throughout the site was too small to read comfortably. They also suggested reducing the density of the text on some pages and using more bulleted text to make the content easier to read.

Discussion

The concept development process enabled the project to evolve through iterative review and comment by the intended end users. The discussion describes how the findings from each round built upon each other and previous research.

Round 1: Proposed Website

The first series of focus groups allowed us to gain insight into the experiences of limited-income women in using the Internet and provided significant direction related to website naming and content development. Most importantly, participants' strong and enthusiastic interest in the project confirmed that the idea of the proposed website was acceptable to and welcomed by limited-income women.

The name "Eat Smart, Be Fit" was favored by an overwhelming majority and was therefore selected as the brand name for the website and related project materials. Participants also liked the idea of receiving practical suggestions about food and fitness that were consistent with their income and location of residence. This finding is consistent with previous research [23] that found that people with limited incomes living in rural communities want practical local information, such as neighborhood events and local service agencies. Information that would allow them to better care for their children also resonated with the participants.

Similar to previous research [20], this study found that participants would provide certain personal information during a website registration process—such as health, nutrition, and physical activity goals and practices—in order to receive tailored advice. While some were willing to provide sensitive information, they wanted these types of questions to be optional rather than required. Because the participants had concerns that some items were irrelevant or unnecessary, any information requested in a registration procedure should also be justified, and an explanation about the purpose of gathering this information should be provided to potential registrants.

Round 2: Concept Testing

The second round of testing revealed that the content, organization, and overall design, or "look and feel," of the website strongly influenced whether users liked the website or not. Graphical images that supported the content and images that featured people who looked like them and their families resonated better with participants. They wanted a colorful website with graphics of diverse families engaging in physical activity or preparing and/or consuming healthy foods. This finding enabled the website design to be focused in a way to better convey the intended messages, and it was consistent with the usability guideline to use images that work for the users rather than the designers [17].

Round 2 also built upon the findings of the first round by confirming that the content chosen for further development was of interest: healthy meals for the family, eating on a budget, and local resources. However, it also demonstrated that the content needed to be adjusted to better fit the audience's needs and expectations, such as changing menu labels to be more appealing and understandable. This finding supported the usability guideline to "Use headings that are unique from one another and conceptually related to the content they describe" [17].

Providing information alone was not appealing to these participants, and they reacted negatively to parts of the site that were too wordy or formal. This finding suggested that the content and features should focus on priority messages and tools rather than be exhaustive and overly detailed. Participants wanted both informational and interactive content that offered practical suggestions for improving nutrition, physical activity, and shopping and budgeting and that provided local community information. Providing practical information and information at a basic literacy level is consistent with research by the Children's Partnership on the preferences of low-income and underserved populations [23].

Round 3: Usability Testing

This round of testing provided feedback regarding the overall appropriateness, appeal, and ease of use of the draft website. Participants were generally very receptive to the website and its components. Users related strongly to nutrition and food budgeting areas, frequently disclosing personal stories related to their own nutritional and shopping practices. They continued to voice a strong interest in having content for children.

Overall, users stated that materials were easy to use and understand, even those with little or no computer experience.

Participants provided suggestions to improve usability through simple formatting changes. They preferred the site to have limited text, larger font, and bulleted text to highlight key ideas. Participants wanted graphics to support content in order to improve understanding. Finally, some of the novice users requested adding user prompts and instructions to navigate links and menus on the pages. Overall, the participants' recommendations directly support those provided by the 2006 US Department of Health and Human Services guidelines for improving health literacy [24].

With these usability test findings, the website needed only a few adjustments to the content and format. The website was then launched in the target communities within 6 weeks of completing the formative research process.

Limitations

This paper presents an observation of attitudes, stated behaviors, preferences, and comments of the participating members of each group. Given our use of qualitative methods, statistical inference and generalization are not possible. Participants reflect a convenience sample of low-income mothers living in rural Maryland who volunteered for the study. Those who were most interested in issues related to nutrition, physical activity, or food budgeting, as well as those with computer/Internet skills may have been more likely to participate. Consequently, the study may be limited by self-selection bias.

Another limitation was the study's focus on development of an Internet-based application rather than other technology-based applications that may be accessible to our target population. Taking into account the spectrum of access options now available may have enabled us to reach them in new and potentially more effective ways.

Lessons Learned

As many researchers have found, recruiting rural populations can be difficult. Several different recruitment strategies were utilized in the current study. We found that recruitment through local community service providers was the most effective and efficient method. Recruitment was harder for the last two rounds, perhaps due to timing (ie, being conducted at the beginning and the end of the summer), weather, and minimal incentives.

We also attempted to over-recruit for each focus group. Although reminder calls were made, no-show rates and cancellations were high even among confirmed participants. A shift from scheduled focus groups to drop-in clinics to increase the flexibility of the time frame for participation did not improve participation rates.

Future data gathering efforts should use a variety of methods to promote participation, including varying locations of interview sites, offering varied incentive options, and enlisting the support of trusted service providers. Conducting intercept interviews in the local food stamp office or area frequented by the priority population may be an alternative strategy to test.

Conclusions

This iterative formative research process illustrated the importance of participatory research. By the time we completed the third round of this research, we had greater confidence in our ability to meet the priority population's needs and expectations because of their ongoing involvement. Participants had strong and clear opinions about what content to include and how to present it in order to make it easier to understand and access. Their recommendations were consistent with published guidelines on how to present materials to improve health literacy.

The research also highlighted the importance of adding new content and features on a regular basis as participants were not interested in a static site. Previous research has indicated that static sites may be a reason for drop-off in health website usage [16]. Keeping the website populated with new content would require continued formative research and usability testing, and we planned to conduct further usability testing after the initial implementation of the website.

This research has shown that despite barriers to technology use, low-income mothers were excited and interested in online materials designed for their needs. Addressing the needs of the "information and technology have-nots" is critical because they have the most to gain from access to appropriate materials. The challenge is to find out what works for our priority populations by moving from researcher-centric development to user-centered methods.

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Conflicts of Interest

None declared.

Multimedia Appendix

Sample website designs used in Round 2

[PPT file(Microsoft Powerpoint), 812KB - jmir_v11i2e21_app1.ppt]

References

1. Ogden CL, Carroll MD, Curtin LR, McDowell MA, Tabak CJ, Flegal KM. Prevalence of overweight and obesity in the United States, 1999-2004. JAMA 2006 Apr 5;295(13):1549-1555 [FREE Full text] [Medline: 16595758] [doi: 10.1001/jama.295.13.1549]
2. Gamm L, Hutchison LL, Dabney BJ, Dorsey AM. Rural Healthy People 2010: A Companion Document to Healthy People 2010. Volume 2. Washington, DC: Southwest Rural Health Research Center; 2003. URL: http://srph.tamhsc.edu/centers/rhp2010/Volume2.pdf [accessed 2009-04-27] [WebCite Cache ID 5gLgBLQtU]
3. ; US Department of Health and Human Services. Healthy People 2010. 2nd edition. Washington, DC: US Government Printing Office; 2000. URL: http://www.healthypeople.gov/Document/tableofcontents.htm#Volume2 [accessed 2008-10-24] [WebCite Cache ID 5bsz1uAtz]
4. ; US Department of Agriculture. Rural Poverty at a Glance, 2004 (Rural Development Research Report Number 100). Washington, DC: USDA Economic Research Service; 2004. URL: http://www.ers.usda.gov/publications/rdrr100/rdrr100.pdf [accessed 2008-04-10] [WebCite Cache ID 5bsz8d1Qg]
5. Brackertz N. Who Is Hard to Reach and Why? ISR Working Paper. Melbourne, Australia: Institute for Social Research; 2007. URL: http://www.sisr.net/publications/0701brackertz.pdf [accessed 2008-04-10] [WebCite Cache ID 5bsz5FOhv]
6. ; US Department of Commerce. A Nation Online: How Americans Are Expanding Their Use of the Internet. Washington, DC: National Telecommunications and Information Administration; 2002. URL: http://www.ntia.doc.gov/ntiahome/dn/nationonline_020502.htm [accessed 2008-10-24] [WebCite Cache ID 5bszBFCA3]
7. Whitehead LC. Methodological and ethical issues in Internet-mediated research in the field of health: an integrated review of the literature. Soc Sci Med 2007 Aug;65(4):782-791 [FREE Full text] [Medline: 17512105] [doi: 10.1016/j.socscimed.2007.03.005]
8. ; US Department of Commerce. Falling through the Net: A Survey of the “Have Nots” in Rural and Urban America. Washington, DC: US Government Printing Office; 1995. URL: http://www.ntia.doc.gov/ntiahome/net2/falling.html [accessed 2008-10-24] [WebCite Cache ID 5bszYVD9W]
9. ; US Department of Commerce. A Nation Online: Entering the Broadband Age. Washington, DC: National Telecommunications and Information Administration; 2004. URL: http://www.ntia.doc.gov/reports/anol/NationOnlineBroadband04.htm [accessed 2008-01-16] [WebCite Cache ID 5UtUlD1k8]
10. Horrigan J. Home Broadband 2008: Adoption stalls for low-income Americans even as many broadband users opt for premium services that give them more speed. Washington, DC: Pew Internet & American Life Project; 2008. URL: http://www.pewinternet.org/pdfs/PIP_Broadband_2008.pdf [accessed 2008-12-12] [WebCite Cache ID 5d0xKlDvT]
11. Atkinson NL, Billing AS, Desmond SM, Gold RS, Tournas-Hardt A. Assessment of the nutrition and physical activity education needs of low-income, rural mothers: can technology play a role? J Community Health 2007 Aug;32(4):245-267 [FREE Full text] [Medline: 17696049] [doi: 10.1007/s10900-007-9047-7]
12. Fox S. Online health search 2006. Washington, DC: Pew Internet & American Life Project; 2006. URL: http://www.pewinternet.org/pdfs/PIP_Online_Health_2006.pdf [accessed 2008-04-10] [WebCite Cache ID 5bszeZSg8]
13. Lazarus W, Lipper L. The Search for High Quality Content for Low-Income and Underserved Communities: Evaluating and Producing What’s Needed. Santa Monica, CA: The Children’s Partnership; 2003. URL: http://www.contentbank.org/AM/Template.cfm?Section=Research_From_The_Childrens_Partnership&Template=/CM/ContentDisplay.cfm&ContentFileID=1050 [accessed 2008-10-24] [WebCite Cache ID 5bszhQMNa]
14. Schmeida M, McNeal RS. The telehealth divide: disparities in searching public health information online. J Health Care Poor Underserved 2007 Aug;18(3):637-647 [FREE Full text] [Medline: 17675719] [doi: 10.1353/hpu.2007.0068]
15. Cashen MS, Dykes P, Gerber B. eHealth technology and Internet resources: barriers for vulnerable populations. J Cardiovasc Nurs 2004;19(3):209-14; quiz 215-6 [FREE Full text] [Medline: 15191264]
16. ; US Department of Health and Human Services. Expanding the Reach and Impact of Consumer e-Health Tools. Washington, DC: US Department of Health and Human Services; 2006. URL: http://www.health.gov/communication/ehealth/ehealthtools/pdf/ehealthreport.pdf [accessed 2008-10-24] [WebCite Cache ID 5bszk6Zll]
17. ; US Department of Health and Human Services. Research-Based Web Design and Usability Guidelines. Washington, DC: US Department of Health and Human Services; 2006. URL: http://usability.gov/pdfs/guidelines_book.pdf [accessed 2008-10-7] [WebCite Cache ID 5bszk6Zll]
18. ; US Department of Health and Human Services. Making Health Communication Programs Work. Washington, DC: US Department of Health and Human Services, National Cancer Institute; 2004. URL: http://www.cancer.gov/PDF/41f04dd8-495a-4444-a258-1334b1d864f7/Pink_Book.pdf [accessed 2008-10-24] [WebCite Cache ID 5bsztTRa0]
19. Solove DJ. A taxonomy of privacy. Univ PA Law Rev 2006;154(3):477-560 [FREE Full text] [WebCite Cache ID 5dbnicWbt]
20. Fox S. Trust and privacy online: Why Americans want to rewrite the rules. Washington, DC: Pew Internet & American Life Project; 2000. URL: http://www.pewinternet.org/~/media//Files/Reports/2000/PIP_Trust_Privacy_Report.pdf.pdf [accessed 2008-10-24] [WebCite Cache ID 5bszqxZNO]

21. Health Engagement Barometer.: Edelman; 2009. URL: http://engageinhealth.com/docs/Edel_HealthBarometer_R13c.pdf [accessed 2009-01-5] [WebCite Cache ID 5gIjlkh8f]
22. Beyea SC, Nicoll LH. Collecting, analyzing, and interpreting focus group data. AORN J 2000 Jun;71(6):1278, 1281-1278, 1283 [FREE Full text] [Medline: 10892538] [doi: 10.1016/S0001-2092(06)61446-4]
23. Lazarus W, Lipper L. Online Content for Low-Income and Underserved Populations: Issue Brief. Santa Monica, CA: The Children's Partnership; 2002. URL: http://www.childrenspartnership.org/AM/Template.cfm?Section=Reports1&Template=/CM/ContentDisplay.cfm&ContentID=4663 [accessed 2008-10-24] [WebCite Cache ID 5bszmiNtz]
24. ; US Department of Health and Human Services. Quick Guide to Health Literacy. Washington, DC: US Department of Health and Human Services, Office of Disease Prevention and Health Promotion; 2006. URL: http://www.health.gov/communication/literacy/quickguide/Quickguide.pdf [accessed 2008-10-24] [WebCite Cache ID 5bszohPJw]

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Original Paper

Acceptability of a Personally Controlled Health Record in a Community-Based Setting: Implications for Policy and Design

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Abstract

Background: Consumer-centered health information systems that address problems related to fragmented health records and disengaged and disempowered patients are needed, as are information systems that support public health monitoring and research. Personally controlled health records (PCHRs) represent one response to these needs. PCHRs are a special class of personal health records (PHRs) distinguished by the extent to which users control record access and contents. Recently launched PCHR platforms include Google Health, Microsoft's HealthVault, and the Dossia platform, based on Indivo.

Objective: To understand the acceptability, early impacts, policy, and design requirements of PCHRs in a community-based setting.

Methods: Observational and narrative data relating to acceptability, adoption, and use of a personally controlled health record were collected and analyzed within a formative evaluation of a PCHR demonstration. Subjects were affiliates of a managed care organization run by an urban university in the northeastern United States. Data were collected using focus groups, semi-structured individual interviews, and content review of email communications. Subjects included: n = 20 administrators, clinicians, and institutional stakeholders who participated in pre-deployment group or individual interviews; n = 52 community members who participated in usability testing and/or pre-deployment piloting; and n = 250 subjects who participated in the full demonstration of which n = 81 initiated email communications to troubleshoot problems or provide feedback. All data were formatted as narrative text and coded thematically by two independent analysts using a shared rubric of a priori defined major codes. Sub-themes were identified by analysts using an iterative inductive process. Themes were reviewed within and across research activities (ie, focus group, usability testing, email content review) and triangulated to identify patterns.

Results: Low levels of familiarity with PCHRs were found as were high expectations for capabilities of nascent systems. Perceived value for PCHRs was highest around abilities to co-locate, view, update, and share health information with providers. Expectations were lowest for opportunities to participate in research. Early adopters perceived that PCHR benefits outweighed perceived risks, including those related to inadvertent or intentional information disclosure. Barriers and facilitators at *institutional*, *interpersonal*, and *individual* levels were identified. Endorsement of a dynamic platform model PCHR was evidenced by preferences for embedded searching, linking, and messaging capabilities in PCHRs; by high expectations for within-system tailored communications; and by expectation of linkages between self-report and clinical data.

Conclusions: Low levels of awareness/preparedness and high expectations for PCHRs exist as a potentially problematic pairing. Educational and technical assistance for lay users and providers are critical to meet challenges related to: access to PCHRs, especially among older cohorts; workflow demands and resistance to change among providers; inadequate health and technology literacy; clarification of boundaries and responsibility for ensuring accuracy and integrity of health information across distributed data systems; and understanding confidentiality and privacy risks. Continued demonstration and evaluation of PCHRs is essential to advancing their use.

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KEYWORDS

Medical records; medical records systems, computerized; personally controlled health records (PCHR); personal health records; electronic health record; human factors; research design; user-centered design; public health informatics

Introduction

A personal health record (PHR) is a digital Web-based collection of a patient’s medical history in which copies of medical records, reports about diagnosed medical conditions, medications, vital signs, immunizations, laboratory results, and personal characteristics like age and weight are stored [1]. PHRs have been much discussed over the past few years, and considerable activity concerning them is occurring in health information technology, policy, and market sectors. In recent years, three personally controlled health record (PCHR) platforms have launched: Google Health, Microsoft’s HealthVault, and the Dossia consortium of large employers (including Walmart, Intel, and AT&T) which has a platform based on our open source Indivo PCHR. The PCHRs are a special class of PHRs distinguished by the extent to which users control record access and contents [2]. User control over these functions is governed by subscription and access control mechanisms and annotation capabilities within the record system [3]. It is generally assumed that increasing individuals’ abilities to view and share their medical histories or clinical decision support messages, including from distributed information sources, multiple care sites, and time periods, will result in better self-care preparation and motivation, reductions in treatment and medication errors, and improved health [2-7].

While anticipated benefits of PCHRs may eventually drive their diffusion, the overall approach of a citizen- or patient-centered health record system that interoperates with, but is not tethered to, a provider system represents a fundamental change from current approaches to health information management. Transforming standard practice may be challenging for a myriad of reasons [8]: low levels of health and technology literacy may impede technology uptake and use [9,10], distrust of Web-based health information systems [11], privacy concerns [12-14], and inequalities in access to/accessibility of computerized health information tools may slow adoption [15,16]. Adoption and use may be negatively effected by fears of disrupted and altered service relationships and pushback from providers. Rapid technology development and potential for benefit from PCHRs underscore the importance of understanding acceptability, barriers, and facilitators to their use.

We conducted patient-centered research on beliefs and reactions to the Indivo PCHR, a model PCHR deployed as part of a federally funded technology demonstration. Indivo is an open source PCHR platform that has served as the model for the burgeoning PCHR movement [2,17]. In situ/in vivo experiences and preferences for using PCHRs such as Indivo are important additions to survey and opinion research about PHRs in general. Indivo combines a Web-based health record with integrated capabilities for running a survey tool and rules engine, decision support and health messaging components, user-defined access controls, and sharing and annotation capabilities [2,7]. We deployed Indivo to a community of early PCHR adopters and undertook a range of formative research efforts to learn more about beliefs and behaviors governing PCHR use, stakeholder and lay understanding of the technology, and reactions to the system. Our primary aim was to learn more about the acceptability of PCHRs using Indivo as a test case by describing assumptions about the technology, as well as barriers and facilitators to its adoption. Our secondary aim was to identify design and policy issues germane to best practice technology development for consideration prior to refining the system for diffusion and evaluation.

Methods

Qualitative data about beliefs, attitudes, and preferences related to the personally controlled health record system were collected over a two-year period (May/June 2006 through April 2008). Questions and observational assessments focused on identifying assumptions, reactions, and preferences germane to the PCHR technology, as well as barriers and facilitators to its use. All study protocols were reviewed and approved by Institutional Review Boards governing human subject research at both the study site and Children’s Hospital Boston.

Setting

The study was sited in an urban area within the northeastern region of the United States. The setting was a community-based, university health maintenance organization, and the samples, described below, were comprised of persons affiliated with the site and setting.

Samples

A range of study participants was included in each of three formative research activities: administrative, clinical, and public health stakeholders (n ~ 20) from the study community participated in focus group and one-to-one interviews. Participants were adults, 35 - 60 years of age, with training in medicine and/or health care administration. There were 12 usability testers and 40 pilot participants, all of whom participated in observational assessments and usability and pilot testing antecedent to the system’s demonstration deployment. Testers included undergraduate, graduate, employee, and retiree populations 25 - 65 years of age. Approximately 250 users 18 - 83 years of age (with an average age of 53) participated in the demonstration study, from which 81 email communications to study administrators were logged and their content analyzed. All participants were English speakers, were volunteers, and provided written informed consent and HIPAA authorization for sharing personal health information when piloting with live records.

Analytic Approach

Narrative data were collected in three formats: (1) transcribed audio-taped focus group interviews conducted with stakeholders and pilot users; (2) written observational notes of usability testing compiled by the study team; and (3) text communication from email exchanges with demonstration participants. Collection and analysis of data for each of these activities involved the following specific activities.

We used a semi-structured protocol to collect focus group data. Questions about health information management, Internet use, and personally controlled health records were asked of early adopters, including administrators and clinicians at the study sites. Follow-up probes were used to elicit information about attitudes, preferences, and reactions to the PCHR model. A trained moderator and an observer facilitated group discussions, and all data were transformed to narrative (transcript) notes for analysis.

We used a formal usability testing protocol to observe interactions with, and reactions to, the PCHR in a semi-standardized fashion. The protocol involved engaging testers in interactions with an advance (beta) version of the final system configured as a live record. Each tester's record was populated with the test user's actual medical record data with individual consent and IRB approval. Testers completed specific tasks presented to them in a checklist of test activities (eg, review your laboratory data, add a "device" to your record in the appropriate location). A range of activities was included in the test, including registering, reviewing personal health information, amending health information, identifying categories of information (eg, laboratory results, problems, medications), completing behavioral health surveys, and sharing health information. Testers were observed by a trained team of developers and the study principal investigator who took notes about questions, failures, reactions, level of interest, and engagement. Each observer was assigned 2 - 3 testers to follow in a demonstration setting. Testers were asked to "talk aloud" their thoughts and actions as they completed the various team-specified functions. The objective was to learn more about how they interacted with the system to solve problems and to assess whether attempted actions matched expectations. At the close of testing sessions, semi-structured discussions were held to elicit feedback from testers. Notes made by observers were compiled as memos in narrative form which were used to fine tune the user interface and inform our understanding of reactions to the technology and individual engagement with personal health information.

We tracked all subject-initiated email communication with the study team through the full pilot period of six months. Emails were individually reviewed, redacted of identifying information, organized, and analyzed for major and minor themes as described above. Two independent, trained analysts reviewed communications, independently coded them, and then reviewed their summaries to arrive at a consensus. Narrative data were summarized for this report.

For analysis of all narrative/text data, two analysts (ERW and LK) worked independently with a shared rubric of major thematic codes to describe the data. Major constructs were operationally defined for thematic analysis as follows: *Awareness of PHRs/PCHRs* was defined as familiarity with the concept and/or practice of Web-based, patient-controlled health record systems. PCHRs were distinguished from PHRs and electronic medical records by the degree to which patients versus providers have control over the system and its information content. *Privacy of personal health information* was defined as the ability of individuals to control access to their PCHR and the security/integrity of health information [18,19]. *Autonomy* was operationally defined as individual control over selection and subscription to data sources; the ability to self-report or update health information; authorization of access and sharing permissions; and control over messaging. Additionally, several pilot users were debriefed about the consent process, considered a key component to the public face of the PCHR [20]. Analysts read all narrative data independently to assign codes to text fragments and develop subsidiary coding schemes. Coding schemes and transcripts were worked iteratively and inductively to refine them and achieve consensus. Data were triangulated across the three assessment activities to build a comprehensive picture of issues related to awareness, privacy, autonomy, and barriers to/facilitators for acceptability and use.

Findings reflect triangulation of data collected at different junctures over the formative evaluation and pilot period but do not reflect a pre/post assessment of acceptability. We report on experiences and perceptions common across multiple respondents. Illustrative quotations are provided in table form (with select exceptions where quotations are included in the descriptive text) to describe prevailing norms and experiences. Barriers and facilitators were identified by the study team, based on close observation of the pilot system implementation in the context of other formative data, and reflect the consensus of the study team, drawing on a synthesis of stakeholder and user reports and experiences generated from the data. Barriers and facilitators are categorized as primarily societal, interpersonal, or individual level factors. Practice recommendations for policy and design are suggested in the discussion section and summarized in a text box based on the pattern of observed barriers and facilitators and formative findings.

Results

Findings which concern levels of awareness of PCHRs, privacy, and autonomy, as well as variations by stakeholder group/role or age group are summarized below and discussed (Table 1).

Awareness of PCHRs

Participants demonstrated low levels of awareness about personal health record technologies including PCHRs. Prior to the pilot deployment, none were using automated systems to store or manage their own health information, and none had heard about or followed public or professional discussions about PCHRs. No age differences were evident in awareness about PCHR technology in general. Variation in understanding about subscription models to sources of personal health information (PHI) may have been present. Younger individuals and students (ie, those in the 18 - 35 approximate age range) appeared more familiar with the concept of subscribing to a data system; however, few subjects appeared to have considered this model for obtaining personal health information.

Overall, participants appeared to overestimate the extent to which personal health information is available and flowing electronically within provider systems. Many assumed that such information flow already occurs or that it was inevitable in the near future. Perceiving oneself as personally excluded from electronic health information systems was common. Desire for inclusion and control over PHI comprised a significant motivator for system adoption/use. No differences in age were apparent in these beliefs and perceptions.

Privacy

In general, we observed a moderate level of concern about privacy characterized by a pragmatic technology-supporting norm in which risks to privacy were considered unavoidable. Several specific mechanisms by which privacy might be threatened were identified, including: intentional identify theft, disclosure and misuse of information by insurance companies, accidental mix-up of records and their contents, mismatch of medical records data with personal health records, and misuse and inappropriate viewing, including “snooping” and attempts by health professionals to track or follow-up on outcomes of former patients and co-workers. Participants recognized the potential that privacy could be breached and that such breaches could result in serious harm. The most salient adverse outcomes related to breach of privacy were threats posed to insurability and/or denial of employment or care. Across all groups of subjects, the possibility of an audit check appeared to be among the most reassuring and accessible options for safeguarding privacy and building confidence.

Perceived risks to privacy were offset by an understanding that one’s privacy is risked in paper information exchange as well. Concerns about inadvertent or intentional breach of privacy were discounted by the high value placed on ready access to health information, especially in emergency conditions.

Students and younger users (typically those under 50) may be more sophisticated than older users about technological strategies for ensuring privacy. They appeared familiar with a range of technologies to improve privacy and security including use of encryption, digital signatures, and certificates. Despite their greater technological sophistication, younger users may possess a limited understanding of harmful consequences of sharing information and maintaining a lax privacy practice. In focus groups, young adult subjects (18 - 35 years of age) expressed widely varying opinions about whether it was safe to share health information with persons who were not providers; moreover, younger individuals appeared to be poorly informed of, and to have a naïve appreciation for, potential risks to insurability or employability related to disclosure of health information/records and problems.

Older and retired participants perceived risks related to a breach of privacy and reported they have “less to lose” than younger and employed persons. Some participants expressed concern about stigma or discrimination resulting from the release of PHI. Risks from inadvertent release of infectious, mental health, and chronic disease diagnoses were all recognized, with no clear emphasis on one category of illness as being particularly problematic. Participants, especially older ones, were worried that information disclosure through a PCHR could impose an emotional burden on family members.

Across age groups, many individuals assumed that sick individuals would be acutely concerned about privacy risks and less willing to participate in electronic information exchange/data sharing than healthy individuals. The assumption that sick persons are more concerned than healthy persons with privacy was not borne out in preliminary findings. For some users, chronic illness appeared to offset perceived risks associated with information sharing and motivated demand for accessible and transmissible information, as indicated by one participant:

> *I would be very interested in having access to all my records. I think this type of program will make my life in particular a whole lot easier.*

Within the pilot, concerns for privacy were rapidly overridden by the need for help understanding technical or clinical issues. Participants readily disclosed personal information about diagnoses, conditions, and complications with project staff through email communication in the context of verifying and understanding information in their record:

> *Hello, I'd like some explanation of the health record that has been posted on my indivo page. There are things there I've never heard of, and important things that aren't there. I don't know what anything means .... Something says I was screened for malignant cancer of the cervix. When? I don't remember anything like that. And viral arthritis? When? What? Please explain, please refer to me to someone who's in charge.*

Some participants shared nonclinical, identifying information, including passwords, in email exchanges with project staff. Actual privacy practices were different from espoused privacy concerns for some participants, and substantial vulnerability to privacy risks was observed.

Autonomy

Users expressed high value and interest in the concept of autonomy and welcomed greater access and control of their health information. While highly valued, autonomy was perceived as a double-edged sword. Sticking points included concerns about the locus of responsibility for maintaining the accuracy and integrity of PHI. Users wanted assurances that outdated or erroneous information that they identified and amended in their personal health record would be updated in subscription data sources. They were concerned about ramifications of intentionally or inadvertently changing PCHR contents and nervous about entering their own information using the system’s tools for annotation. Discomfort among some users with the idea of personal or patient annotation was echoed by providers and health service administrators who framed this concern in terms of quality of care, completeness of health information, and risks for liability.

While individual control over PHI was valued highly by younger/student participants (18 - 35 years of age), substantial variability was evident in opinions about the safety of granting write access control over their records to any other person, including for some, a primary care provider. Some viewed the patient/record owner as the final arbiter of a record’s contents, while others considered the primary care provider as the final arbiter. The value older participants assigned to personal control and autonomy, including as a source of accessible information in emergency conditions, was mitigated by the concern that their records could be inaccessible should they become impaired due to illness or age if they did not arrange for access by significant others or proxies.

Generally speaking, users placed a premium on the ability to control access to their health information and, generally speaking, favorably viewed options to control access to their PHI and share their records with members of their family or close social group (significant others, etc). Nevertheless, few users formally shared their records in practice despite the ability to do so; those that did used workarounds or informal—and riskier—approaches to sharing, rather than the formal sharing mechanism engineered within the system. The pilot system was implemented with a model of strict individual autonomy. This model was intentionally subverted by several users who shared passwords and account information with family members to advance caring relationships. Evidence of this turned up throughout the pilot as sharing of email accounts and record information, typically among older spouses as multiple email communications illustrate (Table 1).

Strict user control of incoming and outgoing messages delivered through the PCHR was viewed by many participants as an essential ingredient of an autonomous system and a prerequisite to sustained use. The ability to filter incoming messages by content and frequency was highly valued. Such abilities may be inconsistent with expectations of automatic tailoring of messages to contents of records and prior health communications. Vertical integration of systems such that messages, alerts, and communications are wholly integrated with user preferences represent design/implementation areas for which tools and best practices may be needed.

Table 1. Awareness, privacy, and autonomy factors bearing on acceptability of personally controlled health records

Construct	Finding	Age/role pattern	Illustrative quotations
Awareness			
Awareness of electronic medical (health) records	Assumption that health information is digital, ubiquitous, accessible	All groups	*[Personal health] information is more and more on computers ... whether I choose to interact with that doesn't change the fact it's online and everyone else is interacting with it ... the only choice I'm making is whether I interact with it.*
Access to electronic health records, PHI	Perceived exclusion of individual access to electronic PHI	All groups	*The truth is that in terms of our access, we're the only one's that don't have it. In terms of my life all my information is electronic. We're the only ones who don't have it: How crazy is that?*
Familiarity with patient-controlled health record systems	No prior use or familiarity, intrigued and assume PCHR will advance quickly	All groups	*I think ten years from now we won't even be discussing this, five years from now ... it'll be a done deal. Five years from now ...*
Privacy			
Ability of individuals to control access to their PCHR and the security/integrity of health information	Moderate concern, pragmatic, technology supporting norm	Young adults naïve to risks from sharing	*The systems will continue to do what they can to maintain [privacy] and the reality of our world is that in some cases as we see in the papers all the time privacy will be breached. And that's part of the reality of the world we live in and continue to live in and the choice we make [to interact with technology and use systems] has nothing to do with that.*
Perceived privacy risks and threats	Concern for abuse of information by insurer, employer	Greater among employed	*Is there anyone who is going to be able to access that information who is going to be damaging to me who is going to use that information in a bad way—an insurance company who can have access to the information anyway and always have?* *The thing I want to be hesitant with, it's kind of a moral issue with a future employer maybe, don't want to see that I've been tested for diabetes and the amount of family history of diabetes ... because they're afraid that I night die when I'm 30 or 40 and they might want to hire me forever ...*
	Assumption that persons with health problems more vulnerable, more concerned	All groups	*On the medical side, having information online, having it shared, I perceive that as a personal benefit ... If I go to one physician/system then to another, that doctor can pull up my information ... I view that as a personal benefit and I want that for my own health. If I had a sensitive health issue or diagnosis, I might view it differently ...* *If I had a sensitive med problem might have more worry about [privacy breach, sharing information] ...*
Perceived qualifiers of privacy risk	Understanding that other information media (including paper records) have risks	Greater among administrators and providers	*I think you are more vulnerable with a paper record. I have seen more errors with paper records, papers misfiled and you see that in a paper record. It's human error. It's usually that the MRN is one digit off ... Is that not a breach of confidentiality? Or, you take pieces of information and put them in an envelope and send it to medical records. That's not very secure if you ask me!*
	Perceived personal benefit of access to health information	All groups	*[It's] to a consumer's advantage to have that information shared by all your providers and to be able to access it yourself to some extent.* *I think on the medical side, having the info online, having it networked with the hospitals I go to, I perceive it as a personal benefit, I'm going to benefit.*
Safeguards against risk	Premium value on audit check	All groups	*But the thing is there's an audit. On a paper [record], there is no audit.* *I can understand how it puts the patient in control of who sees his/her records, but I want to understand that there is a clear and easy-to-use means of monitoring who has access at any given time and the patient has the ability to change that permission at will.*
Autonomy			
Control over subscription, self-reporting, sharing, messaging	Favorable view of autonomy	All groups	*I like the "out-of-the-box" concept of putting the patient in charge via their own control of the records.*

Construct	Finding	Age/role pattern	Illustrative quotations
			You know I kind of think about this as ... when I have a mammogram or couple months ago I had an MRI, I don't want a report from the doctor that says "it's normal" I want "the report". So what I have to do is I have to call, then I have to fax them an okay, then they won't fax it to me ... they have to mail it to me. To me, it's because I want it, it's not their legal obligation to send me a copy of that report. It's their ethical and practice obligation to let me know the results. So I kind of think about this online, record online, it's my record, it's nobody else's record, if I want this [report] in it, it's my choice. I might say that I don't want my neurologist or whatever to put anything in to it.
	Concern about quality, accuracy and locus of responsibility for maintaining record, workflow impacts	Shared by patient, administrator, provider	*[W]hat becomes our responsibility here in terms of patient care? Let's say something goes really bad with a patient and it turns out that there's a piece of information in the PHR that if our clinician had had access to it or had been looking closely at both records, the outcome could have been different ...* [administrator]
			If the patient has their own record, there is a lot of information they don't understand, there could be a lot of phone calls to their provider to explain the information that they don't understand. And there will be a lot of phone calls to their physician to explain. And we can't fit in a visit [to the clinical calendar] to explain ... [provider]
			So as a provider, if I look at it, I have to look at it for what it is: the information that's in there is what the patient wants in there, and there may be other variables, that it's not all there. [provider]
			I have checked my record and the latest two years of immunizations are still missing. There is a window where I can add them but that seems not to be in the spirit of the system. It would be better if such info were added by someone authorized who has the correct data. [patient]
			Apparently I cannot edit the medications in my record and there are errors. I've added annotations, but either I should be able to edit the record, or there should be some way for me to get corrections made. [patient]
	Uncertainty about appropriate and safe read/edit access policies	Evident among young adults/students	*[What kind of access would you give primary care provider?] Read, append, not necessarily write, [primary care providers] don't get to delete things…*
			It would be nice if the physician could delete [information] ... if you update something.
			You should have final say over what's in your record ...
			No one should be able to delete something in a record ...
	Concern about aging, illness and competency to manage records	Evident among older users and retirees	*... Finally, you will have to prepare for the final insult where someone capable of using the system becomes incapacitated and the system still needs the records even though the password and permission is locked in a non-responsive being (accident trauma, Alzheimer disease, etc).*
	Subversion of strict autonomy controls by users in caring social relationships	Evident among older users	*Hi - I answered the Indivo Nov. 15 survey just now. However, it came to our Verizon email address instead of the email address that I use. My name is ____, user name _____ and the email I use is __. The survey came to the email address that (spouse) uses, and he was unable to log in using his user name of _____. We decided it was for me - do you have the correct email addresses for each of us?*
			My wife's account and mine are overlapping and while she can access her site with you, mine has her name and address listed for me. Is there a way of separating them?
	Preference for strict personal control of messaging	All groups	*I would like to control this system so that I receive ONLY specific items [messages] related to my PERSONAL health specifics.*

Barriers and Facilitators

Barriers and facilitators to adoption and use of the system were identified at institutional, interpersonal, and individual levels from across all formative data collected (Table 2). Several of these barriers and facilitators were notable for their broad policy and practice implications and are highlighted here.

Uncertainty about locus and extent of responsibility for ensuring PCHR accuracy given the distributed nature of subscription data sources comprised a barrier to adoption across social levels. Concern was expressed by administrators, clinicians, and patients/individuals about potential liability and quality of care risks associated with patient access to PHI through a clinically disintermediated system that permits user annotation and sharing. The potential for confusion and misalignment of information systems resulting from diverging health information in cases where users annotate or amend patient-reported information in the PCHR was noted. The absence of a mechanism for automatically feeding back annotations to subscription data systems concerned stakeholders from all groups. Concern over this issue may comprise an impediment to adoption at institutional and individual levels.

In a similar fashion, uncertainty about responsibility for clarifying the meaning and contents of records and concern about time requirements to address patient questions affected stakeholder buy-in and challenged norms for interpersonal relationships between patients and providers. While observed levels of problems were lower than anticipated, they were exacerbated by gaps in health and technology literacy. Older/retired persons in particular encountered technical barriers around system access, underscoring the importance of clarifying responsibility and resources for help. Lay and technical vocabularies do not match, causing consternation among users who see unfamiliar and/or frightening content in records. Providers are not always well positioned or resourced to respond to users' questions.

Our PCHR system was available as part of an IRB reviewed demonstration. A dearth of guidelines and precedents for operating human subject research within a PCHR environment posed barriers to implementation and required education of IRBs and review panels. Research norms stipulating tight investigator control of information are contradicted by PCHR models of strict individual autonomy and control of information. The tension between these models needs to be understood and negotiated with IRBs to authorize research-based implementations. We developed and used an automated multistage consent process that included authorization for release of health information as stipulated under the Health Insurance Portability and Accountability Act [19] to alert and educate users to the significance of PCHR-enabled health information exchange. The multistage consent protocol was partitioned into: a first screen that provided summative information about the study and consent; a second screen that included the full consent and HIPAA authorization; and a third screen with a point-by-point affirmation of consent elements and electronic signature. Despite perceiving that the multistage consent process was arduous, users endorsed its length and the sequential conditioning of information as, "telling me something serious was happening" and "letting me know that you [system/investigators] take this approach seriously". IRB review and a multistage consent process appeared to facilitate lay participation and trust in our research demonstration.

Workflow planning and organizational will are required to ensure appropriate effort is given to authenticating users. From the perspective of institutional gatekeepers and stakeholders, building an interoperable bridge with a vendor-based heath information system to subscribe to EMR data required a modest commitment of resources and had a minimal impact on deployment/use. A modest burden was experienced around authenticating participants/users and development to ensure appropriate export of data from source EMRs to PCHRs.

On the other hand, close alignment of the system with trends for consumer-centered health care and information systems facilitated acceptability at the institutional level and primed acceptance for the approach among some users [21]. The perceived value of the system for advancing knowledge and supporting care and the noncommercial nature of the project facilitated buy-in and participation at institutional and individual levels. The value of a patient reporting to a record prior to a medical visit in order to support care and optimize time was highly valued: institutions, patients, and providers all understand time and attention limits around care visits. The potential value of using a PCHR to support efficient use of a limited resource facilitated acceptance. Institutional stakeholders and users readily identified assets of the PCHR approach relative to portals, especially with respect to the suitability of PCHRs for maintaining life-long health information, traveling with individuals as they leave care settings, and supporting "family" records and socially embedded caring relationships.

Finally, the value of using the PCHR as a platform for increasing health literacy and health engagement was evident in feedback from participants provided during usability testing and communications with the study team, and this may facilitate future development. Users were keenly interested in having a personally controlled health record and in the possibility of the technology advancing toward a platform model that supported multiple functions, including user interface functions that would allow mouse-over explanations of medications, drill-down capabilities to investigate treatments, definitions of medical conditions, problems and treatment strategies, summaries of research evidence, and even—among some testers—linkages to research data. Similar interest was expressed in applications supporting personalized feedback and contextualization of health information, including support for individually reported survey/annotations collected within the PCHR. Interest in these functions was evident across user groups but was consistently expressed by younger (primarily student) users and working adults.

Table 2. Barriers and facilitators to adoption and use of a personally controlled health record system

Barriers	Facilitators
Societal level factors	
Poorly defined locus of responsibility for ensuring information accuracy, integrity	Perceived alignment of PCHRs with norms, trends for consumer-centered health care and information systems
Administrative concerns about liability risks if patient record more complete than provider record	Institutional prioritization of HIT to advance health care and communications
Concern about workflow impacts on IT and clinical staff	Stakeholder support for community participatory research
Complications of interoperating with an evolving vendor-based EMR development landscape	“Branding” of test system and study materials as originating from IRB governed study conducted by a trusted nonprofit
Absence of clear policy/practice supports guiding PCHR use including for research and associated human subject guidelines	Stringent data security: storage behind firewalled, individual record encryption, certificate authentication system
Lack of a private, unique identifier for patients	
Interpersonal level factors	
Provider resistance to allowing patients record access	Outreach to participants from trusted clinical staff at the site
Insufficient time for providers to participate in collaborative record review and address questions from patients about record contents	Perceived utility of a system that allows reporting about health behaviors to a record prior to a provider visit to optimize visit time
Concern that PCHR will challenge provider/patient roles, relationships and that providers will be uncomfortable sharing power	Utility of PCHR "family" record model for supporting health throughout families and across generations
	Perceived utility of PCHRs for sharing information among providers in multiple locations to facilitate comprehensive care.
Individual level factors	
Low levels of technological literacy, self-efficacy especially among older cohorts	Technological know how, experience with other individually controlled record systems (ie, banking)
Uncertainty about who is responsible for ensuring information accuracy and integrity: hesitation, low self-efficacy in navigating health information	Experience with a chronic health problem or need for greater/easier access to a family member's health information
Distrust of Web-based health systems and IT	Attitudes favorable to individual control and autonomy
	Discounted worry about consequences of a privacy breach by users who see value in access to information

Discussion

Principal Results

Formative evaluation about acceptability of a PCHR in a community setting confirmed that issues related to privacy, autonomy, and accessibility of technology and health information all play a role in uptake and use of nascent systems. Low levels of awareness about personal health record technologies, including PCHRs, and lack of familiarity with the concept of subscribing to a health information data source may produce barriers to creating robust and complete records for some users. Keen privacy concerns coexist with pragmatic norms when addressing the risk of privacy. These factors were identified within the context of low levels of awareness about PCHR technologies and substantial thirst for access to, and control of, PHI. Privacy and safety conditions prefigured trust and were lynchpins for technology adoption and use, consistent with expectations [12]. Espoused concerns for privacy were belied by somewhat lax privacy practices, indicating a need for careful design-based protections in which users are continually educated and reminded about safe practice. This may be especially so among younger individuals whose privacy concerns may be naïve. The self-selected nature of the pilot sample precludes assessment of the degree to which privacy concerns impeded technology uptake. However, we saw little indication that privacy concerns alone constitute a barrier sufficiently large to impede broad adoption and use.

Strict protection of autonomy was highly valued among PCHR users. Nevertheless, autonomy practices were intentionally subverted within some family and social relationships consistent with others’ reports about management of health information in the home [23]. Perceived imperatives to solve technical problems and/or understand the meaning of health information rapidly eroded privacy and autonomy practices among users. Users readily disclosed personal information and gave others access to their records to solve technical problems or discuss record contents. Expressions of uncertainty about the locus of responsibility for verifying the accuracy of PCHR contents and for ensuring alignment of distributed health information systems where users could annotate the PCHR were voiced by all stakeholder groups and reflect tensions relating to the autonomous PCHR model.

Sharing capabilities were highly valued but underutilized in this early deployment. Findings confirm predictions of the needs for technical assistance and for education of users engaged with this new approach to information [24]. Assessment of, and planning for, the effects of broad technology diffusion on the workflows of a range of stakeholder groups is needed: impacts of this new approach on clinicians, information technology professionals, and staff providing ethical oversight and management of HIT and research need monitoring. Clear operational guidelines, governance systems, and administrative supports are needed, along with relevant consent and technical assistance materials. Caution is warranted when basing PCHR policy and design decisions on opinions about privacy and autonomy without practice-based evaluation, given the possibility for divergence between policy and practice and distortion of others' preferences and sensitivities.

Implications for Policy and Practice

The following summative conclusions for design and policy work to advance PCHRs are offered based on observations from formative research relating to a first community-based deployment of an integrated PCHR:

- Discussion about technical and policy approaches is needed to identify strategies for aligning PCHR and subscription data systems, as feasible, to address the possibility of misalignment of information systems where individuals can amend/annotate patient-reported information in the PCHR. Discussion about design options that allow feedback, flagging or reciprocal notification of amended patient-reported information in the source record may be useful given concerns about misalignment and attendant risks for misinformation across individual user, administrator, and clinician groups. The acuity of this issue may increase with intensifying federal emphasis on rapid advance of PCHRs. In the scenario where the PCHR becomes the "record of record", problems of alignment may be resolved.
- Clear lines of responsibility and dedicated resources are needed to support users and advance their understanding of the contents of their records and the meaning of health information to maximize gains from PCHRs. Gaps in health literacy may eventually diminish as the technology proliferates in the emerging marketplace of health information supports. However, discussion and testing of design-based mechanisms for addressing gaps, for example through mouse-over and drill-down capabilities, is warranted, as are exploration and possibly resource allocation for supports extrinsic to the technology that may serve less literate populations. These may include health coaches, interpreters and guidance staff, and/or technology/information system navigators. Consideration of the possible cost and benefit of supporting new ancillary staff positions may be needed in light of the possibility of interrupted or increased clinician workflow when/if users seek more information about their health and records.
- Clear guidelines and materials to educate users about this new technology, privacy risks and safety mechanisms, including those pertaining to sharing approaches are needed. Social marketing materials may be required to advance technology use, clarify dangers, and address barriers of trust and understanding and reduce potential for abuse. Consideration of demographic differences in need may be required: younger users may be especially naïve to adverse consequences of sharing health information, given their norms for intensive information system use and sharing through electronic social media; older users may face greater barriers related to technology literacy in general and special needs around understanding issues related to competency, proxies, and sharing across generations.
- Creation of a family-focused health record system, seen by many as a logical extension of the PCHR approach [22], is not yet supported by a clear technology and practice model. Subversion by users of strict individual autonomy models for PCHRs suggest the merits and relevance of exploring whether and how personally controlled health records can be designed and rooted in policies that reflect options for social and familial records to support caring relationships and collective knowledge.
- Advances in protocols and models for governing human subject participation in research-based PCHRs and research which enables, or operates through, PCHRs are needed. Education, training, and technical assistance materials are necessary for investigators, IRB panel members and offices, and individuals/subjects. Parallel mechanisms and supports are needed for monitoring fairness, safety, and transparency in commercial and service PCHR applications. For the latter, IRB oversight and consent may not be required although mechanisms for clarifying terms of use, information control, governance, quality assurance, and health information exchange are needed.

Limitations

To the best of our knowledge, this is the first report about the acceptability to users in a community-based setting of a personally controlled health record—in this case, a platform system that puts users in control of PHI from an electronic medical record to which they subscribed. This study was sited in a community of early adopters with relatively high levels of health and technology literacy. This work is limited by its single site/early adopter design and inherent selection effects stemming from that design. Continued study is needed which employs approaches representative of the population and standardized metrics to explore the potential for variations in PCHR acceptability, and barriers and facilitators which reflect age, role, and other characteristics suggested by findings of this formative work. The work is also limited by the early stage of technology development of the test system and the qualitative methods employed. These factors limit inferences about the broader acceptability of the PCHR technology and impact of various barriers/facilitators. Such limitations are, however, typical in formative research of a new technology or concept. Rigorous evaluation of PCHR deployments in expanded samples/settings are recommended to advance understanding of PCHR acceptability and impacts and to develop best practice approaches for addressing the institutional, interpersonal, and individual challenges.

Conclusions

PCHRs are widely viewed as a disruptive innovation that may be transformative in health care. Before we can expect uptake by consumers en masse, potential barriers to adoption and use must be addressed. Early experiences with Indivo, the original reference PCHR, have identified societal, interpersonal, and individual level barriers and facilitators to address through near term system redesign and revised social marketing of the technology. Responding to these observations and continued evaluation may substantially advance the use and relevance of the PCHR platform model otherwise endorsed by users.

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Conflicts of Interest

In the past, Drs Weitzman and Mandl received support from Children’s Hospital Boston to guide the translation of the Indivo technology to the Dossia environment. No other potential conflict of interest relevant to this article was reported.

References

1. Halamka JD, Mandl KD, Tang PC. Early experiences with personal health records. J Am Med Inform Assoc 2008;15(1):1-7 [FREE Full text] [Medline: 17947615] [doi: 10.1197/jamia.M2562]
2. Mandl KD, Simons WW, Crawford WCR, Abbett JM. Indivo: a personally controlled health record for health information exchange and communication. BMC Med Inform Decis Mak 2007;7(1):25 [FREE Full text] [Medline: 17850667] [doi: 10.1186/1472-6947-7-25]
3. Mandl KD, Szolovits P, Kohane IS. Public standards and patients' control: how to keep electronic medical records accessible but private. BMJ 2001 Feb 3;322(7281):283-287 [FREE Full text] [Medline: 11157533] [doi: 10.1136/bmj.322.7281.283]
4. D'Alessandro DM, Dosa NP. Empowering children and families with information technology. Arch Pediatr Adolesc Med 2001 Oct;155(10):1131-1136 [FREE Full text] [Medline: 11576008]
5. Poon EG, Wald J, Schnipper JL, Grant R, Gandhi TK, Volk LA. Empowering patients to improve the quality of their care: design and implementation of a shared health maintenance module in a US integrated healthcare delivery network. Medinfo 2007;12:1002-1006. [Medline: 7911866]
6. Detmer D, Bloomrosen M, Raymond B, Tang P. Integrated personal health records: transformative tools for consumer-centric care. BMC Med Inform Decis Mak 2008;8(1):45 [FREE Full text] [Medline: 18837999] [doi: 10.1186/1472-6947-8-45]
7. Bourgeois FT, Simons WW, Olson K, Brownstein JS, Mandl KD. Evaluation of influenza prevention in the workplace using a personally controlled health record: randomized controlled trial. J Med Internet Res 2008;10(1):e5 [FREE Full text] [Medline: 18343794] [doi: 10.2196/jmir.984]
8. Ash JS, Bates DW. Factors and forces affecting EHR system adoption: report of a 2004 ACMI discussion. J Am Med Inform Assoc 2005;12(1):8-12 [FREE Full text] [Medline: 15492027] [doi: 10.1197/jamia.M1684]
9. Andrus MR, Roth MT. Health literacy: a review. Pharmacotherapy 2002 Mar;22(3):282-302. [Medline: 11898888] [doi: 10.1592/phco.22.5.282.33191]
10. Davis TC, Williams MV, Marin E, Parker RM, Glass J. Health literacy and cancer communication. CA Cancer J Clin 2002;52(3):134-149 [FREE Full text] [Medline: 12018928] [doi: 10.3322/canjclin.52.3.134]
11. Becker C. Technical difficulties. Recent health IT security breaches are unlikely to improve the public’s perception about the safety of personal data. Mod Healthc 2006;36:6-7,16,11. [Medline: 16515213]
12. Tracy CS, Dantas GC, Upshur REG. Feasibility of a patient decision aid regarding disclosure of personal health information: qualitative evaluation of the Health Care Information Directive. BMC Med Inform Decis Mak 2004 Sep 10;4(1):13 [FREE Full text] [Medline: 15361257] [doi: 10.1186/1472-6947-4-13]
13. Myers J, Frieden TR, Bherwani KM, Henning KJ. Ethics in public health research: privacy and public health at risk: public health confidentiality in the digital age. Am J Public Health 2008 May;98(5):793-801. [Medline: 18382010] [doi: 10.2105/AJPH.2006.107706]
14. Safran C, Bloomrosen M, Hammond WE, Labkoff S, Markel-Fox S, Tang PC, et al. Toward a national framework for the secondary use of health data: an American Medical Informatics Association White Paper. J Am Med Inform Assoc 2007;14(1):1-9 [FREE Full text] [Medline: 17077452] [doi: 10.1197/jamia.M2273]
15. Lorence D, Park H. Study of education disparities and health information seeking behavior. Cyberpsychol Behav 2007 Feb;10(1):149-151. [Medline: 17305464] [doi: 10.1089/cpb.2006.9977]
16. Miller EA, West DM. Characteristics associated with use of public and private web sites as sources of health care information: results from a national survey. Med Care 2007 Mar;45(3):245-251. [Medline: 17304082] [doi: 10.1097/01.mlr.0000244509.60556.49]
17. Mandl KD, Kohane IS. Tectonic shifts in the health information economy. N Engl J Med 2008 Apr 17;358(16):1732-1737. [Medline: 18420506] [doi: 10.1056/NEJMsb0800220]

18. Civan A, Skeels MM, Stolyar A, Pratt W. Personal health information management: consumers' perspectives. AMIA Annu Symp Proc 2006:156-160 [FREE Full text] [Medline: 17238322]
19. ; Centers for Disease Control and Prevention (CDC). HIPAA privacy rule and public health. Guidance from CDC and the U.S. Department of Health and Human Services. MMWR Morb Mortal Wkly Rep 2003 May 2;52 Suppl:1-17, 19-20 [FREE Full text] [Medline: 12741579]
20. Clark AM, Findlay IN. Attaining adequate consent for the use of electronic patient records: an opt-out strategy to reconcile individuals' rights and public benefit. Public Health 2005 Nov;119(11):1003-1010. [Medline: 16185734] [doi: 10.1016/j.puhe.2005.08.013]
21. Keselman A, Logan R, Smith CA, Leroy G, Zeng-Treitler Q. Developing informatics tools and strategies for consumer-centered health communication. J Am Med Inform Assoc 2008;15(4):473-483 [FREE Full text] [Medline: 18436895] [doi: 10.1197/jamia.M2744]
22. Bourgeois FC, Taylor PL, Emans SJ, Nigrin DJ, Mandl KD. Whose personal control? Creating private, personally controlled health records for pediatric and adolescent patients. J Am Med Inform Assoc 2008;15(6):737-743. [Medline: 18755989] [doi: 10.1197/jamia.M2865]
23. Moen A, Brennan PF. Health@Home: the work of health information management in the household (HIMH): implications for consumer health informatics (CHI) innovations. J Am Med Inform Assoc 2005;12(6):648-656 [FREE Full text] [Medline: 16049230] [doi: 10.1197/jamia.M1758]
24. Harrison J, Booth N. Applying new thinking from the linked and emerging fields of digital identity and privacy to information governance in health informatics. Inform Prim Care 2003;11(4):223-228. [Medline: 14980062]

Abbreviations

EMR: electronic medical record
HIPAA: Health Insurance Portability and Accountability Act
HIT: health information technology
IRB: institutional review board
PCHR: personally controlled health record
PHI: personal health information
PHR: personal health record

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Original Paper

Content and Frequency of Writing on Diabetes Bulletin Boards: Does Race Make a Difference?

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Abstract

Background: Diabetes-related disparities are well documented among racial minority groups in the United States. Online programs hold great potential for reducing these disparities. However, little is known about how people of different races utilize and communicate in such groups. This type of research is necessary to ensure that online programs respond to the needs of diverse populations.

Objective: This exploratory study investigated message frequency and content on bulletin boards by race in the Internet Diabetes Self-Management Program (IDSMP). Two questions were asked: (1) Do participants of different races utilize bulletin boards with different frequency? (2) Do message, content, and communication style differ by race? If so, how?

Methods: Subjects were drawn by purposeful sampling from participants in an ongoing study of the effectiveness of the IDSMP. All subjects had completed a 6-week intervention that included the opportunity to use four diabetes-specific bulletin boards. The sample (N = 45) consisted of three groups of 15 participants, each who self-identified as American Indian or Alaskan Native (AI/AN), African American (AA), or Caucasian, and was stratified by gender, age, and education. Utilization was assessed by counting the number of messages per participant and the range of days of participation. Messages were coded blindly for message type, content, and communication style. Data were analyzed using descriptive and nonparametric statistics.

Results: In assessing board utilization, AAs wrote fewer overall messages (*P* = .02) and AIs/ANs wrote fewer action planning posts (*P* = .05) compared with Caucasians. AIs/ANs logged in to the program for a shorter time period than Caucasians (*P* = .04). For message content, there were no statistical (*P* ≤ .05) differences among groups in message type. No differences were found in message content between AAs and Caucasians, but AIs/ANs differed in content from both other groups. Caucasians wrote more on food behaviors than AIs/ANs (*P* = .01), and AIs/ANs wrote more about physical activity than Caucasians (*P* = .05) and about walking than the other two groups (*P* = .01). There were no differences in communication style.

Conclusions: Although Caucasians utilized the boards more than the other two groups, there were few differences in message type, content, or style. Since participation in bulletin boards is largely blind to race, age, gender, and other characteristics, it is not clear if finding few differences was due to this optional anonymity or because non-Caucasian participants assumed that they were communicating with Caucasians. If the low variability between racial groups indicates that the IDSMP is flexible enough to meet the needs of multiple racial groups, then online programs may be an accessible and effective tool to reduce health disparities. These questions need to be investigated in future studies.

Trial Registration: Parent trials: Clinicaltrials.gov NCT00372463 and NCT00185601; http://clinicaltrials.gov/ct2/show/NCT00372463 and http://clinicaltrials.gov/ct2/show/NCT00185601 (archived by WebCite at http://www.webcitation.org/5hm2g0AeX and http://www.webcitation.org/5hm2i4XVw)

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KEYWORDS

Self-management; race; Internet; patient education; diabetes

Introduction

The prevalence of diabetes is growing, and more so in some racial groups than others. American Indians/Alaskan Natives (AIs/ANs) are 2.2 times more likely, and non-Hispanic blacks are 1.8 times more likely, to have diabetes than non-Hispanic whites [1]. Diabetes-related mortality is significantly higher for both groups [2]. Population-specific interventions that emphasize individual health behaviors are often cited as an important approach to address these types of health inequalities [2-4]. However, while much has been written on health disparities, less is known about the beliefs and actions of different racial groups as they deal with diabetes. This type of information is critical in order to develop and evaluate interventions and ensure that they respond to the needs of vulnerable populations.

In approaching this subject, it is important to note that racial groups are not homogeneous. There may well be as many differences within a group as between groups. This may explain why some of the literature finds specific beliefs among racial groups while other studies find few differences. For instance, Caballero documents general factors that can affect patient adherence and physician–patient relationships, such as individual and social interaction, judgment and beliefs about the disease, nutritional preferences, quality of life, and religion and faith [5]. Multiple focus groups with African Americans (AAs) and AIs/ANs have documented variations within these and other themes for people with diabetes [6-14]. However, at least one study by Cox et al directly comparing diabetes attitudes, behaviors, and perceived knowledge between low-income AAs and Caucasians with type 2 diabetes found no significant differences [15]. Given these mixed findings, it is especially important to further examine utilization of diabetes self-management programs as these factors may affect the participation and participatory style of people of different races.

Online programs are an attractive addition to self-management education based on their accessibility and potential for reducing health disparities [16-18]. Internet-based programs are easily available, thereby eliminating barriers such as geographic location, work schedules, transportation, and physical disability [19,20]. Participants are relatively anonymous since factors like age, race, gender, socioeconomic status, and disability are not immediately apparent [21]. Some hypothesize that this unique environment helps participants share otherwise embarrassing or sensitive comments and feel that their contributions are valued for their true "quality" [21,22]. Furthermore, the Internet is increasingly becoming a way to reach underserved populations as access for previously underrepresented groups increases [23,24]. Half of those with chronic conditions or disabilities use the Internet, and of that population, 86% have looked for health information [25]. While data on AIs/ANs are sparse, the PEW Internet & American Life Project found in 2005 that 57% of AAs and 70% of whites go online, and in 2008, 43% of AAs had broadband access [23,26]. Jackson et al found that 89% of AAs in their study were willing to use an online diabetes program if they received free computers, and various studies on the Comprehensive Health Enhancement Support System were successful with older sample populations, people without computer skills, and racial minorities [17,27-29].

Yet despite the growth in Internet access and its increasing uses in health care, we know little about how different racial groups utilize and participate in Internet groups. Content analyses of online forums have provided important insights into the various uses and utilization of message boards, especially in the provision of social support [30-33], gender differences [34,35], and general content and utilization [36-41]. Research has also suggested that the association between Internet use and social support can differ by race [42]. However, much more research is needed to explore potential differences and similarities.

This study used a subset of subjects from a larger trial designed to evaluate the effectiveness of the Internet Diabetes Self-Management Program (IDSMP). The IDSMP's predecessor, the Chronic Disease Self-Management Program (CDSMP), has been cited by the Agency for Healthcare Research and Quality as an intervention that could have a significant impact on the health status and health care utilization of racial minorities with diabetes [1]. An online version of the CDSMP has also shown significant improvements in health status that were on par with the community-based program [43].

In the larger trial, participants had to be United States residents over the age of 18 years who spoke English, knew how to read, had basic computer skills, and had Internet access. Exclusion criteria included being pregnant and having undergone cancer treatment. There were no other limitations on comorbidities or HbA_{1c}. A total of 760 adults with type 2 diabetes were recruited, largely through links from other websites and user groups. In addition, links were placed in emails to employees working for large public service agencies. To assure a diverse population, recruitment was targeted toward websites and user groups that served specific populations, such as AA churches and AI user groups.

All participants in the sample for this study completed the IDSMP. This program was designed to emulate small group interaction via the Internet, and all portions of the program were asynchronous. Participants were known to each other only by self-chosen screen names. Approximately 25 participants took part in each 6-week workshop. The workshop consisted of weekly education modules, peer-moderated bulletin boards, and an internal post office where participants could communicate one-on-one. The four bulletin boards were titled Action Planning, Problem Solving, Celebrations, and Difficult Emotions. Each workshop generated between 500 and 700 messages. The program was specifically designed to be culturally neutral, with cultural specificity being supplied by the moderators and other group members.

A previous content analysis of the bulletin boards in the IDSMP AI pilot study offered important insights into participants' experience and needs [36]. This study further investigates these areas for AIs/ANs, AAs, and Caucasians through two main research questions: (1) Do participants of different races utilize bulletin boards differently? (2) Do the type of message, content, and communication style differ by race? If so, how?

Methods

Participant Sample

The sample for the present study (N = 45) was drawn from participants in 20 IDSMP workshops. It was constructed to consist of three 15-person groups of AAs, AIs/ANs, and Caucasians. Due to a limited number of AA men, the sample included all four AA males who had completed workshops at the time of sample selection. Another 11 AA females were randomly selected to complete the group of 15. These participants were then matched to AI/AN and Caucasian participants by gender, age, and years of education. The Stanford Institutional Review Board approved this research project.

Board Utilization

Data included all of the bulletin board messages written by each participant. Utilization was determined by counting the number of posts and responses per participant within each bulletin board as well as the range of days each person logged on (days from first log-on to last log-on). Due to several outliers who wrote many responses, we used a nonparametric analysis. Outliers were found in each of the three racial groups. Wilcoxon signed rank tests were utilized to determine differences between all three pairings of racial groups.

Message Content

The coding unit was one individual message. Messages where one participant responded to another were labeled as “responses,” and all others were considered “posts.” Coding was blind to demographic characteristics. Codes were generated using a hybrid of inductive and deductive methods and were guided by the main social and cultural factors that Caballero cited as considerations for diabetes education programs for racially diverse groups, as well as Lofland’s six areas of description as translated to an online setting [5,44]. The inductive codes were based on the themes found in the literature, such as specific barriers to care and diabetes beliefs [5-14,37,40,44-47]. Deductive codes were based on Grounded Theory and included all codes that did not fit easily into the inductive themes. The full set of 98 codes was combined into 16 nonexclusive codes during multiple coding passes. These codes were organized into three main coding categories: message type (the purpose of the message, such as asking a question or stating a problem), content (the discussion topics), and communication style (the way people address each other, express themselves, and provide support). These categorizations are related to those in previous content analyses, including the purpose of a message, biomedical and socioemotional content, and social cues [37,40,45]. Code validity was assessed by having two researchers double code and compare data from one randomly selected participant from each of the three racial groups. Researchers initially disagreed on and resolved four codes out of 33 messages with a total of 810 coding references, indicating a low incidence of disagreement.

To analyze messages, the percent of a participant’s messages that were labeled with a specific code were averaged by race to control for variations in the number of messages per participant. These numbers, or “mean percent of messages” for a code, were analyzed with analysis of variance (ANOVA), controlling for race. When the ANOVAs were significant ($P \leq .05$) or when there were seven or more percentage points between racial groups, we utilized t tests for further exploration.

Results

Participant Sample

The mean age was 53.7, 52.3, and 50.5 years, respectively, for AIs/ANs, AAs, and Caucasians (range 37 to 61). Average years of education clustered closely at 15.7 for AIs/ANs, 16.1 years for AAs, and 15.9 for Caucasians.

Board Utilization

Participants wrote a combined total of 1067 messages. There were no significant differences in the number of messages for AIs/ANs and AAs. AAs wrote fewer overall messages than Caucasians ($P = .02$), including fewer problem solving posts ($W = -66$, $P = .01$) and action planning responses ($W = -41$, $.01 < P < .02$). Between AIs/ANs and Caucasians, the only significant difference was AIs/ANs posting less on action planning ($W = -57$, $P = .05$). See Table 1 for results.

Table 1. Differences in message frequency by race[a,b,c]

Board	Message Type	AIs/ANs vs AAs				AAs vs Caucasians				AIs/ANs vs Caucasians			
		W	$N_{(s/r)}$	*z*	*P*	W	$N_{(s/r)}$	*z*	*P*	W	$N_{(s/r)}$	*z*	*P*
Action Planning	Posts	33	13	1.14	.25	−10	8	N/A	N/A	**−57**	**13**	**−1.97**	**.05**
	Responses	−9	5	N/A	N/A	**−41**	**9**	**N/A**	**.02-.01** [d]	−6	10	−0.28	.78
Celebrations	Posts	7	9	N/A	N/A	−7	10	−0.33	0.74	−22	11	−0.96	.34
	Responses	−4	7	N/A	N/A	−14	8	N/A	N/A	−3	6	N/A	N/A
Emotions	Posts	3	9	N/A	N/A	−18	10	−0.89	.37	−17	11	−0.73	.47
	Responses	−19	9	N/A	N/A	−25	9	N/A	N/A	−1	11	−0.02	.98
Problem Solving	Posts	−20	12	−0.76	.45	**−66**	**12**	**−2.57**	**.01**	−43	15	−1.21	.23
	Responses	2	12	0.06	.95	−37	12	−1.43	.15	−20	13	−0.68	.50
All Boards	Posts	7	14	0.20	.84	**−65**	**14**	**−2.02**	**.04**	−43	15	−1.21	.23
	Responses	−6	13	−0.19	.85	**−71**	**14**	**−2.21**	**.03**	−36	14	−1.11	.27
	Messages	−4	13	−0.12	.90	**−83**	**15**	**−2.34**	**.02**	−26	15	−0.72	.47

[a] W = sum of signed ranks; $N_{(s/r)}$ = number of signed ranks; N/A = not applicable.

[b] Bold font indicates significance of $P \leq .05$.

[c] All *P* values are 2-tailed.

[d] *P* value determined through exact sampling distribution for $5 < N_{(s/r)} < 9$.

Utilization of the bulletin boards was also measured by the range of days participants logged in to the IDSMP. The maximum number of days from first to last log-in was 42. On average, Caucasians had a significantly longer period of activity, with a median of 42 days, than AIs/ANs, with a median of 40 days (W = −65, *P* = .04). There were no significant differences between AAs and other racial groups. It should be noted that the mean range of activity (30 days) for AIs/ANs was much lower than the median. This is because the activity range for six participants was less than half of the workshop. In contrast, all Caucasian and AA participants were active for at least half of the time.

Message Content

In the qualitative analysis of message codes, a total of 98 codes within message type, content, and communication style were developed and compared. These collapsed into 16 primary codes, shown in Table 2.

Table 2. Primary codes in message type, content, and communication style

	Code	Definition
Message Type	Goal Setting	Mentioning a general or specific goal for oneself, with or without a concrete action attached to it.
	Personal Experience	Relating a personal story or happening.
	Question	Explicit requests to other participants for information or follow-up questions.
	Problem Statement	Describing or stating one's own diabetes-related physical, mental, social, or emotional problem.
Content	Barriers	Physical or mental barriers that the patient believes interferes with his/her own self-care activities.
	Computer Technology	Specific programs, actions, or characteristics related to computers and the Internet.
	Diet	Dietary behaviors, types of food, food recommendations, and feelings around food.
	Emotions	Explicitly expressing emotion or referencing one's feelings in a message.
	Medicine	Medical treatment or management of diabetes (eg, health care workers, medications, and alternative or natural treatments).
	Physical Activity	Aerobic or non-aerobic physical exercise, including planning, accomplishments, behaviors, and feelings.
	Physical Symptoms	Experiences relating to the body, such as physical symptoms, blood glucose, chronic illnesses, future complications, and weight.
	Personal Life	Aspects related to the participant's personal life, such as religion, family, friends, work, and acquaintances with diabetes.
	Self-Management	Self-care activities, including physical activity, diet, medication, general self-management strategies, and other healthy lifestyle practices or behaviors.
Communication Style	Additional Text	Stylizing one's message text in various ways (eg, symbols or adding non-standard letters, punctuation, and capitalization).
	Identification	Mentioning a personal identifying characteristic (eg, age, gender, job, location, name, race, relationships, or serious illnesses).
	Social Support	Providing appraisal, emotional, informational, or tangible support.

For the sample as a whole, codes were considered prevalent if they appeared in 30% or more of each racial group's messages. Two message type codes satisfied this condition, with 60% of a participant's messages relating a personal experience and 43% containing a problem statement. Four content codes also met the criteria, with 56% of an average participant's messages talking about self-management, 54% conveying emotions, 36% including physical activity, and 33% mentioning barriers.

Differences found by comparing codes by race are summarized in Table 3. There were no significant ($P \leq .05$) differences in any message type codes. Content codes showed three significant differences: Caucasians wrote more than AIs/ANs on food behaviors, AIs/ANs wrote more than Caucasians on physical activity, and AIs/ANs wrote more on walking than did Caucasians or AAs. There were no significant differences in content codes between AAs and Caucasians. For communication style codes, the two significant differences were that AAs revealed their gender more often than AIs/ANs and that AAs revealed their name more often than both other groups. Again, there were no differences between AAs and Caucasians in communication style. See Table 3 for results.

Finally, participants of all three races wrote that the bulletin boards helped them in their self-care efforts.

Table 3. Significant differences in mean percent of messages for all codes by race

	Code	Definition	F^a	P> F^b	*P* ^{c}
Style Content Codes	Diet – Food Behaviors	Self-care for food (eg, planning to eat certain foods, scheduling meals, tracking what one eats).	1.54	0.23	.01 Caucasian > AI/AN
	Physical Activity	Aerobic or nonaerobic physical exercise	2.09	0.14	.05 AI/AN > Caucasian
	Physical Activity – Walking	Walking for physical activity, whether outside or on a treadmill	5.17	0.01	.01 AI/AN > Caucasian .01 AI/AN > AA
Communication Codes	Identification – Name	Revealing one’s name by referring to oneself or signing a message	4.78	0.01	.03 AA > Caucasian .01 AA > AI/AN
	Identification – Gender	Revealing gender directly or though relationships and names	3.53	0.04	.01 AA > AI/AN

[a] F tests from ANOVA, with two degrees of freedom.

[b] Probability that the F ratio would be greater by chance if the actual ratio were 1.

[c] *P* ≤ .05 in *t* test between races.

Discussion

Somewhat surprisingly, this study suggests that participants of different races use Internet bulletin boards similarly. While there are some differences between racial groups concerning program utilization, the reasons for this are not clear. Overall, these results could indicate that there are more similarities than differences in participation and discussion in online programs despite the documented, population-specific diabetes beliefs among racial groups [6-14]. This possibility would support Cox et al’s study implication that diabetes self-management programs do not necessarily need to be race specific [15].

Board Utilization

The lower message numbers for AAs and lower activity range for AIs/ANs compared with Caucasians could be related to a number of “upstream” factors, such as Internet and computer access, amount of free time, type of employment, and variations between racial groups documented in the literature, such as barriers to care [5-14]. Perceptions of the IDSMP could influence utilization, too, including the level of comfort online, the acceptability of Internet-based programs, perceived workshop benefits, and relationships with other participants. Finally, message numbers could be related to “lurker” participants, or people who read messages but prefer not to write anything, as documented in previous research [20,48]. These differences should be explored in future studies.

Message Content

One possible explanation for the absence of differences is that participants, regardless of race, had similar diabetes self-management experiences and issues. The sample characteristics could play a role as well since participants were highly educated, self-selected, and had Internet access. A third possibility is that AAs or AIs/ANs could have thought that they were the only members in their workshops who were racial minorities and therefore did not express themselves the same as they would have in a group of the same race. All of these hypotheses would be interesting directions for future research.

Limitations

Since it was necessary to draw participants from across workshops, messages were taken out of context, which may have affected interpretation of message content and social support. The blindness of the coding was affected by two AI/AN participants who revealed their race in messages and 26 participants who revealed their gender. Results should be interpreted in light of the participants’ high education level, age, and preexisting Internet access. In addition, the sample was small, included a limited number of males, and was not randomly selected. This makes it difficult to assess the significance of the results and may obscure additional differences between racial groups. A Bonferroni correction was not possible due to the sample size, so the likelihood of false positives is high. While not ideal, these restrictions are necessary tradeoffs given the demographic composition of the overall IDSMP sample and the need to begin researching online program experiences of racial minority groups.

Conclusion

Bulletin boards are included in the IDSMP based on the hypothesis that sharing experiences and support with other participants can positively impact self-efficacy and potentially improve health outcomes. In order to support participants of all races in the fullest way possible, it is important to explore why AAs and AIs/ANs used message boards less than Caucasians. Additionally, the low variability in messages, outside of sheer numbers, suggests that when participants of different races do use the boards, they use them very similarly, and that there is higher variation within groups than between them. This could indicate that online programs such as the IDSMP are flexible enough to meet the needs of multiple racial groups. If this finding is borne out in further studies, message boards, and by extension, listservs, may be a means of helping to lessen racial disparities by providing readily accessible and effective self-management education.

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Conflicts of Interest

None declared.

References

1. ; Agency for Healthcare Research and Quality. Fact Sheet: Diabetes Disparities Among Racial and Ethnic Minorities. Rockville, MD: Agency for Healthcare Research and Quality; 2001. URL: http://www.ahrq.gov/research/diabdisp.pdf [WebCite Cache ID 5ekwLKkek]
2. ; National Center for Chronic Disease Prevention and Health Promotion. National Diabetes Fact Sheet: National Estimates on Diabetes. 2005 [FREE Full text] [WebCite Cache ID 5b0zgk0SU]
3. Crombie IK, Irvine L, Elliott L, Wallace H. Closing the Health Inequalities Gap: An International Perspective. Copenhagen, Denmark: World Health Organization Regional Office for Europe; 2005. URL: http://www.euro.who.int/document/e87934.pdf [WebCite Cache ID 5ekwd4lXE]
4. ; Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academy of Sciences; 2001. URL: http://www.iom.edu/Object.File/Master/27/184/Chasm-8pager.pdf [WebCite Cache ID 5ekwv5NyH]
5. Caballero AE. Cultural competence in diabetes mellitus care: An urgent need. Insulin 2007 Apr;2(2):80-91. [doi: 10.1016/S1557-0843(07)80019-4]
6. Blanchard MA, Rose LE, Taylor J, McEntee MA, Latchaw LL. Using a focus group to design a diabetes education program for an African American population. Diabetes Educ 1999 ;25(6):917-924. [Medline: 10711073] [doi: 10.1177/014572179902500609]
7. D'Eramo-Melkus G, Spollett G, Jefferson V, Chyun D, Tuohy B, Robinson T, et al. A culturally competent intervention of education and care for black women with type 2 diabetes. Appl Nurs Res 2004 Feb;17(1):10-20. [Medline: 14991551] [doi: 10.1016/j.apnr.2003.10.009]
8. Devlin H, Roberts M, Okaya A, Xiong YM. Our lives were healthier before: focus groups with African American, American Indian, Hispanic/Latino, and Hmong people with diabetes. Health Promot Pract 2006 Jan;7(1):47-55. [Medline: 16410420] [doi: 10.1177/1524839905275395]
9. Egede LE, Bonadonna RJ. Diabetes self-management in African Americans: an exploration of the role of fatalism. Diabetes Educ 2003 ;29(1):105-115. [Medline: 12632689] [doi: 10.1177/014572170302900115]
10. Samuel-Hodge CD, Headen SW, Skelly AH, Ingram AF, Keyserling TC, Jackson EJ, et al. Influences on day-to-day self-management of type 2 diabetes among African-American women: spirituality, the multi-caregiver role, and other social context factors. Diabetes Care 2000 Jul;23(7):928-933 [FREE Full text] [Medline: 10895842] [doi: 10.2337/diacare.23.7.928]
11. Satterfield DW, Lofton T, May JE, Bowman BA, Alfaro-Correa A, Benjamin C, et al. Learning from listening: common concerns and perceptions about diabetes prevention among diverse American populations. J Public Health Manag Pract 2003 Nov;Suppl:S56-S63. [Medline: 14677332]
12. Skelly AH, Dougherty M, Gesler WM, Soward AC, Burns D, Arcury TA. African American beliefs about diabetes. West J Nurs Res 2006 Feb;28(1):9-29. [Medline: 16676724] [doi: 10.1177/0193945905280298.]
13. Taylor C, Keim KS, Sparrer A, Van Delinder J, Parker S. Social and cultural barriers to diabetes prevention in Oklahoma American Indian women. Prev Chronic Dis 2004 Mar 15;1(2) [FREE Full text] [Medline: 15663882]
14. Taylor CA, Keim KS, Fuqua DR, Johnson CA. A diabetes prevention assessment tool for American Indians. Prev Chronic Dis 2005 Sep 15;2(4) [FREE Full text] [Medline: 16164810]
15. Cox RH, Carpenter JP, Bruce FA, Poole KP, Gaylord CK. Characteristics of low-income African-American and Caucasian adults that are important in self-management of type 2 diabetes. J Community Health 2004 Apr;29(2):155-270. [Medline: 15065743] [doi: 10.1023/B:JOHE.0000016719.89848.b1]
16. Jackson CL, Bolen S, Brancati FL, Batts-Turner ML, Gary TL. A systematic review of interactive computer-assisted technology in diabetes care; Interactive information technology in diabetes care. J Gen Intern Med 2006 Feb;21(2):105-110. [Medline: 16390512] [doi: 10.1111/j.1525-1497.2005.00310.x]

17. McTavish FM, Gustafson DH, Owens BH, Hawkins RP, Pingree S, Wise M, et al. CHESS (Comprehensive Health Enhancement Support System): an interactive computer system for women with breast cancer piloted with an underserved population. J Ambul Care Manage 1995 Jul;18(3):35-41. [Medline: 10143478]
18. White M, Dorman SM. Receiving social support online: implications for health education. Health Educ Res 2001 Dec;16(6):693-707 [FREE Full text] [Medline: 11780708] [doi: 10.1093/her/16.6.693]
19. Barrera M, Glasgow RE, McKay HG, Boles SM, Feil EG. Do Internet-based support interventions change perceptions of social support? An experimental trial of approaches for supporting diabetes self-management. Am J Community Psychol 2002 Oct;30(5):637-654. [Medline: 12188054] [doi: 10.1023/A:1016369114780]
20. McKay HG, Feil EG, Glasgow RE, Brown JE. Feasibility and use of an Internet support service for diabetes self-management. Diabetes Educ 1998 ;24(2):174-179. [Medline: 9555356] [doi: 10.1177/014572179802400207]
21. Madara EJ. The mutual-aid self-help online revolution. Soc Policy 1997;27(3):20-26.
22. Salem DA, Bogat AG, Reid C. Mutual help goes on-line. J Community Psychol 1997;25(2):189-207. [doi: 10.1002/(SICI)1520-6629(199703)25:2<189::AID-JCOP7>3.0.CO;2-T]
23. Horrigan JB. Home broadband adoption 2008. Washington, DC: PEW Internet & American Life Project; 2008. URL: http://www.pewinternet.org/pdfs/PIP_Broadband%202007.pdf [WebCite Cache ID 5b10JDxRt]
24. Fox S. Online health search 2006: summary of findings. Washington, DC: Pew Internet & American Life Project; 2006. URL: http://www.pewinternet.org/pdfs/PIP_Online_Health_2006.pdf [WebCite Cache ID 5b102eC2P]
25. Fox S. E-patients with a disability or chronic disease. Washington, DC: Pew Internet & American Life Project; 2007. URL: http://www.pewinternet.org/pdfs/EPatients_Chronic_Conditions_2007.pdf [WebCite Cache ID 5ekxZNXbJ]
26. Fox S. Digital divisions. Washington, DC: Pew Internet & American Life Project; 2005. URL: http://www.pewinternet.org/pdfs/PIP_Digital_Divisions_Oct_5_2005.pdf [WebCite Cache ID 5b104kN79]
27. Jackson CL, Batts-Turner ML, Falb MD, Yeh HC, Brancati FL, Gary TL. Computer and internet use among urban African Americans with type 2 diabetes. J Urban Health 2005 Dec;82(4):575-583. [Medline: 16221917] [doi: 10.1093/jurban/jti126]
28. Owens BH, Robbins KC. CHESS: comprehensive health enhancement support system for women with breast cancer. Plast Surg Nurs 1996;16(3):172-175-172-182. [Medline: 9060757]
29. Gustafson D, Wise M, McTavish F, Taylor JO, Wolberg W, Stewart J, et al. Development and pilot evaluation of a computer-based support system for women with breast cancer. J Psychosoc Oncol 1993;11(4):69-93. [doi: 10.1300/J077V11N04_05.]
30. Coulson NS. Receiving social support online: an analysis of a computer-mediated support group for individuals living with irritable bowel syndrome. Cyberpsychol Behav 2005 Dec;8(6):580-584. [Medline: 16332169] [doi: 10.1089/cpb.2005.8.580]
31. Winefield HR. Support provision and emotional work in an Internet support group for cancer patients. Patient Educ Couns 2006 Aug;62(2):193-197. [Medline: 16139466] [doi: 10.1016/j.pec.2005.07.002]
32. Coulson NS, Buchanan H, Aubeeluck A. Social support in cyberspace: a content analysis of communication within a Huntington's disease online support group. Patient Educ Couns 2007 Oct;68(2):173-178. [Medline: 17629440] [doi: 10.1016/j.pec.2007.06.002]
33. Mo PKH, Coulson NS. Exploring the communication of social support within virtual communities: a content analysis of messages posted to an online HIV/AIDS support group. Cyberpsychol Behav 2008 Jun;11(3):371-374. [Medline: 18537512] [doi: 10.1089/cpb.2007.0118]
34. Gooden RJ, Winefield HR. Breast and prostate cancer online discussion boards: a thematic analysis of gender differences and similarities. J Health Psychol 2007 Jan;12(1):103-114. [Medline: 17158844] [doi: 10.1177/1359105307071744]
35. Ginossar T. Online participation: a content analysis of differences in utilization of two online cancer communities by men and women, patients and family members. Health Commun 2008;23(1):1-12. [Medline: 18443988] [doi: 10.1080/10410230701697100]
36. Jernigan VJ. The Native American Diabetes Self-Management Program [dissertation]. Berkeley, CA: University of California Berkeley; 2007.
37. Shuyler KS, Knight KM. What are patients seeking when they turn to the Internet? Qualitative content analysis of questions asked by visitors to an orthopaedics Web site. J Med Internet Res 2003 Oct 10;5(4):e24 [FREE Full text] [Medline: 14713652] [doi: 10.2196/jmir.5.4.e24]
38. Hoffman-Goetz L, Donelle L. Chat room computer-mediated support on health issues for aboriginal women. Health Care Women Int 2007 Apr;28(4):397-418. [Medline: 17454185] [doi: 10.1080/07399330601180057]
39. Ravert RD, Hancock MD, Ingersoll GM. Online forum messages posted by adolescents with type 1 diabetes. Diabetes Educ 2004 ;30(5):827-834. [Medline: 15510534] [doi: 10.1177/014572170403000518]
40. Lasker JN, Sogolow ED, Sharim RR. The role of an online community for people with a rare disease: content analysis of messages posted on a primary biliary cirrhosis mailinglist. J Med Internet Res 2005 Mar;7(1):e10 [FREE Full text] [Medline: 15829472] [doi: 10.2196/jmir.7.1.e10]
41. Burri M, Baujard V, Etter JF. A qualitative analysis of an internet discussion forum for recent ex-smokers. Nicotine Tob Res 2006 Dec;8 Suppl 1(Suppl):S13-S19. [Medline: 17491166] [doi: 10.1080/14622200601042513]

42. Fogel J, Albert SM, Schnabel F, Ditkoff BA, Neugut AI. Racial/ethnic differences and potential psychological benefits in use of the internet by women with breast cancer. Psychooncology 2003 Mar;12(2):107-117. [Medline: 12619143] [doi: 10.1002/pon.617]
43. Lorig KR, Ritter PL, Laurent DD, Plant K. Internet-based chronic disease self-management: a randomized trial. Med Care 2006 Nov;44(11):964-971. [Medline: 17063127] [doi: 10.1097/01.mlr.0000233678.80203.c1]
44. Lofland J. Analyzing Social Settings: A Guide to Qualitative Observation and Analysis. Belmont, CA: Wadsworth; 1971.
45. Hara N, Bonk CJ, Angeli C. Content analysis of online discussion in an applied educational psychology course. Instr Sci ;28(2):115-152. [doi: 10.1023/A:1003764722829.]
46. Heaney CA, Israel BA. Social networks and social support. In: Karen G, Rimer BK, Lewis FM, editors. Health Behavior and Health Education: Theory, Research, and Practice. 2nd edition. San Francisco, CA: Jossey-Bass; 1999:179-205.
47. Miles MB, Huberman AM. Qualitative Data Analysis. 2nd edition. Thousand Oaks, CA: Sage Publications; 1994.
48. Zrebiec JF, Jacobson AM. What attracts patients with diabetes to an internet support group? A 21-month longitudinal website study. Diabet Med 2001 Feb;18(2):154-158. [Medline: 11251681] [doi: 10.1046/j.1464-5491.2001.00443.x]

Abbreviations

AA: African American
AI: American Indian
AN: Alaskan Native
CDSMP: Chronic Disease Self-Management Program
IDSMP: Internet Diabetes Self-Management Program

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Original Paper

Older Patients' Enthusiasm to Use Electronic Mail to Communicate With Their Physicians: Cross-Sectional Survey

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Abstract

Background: Recent evidence indicates increased access to and use of Internet and non-healthcare-related email by older patients. Because email adoption could potentially reduce some of the disparities faced by this age group, there is a need to understand factors determining older patients' enthusiasm to use email to communicate with their physicians. Electronic mail (email) represents a means of communication that, coupled with face-to-face communication, could enhance quality of care for older patients.

Objective: Test a model to determine factors associated with older patients' enthusiasm to use email to communicate with their physicians.

Methods: We conducted a secondary data analysis of survey data collected in 2003 for two large, longitudinal, randomized controlled trials. Logistic-regression models were used to model the dichotomous outcome of patient enthusiasm for using email to communicate with their physicians. Explanatory variables included demographic characteristics, health status, use of email with people other than their physician, characteristics of the physician-patient relationship, and physician enthusiasm to use email with patients.

Results: Participants included a pooled sample of 4059 patients over 65 years of age and their respective physicians (n = 181) from community-based practices in Southern California. Although only 52 (1.3%) patient respondents reported that they communicated with their physician by email, about half (49.3%) expressed enthusiasm about the possibility of using it. Odds of being enthusiastic decreased with increased age (by 0.97 for each year over 66) but were significantly higher in African Americans (OR = 2.1, CI = 1.42 - 3.06), Hispanics (OR = 1.6, CI = 1.26 - 2.14) and men (OR = 1.3, CI = 1.1 - 1.5). A perception of better communication skills of their physician, lower quality of interaction with physician in traditional face-to-face encounters, and physician enthusiasm to use email with patients were significantly associated with an enthusiasm to use email. Patients who did not use email at all were less enthusiastic compared to those who used email for other reasons. Half of the physician respondents were not enthusiastic about communicating with patients using email.

Conclusions: Despite perceived barriers such as limited access to the Internet, older patients seem to want to use email to communicate with their physicians.

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KEYWORDS

Electronic mail; doctor-patient communication; Internet; doctor-patient relationship

Introduction

Good communication between patients and physicians is a cornerstone of modern, high quality health care. Recent advances in communication technology are generating a variety of communication exchanges that could complement or replace more traditional face-to-face visits and telephone calls.

Because of its pervasiveness and relative ease of use, electronic mail (email) offers a potentially valuable resource for augmenting and improving communication between physicians and patients [1]. Even so, email communication remains an untapped resource in health care [2]. Although many physicians believe email communication can enhance chronic-disease management and improve continuity of care [3], its adoption is generally low [4-6]. Factors such as lack of reimbursement, fears about negative impact on their own quality of life, and concerns surrounding the risk of liability[7,8], reduce physician enthusiasm to use email. Conversely, patient enthusiasm to use email appears to be high [9], even though their actual use of email to communicate with physicians is generally low [4,10]. Given that patient enthusiasm to use email represents the motivational catalyst that could lead to its more routine use, this investigation examined factors affecting enthusiasm among elderly patients to communicate with physicians using email. This age group is at risk of poor communication with physicians, in spite of having multiple co-morbidities, and is slower to adopt new communication technologies.

Despite effective doctor-patient communication being paramount for patients over 65 years of age [11,12], we are not aware of any studies of email use (or enthusiasm to use email) in health care that have specifically studied this age-group. Although activities such as Internet use and email are generally more prevalent in younger age groups [13,14], older adults may also appreciate having this additional medium to communicate their concerns [15].

While older patients may have more barriers that limit their use of the Internet, there exist several reasons why they could be enthusiastic about using email with their physicians. For example, traditional face-to-face communication encounters between older patients and their physicians may be ineffective if the discussions do not raise all issues of concern. Moreover, physicians are often less responsive to the psychosocial issues raised during visits by older patients than to similar concerns of younger patients [16]. Subsequent follow-up email correspondence could also allow older patients to raise additional topics of concern or identify unmet psychosocial needs. Finally, older patients face several communication challenges due to their capacity to remember and follow complex instructions and, thus, a follow-up email summarizing the visit can reinforce instructions [12].

Recent evidence indicates increased access to and use of Internet and non-healthcare-related email by older patients [17]. Because email adoption could potentially reduce some of the disparities faced by this age-group, there is a need for understanding factors determining their enthusiasm to use email with their physicians. In addition, a high level of patient enthusiasm, accompanied by the rapid diffusion of technology in this age group, could also be used as grounds for reimbursement-related policy changes.

We hypothesized that, in addition to demographics and familiarity with technology, older patients' enthusiasm to use email to communicate with their physicians would depend on their health needs and the quality of their relationships. Specifically, patients with greater medical needs and a stronger relationship with their physicians will be more enthusiastic about using email as a communication tool. Our main study objective was to test a model to determine factors associated with older patients' enthusiasm to use email with their physicians. Secondarily, we examined factors associated with physicians' enthusiasm to communicate with their patients using email.

Methods

We conducted a secondary data analysis of survey data collected for two large randomized controlled trials in Southern California, known as Communication in Medical Care 2 and 3 (CMC 2 and 3), which were designed to study and improve physician-patient communication regarding cancer screening. (See Fox et al [18] for background study, CMC 1.)

CMC 2 was a community-based, longitudinal, randomized controlled trial conducted between 1998 and 2003 that involved 111 primary care physicians practicing full time in community-based office practices in Los Angeles County. Patients were recruited from these physicians' practices. The patients were non-institutionalized and between 50 and 80 years of age; were physically and mentally capable of completing a 30-minute interview; and did not have a history of breast, cervical, colorectal, or prostate cancer. Only patients aged 65 - 80 were included in this analysis. Baseline and exit data were collected in 2000 and 2003 through 20-minute telephone interviews with physicians and 30-minute telephone interviews with patients. Data were collected on the patients' health care access and utilization; general demographics; mental and physical health; patterns of physician-patient communication, including use of, and enthusiasm for, using email; and certain characteristics of patient-physician relationships. Survey-response rate for participants, after being enrolled, was 72%.

CMC 3 was focused on patients aged 65 - 79. Their 80 primary care physicians practiced in community-based practices in Southern California (excluding Los Angeles County). Baseline and exit data were collected in 2003 and 2006 through 20-minute telephone interviews with physicians and 30-minute telephone interviews with patients. A total of 5978 patients participated in both the original studies. Overall, the CMC 2 sample of patients from Los Angeles County represented a range of socioeconomic levels and was more diverse in its ethnic representation, whereas the CMC 3 sample represented more suburban areas, was predominantly white, and had somewhat higher socioeconomic levels. Over 11,000 people were contacted for recruitment over the telephone in 2003, from whom we obtained 3188 completed interviews for analysis.

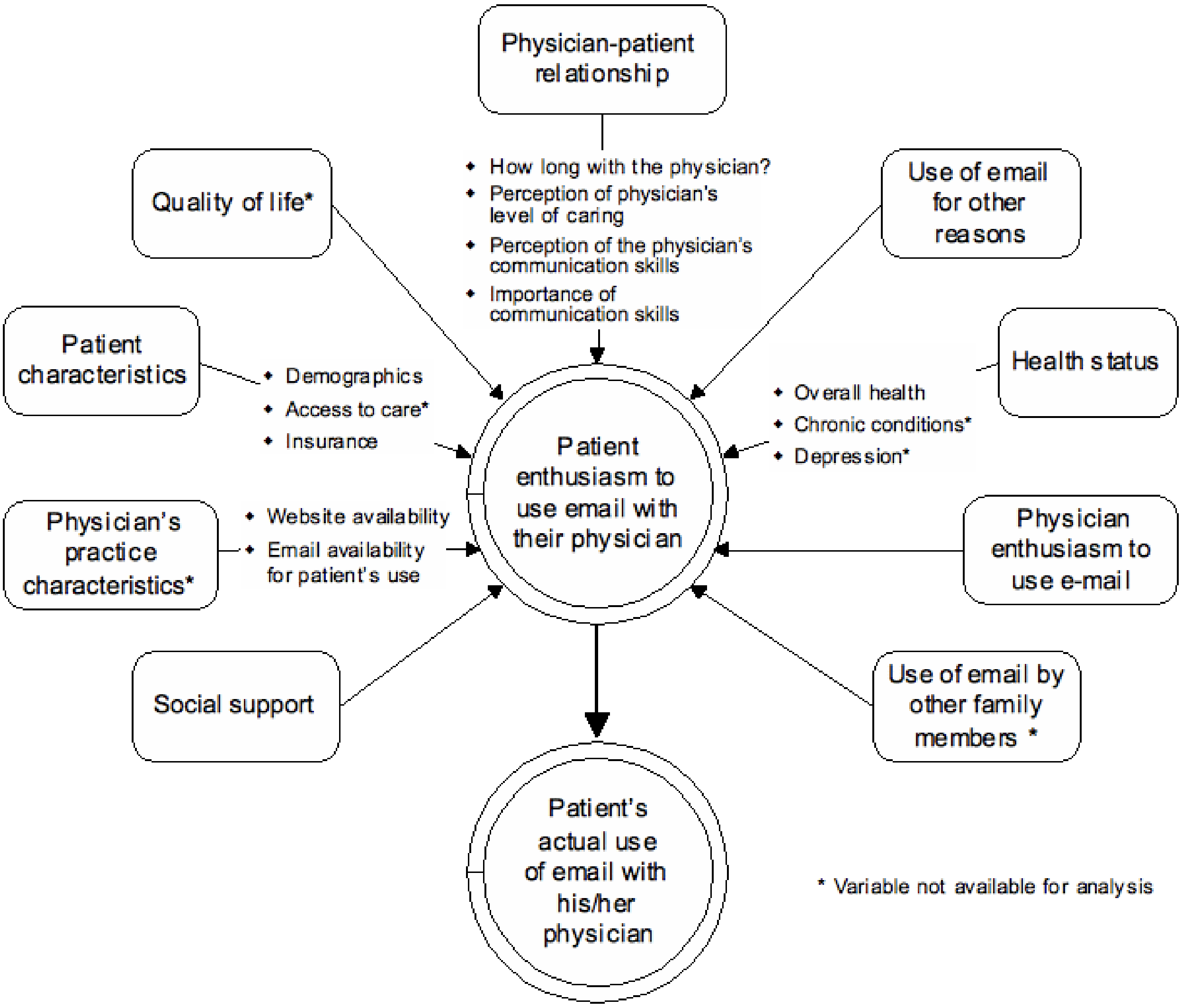
Data Analysis

To allow cross-sectional analyses for our main study objective of determining the factors associated with older patients' enthusiasm to use email with their physicians, we pooled data from CMC 2 exit surveys and the CMC 3 baseline survey in 2003.

The study population of patients was limited to those over 65 years of age in 2003. For patients from the CMC 2 survey, age was determined by adding 3 years to the patient's age in the CMC 2 baseline survey conducted in 2000. For patients from the CMC 3 survey, we used their age at the time of the CMC 3 baseline survey. The proportions of patients and physicians who used or were enthusiastic about using email as a communication tool were calculated from the pooled 2003 data.

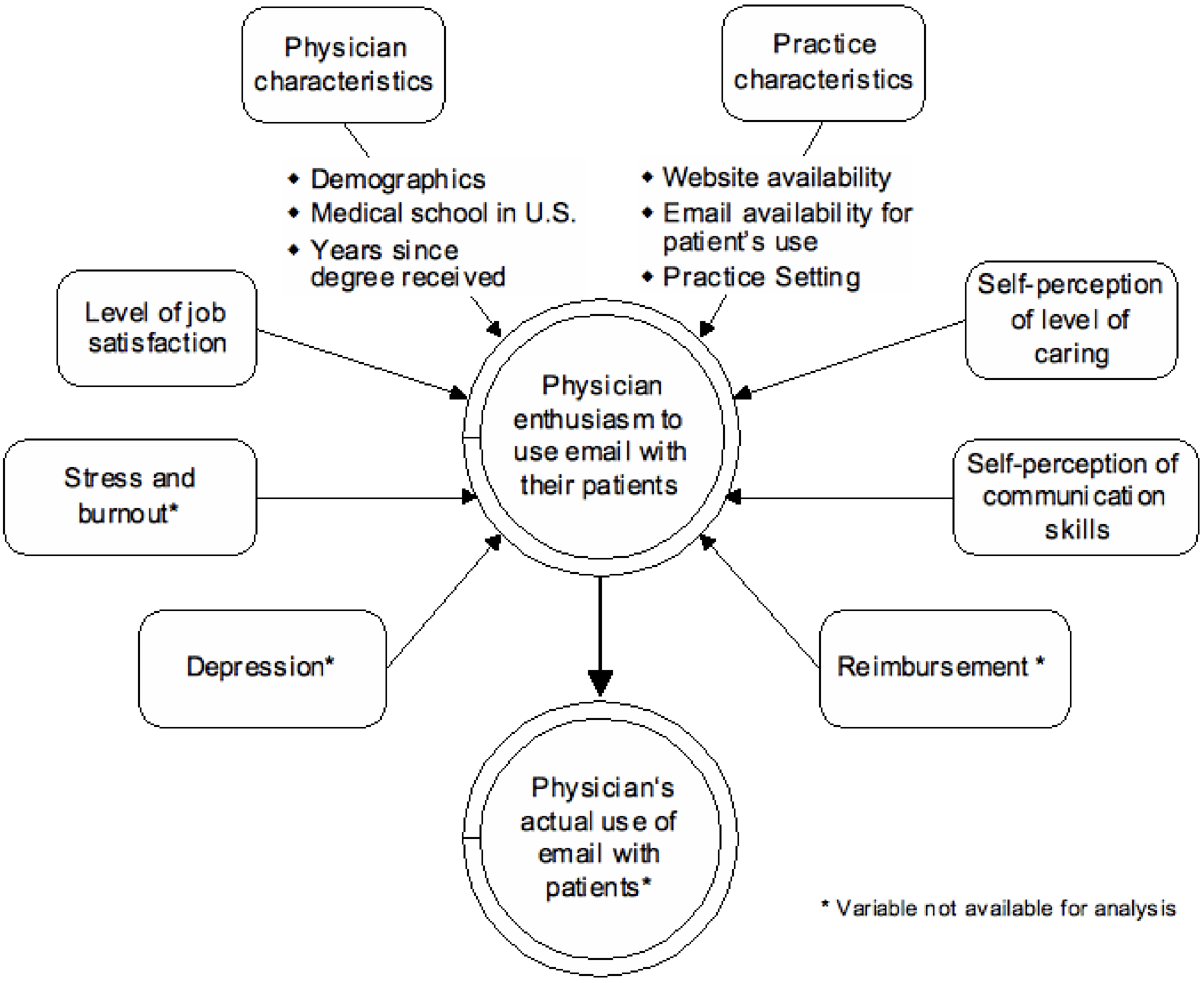
Figure 1 illustrates the potential factors we considered to derive the explanatory variables explaining patient enthusiasm in our model. These included demographic variables (patient age, race, gender, and marital status), health status, social support, quality of life, access to care, use of general email (such as with people other than their physicians), characteristics of physician-patient relationship, and physician's enthusiasm to use email. Because physician enthusiasm could depend on additional factors, we used explanatory variables, including the clinician's age, race, gender, time in the United States, level of job satisfaction, practice characteristics, self-perceptions with respect to caring for their patients, and self-perceptions of communication skills (Figure 2). For the model of physician enthusiasm, several variables were excluded because of their high correlation with other variables in the model. For example, the number of years since the physician had received his or her medical degree was highly correlated with physician age and was therefore excluded from the model. Both Figure 1 and Figure 2 show additional variables we considered but excluded because one or both surveys did not collect any information about them.

Figure 1. Potential determinants of older patients' enthusiasm to use email communication with their physicians



We first used univariate analysis to identify potential explanatory variables of enthusiasm for both patients and physicians using variables collected in both surveys. Chi-square analysis was used to compare the categorical variables, and the *t* test was used for continuous variables. Separate logistic-regression models were used to model the dichotomous outcome as to whether

Figure 2. Potential determinants of physician enthusiasm to use email communication with their patients



there was enthusiasm to use email by patients and physicians. For the cross-sectional analysis of patient enthusiasm, we conducted the logistic regression using generalized estimating equations (GEE) methodology. To account for potential correlations among patients with the same physician, patients were nested within their own physician.

Results

For the cross-sectional analyses, we studied survey responses of 4059 patients over 65 years of age to evaluate the determinants of their enthusiasm to use email with their health care providers. Table 1 shows characteristics of the study population of patients in the pooled sample. The mean age was 73.1 (SD 4.1). Non-Hispanic whites represented 81.1% of the study population, with Hispanics representing 11.9%, African Americans representing 3.8%, and other races representing 3.2%. Almost all had insurance coverage through Medicare, Medi-Cal, government or military insurance, or private insurance. Three-quarters (75.9%) considered themselves in good, very good, or excellent health. On average, the participants had been patients of their current physicians for 7.8 years (SD 6.4). Although most patients felt their physician was always respectful of them (91.2%), only 62.0% thought their physician always allowed enough time to talk. Most patients (89%) rated their provider as having very good, excellent, or “better than most” communication skills.

Table 1. Characteristics of patients over age 65 in the pooled sample from the 2003 CMC 2 exit questionnaire and 2003 CMC 3 baseline questionnaire

Characteristic	Number of patients (Mean)	% (Standard deviation)
Demographics		
Average Age in years (n = 4059)	(73.1)	(4.1)
Age (n = 4059)		
66 - 69	949	23.4
70 - 74	1557	38.4
75 - 79	1366	33.7
80 and older	187	4.6
Gender (n = 4059)		
Male	1671	41.2
Female	2388	58.8
Race (n = 4033)		
Non-Hispanic white	3271	81.1
African American	155	3.8
Asian/Other	128	3.2
Hispanic	479	11.9
Marital status (n = 4052)		
Married or living as married	2496	61.6
Not married	1556	38.4
Insurance[a] (n = 4059)		
Has medical insurance	3985	98.2
Health Status		
Patient’s rating of his/her own health (n = 4050)		
Fair, poor	974	24.1
Good	1301	32.1
Very good	1321	32.6
Excellent	454	11.2
Use of Email for Other Reasons		
Patient (n = 4059)	1456	35.9
Physician/Patient Relationship		
Average years as clinician’s patient (n = 4050)	(7.8)	(6.4)
Perception of physician’s level of caring:		
Patient thinks physician is respectful (n = 3458)		
Never, sometimes	82	2.4
Usually	223	6.5
Always	3153	91.2
Patient thinks physician allows enough time to talk (n = 4047)		
Never, sometimes	466	11.5
Usually	1074	26.5
Always	2507	62
Perception of physician’s communication skills:		

Characteristic	Number of patients (Mean)	% (Standard deviation)
Importance of good communication skills of primary care provider (n = 4033)		
Somewhat important	126	3.1
Very important	1730	42.9
Extremely important	1384	34.3
More important than anything else	793	19.7
Patient’s rating of provider’s communication skills (n = 4047)		
Fair, good	447	11.1
Very good	1003	24.8
Excellent	1600	39.5
Better than most	997	24.6

[a] A patient was defined as having insurance if he or she indicated that they had Medi-Cal, Medicare, government or military insurance, or private insurance.

Few patients (1.3%) indicated that they communicated with their physician through email. Of patients who did not use email to communicate with their physicians, half (49.3%) reported they were enthusiastic about doing so. Table 2 shows the relationship between the potential predictors and the patient’s enthusiasm to use email in a GEE logistic regression model of the pooled population. For each year of increase in patient age, the odds of being enthusiastic decreased by 0.97. African Americans and Hispanics were 2.1 times and 1.6 times more enthusiastic than non-Hispanic whites, respectively. Men had odds that were 1.25 times higher than those of women. Patients who did not use email in general had lower odds (0.17) of being enthusiastic than those who did. Other patient characteristics, such as the patient’s marital status and rating of health status were not significant. The CMC 2 sample was more likely to be enthusiastic about using email, probably because they were younger than those in the CMC 3 sample.

Table 2. Logistic regression analysis of patient enthusiasm to use email in 2003 (all patient characteristics were significant in univariate analysis)

Patient Characteristics	Odds Ratio	95% Confidence Interval	*P* Value
Age	0.97	0.95 - 0.99	< .001
Race (reference group is non-Hispanic white)			
African American	2.08	1.42 - 3.06	< .001
Hispanic	1.64	1.26 - 2.14	< .001
Asian	1.35	.87 - 2.09	.18
Gender (reference group is female)			
Male	1.25	1.06 - 1.47	.01
Marital status (reference group is not married)			
Married	1.08	0.89 - 1.31	.45
Rating of their health status (reference group is excellent)			
Fair or poor	0.83	0.63 - 1.10	.19
Good	0.95	0.74 - 1.24	.72
Very good	0.99	0.76 - 1.30	.95
Years as a patient of their physician	1.00	1.00 - 1.02	.11
Use of email for other reasons (reference group is "do use email for other purposes")			
Do not use email for other purposes	0.17	0.15 - 0.20	<.001
Rating of the importance of physician's communication skills (reference group is most important)			
Somewhat important	0.84	0.51 - 1.38	.49
Very important	0.92	0.77 - 1.12	.41
Extremely important	1.01	0.82 - 1.24	.91
Rating of their physician's communication skills (reference group is fair or good)			
Better than most	1.58	1.17 - 2.14	.01
Excellent	1.36	1.05 - 1.76	.02
Very good	1.20	0.92 - 1.57	.18
Rating of whether physician allows enough time to talk (reference group is always)			
Never	1.14	0.85 - 1.51	.39
Usually	1.43	1.20 - 1.72	<.001
Enthusiastic about communicating using email (reference group is physician is not enthusiastic about communicating using email)	1.31	1.11 - 1.54	.001
Survey group (reference group is CMC 3 baseline survey)			
CMC 2 exit survey	1.27	1.03 - 1.57	.03

The regression model found several physician and patient-physician relationship characteristics to be significant. First, patients whose physician was enthusiastic about using email were 1.3 times more likely to be enthusiastic than patients whose physician was not enthusiastic. Second, patients who rated their physician's communication skills high (better than most) were 1.58 times more likely to be enthusiastic compared to those who rated their physician's communication skills fair/good. Finally, patients whose physicians *usually* allowed enough time to talk were 1.4 times *more* likely to be enthusiastic than patients whose physician *always* allowed enough time to talk. Factors such as duration of the patient-physician relationship did not correlate highly with enthusiasm.

Regarding physicians' enthusiasm to use email (Table 3), approximately half (51.7%) responded that they were not at all enthusiastic about communicating with patients using email. Just over a quarter (26.7%) were somewhat enthusiastic, while only 10% were very or extremely interested in email communication.

Table 3. Characteristics of 181 physicians in the pooled sample from the 2003 CMC 2 exit and 2003 CMC 3 baseline surveys

Physician Characteristic (n = 181)	n (Mean)	% (Standard deviation)
Average age	(49.4)	(9.0)
Average years in US	(38.8)	(15.9)
Avg. years in current practice setting	(12.4)	(8.5)
Age		
< 40	51	28.2
40 - 49	48	26.5
50 - 54	38	21.0
55 and older	44	24.3
Gender		
Male	136	75.1
Female	45	24.9
Race		
Non-Hispanic white	93	51.4
African American, other	12	6.6
Asian/Pacific Islander	40	22.1
Hispanic	36	19.9
Area of birth		
United States	100	55.3
Mexico, Central America, South America	19	10.5
Asia, India	35	19.3
Other	27	14.9
Practice setting		
Private solo practice	97	53.6
Private group practice	49	27.1
HMO, other	35	19.3
Specialty		
Family practice/general practice	96	53.0
Internal medicine	85	47.0
Use of email for other reasons		
Physician	137	75.7

Table 4 shows factors associated with physician enthusiasm to use email according to the logistic regression analysis of the pooled CMC 2 exit and CMC 3 baseline datasets. Notably, the odds of a physician being enthusiastic were 4.96 times higher for physicians who were somewhat or very dissatisfied with their current work setting compared to physicians who were very satisfied. Physicians who reported that they *always* provided educational materials to patients were significantly less enthusiastic about using email than physicians who reported that they *usually* provided those materials (OR = 0.28). There was no association between physician enthusiasm and demographic characteristics, such as the physician's age and gender nor practice characteristics, such as setting or years in current practice. There was also no significant association between physician enthusiasm and the rating of their communication skills or the likelihood that they would build a partnership with their patients.

Table 4. Logistic regression analysis of physician enthusiasm to use email in 2003 (all physician characteristics were significant in univariate analysis)

Physician Characteristics	Odds Ratio	95% Confidence Interval	*P* Value
Age			
(reference group is under 40)			
40 - 49	0.92	0.31 - 2.73	.88
50 - 54	1.05	0.32 - 3.49	.94
55 and older	0.84	0.24 - 2.98	.79
Race			
(reference groups is non-Hispanic white)			
African American	1.18	0.23 - 6.15	.85
Hispanic	2.46	0.84 - 7.17	.10
Asian	2.29	0.80 - 6.52	.12
Gender			
(reference group is male)			
Female	0.37	0.14 - 1.00	.05
Years in US			
(reference group is less than 25 years)			
25 or more years	1.31	0.47 - 3.63	.60
Years in current practice setting			
(reference group is less than 5 years)			
5 - 9	1.87	0.55 - 6.41	.32
10 - 19	2.39	0.78 - 7.29	.13
20 or more	0.94	0.26 - 3.38	.92
Current practice setting			
(reference group is private solo practice)			
Private group practice	1.62	0.65 - 4.05	.31
HMO or other	0.78	0.25 - 2.43	.66
Specialty			
(reference group is internal medicine)			
Family practice	1.79	0.57 - 5.68	.32
General internal medicine	2.11	0.47 - 9.54	.33
Use of email for other reasons			
(reference group is “do use email for other purposes”)			
Do not use email for other purposes	0.62	0.26 - 1.50	.29
Rating of their communication skills with older patients			
(reference group is very good)			
Better than most	1.09	0.39 - 3.03	.87
Excellent	0.71	0.28 - 1.81	.47
Fair or good	1.52	0.42 - 5.46	.52
Rating of the importance of their communication skills			
(reference group is somewhat or very important)			
Most important	1.15	0.54 - 2.43	.73
Rating of their satisfaction with their current work setting			
(reference group is very satisfied)			
Somewhat or very dissatisfied	4.96	1.48 - 16.68	.01
Somewhat satisfied	2.21	0.98 - 5.01	.06

Physician Characteristics	Odds Ratio	95% Confidence Interval	*P* Value
Provides educational materials			
(reference group is usually)			
Always	0.28	0.08 - 0.99	.05
Never or sometimes	0.79	0.33 - 1.90	.60
Builds partnership with patients			
(reference group is usually)			
Always	0.83	0.37 - 1.88	.66
Never or sometimes	0.45	0.10 - 2.04	.30
Provides ample time to talk			
(reference group is usually)			
Always	2.22	0.93 - 5.28	.07
Never or sometimes	0.35	0.10 - 1.19	.09
Survey group			
(reference group is CMC3 baseline survey)			
CMC 2 exit survey	1.43	0.49 - 4.21	.51

Discussion

Electronic communication holds the potential to enhance the patient-physician relationship and quality of care by expanding the opportunities for patients and physicians to interact [8,19,20]. Older patients would likely benefit most from electronic correspondence with their physicians. We found that nearly half the patients surveyed were indeed enthusiastic about using email with physicians. Enthusiasm to use email was affected by several factors that may have significant implications for future research, clinical practice, and policy decisions.

First, even though overall use of email with health care providers was low, older patients and especially non-whites were likely to adopt this technology if given the opportunity. Our findings strongly suggest consideration of email as a medium to overcome communication barriers affecting this population. Public interest in and demand for expanding the use of this technology in the senior population [17] could have significant implications for reimbursement policies. Some insurance carriers reimburse physicians for certain types of email, and the American College of Physicians advises Medicare to reimburse selected use of email [21]. Enthusiasm for email use is likely to grow with increasing access to the Internet and might provide a basis for future reimbursement-related policy changes for the Medicare population.

Second, our study suggests that the patient-physician relationship is relevant in determining patient enthusiasm to use email with a physician. Our study supports findings from a recent study which found that certain aspects of the patient-provider relationship affected interest in the use of computerized patient portals [22]. Consistent with previous research, increasing age and less familiarity with technology were negatively related to enthusiasm [17]. Although we found that enthusiasm to use email among older adults decreased with increasing age, it still remained relatively high overall.

Third, we noted two unexpected findings related to demographics. First, subjects with self-reported poor health status were not highly enthusiastic about using email, contrary to findings reported in previous literature [13,14]. Second, we found that non-white patients were more enthusiastic than white patients about using email, also in contrast to previous findings [13]. Because non-whites generally receive less positive talk (positive talk includes more verbal behavior, agreements, encouragement, and reassurance) and information even within the same medical practice [23], their use of email may overcome some of the communication barriers they face. Being a less socially intimidating forum, an electronic medium could bolster the quality of patient-physician communication, since it might encourage older adults to ask questions and provide vital information more readily than during face-to-face communication [14]. This may be especially relevant in older men; men in general ask fewer questions, receive less positive talk, and are less likely to be included in discussion than women [23]. These reasons may explain why older men are more enthusiastic about using an alternative medium such as email to communicate with physicians.

Adoption by older patients of email as a tool to communicate with their physicians might also depend on the attitudes and beliefs of physicians and the value they place on communicating electronically. Previous work shows the criteria applied by physicians to use email remain subjective and depend on factors besides patient barriers (eg, a patient's access to the Internet), such as reimbursement for time spent writing email [3,24,25]. Although physician characteristics, such as demographic [5] and time and place of training, and practice characteristics, such as the setting and availability of a practice website, were expected to affect enthusiasm for email use, our findings did not substantiate this expectation. The quality of patient-physician communication may also be affected by a physician's morale and job stress [26]. Physicians dissatisfied with their careers cite problems in relationships with their patients and difficulties in caring for them, in addition to problems in communicating with specialists [27]. We expected these physicians to have less enthusiasm for using email but found quite the opposite. A partial explanation for this could be that these physicians found the prospects of an alternative medium of communication with patients especially valuable in addressing problem areas of communication within their practices. Furthermore, both confidentiality issues, such as those posed by HIPAA,and reimbursement-related issues pose additional barriers which dampen physician enthusiasm [7,8]. For example, physicians may have concerns that email will be too time consuming and not worth their time if they are not compensated [28].

Our findings also have implications for strategies to improve the use of email by older patients and their physicians. Availability of the Internet through community resources and efforts to engage family members in the process could significantly affect the use of email by older patients whose access to technology may be limited. Physician enthusiasm could be increased by having continuing medical education programs on electronic communication with a focus on specific barriers noted by physicians (eg, HIPAA limits).

Our study has certain limitations. Our analysis was based on a cross-sectional secondary look at existing data, and data on certain factors that could have played a role in determining enthusiasm (eg, use of email by other family members, reimbursement to physicians) were not collected at the outset. Secondly, while patient enthusiasm may be higher now than it was in 2003, factors determining patient enthusiasm are likely not to have changed dramatically. Our strengths include a large sample size drawn from a large, populous area; a diverse population that is representative of the region; and the inclusion of both genders. We also have a wide representation of primary care with diverse sets of physicians.

In conclusion, our study lends support to our hypothesis that, in addition to factors related to patient demographics and familiarity with technology, enthusiasm to use email depends upon the quality of existing relationships between patients and physicians. We found that older patients, especially non-whites, are highly likely to adopt this technology, but that factors arising from their interactions with physicians in traditional face-to-face encounters or their physician’s interest in the use of email could adversely affect their interest. Significant opportunities exist to use electronic tools to overcome some communication barriers affecting older patients. Further study on whether the adoption of email can reduce communication-related health disparities in the older non-white population is warranted. Public interest and demand in expanding the use of email could potentially lead to changes in reimbursement policies concerning the use of email.

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Conflicts of Interest

None declared.

References

1. Stalberg P, Yeh M, Ketteridge G, Delbridge H, Delbridge L. E-mail access and improved communication between patient and surgeon. Arch Surg 2008 Feb;143(2):164-8; discussion 168-9 [FREE Full text] [Medline: 18283141] [doi: 10.1001/archsurg.2007.31]
2. Moyer CA, Stern DT, Katz SJ, Fendrick AM. "We got mail": electronic communication between physicians and patients. Am J Manag Care 1999 Dec;5(12):1513-1522 [FREE Full text] [Medline: 11066618]
3. Patt MR, Houston TK, Jenckes MW, Sands DZ, Ford DE. Doctors who are using e-mail with their patients: a qualitative exploration. J Med Internet Res 2003 May 15;5(2):e9 [FREE Full text] [Medline: 12857665] [doi: 10.2196/jmir.5.2.e9]
4. Baker L, Wagner TH, Singer S, Bundorf MK. Use of the Internet and e-mail for health care information: results from a national survey. JAMA 2003 May 14;289(18):2400-2406 [FREE Full text] [Medline: 12746364] [doi: 10.1001/jama.289.18.2400]
5. Brooks RG, Menachemi N. Physicians' use of email with patients: factors influencing electronic communication and adherence to best practices. J Med Internet Res 2006;8(1):e2 [FREE Full text] [Medline: 16585026] [doi: 10.2196/jmir.8.1.e2]
6. Moyer CA, Stern DT, Dobias KS, Cox DT, Katz SJ. Bridging the electronic divide: patient and provider perspectives on e-mail communication in primary care. Am J Manag Care 2002 May;8(5):427-433 [FREE Full text] [Medline: 12019595]
7. Katz SJ, Moyer CA. The emerging role of online communication between patients and their providers. J Gen Intern Med 2004 Sep;19(9):978-983 [FREE Full text] [Medline: 15333064] [doi: 10.1111/j.1525-1497.2004.30432.x]
8. Mandl KD, Kohane IS, Brandt AM. Electronic patient-physician communication: problems and promise. Ann Intern Med 1998 Sep 15;129(6):495-500 [FREE Full text] [Medline: 9735088]
9. Sittig DF, King S, Hazlehurst BL. A survey of patient-provider e-mail communication: what do patients think? Int J Med Inform 2001 Apr;61(1):71-80. [Medline: 11248604] [doi: 10.1016/S1386-5056(00)00134-9]

10. Sciamanna CN, Rogers ML, Shenassa ED, Houston TK. Patient access to U.S. physicians who conduct internet or e-mail consults. J Gen Intern Med 2007 Mar;22(3):378-381 [FREE Full text] [Medline: 17356972] [doi: 10.1007/s11606-006-0076-1]
11. Adelman RD, Greene MG, Ory MG. Communication between older patients and their physicians. Clin Geriatr Med 2000;16(1):1-24. [Medline: 10723614]
12. Roter DL. The outpatient medical encounter and elderly patients. Clin Geriatr Med 2000 Feb;16(1):95-107. [Medline: 10723621] [doi: 10.1016/S0749-0690(05)70011-2]
13. Hsu J, Huang J, Kinsman J, Fireman B, Miller R, Selby J, et al. Use of e-Health services between 1999 and 2002: a growing digital divide. J Am Med Inform Assoc 2005;12(2):164-171 [FREE Full text] [Medline: 15561786] [doi: 10.1197/jamia.M1672]
14. Houston TK, Sands DZ, Jenckes MW, Ford DE. Experiences of patients who were early adopters of electronic communication with their physician: satisfaction, benefits, and concerns. Am J Manag Care 2004 Sep;10(9):601-608 [FREE Full text] [Medline: 15515992]
15. Greene MG, Hoffman S, Charon R, Adelman R. Psychosocial concerns in the medical encounter: a comparison of the interactions of doctors with their old and young patients. Gerontologist 1987 Apr;27(2):164-168. [Medline: 3583006]
16. Rost K, Frankel R. The introduction of the older patient's problems in the medical visit. J Aging Health 1993 Aug;5(3):387-401. [Medline: 10127175] [doi: 10.1177/089826439300500306]
17. Fox S. Seniors and the Internet. Pew Internet & American Life Project. Washington, DC: Pew Internet & American Life Project; 2006 Nov 14. URL: http://www.pewinternet.org/Presentations/2006/Seniors-and-the-Internet.aspx [WebCite Cache ID 5ffS28jya]
18. Fox SA, Heritage J, Stockdale SE, Asch SM, Duan N, Reise SP. Cancer screening adherence: does physician-patient communication matter? Patient Educ Couns 2009;5:178-184. [Medline: 19250793]
19. Leong SL, Gingrich D, Lewis PR, Mauger DT, George JH. Enhancing doctor-patient communication using email: a pilot study. J Am Board Fam Pract 2005;18(3):180-188 [FREE Full text] [Medline: 15879565] [doi: 10.3122/jabfm.18.3.180]
20. Eggert C, Protti D. Clinical electronic communications: a new paradigm that is here to stay? Healthc Q 2006;9(4):88-96. [Medline: 17076382]
21. ; American College of Physicians. American College of Physicians 2003 Policy Paper. The changing face of ambulatory medicine—reimbursing physicians for computer-based care: ACP analysis and recommendations to assure fair reimbursement for physician care rendered online. Philadelphia, PA: American College of Physicians; 2007.
22. Zickmund SL, Hess R, Bryce CL, McTigue K, Olshansky E, Fitzgerald K, et al. Interest in the use of computerized patient portals: role of the provider-patient relationship. J Gen Intern Med 2008 Jan;23 Suppl 1(s1):20-26 [FREE Full text] [Medline: 18095039] [doi: 10.1007/s11606-007-0273-6]
23. Roter D, Hall JA. Doctors Talking with Patients/Patients Talking with Doctors. 2nd edition. Westport, CT: Praeger Publishers; 2006.
24. Kittler AF, Carlson GL, Harris C, Lippincott M, Pizziferri L, Volk LA, et al. Primary care physician attitudes towards using a secure web-based portal designed to facilitate electronic communication with patients. Inform Prim Care 2004;12(3):129-138. [Medline: 15606985]
25. Goodyear-Smith F, Wearn A, Everts H, Huggard P, Halliwell J. Pandora's electronic box: GPs reflect upon email communication with their patients. Inform Prim Care 2005;13(3):195-202. [Medline: 16259859]
26. Kaplan SH, Greenfield S, Supran S, Wilson IB. Compromised physician morale, time pressures and the quality of interpersonal care. Assoc Health Serv Res Meet 1999;16:408.
27. DeVoe J, Fryer Jr GE, Hargraves JL, Phillips RL, Green LA. Does career dissatisfaction affect the ability of family physicians to deliver high-quality patient care? J Fam Pract 2002 Mar;51(3):223-228. [Medline: 11978232]
28. Car J, Sheikh A. Email consultations in health care: 2--acceptability and safe application. BMJ 2004 Aug 21;329(7463):439-442 [FREE Full text] [Medline: 15321903] [doi: 10.1136/bmj.329.7463.439]

Abbreviations

CMC: communication in medical care
GEE: generalized estimating equations
HIPAA: Health Insurance Portability and Accountability Act

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