Journal of Medical Internet Research

Journal Impact Factor (JIF) (2022): 7.4
Volume 15 (2013), Issue 5   ISSN 1438-8871   Editor in Chief: Gunther Eysenbach, MD, MPH

Contents

Original Papers

Reviews

Viewpoint

Original Paper

Who Participates in Web-Assisted Tobacco Interventions? The Quit-Primo and National Dental Practice-Based Research Network Hi-Quit Studies

Rajani Shankar Sadasivam[1,2], PhD; Rebecca L Kinney[1], MPH; Kathryn Delaughter[1,2], MS; Sowmya R Rao[1,2,3], PhD; Jessica Hillman Williams[6], PhD, MPH; Heather L Coley[5], MPH; Midge N Ray[4], MSN, MEd, RN; Gregg H Gilbert[6], DDS, MBA; Jeroan J Allison[1], MD, MS; Daniel E Ford[7], MD, MPH; Thomas K Houston[1,2,3], MD, MPH; The National Dental PBRN And QUIT-PRIMO Collaborative Groups[8]

[1]Division of Health Informatics & Implementation Science, University of Massachusetts Medical School, Worcester, MA, United States
[2]VA eHealth Quality Enhancement Research Initiative, Bedford VAMC, Bedford, MA, United States
[3]Center for Health Quality, Outcomes & Economic Research (CHQOER), Bedford, MA, United States
[4]Department of Health Services Administration, School of Health Professions, University of Alabama at Birmingham, Birmingham, AL, United States
[5]Division of General Internal Medicine, University of Alabama at Birmingham, Birmingham, AL, United States
[6]Department of Clinical & Community Sciences, School of Dentistry, University of Alabama at Birmingham, Birmingham, AL, United States
[7]Division of General Internal Medicine, Johns Hopkins School of Medicine, Baltimore, MD, United States
[8]University of Alabama at Birmingham, Birmingham, AL, United States

Corresponding Author:
Rajani Shankar Sadasivam, PhD
Division of Health Informatics & Implementation Science
University of Massachusetts Medical School
55 Lake Ave North
Worcester, MA,
United States
Phone: 1 5089254846
Fax: 1 5088568993
Email: rajani.sadasivam@umassmed.edu

Abstract

Introduction: Smoking is the most preventable cause of death. Although effective, Web-assisted tobacco interventions are underutilized and recruitment is challenging. Understanding who participates in Web-assisted tobacco interventions may help in improving recruitment.

Objectives: To understand characteristics of smokers participating in a Web-assisted tobacco intervention (Decide2Quit.org).

Methods: In addition to the typical Google advertisements, we expanded Decide2Quit.org recruitment to include referrals from medical and dental providers. We assessed how the expanded recruitment of smokers changed the users' characteristics, including comparison with a population-based sample of smokers from the national Behavioral Risk Factors Surveillance Survey (BRFSS). Using a negative binomial regression, we compared demographic and smoking characteristics by recruitment source, in particular readiness to quit and association with subsequent Decide2Quit.org use.

Results: The Decide2Quit.org cohort included 605 smokers; the 2010 BRFSS dataset included 69,992. Compared to BRFSS smokers, a higher proportion of Decide2Quit.org smokers were female (65.2% vs 45.7%, *P*=.001), over age 35 (80.8% vs 67.0%, *P*=.001), and had some college or were college graduates (65.7% vs 45.9%, *P*=.001). Demographic and smoking characteristics varied by recruitment; for example, a lower proportion of medical- (22.1%) and dental-referred (18.9%) smokers had set a quit date or had already quit than Google smokers (40.1%, *P*<.001). Medical- and dental-referred smokers were less likely to use Decide2Quit.org functions; in adjusted analysis, Google smokers (predicted count 17.04, 95% CI 14.97-19.11) had higher predicted counts of Web page visits than medical-referred (predicted count 12.73, 95% CI 11.42-14.04) and dental-referred (predicted count 11.97, 95% CI 10.13-13.82) smokers, and were more likely to contact tobacco treatment specialists.

Conclusions: Recruitment from clinical practices complimented Google recruitment attracting smokers less motivated to quit and less experienced with Web-assisted tobacco interventions.

Trial Registration: Clinicaltrials.gov NCT00797628; http://clinicaltrials.gov/ct2/show/NCT00797628 (Archived by WebCite at http://www.webcitation.org/6F3tqz0b3)

(J Med Internet Res 2013;15(5):e77) doi:10.2196/jmir.2385

KEYWORDS

smoking cessation; Web-assisted tobacco intervention; Google advertisements; medical practice; dental practice; public health informatics

Introduction

Smoking continues to be the number one preventable cause of death [1-5]. To meet the 2020 Healthy People objectives of ending the tobacco epidemic and reducing illness, disability, and death related to tobacco use and secondhand smoke exposure [6], innovative approaches are needed to reach and engage current smokers. Web-assisted tobacco interventions have improved quit rates [7-18] and can potentially reach a large number of smokers [19-21]. However, current methods to recruit smokers to these interventions have some limitations [22-26].

Most Web-assisted tobacco interventions recruit smokers by using search engine or media advertisements [27-28]. These methods require the smokers to actively initiate the first contact with the intervention; thus, the recruited smokers may not be representative of the majority of smokers [22-23], particularly in their readiness to quit. A Cochrane review of 20 Web-assisted tobacco interventions reported that most of these interventions that used search engine recruitment were able to recruit only those smokers ready to quit [29]. These smokers tended to be female and white [29-31]. Recruiting smokers by using just search engine or media advertisements also misses an important opportunity to recruit the majority of smokers, the 70% who see a health care provider at least once per year [3,5].

In our study, we expanded the recruitment of smokers to our evidence-based, Web-assisted tobacco intervention (Decide2Quit.org [32]) to also include provider referrals from medical and dental practices in addition to the usual Google advertisements. Our goal in this paper was to assess whether our expanded recruitment improved variability of our cohort. In particular, we were interested to see if directly recruiting smokers from provider's e-referrals would increase participation of smokers less ready to quit. Finally, we looked longitudinally at these smokers' participation in Decide2Quit.org; specifically, we looked at the association between recruitment source and subsequent use of Decide2Quit.org.

Methods

Study Design

We compared smokers who registered on Decide2Quit.org from May 2010 through July 2011 with smokers who responded to the 2010 BRFSS survey. Decide2Quit.org—a Web-assisted tobacco intervention containing information about quitting smoking, secure asynchronous messaging with a certified tobacco treatment specialist (TTS), an online support group, and a motivational, pushed-email, tailored messaging system—is the core patient intervention in 2 randomized trials. Decide2Quit.org is both a cessation induction and a relapse prevention system. All smokers can benefit from the system, whether they are in the precontemplation, contemplation, or preparation stage, or in the action or maintenance stages. Thus, we recruited smokers at all motivational levels. We used multiple routes to recruit smokers. In the Quality Improvement in Tobacco Provider Referrals & Internet-delivered Microsystem Optimization (Quit-Primo) trial, smokers were referred to Decide2Quit.org from medical practices [33] and in the Hygienists to Internet Quality Improvement in Tobacco (Hi-Quit) trial, smokers were referred from dental practices participating in a practice-based research network. In parallel, we also used Google advertisements to recruit smokers to Decide2Quit.org. These 2 trials were approved by the Institutional Review Boards of the University of Alabama at Birmingham and the University of Massachusetts Medical School.

The Behavioral Risk Factors Surveillance Survey (BRFSS) is a yearly, cross-sectional telephone survey conducted by state health departments with technical and methodological assistance provided by the Centers for Disease Control and Prevention to collect prevalence data on risk behaviors and preventive health practices that affect health status [34]. The health characteristics estimated from the BRFSS pertain to the adult population, aged 18 years or older. For our analysis, we used the 2010 BRFSS dataset because it was in the same time frame as the Decide2Quit.org registrations.

Setting and Sample

The Decide2Quit.org cohort included smokers recruited from 81 medical primary care practices and 51 dental practices across the United States, and through Google advertisements. Primary care medical practices were recruited from a registered database of internal medicine and family/general practitioners. Dental practices were recruited from state lists of registered dentists and through the Dental Practice-Based Research Network [35]. At these practices, we implemented an e-referral program that allowed providers to recruit smokers to Decide2Quit.org at the point-of-care by entering their email addresses into an online form [33,36]. When e-referred, smokers were sent up to 10 email messages encouraging registration over an 8 week period or until the patient registered. To recruit smokers through Google advertisements, 3 ads were posted on Google AdWords [37]. Advertisements were linked to searches for keywords related to smoking (eg, smoking, quit smoking, stop smoking, quit, quit smoking tips, and quit smoking programs) and included a link that took participants directly to the Decide2Quit.org home page where they could choose to register as new participants.

The BRFSS is conducted monthly to collect data about risk behaviors from people in all 50 states, the District of Columbia, Puerto Rico, Guam, and the Virgin Islands. Respondents to the BRFSS were identified by using telephone-based methods; although 95% of US households have telephones, the coverage varies across states and subgroups. No direct methods were used to compensate for nontelephone coverage; however, post-stratification weights were used to partially correct for any bias caused by lack of telephone coverage. These weights also adjusted for differences in probability of selection and nonresponse. A more complete description of the sampling methodology may be found on the BRFSS website [34].

Data Collection

All smokers registering on Decide2Quit.org completed an online survey during registration. We collected demographics (sex, age, ethnicity, education, marital status, and Internet usage) and smoking characteristics (readiness to quit, quit history, number of cigarettes per day, and smoking at home). Readiness to quit was assessed using a question based on the Transtheoretical Model of Change [38]. The readiness question consisted of 5 options: I am not thinking of quitting (precontemplation), I am thinking of quitting (contemplation), I have set a quit date (preparation), I quit today (action), and I have already quit (maintenance). Online activity (number of visits, page visits, asynchronous interactions with TTS, and use of the online support group) was tracked through Web page scripts.

The BRFSS questionnaire includes a standard set of questions asked by all states about current health-related perceptions, conditions, and behaviors, including smoking, as well as demographic questions. We used the question “Do you now smoke cigarettes every day, some days, or not at all?” to identify smokers in the 2010 BRFSS dataset.

Statistical Analyses

All analyses were conducted using Stata version 11 (StataCorp LP, College Station, TX, USA). We first compared demographic characteristics of Decide2Quit.org smokers and BRFSS smokers. Next, we compared demographic and smoking characteristics by Decide2Quit.org recruitment source (Google advertisements vs clinical practice referrals). We also compared the readiness to quit of these smokers. We used the Pearson chi-square test to assess the significant differences between Decide2Quit.org and BRFSS smokers (survey weighted proportions). For each recruitment source, we assessed the number of referrals per successful smoker registration. For medical and dental practices, we divided the total referral count by the number of smokers subsequently registered in that group. For Google, we used the number of click throughs on our advertisement as the referral number and divided this number by the subsequent number of smokers registered in that group. This is an estimate of the number of referred smokers needed per successful registration.

Finally, we assessed whether recruitment source was associated with subsequent use of the system. In this analysis, our dependent variable was use of the system measured by number of pages visited, our independent variable was recruitment source, and our covariates were demographics and smoking characteristics.

We used a count regression because our dependent variable was the number of pages visited. Because of over dispersion of the variance of the distribution of the dependent variable, we used negative binomial regression instead of simple Poisson. From these models, incidence rate ratios (IRR) and adjusted counts of the dependent variable were calculated. Although we primarily used number of pages visited as our system use variable, we also assessed use by using number of visits to the system.

Results

Summary

The Decide2Quit.org sample included 605 registered smokers: 32.6% (n=197) were from Google advertisements, 46.4% (n=280) were from medical practice e-referrals, and 21.0% (n=127) were from dental practice e-referrals. The 2010 BRFSS dataset included 69,992 smokers aged 18 and older.

Decide2Quit.org Versus Behavioral Risk Factors Surveillance Survey

Compared with the national sample of smokers participating in the BRFSS, a higher proportion of Decide2Quit.org smokers were female (65.2% vs 45.7%, *P*=.001), over the age of 35 years (80.8% vs 67.0%, *P*=.001), and had attended some college or were a college graduate (65.7% vs 45.9%, *P*=.001) (Table 1). A small but significant difference was seen in the proportion of smokers who attempted to quit in the past 12 months (5%, *P*=.01).

Number of Referrals Per Smoker Registration by Recruitment Source

The number of medical practice referrals was 1588 resulting in 280 successful registrations; thus, the number of referrals per registration was 5.7. The number of dental practice referrals was 739 with 127 registrations; the number of referrals per registration was 5.8. There were 6992 click throughs on our Google advertisements and a resulting 197 registrations; the number of referrals per registration was 35.5.

We compared Decide2Quit.org’s smokers by recruitment method (Google advertisement, medical practice referral, or dental practice referral, see Table 2). Because Google is frequently the recruitment source for Web-assisted tobacco interventions, we consistently use it as the reference or comparison group.

Table 1. Characteristics of smokers participating in the Behavioral Risk Factor Surveillance Survey (BRFSS) and all smokers (Google, medical-referred, and dental-referred combined) who engaged in the Web-assisted tobacco intervention Decide2Quit.org.

Demographic characteristic	Decide2Quit.org combined, n (%) n=604	BRFSS, (%) [a] n=69,992
Sex [b]		
Male	210 (34.7)	(54.3)
Female	394 (65.2)	(45.7)
Age [b]		
19-34	116 (19.2)	(33.0)
35-54	307 (50.8)	(44.1)
> 55	181 (30.0)	(22.9)
Race [b]		
White	529 (87.6)	(80.7)
Nonwhite	75 (12.4)	(19.3)
Highest grade of school [b]		
< High school	36 (6.0)	(15.7)
High school	171(28.3)	(38.5)
Some college or college graduate	397 (65.7)	(45.9)
During the past 12 months, have you stopped smoking for 1 day or longer because you were trying to quit smoking? [c]		
No	277 (45.9)	(40.9)
Yes	324 (54.1)	(58.8)
Smoking status		
Not thinking about quitting	26 (4.3)	
Thinking of quitting	413 (68.4)	
Set a quit date	72 (11.9)	
Already quit	93 (15.4)	

[a] Weighted for complex survey design

[b] *P*=.001

[c] *P*=.01

Table 2. Demographic characteristics and readiness to quit of smokers by recruitment source.

Demographic characteristic	Recruitment source, n (%)		
	Google advertisement n=197	Dental practice referrals n=127	Medical practice referrals n=280
Sex			
Male	61 (31.0)	43 (33.9)	106 (37.9)
Female	136 (69.0)	84 (66.1)	174 (62.1)
Age (years)			
19-34	29 (14.7)	40 (31.5)	47 (16.8)[a]
35-54	105 (53.3)	59 (46.5)	143 (51.1)
< 55	63 (32.0)	28 (22.1)	90 (32.1)
Race			
White	171 (86.8)	112 (88.2)	246 (87.9)
Nonwhite	26 (13.2)	15 (11.8)	34 (12.1)
Highest grade of school			
< College graduate	134 (68.0)	91 (71.7)	236 (84.3)[b]
College graduate	63 (32.0)	36 (28.4)	44 (15.7)
Smoking status			
Not thinking about quitting	6 (3.1)	11 (8.7)[b]	9 (3.2)[b]
Thinking of quitting	112 (56.9)	92 (72.4)	209 (74.6)
Set a quit date	29 (14.7)	13 (10.2)	30 (10.7)
Already quit	50 (25.4)	11 (8.7)	32 (11.4)

[a] *P*=.001 comparing Google and the applicable column

[b] *P*<.001 comparing Google and the applicable column

Demographics by Recruitment Source

Demographic and smoking characteristics varied by recruitment source (Table 2). Compared with Google and medical-referred smokers, the dental-referred smokers (21.0%) were younger (*P*=.001 and *P*=.002, respectively). Compared with Google (32.0%) and dental-referred (28.4%) smokers, a lower proportion of medical-referred smokers (15.7%) were college graduates (*P*<.001 and *P*=.003, respectively).

Readiness to Quit and Other Smoking Characteristics by Recruitment Source

A lower proportion of medical-referred (22.1%) and dental-referred (18.9%) smokers had set a quit date or had already quit than Google-referred smokers (40.1 %, *P*<.001 for both comparisons). The mean number of cigarettes smoked per day was similar between Google (mean 17.8, SD 10.5) and medical-referred smokers (mean 17.4, SD 9.2), but lower for dental-referred smokers (mean 14.5, SD 8.9; *P*=.002). Fewer dental-referred smokers allowed smoking at home compared with the other 2 groups (dental-referred 34% vs Google 48%, *P*=.36; dental-referred 34% vs medical-referred 45%, *P*=.005). Medical-referred (8.6%) and dental-referred (15.8%) smokers were less likely to have visited smoking cessation websites as compared to Google smokers (40.1%, *P*<.001 for both comparisons).

Smokers' Participation in Decide2Quit.org by Recruitment Source

Medical-referred (mean 2.4, SD 3.4) and dental-referred (mean 2.1, SD 2.6) smokers visited Decide2Quit.org less frequently than Google smokers (mean 2.7, SD 4.0), but this was not statistically significant (*P*=.14 and *P*=.06, respectively). On average, they also visited fewer pages on the website per visit (medical-referred: mean 12.9, SD 13.6; dental-referred: mean 12.3, SD 12.4; Google: mean 17.4, SD 15.2; Google vs medical-referred *P*<.001; Google vs dental-referred *P*=.002). Compared with Google smokers (42.6%), a lower proportion of medical-referred (29.6%, *P*=.01) and dental-referred (22.8%, *P*=.01) smokers messaged the TTS at least once. Although not statistically significant, among those who messaged at least once, medical- and dental-referred smokers also interacted with the TTS less frequently than their Google counterparts (medical-referred: mean 2.0, SD 2.4; dental-referred: mean 2.0, SD 1.7; Google: mean 3.3, SD 6.1). However, this was not statistically significant (Google vs medical *P*=.05, Google vs dental *P*=.13). Medical-referred (23.6%) and dental-referred (12.6%) smokers also used the online support group less frequently than Google smokers (39.1%, *P*=.01 for both comparisons).

Multivariable Comparisons Among Google, Medical-Referred, and Dental-Referred Smokers

After adjustment for demographic characteristics and readiness to quit, Google smokers had higher predicted counts of Web page visits (IRR 17.0, 95% CI 15.0-19.1) compared with the medical-referred (IRR 12.7, 95% CI 11.4-14.0) and dental-referred smokers (IRR 12.0, 95% CI 10.1-13.8) (Table 3). Google smokers were also more likely to use the TTS and an online support group. When we assessed system use using number of visits to the website, the direction and magnitude of the point estimates remained the same.

Table 3. Associations between recruitment source and use of Decide2Quit.org.

Demographic characteristic	Unadjusted		Adjusted	
	IRR (95% CI)	Counts[a] (95% CI)	IRR (95% CI)	Counts[a] (95% CI)
Patient origin				
From Google advertisement	Reference	17.4 (15.3-19.6)	Reference	17.0 (15.0-19.1)
From medical provider	0.7 (0.6-0.9)	12.9 (11.5-14.2)	0.8 (0.7-0.9)	12.7 (11.4-14.0)
From dental provider	0.7 (0.6-0.9)	12.3 (10.4-14.2)	0.7 (0.6-0.9)	12.0 (10.1-13.8)
Sex				
Female	Reference	15.3 (13.9-16.6)	Reference	14.8 (13.6-16.1)
Male	0.8 (0.7-0.9)	12.3 (10.8-13.8)	0.8 (0.7-1.0)	12.1 (10.7-13.5)
Age				
19-34	Reference	14.5 (12.7-16.9)	Reference	14.3 (12.0-16.6)
35-54	1.0 (0.8-1.2)	13.8 (12.4-15.2)	0.9 (0.8-1.1)	13.4 (12.1-14.7)
> 55	1.0 (0.82-1.25)	14.7 (12.8-16.7)	1.0 (0.8-1.2)	14.3 (12.5-16.1)
Race				
White	Reference	11.7 (9.3-14.1)	Reference	11.5 (9.2-13.9)
Nonwhite	1.3 (1.0-1.6)	14.6(13.5-15.7)	1.2 (1.0-0.5)	14.2 (13.1-15.2)
School				
College graduate	Reference	18.4 (15.8-21.1)	Reference	17.8 (15.3-20.4)
< College graduate	0.7 (0.6-0.8)	13.0 (11.9-14.0)	0.7 (0.6-0.9)	12.8 (11.8-13.8)
Smoking status				
Already quit	Reference	16.2(13.3-19.1)	Reference	15.9 (13.1-18.7)
Set a quit date	0.9 (0.7-1.2)	15.1 (12.0-18.3)	1.0 (0.8-1.3)	14.9 (11.9-17.9)
Thinking of quitting	0.9 (0.7-1.1)	13.9 (12.7-15.1)	0.9 (0.8-1.1)	13.5 (12.4-14.6)
Not thinking about quitting	0.6 (0.4-0.9)	9.9 (6.4-13.4)	0.7 (0.5-1.0)	10.1 (6.6-13.5)

[a] Counts are marginal predicted counts products postregression using the X command in STATA.

Discussion

Findings and Conclusions

Approximately 70% of the 44.5 million adult smokers in the United States want to quit, but fewer than 5% of those who do try to quit in a given year succeed [6]. Thus, expanding the reach of effective treatments, such as Web-assisted tobacco interventions, is crucial in increasing quit rates. However, recruitment to Web-assisted tobacco interventions poses unique challenges [22,24-26]. In this study, we expanded recruitment by adding an e-referral approach to the traditional search engine method. In this paper, we assessed how this combination increased the variability of our cohort.

Compared with the population of smokers responding to the 2010 BRFSS, a higher proportion of smokers registering with Decide2Quit.org were female (nearly 20% more). They also were more likely to identify themselves as white in race/ethnicity and be highly educated. However, among those recruited from medical practices, 15.7% reported college education, which was the same proportion reported by BRFSS-participating smokers. Inconsistent with expectations, Decide2Quit.org smokers were older. The rate of prior quit attempts in the past 12 months was similar among those registering with Decide2Quit.org and the national BRFSS.

Our comparisons (as shown in Table 1) highlight the sharp difference in the proportion of women participating in our Web-assisted tobacco intervention as compared with the national sample of smokers. The higher proportion of women also was consistent across our recruitment sources (Google advertisement 69.0% vs medical referral 62.1% vs dental referral 66.1%). Women, in general, may be more likely to participate in a Web-assisted tobacco intervention; therefore, our participation rates may just be reflecting general trends. Across 6 other Web-assisted tobacco interventions, the mean proportion of women participating was 60% (range 52-72) [39-44]. The lower participation rates of men in these interventions suggest that different recruitment approaches or different types of interventions might be needed to engage them in cessation activities.

Although we identified differences in race/ethnicity and education for our Web-engaged smokers compared to the BRFSS, our age distribution was older than the national sample. The older age may be because the decision to make a serious and successful attempt to quit smoking is typically made when a smoker has reached a greater level of maturity than the average smoker (mid- to upper-30s). Other Web-assisted tobacco interventions also report a mean age of 39 years (range 34-49, [39-44]). However, close to one-third of our smokers were over the age of 55. This number may be reflective of the decrease in age barriers to Internet adoption in recent years. [45].

Recruitment from medical and dental practices was more efficient than Google advertising with respect to the number of referrals needed to register a smoker (5.7, 5.8, and 35.5, respectively). Within the population of smokers registering at Decide2Quit.org, the types of smokers who were recruited from clinical practices were different from those who found the intervention site via Google. The general trend in educational status among our Web-engaged smokers varied. Those recruited from medical practices were less educated and less likely to have previously used a Web-assisted tobacco intervention; thus, they more closely resembled the national sample. Dental practice smokers were younger than counterparts from the other recruitment groups. Many younger smokers are seen in dental practices, but may not be seen in medical practices; thus, recruitment from dental practices allowed us to target smokers who were not engaged through Google or medical practices. These dental participants also were lighter smokers, a group that may be especially difficult to engage in interventions to quit smoking.

In addition to engaging smokers with different demographic characteristics, clinical practice-based recruitments also resulted in participation by smokers with a wider range of motivational levels. Our results support previous concerns that recruiting using search engine-based recruitment methods alone may limit the reach of Web-assisted tobacco interventions mainly to smokers highly motivated to quit [46-50]. Currently, most smokers recruited to these interventions are through search engine advertisements or other mass media campaigns, which require the smoker to be motivated to register on the system. For example, out of 2523 smokers recruited to a Web-assisted tobacco intervention [27], most (71%) were recruited through Google Ads or direct mailing. Only 95 smokers (3.8%) were recruited through provider referrals or other proactive recruitment methods. The recruitment to the National Colorectal Cancer Research Alliance (NCCRA) and OncoLink Web-assisted tobacco intervention [28] also were primarily through search engine and mass media campaigns. In the OncoLink study, only 7.3% of 2162 smokers were registered from proactive provider referrals.

As noted, our results indicate that using only search engine or mass media recruitment methods limits the range of smokers engaged. In our study, a higher proportion of Google smokers were ready to quit or had already quit compared with other smokers; medical practice referrals brought in smokers who were often at a lower readiness to quit and less likely to have sought help from online resources. They are an important group of smokers to engage, and Web-assisted tobacco interventions can be designed for smokers not ready to quit (as cessation induction interventions) as well as for smokers ready to quit (as an aid to cessation).

Although we were successful in broadening our sample, we were unable to maintain the engagement of clinical practice-recruited smokers at the same level as Google-recruited smokers. Google participants had higher participation rates at Decide2Quit.org. Previous Web-assisted tobacco intervention studies have shown a relationship between smoking cessation and number of website visits [51], number of website sections viewed [52], and amount of time spent on the website [53]. Thus, Google participants may have disproportionally benefited from the intervention. Google smokers had a higher number of page hits, even after adjusting for demographics and readiness to quit. Google smokers were more educated, had prior experience participating in a Web-assisted tobacco intervention, and were more likely to have set a quit date or quit. Other important predictors of greater use included TTS use and access to an external social network. Future Web-assisted tobacco interventions may need to be flexible in their strategy to maintain engagement for smokers not quite ready to quit [54], perhaps by continually monitoring participation rates and programming their interventions to be more proactive with the groups that are less engaged.

Limitations

Our study has limitations. First, we collected a limited number of characteristics of these smokers; thus, the samples may vary on important unmeasured characteristics. Some of the information was self-reported through an online survey and cannot be validated. We evaluated the impact of only 1 Web-assisted tobacco intervention (Decide2Quit.org), which prevents strict generalizability to all Web-assisted tobacco interventions or other online behavior support. One major difference in participation in the intervention was by readiness to quit. Although, we adjusted for readiness to quit in our model (Table 3), it is certainly possible that residual confounding by readiness is mediating differences in participation by recruitment source.

In conclusion, to maximize the potential of Web-assisted tobacco interventions, expanding methods to attract more smokers is critical. In recruiting users who typically do not participate in these interventions, we demonstrated that clinical practice recruitment does complement Internet search engine recruitment. However, our results also suggest that once recruited, those smokers recruited from clinical practices may not be as active as the Google smokers, suggesting that Web-assisted tobacco interventions may need to tailor their engagement strategies.

Acknowledgments

Funding for these studies was received from the National Cancer Institute, grant R01 CA129091, and the National Institute of Dental and Craniofacial Research, grants U01 DE16746, U01 DE16747, and U19 DE22516. Research reported in this publication was also supported by the National Center for Advancing Translational Sciences of the National Institutes of Health under award number UL1TR000161. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

Conflicts of Interest

None declared.

References

1. Murray CJ, Lopez AD. Alternative projections of mortality and disability by cause 1990-2020: Global Burden of Disease Study. Lancet 1997 May 24;349(9064):1498-1504. [doi: 10.1016/S0140-6736(96)07492-2] [Medline: 9167458]
2. Critchley JA, Capewell S. Mortality risk reduction associated with smoking cessation in patients with coronary heart disease: a systematic review. JAMA 2003 Jul 2;290(1):86-97. [doi: 10.1001/jama.290.1.86] [Medline: 12837716]
3. Fiore MC, Croyle RT, Curry SJ, Cutler CM, Davis RM, Gordon C, et al. Preventing 3 million premature deaths and helping 5 million smokers quit: a national action plan for tobacco cessation. Am J Public Health 2004 Feb;94(2):205-210. [Medline: 14759928]
4. Centers for Disease Control and Prevention (CDC). MMWR Morb Mortal Wkly Rep. 2002 Jul 26. Cigarette smoking among adults--United States, 2000 URL: http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5129a3.htm [accessed 2013-03-25] [WebCite Cache ID 6FO8Mq9VZ]
5. Fiore C, Jaen CR, Baker TB, Tobacco Use and Dependence Guideline Panel. Treating Tobacco Use and Dependence: 2008 Update. Rockville, MD: US Department of Health and Human Services, Public Health Service; 2008 May 1. URL: http://www.ncbi.nlm.nih.gov/books/NBK63952/ [accessed 2013-03-25] [WebCite Cache ID 6FO8BFVpJ]
6. National Institutes of Health, Office of the Director. NIH State-of-the-Science Conference Statement on Tobacco Use: Prevention, Cessation, and Control. NIH Consens State Sci Statements 2006;23(3):1-26 [FREE Full text] [Medline: 17332801]
7. Myung SK, McDonnell DD, Kazinets G, Seo HG, Moskowitz JM. Effects of Web- and computer-based smoking cessation programs: meta-analysis of randomized controlled trials. Arch Intern Med 2009 May 25;169(10):929-937. [doi: 10.1001/archinternmed.2009.109] [Medline: 19468084]
8. Lancaster T, Stead LF. Self-help interventions for smoking cessation. Cochrane Database Syst Rev 2002(3):CD001118. [doi: 10.1002/14651858.CD001118] [Medline: 12137618]
9. Feil EG, Noell J, Lichtenstein E, Boles SM, McKay HG. Evaluation of an Internet-based smoking cessation program: lessons learned from a pilot study. Nicotine Tob Res 2003 Apr;5(2):189-194. [Medline: 12745491]
10. Lenert L, Muñoz RF, Perez JE, Bansod A. Automated e-mail messaging as a tool for improving quit rates in an internet smoking cessation intervention. J Am Med Inform Assoc 2004;11(4):235-240 [FREE Full text] [doi: 10.1197/jamia.M1464] [Medline: 15064291]
11. 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. [doi: 10.1016/S0738-3991(03)00163-0] [Medline: 15140462]
12. Norman C. CATCH-IT report: evaluation of an Internet-based smoking cessation program: lessons learned from a pilot study. J Med Internet Res 2004 Dec 31;6(4):e47; discussion e48 [FREE Full text] [doi: 10.2196/jmir.6.4.e47] [Medline: 15631971]
13. 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. [doi: 10.1111/j.1360-0443.2005.01093.x] [Medline: 15847626]
14. Lenert L, Muñoz RF, Stoddard J, Delucchi K, Bansod A, Skoczen S, et al. Design and pilot evaluation of an internet smoking cessation program. J Am Med Inform Assoc 2003;10(1):16-20 [FREE Full text] [Medline: 12509354]
15. 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 [FREE Full text] [doi: 10.2196/jmir.7.1.e2] [Medline: 15829474]
16. Swartz LH, Noell JW, Schroeder SW, Ary DV. A randomised control study of a fully automated internet based smoking cessation programme. Tob Control 2006 Feb;15(1):7-12 [FREE Full text] [doi: 10.1136/tc.2003.006189] [Medline: 16436397]
17. Muñoz RF, Lenert LL, Delucchi K, Stoddard J, Perez JE, Penilla C, et al. Toward evidence-based Internet interventions: A Spanish/English Web site for international smoking cessation trials. Nicotine Tob Res 2006 Feb;8(1):77-87. [doi: 10.1080/14622200500431940] [Medline: 16497602]

18. Norman CD, McIntosh S, Selby P, Eysenbach G. Web-assisted tobacco interventions: empowering change in the global fight for the public's (e)Health. J Med Internet Res 2008;10(5):e48 [FREE Full text] [doi: 10.2196/jmir.1171] [Medline: 19033147]
19. Cunningham JA. Access and interest: two important issues in considering the feasibility of web-assisted tobacco interventions. J Med Internet Res 2008;10(5):e37 [FREE Full text] [doi: 10.2196/jmir.1000] [Medline: 18984558]
20. Cunningham JA, Selby PL, Kypri K, Humphreys KN. Access to the Internet among drinkers, smokers and illicit drug users: is it a barrier to the provision of interventions on the World Wide Web? Med Inform Internet Med 2006 Mar;31(1):53-58. [doi: 10.1080/14639230600562816] [Medline: 16754367]
21. Velicer WF, Prochaska JO. An expert system intervention for smoking cessation. Patient Educ Couns 1999 Feb;36(2):119-129. [Medline: 10223017]
22. Graham AL, Milner P, Saul JE, Pfaff L. Online advertising as a public health and recruitment tool: comparison of different media campaigns to increase demand for smoking cessation interventions. J Med Internet Res 2008;10(5):e50 [FREE Full text] [doi: 10.2196/jmir.1001] [Medline: 19073542]
23. Murray E, Khadjesari Z, White IR, Kalaitzaki E, Godfrey C, McCambridge J, et al. Methodological challenges in online trials. J Med Internet Res 2009;11(2):e9 [FREE Full text] [doi: 10.2196/jmir.1052] [Medline: 19403465]
24. 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] [doi: 10.2196/jmir.7.1.e6] [Medline: 15829478]
25. Stoddard J, Delucchi K, Muñoz R, Collins N, Stable EP, Augustson E, et al. Smoking cessation research via the internet: a feasibility study. J Health Commun 2005;10(1):27-41. [doi: 10.1080/10810730590904562] [Medline: 15764442]
26. Cobb NK, Graham AL. Characterizing Internet searchers of smoking cessation information. J Med Internet Res 2006;8(3):e17 [FREE Full text] [doi: 10.2196/jmir.8.3.e17] [Medline: 17032633]
27. Gordon JS, Akers L, Severson HH, Danaher BG, Boles SM. Successful participant recruitment strategies for an online smokeless tobacco cessation program. Nicotine Tob Res 2006 Dec;8 Suppl 1:S35-S41. [Medline: 17491169]
28. Wei SJ, Metz JM, Coyle C, Hampshire M, Jones HA, Markowitz S, et al. Recruitment of patients into an internet-based clinical trials database: the experience of OncoLink and the National Colorectal Cancer Research Alliance. J Clin Oncol 2004 Dec 1;22(23):4730-4736. [doi: 10.1200/JCO.2004.07.103] [Medline: 15570073]
29. Civljak M, Sheikh A, Stead LF, Car J. Internet-based interventions for smoking cessation. Cochrane Database Syst Rev 2010(9):CD007078. [doi: 10.1002/14651858.CD007078.pub3] [Medline: 20824856]
30. Hutton HE, Wilson LM, Apelberg BJ, Tang EA, Odelola O, Bass EB, et al. A systematic review of randomized controlled trials: Web-based interventions for smoking cessation among adolescents, college students, and adults. Nicotine Tob Res 2011 Apr;13(4):227-238. [doi: 10.1093/ntr/ntq252] [Medline: 21350042]
31. Shahab L, McEwen A. Online support for smoking cessation: a systematic review of the literature. Addiction 2009 Nov;104(11):1792-1804. [doi: 10.1111/j.1360-0443.2009.02710.x] [Medline: 19832783]
32. Houston TK, Ford DE. A tailored Internet-delivered intervention for smoking cessation designed to encourage social support and treatment seeking: usability testing and user tracing. Inform Health Soc Care 2008 Mar;33(1):5-19. [doi: 10.1080/14639230701842240] [Medline: 18604759]
33. Houston TK, Sadasivam RS, Ford DE, Richman J, Ray MN, Allison JJ. The QUIT-PRIMO provider-patient Internet-delivered smoking cessation referral intervention: a cluster-randomized comparative effectiveness trial: study protocol. Implement Sci 2010;5:87 [FREE Full text] [doi: 10.1186/1748-5908-5-87] [Medline: 21080972]
34. Centers for Disease Control and Prevention (CDC) Office of Surveillance, Epidemiology, and Laboratory Services. CDC. Behavioral Risk Factor Surveillance System: 2010 Survey Data URL: http://www.cdc.gov/brfss/technical_infodata/surveydata/2010.htm [accessed 2012-10-08] [WebCite Cache ID 6BGROyW6b]
35. Gilbert GH, Williams OD, Rindal DB, Pihlstrom DJ, Benjamin PL, Wallace MC, DPBRN Collaborative Group. The creation and development of the dental practice-based research network. J Am Dent Assoc 2008 Jan;139(1):74-81. [Medline: 18167389]
36. Sadasivam RS, Delaughter K, Crenshaw K, Sobko HJ, Williams JH, Coley HL, et al. Development of an interactive, Web-delivered system to increase provider-patient engagement in smoking cessation. J Med Internet Res 2011;13(4):e87 [FREE Full text] [doi: 10.2196/jmir.1721] [Medline: 22011394]
37. Google. AdWords URL: https://www.google.com/accounts/ServiceLogin?service=adwords&hl=en_US&ltmpl=regionalc&passive=false&ifr=false&alwf=true&continue=https://adwords.google.com/um/gaiaauth?apt%3DNone&error=newacct [WebCite Cache ID 6BGRiZhQG]
38. DiClemente CC, Prochaska JO, Fairhurst SK, Velicer WF, Velasquez MM, Rossi JS. The process of smoking cessation: an analysis of precontemplation, contemplation, and preparation stages of change. J Consult Clin Psychol 1991 Apr;59(2):295-304. [Medline: 2030191]
39. Smit ES, de Vries H, Hoving C. Effectiveness of a Web-based multiple tailored smoking cessation program: a randomized controlled trial among Dutch adult smokers. J Med Internet Res 2012;14(3):e82 [FREE Full text] [doi: 10.2196/jmir.1812] [Medline: 22687887]

40. Wangberg SC, Nilsen O, Antypas K, Gram IT. Effect of tailoring in an internet-based intervention for smoking cessation: randomized controlled trial. J Med Internet Res 2011;13(4):e121 [FREE Full text] [doi: 10.2196/jmir.1605] [Medline: 22169631]
41. Danaher BG, Lichtenstein E, McKay HG, Seeley JR. Use of non-assigned smoking cessation programs among participants of a Web-based randomized controlled trial. J Med Internet Res 2009;11(2):e26 [FREE Full text] [doi: 10.2196/jmir.1172] [Medline: 19632976]
42. Brendryen H, Drozd F, Kraft P. A digital smoking cessation program delivered through internet and cell phone without nicotine replacement (happy ending): randomized controlled trial. J Med Internet Res 2008;10(5):e51 [FREE Full text] [doi: 10.2196/jmir.1005] [Medline: 19087949]
43. 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] [doi: 10.2196/jmir.993] [Medline: 19017582]
44. Japuntich SJ, Zehner ME, Smith SS, Jorenby DE, Valdez JA, Fiore MC, et al. Smoking cessation via the internet: a randomized clinical trial of an internet intervention as adjuvant treatment in a smoking cessation intervention. Nicotine Tob Res 2006 Dec;8 Suppl 1:S59-S67. [Medline: 17491172]
45. Zickuhr K, Smith A. Internet adoption over time. Washington, DC: Pew Internet & American Life Project; 2012 Jan 18. URL: http://pewinternet.org/Reports/2012/Digital-differences/Main-Report/Internet-adoption-over-time.aspx [accessed 2013-01-23] [WebCite Cache ID 6DtHHQmz7]
46. 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] [doi: 10.2196/jmir.9.1.e1] [Medline: 17478410]
47. Koelen MA, van den Ban AW. Health Education and Health Promotion. Wageningen, NL: Wageningen Academic Publishers; 2004.
48. 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]
49. Schonlau M, Fricker RD, Elliott MN. Conducting Research Surveys via E-mail and the Web. Santa Monica, CA: Rand; 2002.
50. Im EO, Chee W. Quota sampling in internet research: practical issues. Comput Inform Nurs 2011 Jul;29(7):381-385. [doi: 10.1097/NCN.0b013e3181f9dc45] [Medline: 20975541]
51. Saul JE, Schillo BA, Evered S, Luxenberg MG, Kavanaugh A, Cobb N, et al. Impact of a statewide Internet-based tobacco cessation intervention. J Med Internet Res 2007;9(3):e28 [FREE Full text] [doi: 10.2196/jmir.9.4.e28] [Medline: 17942390]
52. Strecher VJ, McClure J, Alexander G, Chakraborty B, Nair V, Konkel J, et al. The role of engagement in a tailored web-based smoking cessation program: randomized controlled trial. J Med Internet Res 2008;10(5):e36 [FREE Full text] [doi: 10.2196/jmir.1002] [Medline: 18984557]
53. Cobb NK, Graham AL, Bock BC, Papandonatos G, Abrams DB. Initial evaluation of a real-world Internet smoking cessation system. Nicotine Tob Res 2005 Apr;7(2):207-216 [FREE Full text] [doi: 10.1080/14622200500055319] [Medline: 16036277]
54. Japuntich SJ, Leventhal AM, Piper ME, Bolt DM, Roberts LJ, Fiore MC, et al. Smoker characteristics and smoking-cessation milestones. Am J Prev Med 2011 Mar;40(3):286-294 [FREE Full text] [doi: 10.1016/j.amepre.2010.11.016] [Medline: 21335259]

Abbreviations

BRFSS: Behavioral Risk Factors Surveillance Survey
IRR: incidence rate ratio
TTS: tobacco treatment specialist

Edited by G Eysenbach; submitted 09.10.12; peer-reviewed by L Akers, S McIntosh, J Fellows; comments to author 11.01.13; revised version received 01.02.13; accepted 21.02.13; published 01.05.13.

Please cite as:
Sadasivam RS, Kinney RL, Delaughter K, Rao SR, Williams JH, Coley HL, Ray MN, Gilbert GH, Allison JJ, Ford DE, Houston TK, The National Dental PBRN And QUIT-PRIMO Collaborative Groups
Who Participates in Web-Assisted Tobacco Interventions? The Quit-Primo and National Dental Practice-Based Research Network Hi-Quit Studies
J Med Internet Res 2013;15(5):e77
URL: http://www.jmir.org/2013/5/e77/
doi:10.2196/jmir.2385
PMID:23635417

Original Paper

Making Sense of Mobile- and Web-Based Wellness Information Technology: Cross-Generational Study

Daniel Kutz[1]; Kalpana Shankar[2], PhD; Kay Connelly[3], PhD

[1]School of Library and Information Science, Indiana University, Bloomington, IN, United States
[2]School of Information & Library Studies, Unversity College, Dublin, Ireland
[3]School of Informatics and Computing, Indiana University, Bloomington, IN, United States

Corresponding Author:
Daniel Kutz
School of Library and Information Science
Indiana University
1320 E. 10th St., LI 011
Bloomington, IN, 47405-3907
United States
Phone: 1 8128552018
Fax: 1 8128556166
Email: dokutz@indiana.edu

Abstract

Background: A recent trend in personal health and wellness management is the development of computerized applications or information and communication technologies (ICTs) that support behavioral change, aid the management of chronic conditions, or help an individual manage their wellness and engage in a healthier lifestyle.

Objective: To understand how individuals across 3 generations (young, middle-aged, and older) think about the design and use of collaborative health and wellness management technologies and what roles these could take in their lives.

Methods: Face-to-face semistructured interviews, paper prototype systems, and video skits were used to assess how individuals from 3 age cohorts (young: 18-25 years; middle-aged: 35-50 years; and older: ≥65 years) conceptualize the role that health and wellness computing could take in their lives.

Results: A total of 21 participants in the 3 age cohorts took part (young: n=7; middle-aged: n=7; and older: n=7). Young adults expected to be able to actively manage the presentation of their health-related information. Middle-aged adults had more nuanced expectations that reflect their engagement with work and other life activities. Older adults questioned the sharing of health information with a larger audience, although they saw the value in 1-way sharing between family members or providing aggregated information.

Conclusions: Our findings inform our suggestions for improving the design of future collaborative health and wellness applications that target specific age groups. We recommend that collaborative ICT health applications targeting young adults should integrate with existing social networking sites, whereas those targeting middle-aged and older adults should support small social networks that rely on intimate personal relationships. Systems that target middle-aged adults should support episodic needs, such as time-sensitive, perhaps intermittent, goal setting. They should also have a low barrier to entry, allowing individuals who do not normally engage with the Internet to participate with the application for the specific purposes of health engagement. Collaborative ICT health applications targeting older adults should allow discreet 1-way sharing, and also support sharing of information in aggregate with others' data. These systems should also provide mechanisms to preselect recipients of different kinds of data, or to easily direct specific information to individuals in real time.

(J Med Internet Res 2013;15(5):e83) doi:10.2196/jmir.2124

KEYWORDS

ubiquitous computing; health promotion; wellness; human-computer interaction; design; generational differences

Introduction

Information and communication technologies (ICTs) that can harness the knowledge and support of other people and allow individuals to manage and understand their health and wellness can empower individuals to actively manage their health, change their behaviors, and learn more about health conditions [1,2]. Examples include general social networking platforms, such as Facebook [3], online patient communities [4], smartphone applications [5], and exercise-oriented video games [6]. These applications generate data about and for the individual, and data that can influence their health-related decision making and technology adoption. Individuals' preferences about using such applications, useful features, and related factors will be predicated upon their previous experiences with ICTs, similar systems, and other contextualizing concerns, including what others think about them. The popularity and potential of user-targeted health applications for personal empowerment argues for research that can provide us with a deeper understanding of how people perceive such technologies and their interests and concerns about sharing health-related information.

Many of these commercially available wellness-focused ICTs seem to take a one-size-fits-all approach. However, it stands to reason that generational and other demographic differences influence how people think about health in general, the role of personal relationships in health management, and new technologies. A recent study by the Pew Research Center [7] shows that all generations are using technology more often, but for different purposes. These differences should be examined more closely if ICTs are to be effective in promoting healthy behavior across all generations. Furthermore, generational differences in technology adoption and use of health and wellness management may suggest design implications for understanding the generational differences when it comes to the use of ICTs for health.

Background and Rationale

In this paper, we examine generational attitudes, interests, and motivations toward the use of ICTs for wellness tracking. Comparative studies on the use of ICTs for health and wellness are generally focused on the role and efficacy of using online sources for obtaining health information online [8-12] or has tended to focus on a particular population (eg, caretakers of older adults [13] or teenage girls [14]), or tailoring solutions to meet immediate health needs (eg, diabetes patients [15], overweight children and adolescents [6], juvenile arthritis [16], and physical activity intervention of young populations [17]). The foci of such studies seem to be on chronic conditions [18-20], take a conceptual approach [21-25], or do not break down generational differences in sufficient detail [26-30].

The body of research on older adults and ICTs also seems to reinforce a design-centered approach of examining preexisting systems and identifying usability issues. For example, Pak et al [31] examined how older and young adults navigate information systems and found results that were consistent with preexisting research, namely that older adults use computing technology less than younger adults and lack spatial and orientation abilities. Haverhals et al [18] examined the use of personal health applications for medication management and identified 5 usage challenges (information seeking, having autonomy in treatment decisions, identifying medication dosages, information discrepancy in identifying therapies, and health-information coordination). Kim et al [32] examined how older adults use a personal health record and found that they do not actively engage with these systems due to low technological skills, health literacy, and cognitive capabilities. Nijland et al [30] examined an Internet-based self-care system and identified design issues (lack of tailoring, navigation, efficiency and reliability issues, and legal concerns) that impede use and understanding.

Although this type of work is valuable, we argue that there is more than usability and the cognitive/physical deficit to focus on in the aging population. Instead, attitudes and concerns need to become part of the research agenda as part of the larger societal shift toward personal responsibility for health and wellness and the use of ICTs for doing so. These trends have been brought on by a variety of factors, including economic necessity, the availability of epidemiological knowledge (ie, awareness of health trends at the population level), and a new “moral regime” that advocates for the existence of healthier societies [33]. With this emphasis on prevention comes an expectation that individuals will actively engage in the management of their health. In parallel, the widespread availability and comparatively low cost of information communication technology has resulted in the emergence of numerous commercial products that allow for the tracking and sharing of health information. For the individual, ICTs provide many options for obtaining health information, tracking exercise and diet, and communicating with medical professionals, and as existing research shows [1,2], these systems promote healthy behavior.

Objective

The objective of our study was to better understand individuals' motivations for wanting to use ICTs for wellness tracking (if at all) and the generational differences that exist.

Given the popularity of ICT's for health and wellness tracking, it is essential that researchers understand generational differences among different age groups as they engage with health and wellness technology. A better understanding of how individuals from various age groups conceptualize health and wellness tracking and sharing will allow for creation of better-tailored ICTs that can promote mediated behavior change.

It is essential that researchers understand generational differences among different age groups as they engage with health and wellness technology. Although there have been studies that investigate these generational differences, they have primarily focused on usability concerns [18,30-32] or research on why older adults do not use health-related Internet resources [9-12] What has received less attention is research on motivation, that is research that goes about obtaining a better understanding of how individuals from various age groups conceptualize health and wellness tracking and sharing. An understanding of these motivations and concerns will allow for creation of better-tailored ICTs that can promote better-mediated behavior change. To date, little work exists that examines generational conceptualizations of health technologies. We intend to address this gap in this paper.

Methods

Our prototype health-tracking systems were presented to 3 distinct groups of individuals: young adults (aged 18-25 years), middle-aged adults (aged 35-50 years), and older adults (age 65 years and older). We had a total of 21 participants with 7 in each age category (Table 1). Interviews were held in the fall of 2010 and spring/early summer of 2011. The Indiana University institutional review board approved our protocol. After obtaining informed consent, we administered a brief questionnaire to each participant in which we asked basic demographic questions and questions about the participant's previous experiences with various ICTs and health applications. We showed brief videos that explained the functionality of our health-tracking systems and followed with a 1 to 1.5 hour semistructured interview, accompanied by visualizations related to the tracking system.

Study Design

We developed 2 hypothetical personal health-monitoring systems that would allow us to probe individuals' perceptions toward the collection, sharing, and transmission of health-related information (ie, context data about diet and exercise that can be interpreted, shared, or examined). The aim of our project was not to focus on the usability of any particular system, but instead to explore a user's motivation in order to elicit a broader discussion around the kinds of technologies (location sensing, social networking, information sharing, and collaboration) that are increasingly being used in pervasive health applications. Our approach is a formative approach inspired by work done by Beaudin et al [34] who created conceptual mock-ups in order "to elicit feedback about longitudinal tracking ideas" which serve as "probes to elicit detailed reactions and self-reflection during interviews." We used a combination of mock low-fidelity prototypes [35,36] and video skits [37-39] to provide background information about the applications and suggested uses for the system. Because we were dealing with a hypothetical health-tracking system, we had to choose interaction metaphors that would push for a broader discussion and provide some similarity, while at the same time making sure it did not go too far off-field where the participants would not understand how the system functions.

The research participants were in different stages of life; therefore, we chose to create video skits that would reflect these differences (campus living versus home living) to help better facilitate envisioning and understanding of the technology. The use of a video skit is informed by Mancini et al [37] who used it as a methodological tool to help the viewer understand the ubiquitous technology presented to participants. The first video system demonstrated the use of a campus-based debit card (referred to as campus card) that university students could use to purchase food, either in campus eateries or in local shops and restaurants. The accompanying video showed a student purchasing food items in a general shop located in a school dormitory. A voiceover narrated the problems involved in maintaining a healthy diet while at school. The narrator then introduced our hypothetical food tracking system as a way to track and manage food choices.

The second video illustrated a hypothetical "smart kitchen surface" on which users could place food items and it would then weigh and track what was consumed. The accompanying video showed a middle-aged adult shopping at a local supermarket and then going home to interact with the smart kitchen. The voiceover again presented the challenges of healthy eating and introduced the prototype system as one tool for managing one's eating habits.

After participants watched both videos (the order of the videos was randomized), we showed them the 2 sets of visualizations related to the prototypes. Semistructured interview questions first probed participants about what came to mind when they saw the mock-ups; this provided us with insight with respect to what understanding they were bringing to the interview about similar systems. Further questions asked them to provide an explanation of how they expected the system to function, if and what information was being tracked, if and how information was being shared, if they would feel comfortable using such a health-tracking system, and if such a system would be useful to them or to anyone they know. We chose to do semistructured interviews because it allowed us to follow conversational segues, which provided us with a richer set of data. For example, it uncovered religious-cultural and commercialized agricultural-industry concerns that we would not have been able to collect if the interview was fully structured.

The first author analyzed all interview transcripts using inductive thematic analysis to look for emergent themes and patterns without necessarily relying on a preexisting framework or set of ideas [40]. All authors then discussed themes and refined them. Subsequent passes through the data were used to code for intergenerational differences among the themes of interest. The process was repeated until consensus on findings was reached.

Table 1. Demographic summary of the participants in the study (N=21).

Group and participant #	Sex	Profession	Technology comfort level	Education
Young				
1	F	Master’s student	Comfortable	Bachelor’s degree
2	M	Unemployed	Somewhat comfortable	Bachelor’s degree
3	F	Undergraduate student	Very comfortable	Some college
4	F	Undergraduate student	Comfortable	Some college
5	F	Doctoral student	Comfortable	Master’s degree
6	F	Unemployed	Uncomfortable	Juris Doctor
7	F	Speech therapist	Somewhat comfortable	Master’s degree
Middle-aged				
8	F	Administrative	Uncomfortable	Bachelor’s degree
9	F	Administrative	Very comfortable	Master’s degree
10	F	Doctoral candidate	Somewhat comfortable	Master’s degree
11	M	Supervisor	Very comfortable	Bachelor’s degree
12	M	Doctoral candidate	Comfortable	Master’s degree
13	M	Computer programmer	Very comfortable	Master’s degree
14	M	Carpenter	Comfortable	High school
Older				
15	M	Retired doctor	Comfortable	MD
16	M	Retired faculty	Somewhat comfortable	PhD
17	F	Retired manager	Uncomfortable	Some college
18	M	Retired detective	Somewhat comfortable	Some college
19	M	Psychotherapist	Uncomfortable	Master’s degree
20	F	Retired teacher	Somewhat comfortable	Master’s degree
21	M	Retired therapist	Uncomfortable	Master’s degree

Prototype Development Process

We created 2 sets of mock-up interfaces that further explained the functionality of our hypothetical video systems. The first set was explicitly designed to represent mapping systems that are present in smartphones, cars, portable devices, and computers (eg, Google Maps or Microsoft Bing). However, instead of tracking distance to geographic markers, the system tracked individuals’ food purchasing habits as they purchased groceries and meals at restaurants. The intent of the system was to show the user their meal and food purchasing patterns in a geographical fashion. The second series of mock-ups was evocative of a social network–sharing site. This mock-up showed thumbnail profiles of individuals next to what looks like a timeline or historical graph. The goal of this mock-up was to show an interface that was representative of a social networking site; however, in this case nutritional information was being shared. What was being tracked and shared was nutritional health information, what foods were consumed by these individuals, and the nutritional content of the food consumed. We chose these 2 specific metaphors for representing our wellness system because we expected participants to be most familiar with social networking and using online maps. We did not use a simpler or a more common genre of existing information systems (eg, email or an online e-commerce website) because we wanted to use metaphors that could be used to show people’s behavior or geographic information. We wanted to create a generalized prototype that would allow for the exploration of a user’s conceptualization, while at the same time not having it be too limiting (eg, by showing a Facebook page) or so far off-field that the user would not understand what the prototype was that we were showing. Example screenshots of our mock-ups are shown below in Figures 1 and 2.

We created several screenshots of the mock-up for each system, each of which highlighted different features of the prototype’s purpose and functionality. When presented with these mock-ups we asked our participants to verbalize to us their conceptualizations and expectations of each system based on both these interfaces and the accompanying videos. To prevent any potential order bias, we randomized which interface was shown first to the participant.

It is important to recall that our goal was not to evaluate a particular system, but to use the mock-ups to serve as conversational probes in order to elicit participants’ understanding, comfort toward, and perceived usefulness of the data being captured, stored, and shared. Both our pilot and study data indicate the probes served this purpose.

Changes to the Study

The video for young adults focused on the purchasing of food whereas the video for older adults focused on food preparation. We initially intended to only show the age-oriented video to each group with the middle-aged adults seeing the video created for the older adults. However, when we tested the research protocol, participants raised questions that were addressed in the age-oriented video not shown to their age group. Therefore, we decided to show both videos to all participants during the study. We initially considered that there would be a risk of young adults not being able to associate with the content in the older adult video content and vice versa. However, we decided that this risk was minimal because both videos showed common activities (the purchasing of food) that all age groups engage in.

Participants

Recruitment

Members were recruited via flyers distributed at various locations, including the university health center, university speech and hearing clinic, local retirement communities, libraries, and other local institutions.

Technology Experience

Participants answered a brief questionnaire about basic demographics (education, age, and gender) as well as previous use and ownership of and general familiarity with ICTs. Young adults self-reported as the most technologically knowledgeable demographic, with most stating in the survey that they were comfortable to very comfortable with the role that technology played in their lives. Middle-aged adults were mixed in their responses. Older adults primarily reported that they felt uncomfortable around technology. Younger adults primarily used laptop computers and owned cellphones. They also all responded that they used some form of social networking software. These findings are not surprising, as existing survey research by the Pew Research Center indicates that 83% of Millennials (young adults aged between 18-33 years) interviewed use social networking sites [7]. Middle-aged adults' computer usage was split between desktops and laptops with cellphone ownership being unanimous. Older adults were more likely to own a desktop computer instead of a laptop. These findings match results from a study by Pew Research Center that indicated that 70% of Millennials owned a laptop, compared to 43% and 33% ownership by the older Boomer generation (adults aged between 57-65 years) and the Silent generation (adults aged between 66-74 years), respectively [41].

Figure 1. Social networking–inspired mock-up.

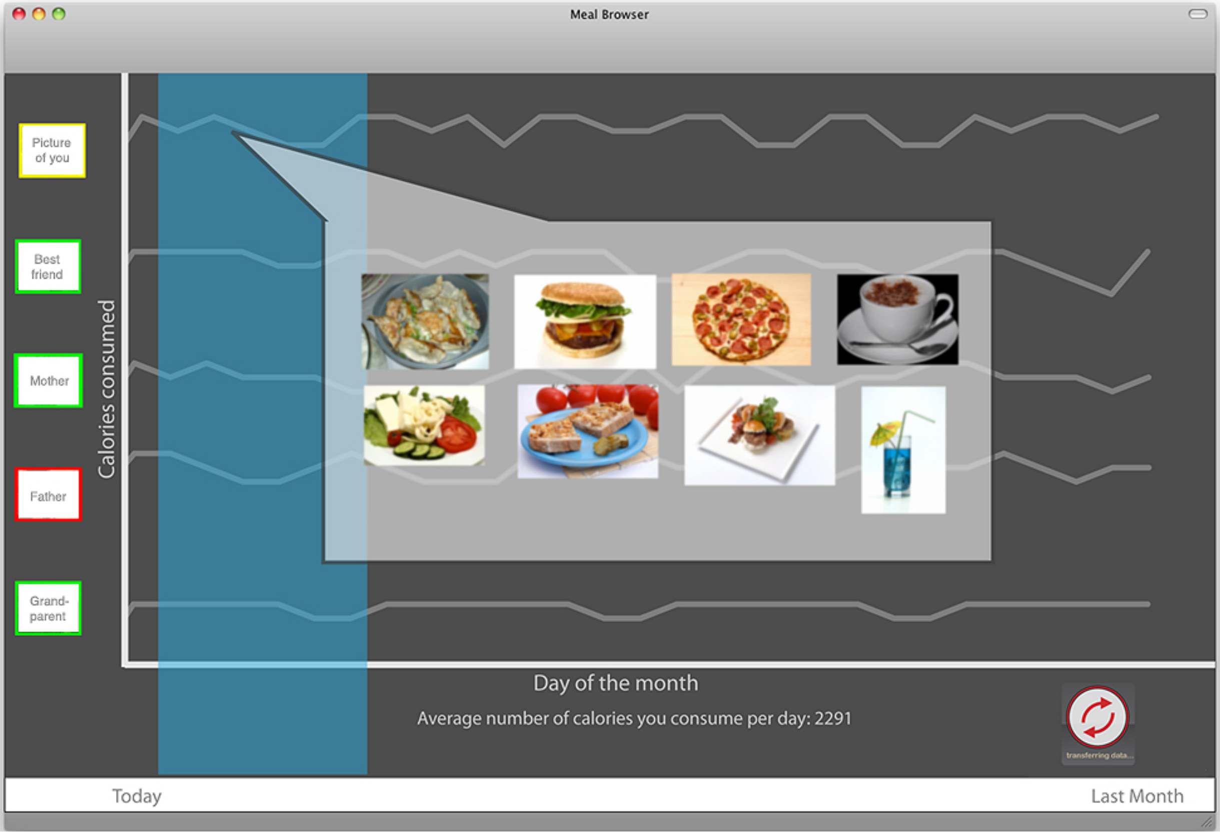
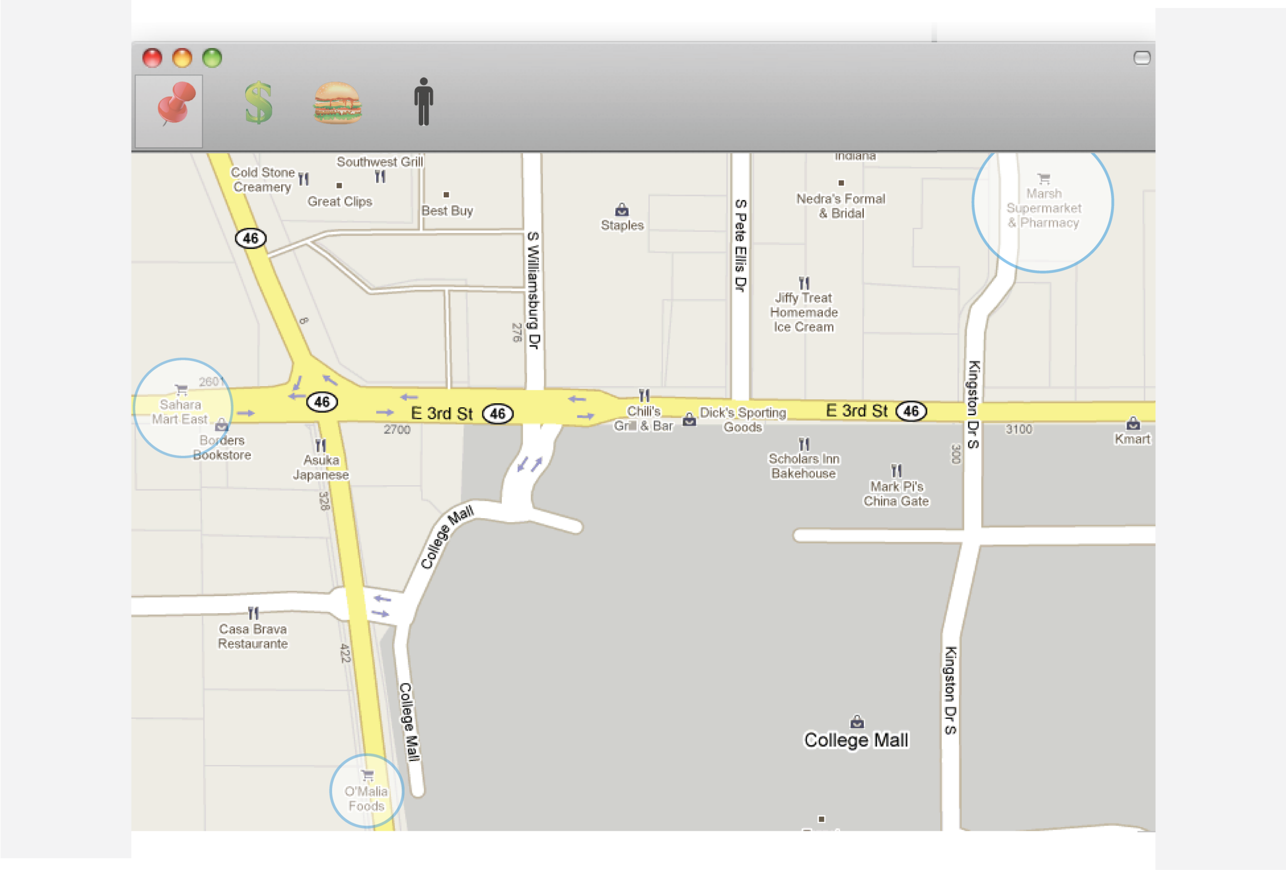


Figure 2. Geographical-inspired mock-up.



Results

In this section, we discuss the 3 identified themes that displayed clear generational distinctions that coalesced from the interview data: passive and active engagement, data and information sharing, and social networking. An overview of our findings is presented in Table 2, and a more detailed discussion of our identified themes follows.

Data and Information Sharing

Our prototyped systems drew upon existing research that showed that a person is better able to engage in positive health behaviors when they have the social support of an existing network of peers [42,43]. However, analysis of the interview transcripts suggested distinct differences in how the age groups felt about using a mapping or social networking application to share one's health-related activities. The young adults tended to see significant value in sharing information because it would allow for friends to provide support. These individuals expected that if they posted something, it was open to comment and that was a welcome form of support: "Somebody could say, 'Wow, you really should watch your salt, or your sodium intake,'" and "'Looks like you've been taking in a lot of vitamin B_{12} this week...that could be dangerous for this organ,'" and "You're wagging your finger at them, 'You're not being so healthy this week, I saw what you bought'" (Y2). Others brought up the ability to show off or brag when doing well as a way to motivate positive behaviors in others: "[It] might be the case that you would need to share that information, to either validate what you are saying, or just brag about it even," and "We are all able to view these to kind of motivate each other" (Y3).

Middle-aged adults integrated the potential use of these health and wellness tracking systems into the framework of their existing social relationships. For this group, the broadcasting of activities was also seen as being useful in helping support more intimate social relationships for specific health goals, as opposed to the younger group's willingness to sharing data more broadly. For example, M9 said, "I always have a workout partner with me that knows this is what my goal is...and if I start slacking, then I want you to say, 'Are you feeling okay?'" and "I really can't see why I'd want to know what a particular person consumed, unless I was perhaps a parent looking at the student."

Older adults could see the benefit in sharing health data with their family and close friends. The focus on family by older participants is in-line with previous research that showed that older adults often feel they have a moral duty to see and provide suggestions about health to their children [44]. In other scenarios, older adults frequently expressed that sharing did not make sense to them. They often just didn't see why someone outside of the family might be interested: "...don't know why somebody would care about this other than my family" (O17). Similarly, they did not see why they would care to see anyone else's information. When questioned if there would be any value in viewing the shopping and dietary habits of other individuals, O17 responded with a clear no: "I can't think of any reason...unless you're just plain nosy!"

When asked who should be able to see their information, O16 responded, "...any researcher can see this or that you can see it because I want you to monitor my diet or I'm interested in your research program." However, when asked if in return they would be able to see the dietary habits of the researcher they responded with: "I don't care what you eat. I would object to a system that allowed me to look at anybody that I wanted to see what they were eating."

Social Networking

Another clear distinction identified across generations was the familiarity with and expectations from social networking software. All members of the youngest age group quickly identified the social networking mock-up, and to a lesser extent the map mock-up, as having a very strong social networking component to them. Once this group identified the social networking connection, the mock-ups immediately made more sense. They described information sharing using metaphors drawn from social networking technologies (eg, lists and profiles): "Sharing would be to people, maybe that you've already selected" (Y1). They discussed the implicit expectation of reciprocal sharing of information: "...other people in my family or my household, or friends that I could maybe do some social networking with, and see, 'Oh, what's Sarah been eating this week?'" (Y2). They also clearly felt they could control information flow about themselves through managing lists of friends: "I have different groups of friends, so maybe I have a family group, but maybe I also have a work group. And so maybe I could select who I want to share the info with" (Y3). This suggests the active control and expectation that this age has when it comes to managing their online personae and what is shared with others. Younger adults also referenced sharing even when social networking was not explicitly embedded in the interface. For example, when asked about the functionality of the map health and wellness tracking system, Y3 responded: "...you can add friends on kind of a like a GPS [Global Positioning System] and then if they are logged into certain places, then you can say, we are both at [a local grocery store] and maybe meet up."

Four of the participants in the middle-aged group (M9, M11, M12, and M14) referred to social networking, but with less frequency and detail than the younger adults. The youngest middle-aged adult, 35-year-old M13, made a strong association with social networking. The other 2 individuals in this group (M8, M10) did not make associations with social networking until much later in their interviews. For example, in the case of M8, it was only after the interviewer highlighted and explained some of the features and functionality of the health tracking did the participant draw parallels to social networking sites: "I mean now I'm starting to try and compare it to something like Facebook."

Additionally, the middle-aged adults who referred to social networking indicated that these systems were perceived as a diversion...something to do with free time: "It could just be fun to check some things out, similar to a Facebook-type interaction" (M11). They were also aware that they approached social networking differently than their younger counterparts: "There is definitely a generational split. The younger individuals, they see this information different [*sic*]. They have different perceptions of privacy of information" (M9). Participant M10 found it strange that people would constantly update their Facebook profile and indicated that he was more likely to curate: "I judiciously determine that something would be of interest to a large number of people."

The older adults' expectations of how the health and wellness tracking systems functioned were far more varied. Participant responses tended to be informed by the technologies they had encountered in their careers, confirming findings in previous research [45]. Participant O15, who had a medical background, referred to the thumbnails of individuals and activity data on the social networking modeled health and wellness tracking system as being like a cardiogram or medical record. He did not see the purpose of viewing an individual's health behavior; they considered the data to be representative of an entire population: "General population. I would think that this represented. If we multiplied this by 100,000 people, I would guess this would show some descriptive statistic, median or mean." A former professor, O16 frequently referenced databases: "It would be putting data into a database that kept a running track of what I was doing, eating, whatever. It would be updating essentially." However, databases were not the only analogy employed during the sense-making process by the older adults. Participant O16 hypothesized several ways in which data could be collected or retrieved, from natural language queries ("I could simply ask a question") to manual data entry.

Emergent Theme: Passive and Active Engagement

One of the strongest and unexpected age-related themes we identified is that participants would either respond in what we call a passive or active manner when discussing how they would expect to engage with a health-monitoring system. Unlike the social networking theme, which is something we were specifically probing for, the passive and active engagement themes are an emergent finding. An individual taking a passive approach would expect the technology to do what is required with minimal intervention by the user (if they had a positive stance toward the system), or if they had some concerns, participants would express the expectation that nothing could really be done outside of opting out. However, individuals that expected to take a more active approach with their technology use expected the system to provide them with the right resources and capabilities to do so. This group expected these tools would allow them to adjust how the system functioned, curate data, and control data sharing and broadcasting.

Older adults were more likely to take a more passive approach and be willing to delegate responsibility to other actors to managing access to the data and the system itself. For example, when asked from whom information should be hidden, O16 stated: "That's a good question to be determined by the people who set up the system." Other older respondents were willing to delegate responsibility to the system itself, which suggests that that the respondent trusted the system to be capable of correctly evaluating and managing their health-related information. For example, when asked who would have access to dietary information, O17 stated: "That would be a decision for the system to make." She later said: "I trust it."

Although the responses from middle-aged adults were mixed, what makes this group stand out from the other 2 is their focus on and concerns for the effects that collaborative health-tracking technology would have on their jobs and careers. For example, M9 said she would consider using a health-tracking system on a limited basis with “real life” friends, but her main concern was that her employer not have any access to this information: “If...[employer] is not going to be able to scan our little card and track what we’re doing and see what we’re doing, I would have no problem using a program like that.”

The young adult participants consistently used active language when describing the systems. They expected to be given tools that would allow them to actively manage their online persona via lists, access controls, and updates. They expected that they would have control of their data, or at least how their data would be made available to the public or certain individuals. When asked if they would be willing to share their data to support healthy behavior, Y3 replied: “Yeah, and I think I would be...as long as I had, you know, the privilege, I guess, to be able to modify that whenever I wanted to, and select if I wanted to share how and whenever I wanted to ...if I’m choosing to be a part of this type of program and I was able to just do the select the people that I wanted, or whatever, then I would imagine that I would share that information. Otherwise, I wouldn’t be a part of the program.”

Based on our identified themes, we believe that the generational differences we elicited in this study have significant generalizable design implications for designing new health and wellness technologies.

Interpretation of Themes

Although we discussed 3 themes as distinct findings for the sake of clarity, they were strongly interrelated. For example, when discussing the process of broadcasting health-related information subject, Y3 stated: “...show it with this predetermined group that I had already selected, then it would be more motivating than just showing it to myself.” This response illustrates the preferred metaphor of this age group (social networking) expressed via the concept of predetermined groups. However, it also expresses a sense of active engagement with controlling the system (“that I had already selected”) and the assumption that sharing information about one’s health activities would be more motivating to engage in healthy behavior.

As we described, young and some middle-aged adults drew upon metaphors from social networking software to explain how these systems would work and the meaning it would have in their lives. For the younger generations, social networking tools are essential adjuncts to their lives. As such, it is not surprising that they would draw parallels to social networking technology in our health-tracking mock-ups. However, for middle-aged (and older) adults, online social networks were primarily seen as a novel distraction to supplement preexisting established social networks and as a way to occasionally check-in on contacts. Older adults’ reactions to these systems, however, were frequently ones of cautious skepticism. This is consistent with previous research that shows older adults will respond with ambivalence to computing technology that, in their mind, does not address their day-to-day needs [46].

Their strong connection to social networking may explain why young adults also took an active approach toward managing their online persona, whereas older adults, who gravitated toward databases and similar work-oriented applications (over which they would presumably have less personal or individual control) to describe the system, did not. Younger adults also took an active approach toward managing other people’s perceptions of them. For this generation, manipulating and crafting how one is represented online is a perfectly reasonable strategy to employ: “Because it sounds kind of like things you can almost like play around with, because it gives you option to manipulate data” (Y4). Older adults that spoke passively were uncomfortable of such management: “Oh hell, there is no room for lying. I wouldn’t share that. Not at all, I mean, if you are lying, then I think that negates everything” (O16). Participant O19 considered this online management as not being truthful: “People just mostly tell all the shiny, happy side of themselves and nobody really knows what’s going on by looking at that stuff.”

The young adults stated that they would publicize to groups or lists, which again indicates the use of social networking software metaphors and an active management approach. However, the middle-aged adults stated that they would possibly publicize their information, but only for an audience of existing friends with which they are actively and collectively striving toward certain health-related goals. The older adults did not see any use in publicizing health-related information, and only after further discussion would they acknowledge that possibly there could be a value in broadcasting, but only to other family members. The 2 older groups raised concerns about broadcasting health-related information to potentially inappropriate audiences, such as employers.

For older adults, the concept of sharing is not related to broadcasting, but sharing information for research purposes or the family unit. These differences reinforce findings from the aging literature that have found that the quality of relationships is preferred over quantity as people age so information tends to be shared with fewer people, but more deeply [47]. A system that is designed solely around the idea of sharing health-related information for motivational purposes might not gain much traction among older adults. Designers may need to take this into account when designing for these populations.

Table 2. Summary of identified generational distinctions.

Theme	Young adults	Middle-aged adults	Older adults
Participation and engagement	Active engagement	In between	Passive engagement
Data and information sharing	Open sharing with expected response	Sharing of information with existing networks	Sharing does not make sense
Social networking	Tied strongly to sharing and their conceptualization of how systems should function	Acknowledgement of awareness, although tied to existing networks	Some awareness, but not direct interest in participation

Discussion

The narratives that people use to make sense of new technologies may vary widely by age, life experience, and concerns external to the ICT. However, we believe that those divergent framings are a potentially rich resource of guiding principles for designers of new health and wellness applications, particularly those targeting specific age groups.

Design Recommendations

It may be obvious that one would not design the same approach for a 20-year-old and an 80-year-old with respect to other ICTs, but application developers often adopt such one-size-fits-all mindsets toward health and wellness systems.

We present design recommendations informed by the findings of our study. Table 3 provides an overview of these recommendations. These recommendations are meant to improve acceptance and adoption of future health and wellness information systems.

Social Networking

Our study reflects the way other researchers have found that young adults use social networking sites: although they might desire the ability to broadcast their health information to a large social network for support and motivation, our findings seem to indicate that they expect these applications to afford them the ability to manage content and recipients.

Active management implicitly brings up the question of informational privacy. Although at one time there was the expectation that this age group was somewhat indifferent to privacy, more recent research indicates otherwise [48,49]. These more recent findings are consistent with the results from our study. Young adults expressed that they would want to manage their privacy by drawing upon metaphors of current popular social networking software (lists, groups, and other privacy settings). Our findings suggest that this age group may expect systems to provide them with the tools to actively manage and control their online personae.

Design Recommendation 1

Collaborative ICT health applications targeting young adults should integrate with existing social networking sites so users can make use of their current social networks as well as familiar tools for information and network management.

Middle-aged and older adults had more nuanced expectations when it came to sharing health-related information. Middle-age adults expected sharing to be limited to individuals who are part of their real world social networks or subgroups that have a shared interest (eg, fitness groups), whereas older adults envisioned the system to work with familial networks. Existing social networking sites, such as Facebook, encourage larger networks in several ways. Their open nature allows people to search for acquaintances, and allows “friends of friends” to see and interact with each other through a mutual acquaintance. Varying expectations and social conventions lead some people to make friend requests to others who may deem the friendship remote at best. Yet it can be uncomfortable for a person to deny a friend request from a remote acquaintance, or remove someone from their network whom they no longer feel close to. This results in networks that grow over time to be quite large. Thus, although integration of health applications into existing social networks may be inappropriate for many users, the ability to use familiar tools and integrate information and networks across platforms may be a preferred feature.

Design Recommendation 2

Collaborative ICT health applications targeting middle-aged and older adults should support small social networks that rely on intimate personal relationships.

This recommendation also addresses the more passive engagement style of older adults as a side effect. With a smaller network, there is less need to actively manage sharing of information through lists and other access control. However, a small network does not necessarily mean that it is desirable to share all information with everyone at all times. Thus, an application should support other modes of sharing than simple broadcast, which is standard fare for current social networking applications.

Design Recommendation 3

Collaborative ICT health applications targeting older adults should incorporate mechanisms to preselect recipients of different kinds of data, or to easily direct specific information to individuals in real time.

Fortunately, this is more easily done with a smaller social network. For example, when an older adult links a new pedometer to their tracking software, the interface can show them (on 1 screen) all of the people in their current network and the older adult can select who should receive their step counts and in what form (eg, daily, weekly, or in aggregate). Similarly, if an older adult inputs a new exercise goal, they can specify who should receive that goal from their network. This is a much easier process than when the network is large and a person must decide who among hundreds of friends should have access.

Table 3. Overview of design recommendations.

Age group	Recommendation
Young adults	Have preexisting expectations based on social networking experience. Expect integration with existing social networking sites.
Middle-aged adults	Should support smaller social networks and existing relationships. Needs to support different modes of sharing besides broadcast. Have a low barrier of entry. Support intermittent, episodic use.
Older adults	Support different modes of sharing besides broadcast; simplify the process of preselecting recipients to receive information. Have a low barrier of entry. Allow for 1-way or aggregate sharing.

Design Recommendation 4

Collaborative ICT health applications targeting middle-aged and older adults should have a low barrier to entry, allowing individuals who do not normally engage with the Internet to participate with the application for the specific purposes of health engagement.

Individuals in these physical social networks may not have a regular online presence; therefore, health-tracking systems should have a low barrier of entry. Examples of how to achieve this low barrier may be to develop a mobile application capable of working on most cell phones, or a low-cost, special-purpose display that can be purchased at a local department store and simply plugged in.

Episodic Support

Comments from the middle-aged adults indicate that this age group might take a more episodic or goal-oriented approach toward using health information–management systems (eg, to meet a specific goal, such as walking 3 times a week). For example, M12 stated, “I want to be able to start out running and get up to 3.5 miles a day under 30 minutes. That’s my goal. That’s my goal every winter.” As such, a system targeting this age group should facilitate these episodic needs.

Design Recommendation 5

Collaborative ICT health applications targeting middle-age adults should support episodic needs, such as time-sensitive, perhaps intermittent, goal setting.

One-Way and Aggregated Sharing

Some middle-aged adults mentioned the benefit of 1-sided sharing of health-related information, such as a parent wanting to see what their young adult children were doing, but not vice versa: “If you had children and you wanted to watch what they were eating...you could monitor, in a good way hopefully, their eating habits” (M10). A few of the older adults saw value in comparing their health information with aggregated information from a group. For example, O15 considered that the sharing of aggregate information as “being useful in a research study. For example, here is individual variation among adult males or males over 50 or whatever.” This individual did express some concern in regards to anonymity and security: “I would want some reassurance before I got involved in the system, yeah. Just how the data is going to be used.”

Design Recommendation 6

Collaborative ICT health applications targeting middle-aged or older adults should allow discreet 1-way sharing and also support sharing of information in aggregate with others’ data.

For example, an older adult may be willing to share their data with others if it appears in aggregate with a larger group, but not on an individual basis. If data presented in the health application interface always appears in aggregate, then the lack of individual data does not indicate a lack of willingness to share with others.

Conclusion

The recent popularity and availability of computerized wellness and health tracking and sharing systems made us question how users understand and conceptualize such systems. Although the research literature focuses on the use of these systems by specific subpopulations, commercial products seem to take a one-size-fits-all approach. However, health and wellness management is strongly situated at the family level and is a cross-generational activity. As such, it is important to understand cross-generational differences and attitudes toward these health and wellness tracking systems. Our study set out to identify these differences, of which we found several salient examples. These include nuanced expectations of middle-aged adults, young adults’ expectations of being able to actively manage their health and wellness information, and older adults’ interest in smaller social networks and intimate relationships. These expectations need to be taken into account by designers of health and wellness applications if they want to develop systems that target specific generations or be used successfully to support health and wellness across the life span.

Unanswered Questions and Future Research

We touched briefly upon the privacy and security concerns respondents had with respect to employers, family members, and others accessing their health data, but did not explore these themes thoroughly and will likely do so in the future. Many of these issues in health information have been extensively explored by other researchers as well [50-54]. We are also aware that there is a gender difference across our populations, which may influence technology interest and adoption as well as attitudes toward personal health.

Limitations

Although the interviews provided us with a rich set of data, we acknowledge limitations. The small size of the group allows only preliminary themes of interest to surface. The individuals we interviewed were similar in socioeconomic status, experience with information technology, and education levels. There are also some limitations in defining our older adult’s category as including all participants over 65 years. In the Pew Research Center’s Internet study, there were some remarkable differences in technology use between the Silent generation (ages 66-74 years) and the GI generation (ages 75+). For example, 58% of the Silent generation were online versus 30% of the GI generation [7]. Lastly, we are also aware that our study has some socioeconomic limitations. Except for 1 individual, everyone had (or was in the process of getting) an undergraduate college education. Furthermore, their socioeconomic status puts all participants into the middle class; thus, we do not have any knowledge how responses would have varied from lower or higher income individuals. Future studies will examine these identified limitations and the impact they have on the use of collaborative health and wellness management technologies.

Acknowledgments

We wish with thank Samantha Mardyla and Allen C Shyu for their help developing the videos and their scripts, and Dr Lesa Huber and Peter Grogg for their assistance in recruiting participants. Funding for this project was provided by the Center for Applied Cybersecurity Research through a generous grant from the Lilly Endowment, Inc.

Conflicts of Interest

None declared.

Multimedia Appendix 1

This video demonstrates the use of a campus-based debit card (referred to as campus card) that university students could use to purchase food, either in campus eateries or in local shops and restaurants.

[WMV File (Windows Media Video), 23MB - jmir_v15i5e83_app1.wmv]

Multimedia Appendix 2

This video illustrates a hypothetical “smart kitchen surface” that would allow users to place food items from their kitchen on a flat surface that would then weigh and track what was consumed.

[WMV File (Windows Media Video), 26MB - jmir_v15i5e83_app2.wmv]

References

1. Neville LM, O'Hara B, Milat AJ. Computer-tailored dietary behaviour change interventions: a systematic review. Health Educ Res 2009 Aug;24(4):699-720 [FREE Full text] [doi: 10.1093/her/cyp006] [Medline: 19286893]
2. van den Berg MH, Schoones JW, Vliet Vlieland TP. Internet-based physical activity interventions: a systematic review of the literature. J Med Internet Res 2007;9(3):e26 [FREE Full text] [doi: 10.2196/jmir.9.3.e26] [Medline: 17942388]
3. Newman M, Lauterbach D, Munson S, Resnick P, Morris M. It's not that I don't have problems, I'm just not putting them on Facebook: challenges and opportunities in using online social networks for health. In: Proceedings of the ACM 2011 conference on computer supported cooperative work. 2011 Presented at: The 2011 ACM Conference on Computer Supported Cooperative Work; March 19-23, 2011; Hangzhou, China p. 341-350.
4. Brubaker JR, Lustig C, Hayes GR. PatientsLikeMe: empowerment and representation in a patient-centered social network. In: Workshop in CSCW Research in Healthcare: past, present and future. 2010 Presented at: CSCW ’10: ACM conference on computer supported cooperative work; Feb 6-10, 2010; Savannah, GA.
5. Kirwan M, Duncan MJ, Vandelanotte C, Mummery WK. Using smartphone technology to monitor physical activity in the 10,000 Steps program: a matched case-control trial. J Med Internet Res 2012 Apr;14(2):e55 [FREE Full text] [doi: 10.2196/jmir.1950] [Medline: 22522112]
6. Madsen KA, Yen S, Wlasiuk L, Newman TB, Lustig R. Feasibility of a dance videogame to promote weight loss among overweight children and adolescents. Arch Pediatr Adolesc Med 2007 Jan;161(1):105-107. [doi: 10.1001/archpedi.161.1.105-c] [Medline: 17199076]
7. Zickuhr K. Generations 2010. Washington, DC: Pew Internet & American Life Project; 2010 Dec 16. URL: http://www.pewinternet.org/~/media//Files/Reports/2010/PIP_Generations_and_Tech10.pdf [accessed 2012-03-24] [WebCite Cache ID 66PBnvPlj]
8. Eysenbach G. Credibility of health information and digital media: new perspectives and implications for youth. In: Metzger MJ, Flanigan AJ, editors. Digital Media, Youth and Credibility. Cambridge, MA: MIT Press; 2008:123-154.
9. Feufel MA, Stahl SF. What do web-use skill differences imply for online health information searches? J Med Internet Res 2012 Jun;14(3):e87 [FREE Full text] [doi: 10.2196/jmir.2051] [Medline: 22695686]
10. Nahm ES, Preece J, Resnick B, Mills ME. Usability of health Web sites for older adults: a preliminary study. Comput Inform Nurs 2004;22(6):326-34; quiz 335. [Medline: 15602301]

11. van Deursen AJ, van Dijk JA. Internet skills performance tests: are people ready for eHealth? J Med Internet Res 2011 Apr;13(2):e35 [FREE Full text] [doi: 10.2196/jmir.1581] [Medline: 21531690]
12. Zulman DM, Kirch M, Zheng K, An LC. Trust in the internet as a health resource among older adults: analysis of data from a nationally representative survey. J Med Internet Res 2011 Feb;13(1):e19 [FREE Full text] [doi: 10.2196/jmir.1552] [Medline: 21324832]
13. Consolvo S, Roessler P, Shelton B, LaMarca A, Schilit B, Bly S. Technology for care networks of elders. IEEE Pervasive Comput 2004 Apr 2004;3(2):22-29. [doi: 10.1109/MPRV.2004.1316814]
14. Toscos T, Faber A, An S, Gandhi MP. Chick clique: persuasive technology to motivate teenage girls to exercise. In: CHI '06 Extended Abstracts on Human Factors in Computing Systems. 2006 Apr 24 Presented at: CHI 2006 Conference on Human Factors in Computing Systems; April 22-27, 2006; Montréal, QC p. 1873-1878. [doi: 10.1145/1125451.1125805]
15. Mamykina L, Miller AD, Mynatt ED, Greenblatt D. Constructing identities through storytelling in diabetes management. In: Proceedings of the 28th International Conference on Human Factors in Computing Systems. 2010 Presented at: 28th International Conference on Human Factors in Computing Systems; April 10-15, 2010; Atlanta, GA. [doi: 10.1145/1753326.1753507]
16. Stinson J, McGrath P, Hodnett E, Feldman B, Duffy C, Huber A, et al. Usability testing of an online self-management program for adolescents with juvenile idiopathic arthritis. J Med Internet Res 2010 Jul;12(3):e30 [FREE Full text] [doi: 10.2196/jmir.1349] [Medline: 20675293]
17. Lau PW, Lau EY, Wong del P, Ransdell L. A systematic review of information and communication technology-based interventions for promoting physical activity behavior change in children and adolescents. J Med Internet Res 2011;13(3):e48 [FREE Full text] [doi: 10.2196/jmir.1533] [Medline: 21749967]
18. Haverhals LM, Lee CA, Siek KA, Darr CA, Linnebur SA, Ruscin JM, et al. Older adults with multi-morbidity: medication management processes and design implications for personal health applications. J Med Internet Res 2011 Jun;13(2):e44 [FREE Full text] [doi: 10.2196/jmir.1813] [Medline: 21715286]
19. Mamykina L, Mynatt E, Davidson P, Greenblatt D. MAHI: Investigation of social scaffolding for reflective thinking in diabetes management. 2008 Presented at: Twenty-Sixth Annual SIGCHI Conference on Human Factors in Computing Systems; April 5-10, 2008; Florence, Italy. [doi: 10.1145/1357054.1357131]
20. Siek K, Connelly K, Rogers Y, Rohwer P, Lambert D, Welch JL. When do we eat? An evaluation of food items input into an electronic monitoring application. In: Proceedings of the First International Conference on Pervasive Computing Technologies for Healthcare; 2006; Innsbruck, Austria. 2006 Presented at: First International Conference on Pervasive Computing Technologies for Healthcare; Nov 29-Dec 1, 2006; Innsbruck, Austria p. 1-10. [doi: 10.1109/PCTHEALTH.2006.361684]
21. Consolvo S, Everitt K, Smith I, Landay JA. Design requirements for technologies that encourage physical activity. In: Proceedings of the Conference on Human Factors and Computing Systems. 2006 Presented at: CHI; April 24-27, 2006; Montreal, QC. [doi: 10.1145/1124772.1124840]
22. Fotheringham MJ, Owen N. Introduction: Interactive health communication in preventive medicine. Am J Prev Med 2000 Aug;19(2):111-112. [Medline: 10913901]
23. Maitland J. Towards negotiation as a framework for health promoting technology. SIGHIT Rec 2011 Mar 2011;1(1):10. [doi: 10.1145/1971706.1971710]
24. Marcus BH, Nigg CR, Riebe D, Forsyth LH. Interactive communication strategies: implications for population-based physical-activity promotion. Am J Prev Med 2000 Aug;19(2):121-126. [Medline: 10913903]
25. Toscos T, Connelly K. Using behavior change theory to understand and guide technological interventions. In: Hayes BM, Aspray W, editors. Health Informatics: A Patient-Centered Approach to Diabetes. Cambridge, MA: MIT Press; 2010.
26. Chi PY, Chen JH, Chu HH, Lo JL. Enabling calorie-aware cooking in a smart kitchen. In: Proceedings of the 3rd International Conference on Persuasive Technology. 2008 Presented at: 3rd International Conference on Persuasive Technology; June 4-6, 2008; Oulu, Finland. [doi: 10.1007/978-3-540-68504-3_11]
27. Frost JH, Massagli MP. Social uses of personal health information within PatientsLikeMe, an online patient community: what can happen when patients have access to one another's data. J Med Internet Res 2008;10(3):e15 [FREE Full text] [doi: 10.2196/jmir.1053] [Medline: 18504244]
28. Lin JJ, Mamykina L, Lindtner S, Delajoux G, Strub HB. Fish'n'Steps: Encouraging physical activity with an interactive computer game. 2006 Presented at: Ubiquitous Computing; September 17-21, 2006; Irvine, CA. [doi: doi:10.1007/11853565_16]
29. Nguyen DH, Kobsa A, Hayes GR. An empirical investigation of concerns of everyday tracking and recording technologies. In: Proceedings of the 10th international conference on Ubiquitous computing. 2008 Presented at: 10th International Conference on Ubiquitous Computing; September 21–24, 2008; Seoul, Korea. [doi: 10.1145/1409635.1409661]
30. Nijland N, van Gemert-Pijnen J, Boer H, Steehouder MF, Seydel ER. Evaluation of Internet-based technology for supporting self-care: Problems encountered by patients and caregivers when using self-care applications. J Med Internet Res 2008 May;10(2):e13 [FREE Full text] [doi: 10.2196/jmir.957] [Medline: 18487137]
31. Pak R, Price MM, Thatcher J. Age-sensitive design of online health information: comparative usability study. J Med Internet Res 2009 Nov;11(4):e45 [FREE Full text] [doi: 10.2196/jmir.1220] [Medline: 19917549]

32. Kim EH, Stolyar A, Lober WB, Herbaugh AL, Shinstrom SE, Zierler BK, et al. Challenges to using an electronic personal health record by a low-income elderly population. J Med Internet Res 2009 Oct;11(4):e44 [FREE Full text] [doi: 10.2196/jmir.1256] [Medline: 19861298]
33. Mathar T, Jansen Y. In: Mathar T, Jansen YJFM, editors. Health Promotion and Preventions Programmes in Practice: How Patients' Health Practices are Rationalized, Reconceptualized and Reorganised. Bielefeld: Transcript Verlag; 2010.
34. Beaudin JS, Intille SS, Morris ME. To track or not to track: user reactions to concepts in longitudinal health monitoring. J Med Internet Res 2006;8(4):e29 [FREE Full text] [Medline: 17236264]
35. Snyder C. Paper Prototyping: The Fast and Easy Way to Design and Refine User Interfaces. San Francisco, CA: Morgan Kaufmann; 2003.
36. Walker M, Takayama L, Landay JA. High-fidelity or low-fidelity, paper or computer? Choosing attributes when testing web prototypes. In: Proceedings of the Human Factors and Ergonomics Society 46th Annual Meeting. 2002 Presented at: Human Factors and Ergonomics Society 46th Annual Meeting; September 30-October 4, 2002; Baltimore, MD p. 661-665.
37. Mancini C, Rogers Y, Bandara AK, Coe T, Jedrzejczyk L, Joinson AN, et al. Contravision: Exploring users' reactions to futuristic technology. In: Proceedings of the 28th International Conference on Human factors in Computing Systems. 2010 Presented at: 28th International Conference on Human factors in Computing Systems; April 10–15, 2010; Atlanta, GA p. 10-15. [doi: 10.1145/1753326.1753350]
38. Bardram J, Bossen C, Lykke-Olesen A, Nielsen R, Madsen KH. Virtual video prototyping of pervasive healthcare systems. In: Proceedings of the 4th Conference on Designing Interactive Systems: Processes, Practices, Methods, and Techniques. 2002 Presented at: 4th Conference on Designing Interactive Systems: Processes, Practices, Methods, and Techniques; June 25-28, 2002; London, England p. 167-177. [doi: 10.1145/778712.778738]
39. Mackay WE, Ratzer AV, Janecek P. Video artifacts for design: Bridging the gap between abstraction and detail. In: DIS '00 Proceedings of the 3rd conference on Designing interactive systems: processes, practices, methods, and techniques. New York: ACM; 2000 Presented at: Dis2000, Designing Interactive Systems; Processes, Practices, Methods, and Techniques; August 17-19, 2000; New York.
40. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. International Journal of Qualitative Methods 2006;5(1):80-92.
41. Zickuhr K. Generations and their gadgets. Washington, DC: Pew Internet & American Life Project; 2011 Feb 03. URL: http://pewinternet.org/~/media//Files/Reports/2011/PIP_Generations_and_Gadgets.pdf [accessed 2011-02-03] [WebCite Cache ID 66PCJolu3]
42. Cohen S, Janicki-Deverts D. Can we improve our physical health by altering our social networks? Perspect Psychol Sci 2009 Jul 1;4(4):375-378 [FREE Full text] [doi: 10.1111/j.1745-6924.2009.01141.x] [Medline: 20161087]
43. House J, Landis K, Umberson D. Social relationships and health. Science 1988 Jul 29;241(4865):540-545. [doi: 10.1126/science.3399889]
44. Grimes A, Tan D, Morris D. Toward technologies that support family reflections on health. In: Proceedings of the ACM 2009 international conference on supporting group work. 2009 Oct 5 Presented at: ACM international conference on supporting group work; May 10-13, 2009; Sanibel Island, FL p. 10-13. [doi: 10.1145/1531674.1531721]
45. Morrell R, Mayhorn C, Echt K. Why older adults use or do not use the internet. In: Burdick D, Kwon S, editors. Gerotechnology: Research and Practice in Technology and Aging. New York: Springer Publishing; 2004.
46. Selwyn N. The information aged: A qualitative study of older adults' use of information and communications technology. Journal of Aging Studies 2004 Nov 2004;18(4):369-384. [doi: 10.1016/j.jaging.2004.06.008]
47. Antonucci T, Birditt L, Akiyama H. Convoys of social relations: An interdisciplinary approach. In: Bengtson VB, Gans D, Putney NM, Silverstein M, editors. Handbook of Theories of Aging Vol 2. New York: Springer; 2009.
48. boyd D, Hargittai E. First Monday. 2010 Aug 02. Facebook privacy settings: Who cares URL: http://firstmonday.org/htbin/cgiwrap/bin/ojs/index.php/fm/article/view/3086/2589 [accessed 2013-04-07] [WebCite Cache ID 6Fhg7h3oj]
49. Hoofnagle CJ, King J, Li S, Turow J. How different are young adults from older adults when it comes to information privacy attitudes and policies. SSRN Working Paper Series 2010;4(19):1-20. [doi: 10.2139/ssrn.1589864]
50. Caine KE, Zimmerman CY, Schall-Zimmerman Z, Hazlewood WR, Jean Camp L, Connelly KH, et al. DigiSwitch: A device to allow older adults to monitor and direct the collection and transmission of health information collected at home. J Med Syst 2011 Oct;35(5):1181-1195. [doi: 10.1007/s10916-011-9722-1] [Medline: 22038195]
51. Langheinrich M. A privacy awareness system for ubiquitous computing environments. In: Proceedings of the 4th international conference on Ubiquitous Computing. 2002 Presented at: 4th International Conference on Ubiquitous Computing; Sept 29-Oct 1, 2002; Göteborg, Sweden.
52. Courtney KL. Privacy and senior willingness to adopt smart home information technology in residential care facilities. Methods Inf Med 2008;47(1):76-81. [Medline: 18213432]
53. Rindfleisch TC. Privacy, information technology, and health care. Commun. ACM ;40(8):92-100. [doi: 10.1145/257874.257896]
54. Nguyen DH, Kobsa A, Hayes GR. An empirical investigation of concerns of everyday tracking and recording technologies. In: Proceedings of the 10th international conference on ubiquitous computing. 2008 Sep 21 Presented at: 10th International Conference on Ubiquitous Computing; September 21-24, 2008; Seoul, Korea. [doi: 10.1145/1409635.1409661]

Abbreviations

ICT: information and communication technology

Edited by G Eysenbach; submitted 06.04.12; peer-reviewed by T Chomutare; comments to author 30.07.12; revised version received 29.10.12; accepted 31.12.12; published 14.05.13.

Please cite as:
Kutz D, Shankar K, Connelly K
Making Sense of Mobile- and Web-Based Wellness Information Technology: Cross-Generational Study
J Med Internet Res 2013;15(5):e83
URL: http://www.jmir.org/2013/5/e83/
doi:10.2196/jmir.2124
PMID:23900035

Review

Technology-Based Interventions for Mental Health in Tertiary Students: Systematic Review

Louise Farrer[1,2], PhD; Amelia Gulliver[1], PhD; Jade KY Chan[1], MSc; Philip J Batterham[1], PhD; Julia Reynolds[1], MPsych(Clin); Alison Calear[1], PhD; Robert Tait[1,3], PhD; Kylie Bennett[1], BSc, BA(Hons); Kathleen M Griffiths[1], PhD

[1]Centre for Mental Health Research, The Australian National University, Canberra ACT, Australia
[2]Young and Well Cooperative Research Centre, Melbourne VIC, Australia
[3]National Drug Research Institute, Curtin University, Perth WA, Australia

Corresponding Author:
Louise Farrer, PhD
Centre for Mental Health Research
The Australian National University
Building 63, Eggleston Road
The Australian National University
Canberra ACT, 0200
Australia
Phone: 61 2 6125 8859
Fax: 61 2 6125 0733
Email: louise.farrer@anu.edu.au

Abstract

Background: Mental disorders are responsible for a high level of disability burden in students attending university. However, many universities have limited resources available to support student mental health. Technology-based interventions may be highly relevant to university populations. Previous reviews have targeted substance use and eating disorders in tertiary students. However, the effectiveness of technology-based interventions for other mental disorders and related issues has not been reviewed.

Objective: To systematically review published randomized trials of technology-based interventions evaluated in a university setting for disorders other than substance use and eating disorders.

Methods: The PubMed, PsycInfo, and Cochrane Central Register of Controlled Trials databases were searched using keywords, phrases, and MeSH terms. Retrieved abstracts (n=1618) were double screened and coded. Included studies met the following criteria: (1) the study was a randomized trial or a randomized controlled trial, (2) the sample was composed of students attending a tertiary institution, (3) the intervention was delivered by or accessed using a technological device or process, (4) the age range of the sample was between 18 and 25 years, and (5) the intervention was designed to improve, reduce, or change symptoms relating to a mental disorder.

Results: A total of 27 studies met inclusion criteria for the present review. Most of the studies (24/27, 89%) employed interventions targeting anxiety symptoms or disorders or stress, although almost one-third (7/24, 29%) targeted both depression and anxiety. There were a total of 51 technology-based interventions employed across the 27 studies. Overall, approximately half (24/51, 47%) were associated with at least 1 significant positive outcome compared with the control at postintervention. However, 29% (15/51) failed to find a significant effect. Effect sizes were calculated for the 18 of 51 interventions that provided sufficient data. Median effect size was 0.54 (range –0.07 to 3.04) for 8 interventions targeting depression and anxiety symptoms and 0.84 (range –0.07 to 2.66) for 10 interventions targeting anxiety symptoms and disorders. Internet-based technology (typically involving cognitive behavioral therapy) was the most commonly employed medium, being employed in 16 of 27 studies and approximately half of the 51 technology-based interventions (25/51, 49%). Distal and universal preventive interventions were the most common type of intervention. Some methodological problems were evident in the studies, with randomization methods either inadequate or inadequately described, few studies specifying a primary outcome, and most of the studies failing to undertake or report appropriate intent-to-treat analyses.

Conclusions: The findings of this review indicate that although technological interventions targeting certain mental health and related problems offer promise for students in university settings, more high quality trials that fully report randomization methods, outcome data, and data analysis methods are needed.

(J Med Internet Res 2013;15(5):e101) doi:10.2196/jmir.2639

KEYWORDS

systematic review; technology; intervention; universities; students; mental health

Introduction

University students are predominantly at an age when the incidence of mood and anxiety disorders is peaking—mental health problems are most likely to begin before 24 years of age [1]. Combined with the stresses that the transition to university may provoke [2], it is not surprising that mental disorders are responsible for a high level of disability burden in university students [3-5], with a recent US study reporting a prevalence level of nearly 50% in the previous year [6]. Mental disorders also have a negative impact on academic participation and outcomes [1,3,7]. Universities provide a unique opportunity to prevent and treat mental disorders in a high-risk group and have the potential to host comprehensive approaches that cover prevention, early intervention, and treatment strategies [1,3,8]. However, many universities have limited resources available to support comprehensive approaches to student mental health, and students are often reluctant to seek help from traditionally structured student counseling centers [5,8]. It is estimated that less than one-quarter of university students with a mental disorder seek help during any 1 year [6]. Consequently, only a minority of university students with mental health problems receive adequate help [4].

Electronic media has the potential to play a significant role in developing university-based approaches to improving mental health. It is reported that young people seek help or information for emotional and mental health problems online [9-11] and, in the university population, electronic media seems to be useful in screening, increasing mental health literacy, and encouraging at-risk students to access support and treatment [1,5,8,12,13]. Online interventions may be highly relevant to university populations as they can be easily accessed, are cost effective for large populations, and may be perceived as less stigmatizing than traditional approaches to care [14,15]. Universities have traditionally delivered mental health services in clinical settings, such as face-to-face individual or group-based consultations [8], which tend to be more costly and time-intensive than distal interventions [15]. Consequently, there is a need to identify effective mental health interventions that can be distributed to students in a virtual setting and cover the spectrum of interventions from prevention to treatment.

Numerous studies and several reviews have evaluated Internet-based and non-Internet-based interventions for substance misuse and eating disorders in tertiary student populations [16-22]. However, relatively few studies have focused on the online interventions for mood disorders, anxiety disorders, or other mental health issues in university students. One review has examined the effectiveness of anxiety and depression interventions of any modality in a higher education setting [1]. Most of the identified studies adopted a face-to-face approach and were time consuming and costly. However, the authors suggested that the Web may be an ideal way to deliver promising interventions to higher education students [1].

General population reviews of Web-based depression and anxiety interventions have indicated that such interventions can be effective for treating common mental disorders, with moderate to large effect sizes [23-25]. However, with the exception of eating disorders and substance misuse, there have been no systematic reviews specifically targeted at the effectiveness of Internet or other technology-based mental health interventions for university students. Consequently, the present study comprises a systematic review of published randomized trials of technology-based interventions which included a mental health symptoms outcome measurement and were evaluated in a university setting for disorders other than substance use disorders and eating disorders. The aim of this review is to evaluate both the effectiveness of these interventions and the methodological quality of studies identified in the systematic literature search.

Method

Search Methodology

The PubMed, PsycInfo, and Cochrane Central Register of Controlled Trials databases were searched using keywords, phrases, and Medical Subject Headings (MeSH) terms in May 2012. The search strategy (see Multimedia Appendix 1) involved terms that covered 3 broad concepts: (1) setting or population in which the intervention was conducted (university) AND (2) the focus of the intervention (mental disorder/mental health promotion), AND (3) the modality in which the intervention was delivered or accessed (technology such as the Internet, telephone, etc). Keywords, MeSH terms, and phrases pertaining to concept 1 (university) and concept 3 (technology) were developed by the researchers. Those pertaining to concept 2 (mental disorder/health) were derived from the International Classification of Diseases (ICD-10) list of mental disorders from the National Health and Medical Research Council (NHMRC) keywords for mental health research and additional terms identified by the researchers. The present review conforms to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [26]. A PRISMA checklist is provided in Multimedia Appendix 2.

Study Identification

Figure 1 displays the flowchart for the selection of the included studies, which involved multiple stages. The first stage involved screening to eliminate clearly irrelevant abstracts. A total of 2274 abstracts were returned by the database searches, of which

656 abstracts were identified as duplicates and excluded. The remaining 1618 abstracts were screened by 2 raters (LF or AG and JC) according to the following criteria:

1. The study investigated (1) an intervention for a mental health problem or disorder, or the promotion of positive mental health, or (2) the study measured a mental health–related outcome in relation to the intervention.

2. The intervention was either disseminated via or accessed using a technological device (eg, computer, smartphone, telephone) or process (eg, email, Internet, SMS/text-messaging, video).

3. The study was conducted in a university setting with students or young people.

4. The study was not a thesis or a conference proceeding.

5. The article was written in English.

Studies that were considered relevant by both raters were retained and those that were identified as relevant by only 1 rater were rescreened by both raters according to the preceding criteria. Following the second screen, abstracts that both raters considered relevant were retained. The remaining abstracts were discussed by the 2 raters and relevant abstracts were mutually agreed upon following discussion. A total of 125 abstracts were identified as relevant following the initial screening stage. An additional 40 papers were located through handsearching the reference lists of papers from the initial 125 identified abstracts and reviews located through the original 1618 abstracts. In addition, JC screened the reference lists on Beacon [27], a portal listing online applications for mental and physical disorders. This yielded a total of 165 papers that underwent the second stage of screening and were included if they met the following stricter criteria:

1. Study design: the study was a randomized controlled trial (RCT) or a randomized trial (ie, an equivalence trial).

2. Recruitment population: the sample was composed of students attending a tertiary institution, such as university, college, or a Technical and Further Education (TAFE) institution.

3. Intervention type: the intervention or some portion of the intervention (eg, reminder or follow-up contact) was either delivered by or accessed using a technological device or process (Internet, telephone, video). Studies that used technology only to conduct screening or measure outcomes (which are not considered part of the intervention) did not satisfy this criterion.

4. Age: the age range of the sample was between 18 and 25 years or the mean age of the sample was between 18 and 25 years. If sample age was not able to be sourced directly from the authors, studies that sampled undergraduates without specifying age were included.

5. Intervention focus: the intervention was designed to improve, reduce, or change symptoms relating to a mental disorder (as defined by the DSM-IV and ICD-10).

Studies that were considered relevant by both raters were retained and those that were identified as relevant by only 1 rater were rescreened by a third rater. A total of 108 papers were retained for coding by 2 coders (LF or AG and JC). Three of these papers [28-30] were subsequently excluded for the following reasons: outcome data reported elsewhere (ie, summary papers, n=2) [28,30], and a non-peer-reviewed conference proceeding (n=1) [29]. Of the remaining 105 papers, 63 papers examined interventions for substance use problems (alcohol, tobacco, and other drugs) and 14 papers examined interventions for eating disorders, weight gain, or body image. These papers were excluded from the current review as they have been the subject of previous reviews. The remaining 28 papers included in this review examined interventions for other mental health problems and related issues (depression, anxiety disorders, stress, Internet addiction, psychological distress, and hardiness/acculturation).

Coding of the Included Papers

A total of 28 papers were included. However, 2 papers [31,32] reported data from the same study leaving a total of 27 studies for analysis. Each of the 27 included studies was coded by 2 raters (LF or AG and JC) with a preformulated rating sheet with relevant data extracted and recorded. Data coding comprised the following: country where the study was conducted, participant characteristics and recruitment method, type and length of intervention and the technology used, whether or not the intervention was distal, amount of human contact involved in the intervention, whether or not intention-to-treat (ITT) analysis was employed, an overall quality rating for the study, the primary outcome measure for the study, measurement occasions, whether or not the intervention was significantly superior to the control at each measurement occasion, and Hedge’s *g* effect sizes for the difference between each intervention and the control group at each measurement occasion.

Type of intervention (ie, intervention target group) was categorized using the framework described by Mrazek and Haggerty [33]. *Universal programs* were those available for all (no screening involved), *selective programs* were those that selected individuals at risk of a mental health condition (involved screening), *indicated programs* were those that selected individuals displaying symptoms of a mental health condition in the absence of a mental disorder (involved screening), and *treatment programs* were those that targeted individuals diagnosed with a mental disorder.

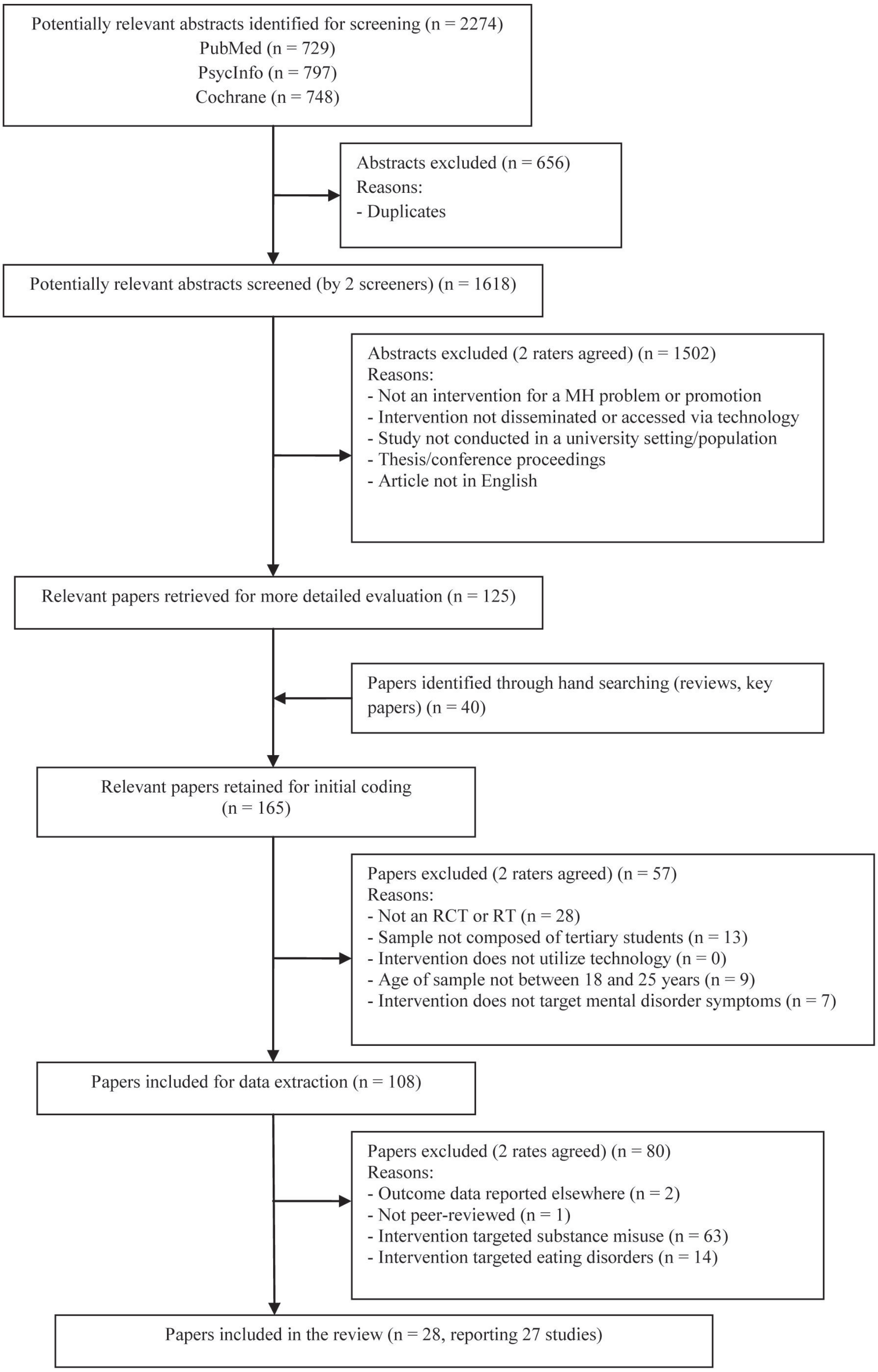
Amount of human contact was coded based on categories identified by Newman and colleagues [34]: (1) self-administered therapy (therapist/human contact for assessment, at most), (2) predominantly self-help (therapist/human contact beyond assessment for periodic check-ins, teaching clients how to use the self-help tool, and/or for providing the initial therapeutic rationale; if any assistance in the use of therapeutic tools was provided, it did not involve more than 1.5 hours of the therapist’s/human’s time), (3) minimal-contact therapy (active involvement of a therapist/human, although to a lesser degree than traditional therapy for this disorder; including any treatment in which the therapist/human assisted the client in the application of specific therapy techniques and that involved more than 1.5 hours of the therapist’s/human’s time), and (4) predominantly therapist-administered treatments (clients had regular contact with a therapist/human for a typical number of sessions, but the study attempted to determine whether the use of a self-help tool augmented the impact of the standard therapy). In studies in which reminders were provided and no human involvement or tailoring was reported, the reminders were considered to be automated, and the study was categorized as self-administered. Interventions were considered to be distal if they “traveled” to the recipient, rather than the recipient being required to physically go to a location to participate in the intervention.

Study quality was assessed using the risk of bias criteria proposed by the Cochrane Effective Practice and Organisation of Care Group [35], a measure designed to assess potential sources of bias for studies involving a control group. Items are designed to measure bias relating to inadequate random allocation sequence and allocation concealment, differences in baseline outcome measurements and characteristics, inadequate treatment of missing outcome data, researcher knowledge of allocated interventions, contamination between the conditions, selective outcome reporting, as well as any other risk of bias. A score of 1 was awarded for each criterion adequately addressed within the paper with potential scores ranging from 0 to 9.

Data Analysis

A quantitative meta-analysis was not conducted because of the heterogeneous nature of the studies. Descriptive information regarding whether the study reported a significant time × group interaction was reported. This information was reported for the primary symptom outcome measure(s) as specified by the authors. In the event that a primary outcome was not specified or multiple measures of the same construct were examined (eg, multiple measures of depressive symptoms), only the first outcome that was described in the measures section of the paper was reported. Where possible, Hedge’s *g* effect sizes were calculated using mean posttest and follow-up scores and standard deviations for each intervention group and the control group. Effect sizes were not calculated in several instances in which means and standard deviations were not reported at all or were not reported for the overall sample, or if the number of participants analyzed in the intervention and control groups was unclear or not reported. Negative effect sizes indicate that the control group outperformed the intervention group. For studies that conducted both ITT and completer analyses, results pertaining to the ITT analyses were reported. Analyses for follow-up were not conducted because of the heterogeneity of the follow-up periods. The association between various study characteristics and whether or not studies reported statistically significant results at postintervention favoring the intervention was explored using a series of Fisher exact tests for categorical variables and Mann-Whitney *U* tests for continuous variables. Data were analyzed by comparing intervention and control conditions within studies. For completeness, all interventions are presented in Multimedia Appendix 3 (4 interventions did not employ technology). However, only interventions that contained technology were compared for analysis. Therefore, from the 27 studies, a total of 51 comparisons were made (each study could examine more than 1 comparison).

Figure 1. Study identification flow diagram.



Results

Study Characteristics

Multimedia Appendix 3 shows the characteristics of the included studies (N=27). Studies were categorized according to the symptoms or disorder that the intervention targeted as reported by the study authors. The conditions targeted were depression and anxiety (n=7) [36-42], anxiety symptoms (n=4) [31,43-45], examination anxiety (n=4) [46-49], specific phobia (n=3) [50-52], stress (n=2) [53,54], social anxiety (n=1) [55], computer-related anxiety (n=1) [56], posttraumatic stress (n=1) [57], generalized anxiety disorder (n=1) [58], psychological distress (n=1) [59], hardiness and acculturation (n=1) [60], and Internet addiction (n=1) [61].

Origin

Most studies targeting depression and anxiety were conducted in the United States [36-38,40,41] with the remaining 2 from Australia [39,42]. Studies targeting anxiety disorders and stress were conducted in a wider range of countries with 7 from the United States [44,46,50,51,53,54,58], 4 from Italy [43,45,47,49], and 1 each from Australia [31], United Kingdom [48], Belgium [52], Spain [55], and the Netherlands [57]. Studies targeting other mental health issues were from the United States [60], United Kingdom [59], and China [61].

Interventions

Intervention Type

Ten studies employed universal interventions, and fewer studies focused on indicated (n=7), selective (n=7), and treatment (n=3) interventions.

Depression and Anxiety Symptoms (n=7)

Of the studies for depression and anxiety symptoms, 43% (3/7) examined selective interventions [39,41,42], with the remaining studies assessing universal (2/7, 29%) [36,37], indicated (1/7, 14%) [38], and treatment (1/7, 14%) [40] interventions. The 4 selective or indicated studies [38,39,41,42] evaluated cognitive behavioral therapy (CBT)-based interventions, the 2 universal intervention studies [36-37] focused on relationship skills training, and the treatment study [40] examined the effectiveness of an intervention based on physical activity and Web-based social cognitive theory (SCT) as an adjunct to mental health counseling.

Anxiety Symptoms (n=4)

Of the 4 studies targeting anxiety symptoms, 3 were universal [44,45] and 1 was indicated [31]. The 3 universal studies delivered either relaxation [43,45] or exposure-based interventions [44], and the indicated study delivered CBT [31].

Examination Anxiety (n=4)

Of the 4 studies targeting examination anxiety, 2 were universal [47,49], 1 was selective [48], and 1 was indicated [46]. The 2 universal studies delivered stress inoculation training [47,49], the selective study delivered CBT or education interventions [48], and the indicated study delivered systematic desensitization and relaxation [46].

Specific Phobia (n=3)

Of the 3 studies targeting specific phobias, 2 were indicated studies [50,51] and 1 was a treatment study [52]. The 2 indicated studies targeted spider phobia [50] and acrophobia [51], and delivered exposure therapy. The treatment study targeted spider phobia and delivered exposure therapy [52].

Stress (n=2)

Of the 2 studies targeting stress, 1 was universal [54] and 1 was selective [53]. The universal study delivered real and virtual reality physical activity [54] and the selective study delivered health information and motivational feedback interventions [53].

Other Anxiety Disorders (n=4)

The study targeting computer-related anxiety was universal and delivered hypnosis or biofeedback [56]. The study targeting posttraumatic stress was selective and delivered structured writing [57]. The study targeting generalized anxiety disorder was indicated and delivered exposure, expressive writing, or auto-photic stimulation (APS) interventions [58]. The study targeting social anxiety disorder was a treatment study delivering CBT [55].

Other Mental Health Problems and Issues (n=3)

For the 3 studies examining other issues, 1 used a universal intervention targeting hardiness and acculturation [60], 1 was an indicated study focused on Internet addiction [61], and 1 was a selective study targeting psychological distress [59]. Two of the studies delivered education [59,60], and the remaining study delivered motivational interviewing [61].

Technology Employed

The 51 interventions examined in the present review employed a range of broad technology types including the Internet (n=18), audio (n=9), virtual reality (n=6), video (n=4), stand-alone computer programs (n=1), and/or a combination of these (Internet plus computer program, n=5; audio plus video, n=5; computer plus audio, n=1; Internet plus audio, n=1; Internet plus APS, n=1). There were no telephone-only interventions. The interventions were delivered using a range of specific devices, including computer (n=24), mobile phone (n=4), Moving Picture Experts Group Layer-3 (MP3) audio file (n=3), Digital Versatile Disc (DVD; n=3), compact disc (CD; n=2), virtual reality devices (n=6), audiotape player (n=4), video player (n=2), and combinations of these, including computer plus audio player (n=2) and computer plus APS (n=1). CBT interventions tended to be Internet-based and were commonly delivered using websites and in conjunction with therapist support in-person or via email. Email was the most common method of monitoring. Educational interventions tended to be delivered using stand-alone computer-based programs and videos. Interventions involving exposure, stress inoculation training, and relaxation tended to be delivered via audio (audiotape, CD, and MP3), combined audio and video (DVD), mobile phone, or virtual reality.

Intervention Length and Delivery

Intervention length ranged from 15 minutes to 10 weeks. For interventions of less than 1 week in duration, intervention length ranged from 15 to 60 minutes (mean 34.23, SD 13.82). For interventions that were 1 week or longer, the mean intervention length was 4.1 weeks (SD 3.04). Length of time to follow-up ranged from immediately postintervention to 12 months postintervention. Of the 51 technology-based interventions employed, 27 (52.9%) were delivered distally, 18 (35.3%) were delivered nondistally, and 6 (11.8%) contained distal and nondistal components. Of the 25 Internet-based interventions, 13 (52.0%) were completely distal, 6 (24.0%) contained a combined distal and nondistal component, and 6 (24.0%) interventions were not distal [39,42,61].

Level of Human Contact

Over half of the interventions were self-administered (30/51, 59%), and approximately one-fifth were predominantly self-help (10/51, 20%). For interventions that were predominantly self-help, human contact was most commonly provided in the form of email monitoring or moderation of a discussion forum. Four interventions (8%) involved minimal contact and tended to include more intensive therapist involvement via email. Interventions classified as therapist administered (7/51, 14%) were often face-to-face interventions that served as comparison groups to a technology-based intervention, or were face-to-face interventions with a technology-based component as an adjunct (ie, Internet-based homework) [40,42].

Participants

By definition, the mean age of participants fell between 18 and 25 years. Most samples were composed solely of undergraduate university students. Two studies targeted specific groups of students: nursing students [44] and Asian-Indian students [60]. Females formed the majority of participants in most studies, with the exception of 5 studies in which males were either the majority (n=3) [46,51,60] or the sample contained equal numbers of males and females (n=2) [43,45]. The most common recruitment methods were university-wide emails, advertisements in university publications or during lectures, and flyers posted around university campuses. In 7 studies, samples were recruited through undergraduate psychology or health courses [31,36,38,39,50,54,56].

Outcome Measures

Four of the 7 depression and anxiety studies used the Beck Depression Inventory (BDI) and the Beck Anxiety Inventory (BAI) as their primary outcome measures [36-38,41]. Three of the 4 studies targeting anxiety symptoms used the State Trait Anxiety Inventory (STAI) as their primary outcome measure [43-45], as did 2 of the 4 studies targeting examination anxiety [47,49]. The 2 remaining studies targeting examination anxiety used the Test Anxiety Inventory (TAI) [46,48]. Studies targeting specific phobias used the Fear of Spiders Questionnaire [50], the Acrophobia Questionnaire [51], and an 11-point fear rating scale [52]. The 2 studies targeting stress used either the Perceived Stress Scale [53] or the Momentary Mood States Checklist [54]. The single studies targeting social anxiety, computer-related anxiety, posttraumatic stress, generalized anxiety disorder, psychological distress, hardiness, acculturation and social support, and Internet addiction used measures specific to the disorder being targeted.

Study Quality

Sample sizes across all studies ranged from 20 to 283 (median 60). Most studies were RCTs (n=26), and 1 study was a randomized trial [46]. Of the 26 RCTs, 10 studies employed a no-intervention control, 9 studies used attention control groups, 6 studies used a wait-list control, and in 1 study, participants were assigned to a wait-list control but also received treatment as usual. Quality ratings for the studies employing a control group ranged from 1 to 6, with an overall mean rating of 4.42 of a possible 9 points. The mean quality ratings for categories of studies were stress (mean 5.0, range 4-6); other anxiety disorders, such as seasonal affective disorder, posttraumatic stress disorder, generalized anxiety disorder, and computer-related anxiety (mean 5.0, range 4-6); other issues, such as psychological distress, acculturation, and Internet addiction (mean 4.67, range 3-6); depression and anxiety symptoms (mean 4.43, range 3-6); specific phobias (mean 4.33, range 3-5); anxiety symptoms (mean 4.0, range 3-5); and examination anxiety (mean 3.67, range 1-6). Table 1 shows the number of studies that satisfied each of the quality rating criteria.

Table 1. Numbers (and percentages) of studies (with control groups) meeting quality rating criteria of the Cochrane Effective Practice and Organisation of Care (EPOC).

Criterion #	EPOC quality rating criteria	Studies, n (%)
1	Was the allocation sequence adequately generated?	5 (19.2)
2	Was the allocation adequately concealed?	1 (3.8)
3	Were baseline outcome measurements similar?	17 (65.4)
4	Were baseline characteristics similar?	11 (42.3)
5	Were incomplete outcome data adequately addressed?	10 (38.5)
6	Was knowledge of the allocated interventions adequately prevented during the study?	0 (0)
7	Was the study adequately protected against contamination?	24 (92.3)
8	Was the study free from selective outcome reporting?	21 (80.8)
9	Was the study free from other risks of bias?	26 (100)

As indicated in Table 1, few studies used or reported adequate randomization methods. In terms of baseline outcome measurement, more than half of studies reported that there were no significant differences present across study groups at baseline. Less than half of studies, however, reported that the characteristics of the providers of the intervention and control conditions were similar (criteria 4). Approximately one-third of studies reported that they used methods to adequately address incomplete data. No studies met criteria 6 (Was knowledge of the allocated interventions adequately prevented during the study?).

Of the entire 27 studies, 8 studies undertook ITT analyses, and 13 did not. Six studies did not report this information. Of the 8 ITT studies, half (n=4) reported data from a full sample (no attrition), 2 used maximum likelihood estimation methodology, 1 used the last observation carried forward, and 1 used a mixed models analysis.

Intervention Efficacy

Depression and Anxiety Symptoms

Among the 7 studies targeting depression and anxiety symptoms, there were 10 interventions that were compared to a control group (some studies had multiple intervention arms). Six interventions were CBT-based (delivered either online or using a stand-alone computer), 2 interventions involved relationship focused skills training, 1 intervention comprised physical activity and SCT, and 1 intervention involved online peer-support.

Effective/Mixed Results

Postintervention, 3 of the CBT-based interventions were associated with a significant time × group interaction favoring the intervention group on both depression and anxiety symptom outcomes. The remaining CBT interventions (n=3) only found effects for anxiety symptoms postintervention, as did the online peer-support intervention. Only 1 of the relationship skills training interventions found a significant interaction at posttest for depression symptoms [36]. The second relationship skills training intervention study found a positive effect for anxiety at 10-month follow-up [37].

Not Effective

The physical activity and Web-based SCT intervention did not find a significant group × time interaction postintervention for either depression or anxiety [40].

Anxiety Symptoms

Among the 4 studies targeting anxiety symptoms, 9 interventions were examined. Six interventions were relaxation-based: video plus an audio narrative (n=2), video alone (n=1), audio narrative alone (n=2), and virtual reality headset plus audio narrative (n=1). Two interventions were exposure-based: audiotape alone (n=1) and audiotape plus progressive muscle relaxation (n=1). One intervention was CBT-based.

Effective/Mixed Results

The 2 exposure-based interventions were effective for reducing anxiety relative to a control condition [44]. Video and audio relaxation combined was associated with significant within-group decline in anxiety symptoms in 1 study [43], but data was not compared with a control group and this intervention was also not found to be effective in another study [45].

Not Effective

Video alone, audio alone, and a virtual reality headset plus an audio narrative were not found to be effective for reducing anxiety symptoms [43,45]. The only online CBT intervention was also not associated with a significant interaction in favor of the intervention [31].

Examination Anxiety

Among the 4 studies targeting examination anxiety, 11 interventions were examined. Two interventions examined computer-assisted exposure plus audio relaxation, 8 interventions examined stress inoculation delivered by video and audio (n=3), video alone (n=2), and audio alone (n=3), and 1 intervention examined online CBT.

Effective

One study examining 4 stress inoculation interventions (video plus audio vs video only vs audio via MP3 only vs audio via CD only) found that all interventions were effective in reducing anxiety symptoms relative to a no-intervention control condition [47]. Online CBT was also found to be effective for symptoms of examination anxiety [48]. The study examining exposure plus audio relaxation found that computer-based delivery was equivalent to group-based delivery of the intervention [46].

Not Effective

The remaining study examining stress inoculation interventions did not provide sufficient data to determine the effectiveness of the interventions relative to the control group [49].

Specific Phobia

Among the 3 studies targeting specific phobia, 5 interventions were examined. All interventions were exposure-based. Three were delivered using virtual reality and 2 were delivered using video.

Effective

Virtual reality exposure interventions for spider phobia [50] and acrophobia [51] were associated with significant reductions in anxiety symptoms relative to a control group. Exposure using video was also effective in the treatment of spider phobia [52].

Stress

Among the 2 studies examining stress, 4 interventions were examined. Interventions included online education (n=1) or online motivational feedback (n=1) [53], a virtual reality simulation of the outdoors while walking on a treadmill (n=1), or a virtual reality simulation alone (n=1) [54].

Not Effective

None of the interventions were effective in reducing stress.

Other Anxiety Disorders

The study targeting social anxiety disorder examined online CBT [55]. The study targeting computer-related anxiety examined computer-assisted biofeedback [56]. The study targeting posttraumatic stress examined online structured writing exercises [57]. The study targeting generalized anxiety disorder examined 3 interventions: online exposure, online expressive writing, and APS [58].

Effective

Postintervention, online CBT was found to be effective for treating social anxiety disorder [55], biofeedback was effective for symptoms of computer-related anxiety [56], structured writing was effective for symptoms of posttraumatic stress [57], and online exposure and APS were effective for symptoms of generalized anxiety disorder [58].

Not Effective

Online expressive writing was not found to be effective for symptoms of generalized anxiety disorder [58].

Other Mental Health Problems and Issues

One study targeting psychological distress examined 2 interventions: online education and online education plus an online support group [59]. One study targeting hardiness, acculturation, and social support examined online information [60]. One study targeting Internet addiction examined 3 interventions: online motivational interviewing with feedback in a laboratory setting, online motivational interviewing without feedback in a laboratory setting, and online motivational interviewing without feedback in the participant's own setting [61].

Effective/Mixed Results

An online education intervention and a social support intervention each demonstrated within-group decline in psychological distress over time, but were not compared with a control group [59]. However, a combined intervention involving both the online education intervention and the support group was not more effective than education alone [59]. All of the motivational interviewing interventions targeting Internet addiction were associated with significant within-group decline in symptoms over time [61], but the interaction effect with the control was not tested. However, the control group did not show significant within-group decline over time.

Not Effective

Online information was not found to be effective in the study targeting hardiness and acculturation [60].

Effect Sizes

For interventions targeting depression and anxiety symptoms with available data (n=8), effect sizes ranged from –0.07 to 3.04 (median 0.54; depression = 0.48, anxiety = 0.77). Across interventions targeting anxiety symptoms and disorders with available data (n=10), effect sizes ranged from 0.07 to 2.66 (median 0.84). Because of insufficient or unavailable data, effect sizes were unable to be calculated for 33 of the 51 interventions (64%) or 14 of the 27 studies (52%), which included all of the interventions targeting stress, computer anxiety, psychological distress, hardiness and acculturation, and Internet addiction.

Less than half of studies provided sufficient data to calculate effect sizes. For interventions that targeted depression and anxiety, effect sizes were as follows for the 1 universal (alpha = –0.74), 6 selective (alpha = 0.81), 1 indicated (alpha = 0.54), and 1 treatment (alpha = 0.18) interventions. For interventions targeting anxiety symptoms and disorders, none of the 16 universal interventions (5 trials) had had sufficient data to calculate effect size. Alpha levels were as follows for the 3 selective interventions (alpha = 0.67), 5 indicated interventions (alpha = 0.49), and 2 treatment interventions (alpha = 1.83).

Association Between Positive Outcomes and Study Characteristics

Mann-Whitney *U* tests demonstrated no association between study outcome favoring the intervention and the following study characteristics: number of intervention sessions (*U*=35.0, *P*=.21), length of intervention (weeks; *U*=43.5, *P*=.67), sample size (*U*=40.5, *P*=.53), and quality rating (*U*=41.5, *P*=.56). Fisher exact tests also demonstrated no association between study outcome favoring the intervention and type of control group (attention placebo: n=9; wait list: n=6; no intervention: n=10, *P*=.84); type of technology used (Internet, includes all interventions that are Internet-based or involved an Internet component: n=34; other: n=21, *P*=.57); whether or not the intervention was distal (yes, includes completely and partially distal interventions: n=33; no: n=22; *P*=.74); and amount of human contact (self-administered: n=30; predominantly self-help: n=10; minimal-contact therapy: n=4; predominantly therapist-administered treatments: n=7; *P*=.30). The success rates of different types of interventions at achieving a study outcome favoring the intervention appeared dissimilar between the universal (n=25, 56%), selective (n=12, 67%), indicated (n=13, 75%), and treatment (n=5, 80%) trials. However, chi-square tests demonstrated that this difference was not significant (*P*=.74).

Discussion

Principal Findings

This systematic review identified 27 studies reporting RCTs of technology interventions targeting depression, anxiety, and related mental health issues, excluding substance misuse and eating disorders. Most of the studies (24/27, 89%) employed interventions focused on anxiety symptoms or disorders or stress, although 29% of these 24 studies (n=7) targeted both depression and anxiety. No study reported that they targeted depression alone in this population. Internet-based technology (typically involving CBT) was the most commonly employed medium, and it was used in 16 studies and almost half of the interventions. Distal and universal preventive interventions were the most common type of intervention. No study investigated the effectiveness of telephone interventions, and only 3 of 27 interventions (11%) targeted treatment. Audio and video were commonly used for exposure, stress inoculation, and relaxation training. More trials were undertaken in the United States than in any other country (13/27, 48%).

Overall, approximately half (n=24, 47%) of the 51 technology interventions were associated with at least 1 significant positive outcome compared with the control at postintervention, with 29% (n=15) failing to find a significant effect. Only 2 interventions (from 1 study) did not have a control group for comparison, and the remaining 10 interventions (from 3 studies) did not provide sufficient data on interaction effects to determine efficacy compared with the control. The studies finding a positive outcome compared with the control included 7 of the 10 technology-related interventions employed in the anxiety and depression studies, 2 of the 9 technology interventions in the anxiety studies, all 5 of the specific phobia interventions, none of the 4 stress interventions, and 4 of 5 interventions targeting other anxiety disorders. None of the 6 interventions targeting other conditions were demonstrated to be effective relative to controls, with 3 of these belonging to 1 study that did not provide sufficient data to determine efficacy compared with control [61]. Similarly, mixed results have been found in prior reviews of both Internet-based eating disorder prevention interventions [20] and in Internet-based alcohol use interventions [62].

Thus, the findings of the current review indicate that technological interventions targeting certain mental health and related problems offer promise for students in university settings. The data suggest that technology-based CBT may be particularly useful in targeting anxiety and, to a lesser extent, depressive symptoms in interventions targeting both depression and anxiety. A previous review on Internet-based interventions found comparable effect sizes for both depression (alpha = 0.42 to 0.65) and anxiety (alpha = 0.29 to 1.74) preventive and treatment interventions involving CBT [24]. Exposure approaches, including those involving virtual reality technology, offer promise for specific phobias. Moreover, the focus on universal intervention and prevention approaches including selective and indicated samples and the evidence that these may be effective are promising, especially given findings in the general community that optimal and comprehensive current treatment approaches alone cannot avert the majority of burden of disorders such as depression [63]. Prevention interventions delivered early in the life course have the potential to avert the greatest burden.

It is important to acknowledge that the interventions included in the present review may not have been designed specifically for the university population; rather, the students may have simply been a convenient research sample. For studies clearly designed for university students in the tertiary setting (ie, exam anxiety [46-49], academic worry [58], stress [53], psychological distress [59], and adjustment and acculturation in international students [60]), there was no clear advantage for the development specifically within this population, with 3 [47,48,58] of the 8 studies finding at least 1 significant positive outcome compared with the control at postintervention.

However, the review also highlights that there are significant gaps in the current state of knowledge in this area. Very few studies have focused on the use of technology in the university setting for the treatment of mental disorders (n=3), and in very few cases did more than 1 study target the prevention or treatment of specific disorders. Most of the studies focused on anxiety symptoms or disorders. Moreover, some methodological problems were evident in the studies, with many studies failing to report sufficient information about randomization, or less frequently, suffering from inadequate randomization methods, few studies specifying a primary outcome, and most of the studies failing to undertake or report appropriate intent-to-treat analyses. It is also of note that none of the studies met criterion 6 of the EPOC quality scale. This criterion specifically refers to the blinding of outcome assessments (ie, “Score ‘low risk’ if the authors state explicitly that the primary outcome variables were assessed blindly, or the outcomes are objective, eg, length of hospital stay” [35]). This is an inherent problem with self-report population studies. Where outcome assessments are carried out using Internet-based self-report surveys and not clinical assessment, it is not possible to precisely meet this criterion because the participants (the outcome assessors) are themselves typically not blind to their assigned conditions in studies of psychological interventions in general as well as in Web-based research [64]. Study quality criteria designed specifically for Internet-based research would enable more accurate assessment of this characteristic. Nevertheless, it is imperative that studies explain in sufficient detail the methods they used to accurately assess study quality. In addition, more than half of the studies (14/27, 52%), including all those focused on conditions other than depression and anxiety, and almost all of the trials with universal samples (9/10, 90%) failed to provide sufficient data to calculate effect sizes. This information is vital to comparatively assess the effect of interventions accurately. All future studies in this area should endeavor to provide this information to enable appropriate comparison between studies. As would be expected, treatment trials recorded the largest effect sizes (alpha = 1.35) across all studies targeting depression and anxiety, or anxiety symptoms and disorders, followed by selective (alpha = 0.67) and indicated (alpha = 0.52) trials.

None of the studies reported information about cost-effectiveness. However, 1 study targeting depression and anxiety provided broad information about costs of dissemination for the workshop leader (US $2000/10-15 participants), coaching emails, and face-to-face booster sessions (US $55/hour) [41]. To the author’s knowledge, no trials of technology-based interventions in tertiary students have examined cost-effectiveness per se, although there has been 1 study of the cost-effectiveness of translating the English-language program MoodGYM and the website BluePages for delivery to Norwegian university students [65]. This is not unexpected despite the argument that Internet-based research is useful at reducing the cost of public health, a recent review of all health-related Internet-based interventions, including mental health, found a total of only 8 studies that reported on cost-effectiveness [66]. Further information about the cost-effectiveness of Internet-based research in university students is required.

Somewhat surprisingly, we failed to find an association between any of the characteristics of the studies or their methodological quality and whether they reported positive outcomes. In particular, it might have been predicted that there would be an association between length of intervention or number of intervention sessions and achieving a study outcome favoring the intervention group. The reason for this is unclear, but may reflect the heterogeneity of the studies across many variables and the small number of interventions for each condition, precluding investigation of the association for each condition separately.

Limitations

There are some limitations to the present review that require consideration. Firstly, it is clear that some interventions were developed for university students (ie, the specific issues they face), and that others may have been simply tested in this population. Because of this, the included interventions may not have taken full advantage of the opportunities for technology-based interventions in a tertiary setting, which has important implications for the dissemination of these interventions within universities. However, some of the interventions were clearly university-specific with several of the anxiety interventions targeting student-focused problems, such as exam anxiety and stress in students, as well as adjustment and acculturation in international students. The present review searched 3 databases and it is possible that some relevant journals are not indexed by these databases. However, an attempt was made to address this by handsearching previous reviews, key papers, and the Beacon portal [67]. In addition, the restriction of the inclusion criteria to English-language journal papers may have introduced a level of bias into the present review.

Conclusions

It is clear that further research is required in university settings to investigate the effectiveness of technological interventions for specific mental disorders in the tertiary student population, to compare the relative efficacy of and engagement with different types of technological intervention within a disorder and ultimately to evaluate the most appropriate means by which such interventions might routinely be implemented in university settings.

Acknowledgments

This project was resourced by the Young and Well CRC. The Young and Well CRC is established under the Australian Government’s Cooperative Research Centres Program.

Conflicts of Interest

KG is a co-developer of MoodGYM, which was evaluated as part of 2 [39,42] of the included trials.

Multimedia Appendix 1

PubMed search terms/search history.

[PDF File (Adobe PDF File), 50KB - jmir_v15i5e101_app1.pdf]

Multimedia Appendix 2

PRISMA checklist.

[PDF File (Adobe PDF File), 149KB - jmir_v15i5e101_app2.pdf]

Multimedia Appendix 3

Full data from the review.

[PDF File (Adobe PDF File), 509KB - jmir_v15i5e101_app3.pdf]

References

1. Reavley N, Jorm AF. Prevention and early intervention to improve mental health in higher education students: a review. Early Interv Psychiatry 2010 May;4(2):132-142. [doi: 10.1111/j.1751-7893.2010.00167.x] [Medline: 20536969]
2. Compas BE, Wagner BM, Slavin LA, Vannatta K. A prospective study of life events, social support, and psychological symptomatology during the transition from high school to college. Am J Community Psychol 1986 Jun;14(3):241-257. [Medline: 3739977]
3. Buchanan JL. Prevention of depression in the college student population: a review of the literature. Arch Psychiatr Nurs 2012 Feb;26(1):21-42. [doi: 10.1016/j.apnu.2011.03.003] [Medline: 22284078]
4. Hunt J, Eisenberg D. Mental health problems and help-seeking behavior among college students. J Adolesc Health 2010 Jan;46(1):3-10. [doi: 10.1016/j.jadohealth.2009.08.008] [Medline: 20123251]
5. Mowbray CT, Megivern D, Mandiberg JM, Strauss S, Stein CH, Collins K, et al. Campus mental health services: recommendations for change. Am J Orthopsychiatry 2006 Apr;76(2):226-237. [doi: 10.1037/0002-9432.76.2.226] [Medline: 16719642]
6. Blanco C, Okuda M, Wright C, Hasin DS, Grant BF, Liu SM, et al. Mental health of college students and their non-college-attending peers: results from the National Epidemiologic Study on Alcohol and Related Conditions. Arch Gen Psychiatry 2008 Dec;65(12):1429-1437 [FREE Full text] [doi: 10.1001/archpsyc.65.12.1429] [Medline: 19047530]
7. Eisenberg D, Gollust SE, Golberstein E, Hefner JL. Prevalence and correlates of depression, anxiety, and suicidality among university students. Am J Orthopsychiatry 2007 Oct;77(4):534-542. [doi: 10.1037/0002-9432.77.4.534] [Medline: 18194033]

8. Drum DJ, Denmark AB. Campus suicide prevention: bridging paradigms and forging partnerships. Harv Rev Psychiatry 2012;20(4):209-221. [doi: 10.3109/10673229.2012.712841] [Medline: 22894730]
9. Burns JM, Davenport TA, Durkin LA, Luscombe GM, Hickie IB. The internet as a setting for mental health service utilisation by young people. Med J Aust 2010 Jun 7;192(11 Suppl):S22-S26. [Medline: 20528703]
10. Escoffery C, Miner KR, Adame DD, Butler S, McCormick L, Mendell E. Internet use for health information among college students. J Am Coll Health 2005;53(4):183-188. [doi: 10.3200/JACH.53.4.183-188] [Medline: 15663067]
11. Gray NJ, Klein JD, Noyce PR, Sesselberg TS, Cantrill JA. Health information-seeking behaviour in adolescence: the place of the internet. Soc Sci Med 2005 Apr;60(7):1467-1478. [doi: 10.1016/j.socscimed.2004.08.010] [Medline: 15652680]
12. Haas A, Koestner B, Rosenberg J, Moore D, Garlow SJ, Sedway J, et al. An interactive web-based method of outreach to college students at risk for suicide. J Am Coll Health 2008;57(1):15-22. [doi: 10.3200/JACH.57.1.15-22] [Medline: 18682341]
13. Ryan ML, Shochet IMM, Stallman HM. Universal online interventions might engage psychologically distressed university students who are unlikely to seek formal help. Advances in Mental Health 2010 Aug 2010;9(1):73-83. [doi: 10.5172/jamh.9.1.73]
14. Eisenberg D, Downs MF, Golberstein E, Zivin K. Stigma and help seeking for mental health among college students. Med Care Res Rev 2009 Oct;66(5):522-541. [doi: 10.1177/1077558709335173] [Medline: 19454625]
15. 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. [doi: 10.1111/j.1440-1584.2007.00859.x] [Medline: 17441815]
16. Beintner I, Jacobi C, Taylor CB. Effects of an Internet-based prevention programme for eating disorders in the USA and Germany--a meta-analytic review. Eur Eat Disord Rev 2012 Jan;20(1):1-8. [doi: 10.1002/erv.1130] [Medline: 21796737]
17. Elliott JC, Carey KB, Bolles JR. Computer-based interventions for college drinking: a qualitative review. Addict Behav 2008 Aug;33(8):994-1005 [FREE Full text] [doi: 10.1016/j.addbeh.2008.03.006] [Medline: 18538484]
18. Ferrer-García M, Gutiérrez-Maldonado J. The use of virtual reality in the study, assessment, and treatment of body image in eating disorders and nonclinical samples: a review of the literature. Body Image 2012 Jan;9(1):1-11. [doi: 10.1016/j.bodyim.2011.10.001] [Medline: 22119329]
19. Hutton HE, Wilson LM, Apelberg BJ, Tang EA, Odelola O, Bass EB, et al. A systematic review of randomized controlled trials: Web-based interventions for smoking cessation among adolescents, college students, and adults. Nicotine Tob Res 2011 Apr;13(4):227-238. [doi: 10.1093/ntr/ntq252] [Medline: 21350042]
20. Newton MS, Ciliska D. Internet-based innovations for the prevention of eating disorders: a systematic review. Eat Disord 2006;14(5):365-384. [doi: 10.1080/10640260600952522] [Medline: 17062448]
21. Tait RJ, Christensen H. Internet-based interventions for young people with problematic substance use: a systematic review. Med J Aust 2010 Jun 7;192(11 Suppl):S15-S21. [Medline: 20528701]
22. Yager Z, O'Dea JA. Prevention programs for body image and eating disorders on University campuses: a review of large, controlled interventions. Health Promot Int 2008 Jun;23(2):173-189 [FREE Full text] [doi: 10.1093/heapro/dan004] [Medline: 18263883]
23. Andersson G, Cuijpers P. Internet-based and other computerized psychological treatments for adult depression: a meta-analysis. Cogn Behav Ther 2009;38(4):196-205. [doi: 10.1080/16506070903318960] [Medline: 20183695]
24. Griffiths KM, Farrer L, Christensen H. The efficacy of internet interventions for depression and anxiety disorders: a review of randomised controlled trials. Med J Aust 2010 Jun 7;192(11 Suppl):S4-11. [Medline: 20528707]
25. Reger MA, Gahm GA. A meta-analysis of the effects of internet- and computer-based cognitive-behavioral treatments for anxiety. J Clin Psychol 2009 Jan;65(1):53-75. [doi: 10.1002/jclp.20536] [Medline: 19051274]
26. Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. Int J Surg 2010;8(5):336-341. [doi: 10.1016/j.ijsu.2010.02.007] [Medline: 20171303]
27. Beacon. URL: https://beacon.anu.edu.au/ [accessed 2013-05-07] [WebCite Cache ID 6GQTM94oL]
28. Dev P, Winzelberg AJ, Celio A, Taylor CB. Student bodies: psycho-education communities on the web. Proc AMIA Symp 1999:510-514 [FREE Full text] [Medline: 10566411]
29. Finkelstein J, Lapshin O, Wasserman E. Comparison of long-term results of computer-assisted anti-stigma education and reading anti-stigma educational materials. AMIA Annu Symp Proc 2007:245-248 [FREE Full text] [Medline: 18693835]
30. Grassi A, Preziosa A, Villani D, Riva A. A relaxing journey: The use of mobile phones for well-being improvement. Annual Review of CyberTherapy and Telemedicine 2007;5:123-131.
31. Kenardy J, McCafferty K, Rosa V. Internet-delivered indicated prevention for anxiety disorders: a randomized controlled trial. Behav Cognit Psychother 2003;31(3):279-289. [doi: 10.1017/S1352465803003047]
32. Kenardy J, McCafferty K, Rosa V. Internet-delivered indicated prevention for anxiety disorders: Six-month follow-up. Clinical Psychologist 2006;10(1):39-42. [doi: 10.1080/13284200500378746]
33. Mrazek PB, Haggerty RJ. Reducing Risks for Mental Disorders: Frontiers for Preventive Intervention Research. Washington, DC: National Academy Press; 1994.
34. Newman MG, Szkodny LE, Llera SJ, Przeworski A. A review of technology-assisted self-help and minimal contact therapies for anxiety and depression: is human contact necessary for therapeutic efficacy? Clin Psychol Rev 2011 Feb;31(1):89-103. [doi: 10.1016/j.cpr.2010.09.008] [Medline: 21130939]

35. Cochrane Effective Practice and Organisation of Care Group. EPOC resources URL: http://epoc.cochrane.org/epoc-resources [accessed 2012-11-26] [WebCite Cache ID 6CSHcMZR2]
36. Braithwaite SR, Fincham FD. ePREP: computer based prevention of relationship dysfunction, depression and anxiety. Journal of Social and Clinical Psychology 2007 May 2007;26(5):609-622. [doi: 10.1521/jscp.2007.26.5.609]
37. Braithwaite SR, Fincham FD. A randomized clinical trial of a computer based preventive intervention: replication and extension of ePREP. J Fam Psychol 2009 Feb;23(1):32-38. [doi: 10.1037/a0014061] [Medline: 19203157]
38. Cukrowicz KC, Joiner TE. Computer-based intervention for anxious and depressive symptoms in a non-clinical population. Cogn Ther Res 2007 Apr 2007;31(5):677-693. [doi: 10.1007/s10608-006-9094-x]
39. Ellis LA, Campbell AJ, Sethi S, O'Dea BM. Comparative randomized trial of an online cognitive-behavioral therapy program and an online support group for depression and anxiety. J Cyber Ther Rehabil 2011;4(4):461-467.
40. Mailey EL, Wójcicki TR, Motl RW, Hu L, Strauser DR, Collins KD, et al. Internet-delivered physical activity intervention for college students with mental health disorders: a randomized pilot trial. Psychol Health Med 2010 Dec;15(6):646-659. [doi: 10.1080/13548506.2010.498894] [Medline: 21154018]
41. Seligman ME, Schulman P, Tryon AM. Group prevention of depression and anxiety symptoms. Behav Res Ther 2007 Jun;45(6):1111-1126. [doi: 10.1016/j.brat.2006.09.010] [Medline: 17074301]
42. Sethi S, Campbell AJ, Ellis LA. The use of computerized self-help packages to treat adolescent depression and anxiety. Journal of Technology in Human Services 2010 Aug 2010;28(3):144-160. [doi: 10.1080/15228835.2010.508317]
43. Grassi A, Gaggioli A, Riva G. The green valley: the use of mobile narratives for reducing stress in commuters. Cyberpsychol Behav 2009 Apr;12(2):155-161. [doi: 10.1089/cpb.2008.0156] [Medline: 19275475]
44. Stephens RL. Imagery: a treatment for nursing student anxiety. J Nurs Educ 1992 Sep;31(7):314-320. [Medline: 1326031]
45. Villani D, Riva G. Presence and relaxation: A preliminary controlled study. PsychNology Journal 2008;6(1):7-25.
46. Buglione SA, Devito AJ, Mulloy JM. Traditional group therapy and computer-administered treatment for test anxiety. Anxiety Research 1990 Jun 1990;3(1):33-39. [doi: 10.1080/08917779008248739]
47. Grassi A, Gaggioli A, Riva G. New technologies to manage exam anxiety. Stud Health Technol Inform 2011;167:57-62. [Medline: 21685642]
48. Orbach G, Lindsay S, Grey S. A randomised placebo-controlled trial of a self-help Internet-based intervention for test anxiety. Behav Res Ther 2007 Mar;45(3):483-496. [doi: 10.1016/j.brat.2006.04.002] [Medline: 16814744]
49. Riva G, Grassi A, Villani D, Gaggioli A, Preziosa A. Managing exam stress using UMTS phones: the advantage of portable audio/video support. Stud Health Technol Inform 2007;125:406-408. [Medline: 17377312]
50. Hoffman HG, Garcia-Palacios A, Carlin A, Furness III TA, Botella-Arbona C. Interfaces That Heal: Coupling Real and Virtual Objects to Treat Spider Phobia. International Journal of Human-Computer Interaction 2003 Oct 2003;16(2):283-300. [doi: 10.1207/S15327590IJHC1602_08]
51. Rothbaum BO, Hodges LF, Kooper R, Opdyke D, Williford JS, North M. Effectiveness of computer-generated (virtual reality) graded exposure in the treatment of acrophobia. Am J Psychiatry 1995 Apr;152(4):626-628. [Medline: 7694917]
52. Vansteenwegen D, Vervliet B, Iberico C, Baeyens F, Van den Bergh O, Hermans D. The repeated confrontation with videotapes of spiders in multiple contexts attenuates renewal of fear in spider-anxious students. Behav Res Ther 2007 Jun;45(6):1169-1179. [doi: 10.1016/j.brat.2006.08.023] [Medline: 17045959]
53. Chiauzzi E, Brevard J, Thum C, Thurn C, Decembrele S, Lord S. MyStudentBody-Stress: an online stress management intervention for college students. J Health Commun 2008 Sep;13(6):555-572. [doi: 10.1080/10810730802281668] [Medline: 18726812]
54. Plante TG, Aldridge A, Su D, Bogdan R, Belo M, Kahn K. Does virtual reality enhance the management of stress when paired with exercise? An exploratory study. International Journal of Stress Management 2003 2003;10(3):203-216. [doi: 10.1037/1072-5245.10.3.203]
55. Botella C, Gallego MJ, Garcia-Palacios A, Guillen V, Baños RM, Quero S, et al. An Internet-based self-help treatment for fear of public speaking: a controlled trial. Cyberpsychol Behav Soc Netw 2010 Aug;13(4):407-421. [doi: 10.1089/cyber.2009.0224] [Medline: 20712499]
56. Farnill D. A comparison of hypnosis and computer-assisted biofeedback in computer-anxiety reduction. Australian Journal of Clinical and Experimental Hypnosis 1985 May:31-35.
57. 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]
58. Wolitzky-Taylor KB, Telch MJ. Efficacy of self-administered treatments for pathological academic worry: A randomized controlled trial. Behav Res Ther 2010 Sep;48(9):840-850. [doi: 10.1016/j.brat.2010.03.019] [Medline: 20663491]
59. Freeman E, Barker C, Pistrang N. Outcome of an online mutual support group for college students with psychological problems. Cyberpsychol Behav 2008 Oct;11(5):591-593. [doi: 10.1089/cpb.2007.0133] [Medline: 18817485]
60. Kanekar A, Sharma M, Atri A. Enhancing social support, hardiness, and acculturation to improve mental health among Asian Indian international students. Int Q Community Health Educ 2009;30(1):55-68. [doi: 10.2190/IQ.30.1.e] [Medline: 20353927]

61. Su W, Fang X, Miller JK, Wang Y. Internet-based intervention for the treatment of online addiction for college students in China: a pilot study of the Healthy Online Self-helping Center. Cyberpsychol Behav Soc Netw 2011 Sep;14(9):497-503. [doi: 10.1089/cyber.2010.0167] [Medline: 21294635]
62. White A, Kavanagh D, Stallman H, Klein B, Kay-Lambkin F, Proudfoot J, et al. Online alcohol interventions: a systematic review. J Med Internet Res 2010;12(5):e62 [FREE Full text] [doi: 10.2196/jmir.1479] [Medline: 21169175]
63. Andrews G, Titov N. Depression is very disabling. Lancet 2007 Sep 8;370(9590):808-809. [doi: 10.1016/S0140-6736(07)61393-2] [Medline: 17826154]
64. Eysenbach G, CONSORT-EHEALTH Group. CONSORT-EHEALTH: improving and standardizing evaluation reports of Web-based and mobile health interventions. J Med Internet Res 2011;13(4):e126 [FREE Full text] [doi: 10.2196/jmir.1923] [Medline: 22209829]
65. Lintvedt OK, Griffiths KM, Eisemann M, Waterloo K. Evaluating the translation process of an Internet-based self-help intervention for prevention of depression: a cost-effectiveness analysis. J Med Internet Res 2013;15(1):e18 [FREE Full text] [doi: 10.2196/jmir.2422] [Medline: 23343481]
66. Tate DF, Finkelstein EA, Khavjou O, Gustafson A. Cost effectiveness of internet interventions: review and recommendations. Ann Behav Med 2009 Aug;38(1):40-45 [FREE Full text] [doi: 10.1007/s12160-009-9131-6] [Medline: 19834778]
67. Hopewell S, Clarke M, Lefebvre C, Scherer R. Handsearching versus electronic searching to identify reports of randomized trials. Cochrane Database Syst Rev 2007(2):MR000001. [doi: 10.1002/14651858.MR000001.pub2] [Medline: 17443625]

Abbreviations

APS: auto-photic stimulation
BAI: Beck Anxiety Inventory
BDI: Beck Depression Inventory
CBT: cognitive behavioral therapy
CD: compact disc
DVD: Digital Versatile Disc
EPOC: Effective Practice and Organisation of Care
ITT: intention-to-treat
MeSH: Medical Subject Headings
NHMRC: National Health and Medical Research Council
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SCT: social cognitive theory
STAI: State Trait Anxiety Inventory
TAFE: Technical and Further Education

Edited by G Eysenbach; submitted 28.03.13; peer-reviewed by D Eisenberg, YS Bin; comments to author 16.04.13; revised version received 19.04.13; accepted 19.04.13; published 27.05.13.

Please cite as:
Farrer L, Gulliver A, Chan JKY, Batterham PJ, Reynolds J, Calear A, Tait R, Bennett K, Griffiths KM
Technology-Based Interventions for Mental Health in Tertiary Students: Systematic Review
J Med Internet Res 2013;15(5):e101
URL: http://www.jmir.org/2013/5/e101/
doi:10.2196/jmir.2639
PMID:23711740

Viewpoint

Social Media and the Empowering of Opponents of Medical Technologies: The Case of Anti-Vaccinationism

Kumanan Wilson[1], MD, MSc, FRCP; Jennifer Keelan[2], PhD

[1]Ottawa Hospital Research Institute, University of Ottawa, Department of Medicine, Ottawa, ON, Canada
[2]University of Toronto, School of Public Health, Toronto, ON, Canada

Corresponding Author:
Kumanan Wilson, MD, MSc, FRCP
Ottawa Hospital Research Institute, University of Ottawa
Department of Medicine
The Ottawa Hospital, Civic Campus, Box 684, Administrative Services Building, Room 1009
1053 Carling Avenue,
Ottawa, ON, K1Y4E9
Canada
Phone: 1 613 798 5555 ext 17921
Fax: 1 613 761 5492
Email: kwilson@ohri.ca

Abstract

Social media has contributed positively to the interaction between proponents of medical products and technologies and the public by permitting more direct interaction between these two groups. However, it has also provided opponents of these products a new mechanism to organize opposition. Using the example of anti-vaccinationism, we provide recommendations for how proponents of medical products and technologies should address this new challenge.

(J Med Internet Res 2013;15(5):e103) doi:10.2196/jmir.2409

KEYWORDS

social media; immunization

Introduction

Social media has been defined as "a group of Internet-based applications that…allow the creation and exchange of user generated content" [1]. These platforms range from social networking sites such as Facebook, to content sharing sites such as YouTube and Picasa, and even to interactive virtual worlds such as Second Life and World of Warcraft. Rapidly increasing in popularity and influence, social media presents a double-edged sword for proponents of medical technologies. On one hand, social media has transformed how companies communicate with potential consumers of medical pharmaceuticals and technologies. Both consumers and producers have a range of novel communication channels available to them that can rapidly match consumer interests and needs with available products and services. Social media platforms provide companies with new communication channels, relatively inexpensive and targeted advertising opportunities, and a consumer-mediated information stream that could potentially improve consumers' trust in information and brand loyalty to companies through information shared online. Social media has also given consumers communications tools that enable them to rapidly seek health information, share medical advice, directly manage health conditions, and benefit from, and contribute to, a community discourse by rating, ranking, and describing experiences with medical products. These applications have been developed partly in response to a shift in how consumers see their role in managing their health in an increasingly complex and patient-oriented medical system [2-4].

However, along with these opportunities for empowering both health consumers and producers alike comes potential peril [5]. Social media activities have raised alarms in the medical research community over companies having more effective tools to directly market health products to consumers—an activity regulated in most jurisdictions outside the United States [6,7]. The direct marketing of pharmaceuticals, procedures, devices, and medical tests to consumers is thought to lead to overconsumption or inappropriate consumption of medical technologies [8,9]. Conversely, social media also presents new opportunities for opposition to medical technologies, most notably for those that raise the ire or concern of some citizens, such as religious opposition to stem cell or novel fertility technologies. Social media provides a new platform for these individuals to organize, communicate, and undermine industry messages. It allows these individuals to circumvent traditional communication mechanisms and therefore does not require their messages to be either acceptable or relevant to mainstream broadcasters. It thus permits a minority of motivated individuals to potentially control the discourse and, at times, contribute to the spread of misinformation, damaging an otherwise useful interaction between proponents and consumers. An example of where this disruptive new media has been particularly problematic, and which offers cautionary messages to advocates of other technologies, is in the field of immunization. We have been studying this phenomenon and provide a summary of our experiences and lessons for advocates of new and existing technologies.

Social Media and the Anti-Vaccination Movement

Anti-vaccinationism has existed since the introduction of the first vaccine. Individuals who have alternate belief systems have mobilized, typically geographically, to communicate their concerns. This has led to sporadic vaccine rejection movements. More recently, the claim that the MMR (measles-mumps-rubella) vaccine or thimerosal containing vaccines are associated with autism continues to persist despite numerous studies refuting the link [10]. This rumor, largely initiated by a since-withdrawn paper in the *Lancet*, has resulted in vaccine rejection and contributed to over 26,000 cases of measles in Europe in 2011 [11,12].

What is social media's role in all of this? Traditionally, geographic proximity was necessary for mobilizing anti-vaccination forces. However, social media has circumvented this potential barrier, allowing individuals from disparate regions who likely would not have otherwise communicated to come into contact. In this process, individuals who had otherwise had their viewpoints rejected and been marginalized can be emboldened and can feel empowered. Social media also provides these individuals with new dynamic mechanisms to communicate their viewpoints. We observed this in several ways while studying vaccine concerns. We first observed the congregation of anti-vaccination viewpoints on YouTube [13]. Individuals utilized YouTube to upload videos that highlighted vaccine concerns and commented on each other's videos in a quasi social-network manner. Our observation was reinforced by the fact that anti-vaccination videos had more views and higher ratings than pro-vaccine videos. We observed similar vaccine concerns on the social media site MySpace when studying postings related to the HPV vaccine [14]. Examining these blogs revealed geographical clustering of anxiety—with Texas' attempt to make the HPV vaccine mandatory leading to a plethora of anti-HPV vaccine blogs in that state. Our assessment of the blogging sentiments also revealed potential future challenges in having boys accept the vaccine given that boys' blogs were determined to be more negative. We even observed organized anti-vaccine behavior when we surveyed health communications in the virtual world Second Life [15] (see Figure 1 for a screen capture showing the Vaccine 911 auditorium; Vaccine 911 is a vaccine critical organization that presents weekly lectures on immunization in Second Life).

As can be surmised, these pernicious activities can pose a real threat to mainstream messaging. If vaccination, one of the most important mechanisms for reducing mortality and morbidity where all established sources of information support the practice, can be undermined by social media activities, more novel technologies are at real risk of being similarly undermined [16]. Other examples of where traditional health messages have been undermined using social media include the promotion of anorexia and the spread of misinformation pertaining to rheumatoid arthritis [17,18].

Figure 1. Screen capture from the Second Life Site of the Vaccine 911 auditorium: The Iowa Wellness and Spinal Tuning Center (SLurl 163,122,28; Image taken Dec 15, 2008).

Recommendations

What strategies should advocates of medical technologies employ to combat the social mobilization of opposition to their products derived from marginalized opinions, hearsay, and inaccurate representation of the science involved? Here are a few recommendations stemming from our observations.

Social Media Monitoring

This is now an established part of marketing strategies. Numerous services are available to track online comments and social media activity about a new product and also to analyze sentiment, providing businesses with an opportunity to interact with customers, and to potentially intervene and prevent viral marketing campaigns by responding rapidly to customer concerns [19]. This is a necessary first step for any pre-emption efforts. Moving beyond social media monitoring, advocates of medical technologies may also want to consider monitoring search behavior related to their products. In health, search term surveillance has shown promise in identifying behavior patterns and anticipating disease outbreaks [20].

Be Where the Conversation Is

The US Centers for Disease Control and Prevention has made it part of their outreach mandate to master the various social media platforms so that, as much as possible, they can deliver scientifically accurate and appropriate content at the point when a consumer is seeking information, either via a Google keyword search, blogging on Facebook, watching videos on YouTube, or scanning related news items [21].

Interacting Through Social Media

This is a delicate task that needs to be approached with caution. When exploring social media contact, proponents of medical products may encounter a lot of negative sentiment. However, responding to the sentiments may simply provide a platform and greater audience for the more extreme viewpoints. Proponents of medical products need to recognize that opposition to their products will lie along a spectrum. There will be those who are ideologically opposed, and no effort to persuade them will be successful and will likely only intensify their opposition. We observed this when studying anti-vaccination attitudes and found that individuals often frequent social media sites to hear like-minded viewpoints and are not interested in hearing alternate viewpoints [13]. While vaccination may be a somewhat extreme example given the intensity of rhetoric that characterizes the discussions, nanotechnology, stem cells, and reproductive technologies could also create similar opposition. Proponents of medical technologies need to recognize that their target is the ambivalent individual. An individual who has no strongly held opinion and is susceptible to influence by a persuasive argument or an argument that resonates with a strong pre-existing belief system they hold (for example religious/political views). This leads to our fourth recommendation.

Recognizing the Power of Social Media

While some of the more radical viewpoints on social media may seem bizarre, dismissing the overall sentiments on social media would be a mistake. Public figures may champion these viewpoints (Jenny McCarthy on vaccines and Prince Charles on nanotechnology) giving the viewpoints' credibility among more moderate participants. Further, heavy-handed tactics by proponents of new technology may backfire because of the ability to create opposition through social media. Finally, and perhaps most importantly, there may be a basis of truth to the concerns voiced on social media sites. Proponents of medical products would be well served to listen to this discourse, ignore the extreme contributors, and prepare to address the concerns of the more moderate contributors. Companies that respectfully acknowledge these concerns and respond with clear actions, demonstrating that these concerns are being listened to, will build trust in their products. In contrast, companies ignoring the media and its messages will do so at their own peril.

Social media has been described as a game changer and proponents of medical products will have to develop mechanisms to understand and manage its influence. In many ways, social media has been beneficial, serving to improve the interaction between proponents of products and the public, in addition to providing members of the public an opportunity to provide valid criticism. However, the risk of discourse being hijacked by an extreme minority can be destructive to the relationship between producer and consumer. Ours are but a few of the suggestions to guide proponents of medical technologies as they navigate this new media and its impact.

Conflicts of Interest

None declared.

References

1. Kaplan AM, Haenlein M. Users of the world, unite! The challenges and opportunities of Social Media. Business Horizons 2010;53:59-68.
2. Beard L, Schein R, Morra D, Wilson K, Keelan J. The challenges in making electronic health records accessible to patients. J Am Med Inform Assoc 2012;19(1):116-120 [FREE Full text] [doi: 10.1136/amiajnl-2011-000261] [Medline: 22120207]
3. Cugelman B, Thelwall M, Dawes P. Online interventions for social marketing health behavior change campaigns: a meta-analysis of psychological architectures and adherence factors. J Med Internet Res 2011;13(1):e17 [FREE Full text] [doi: 10.2196/jmir.1367] [Medline: 21320854]

4. Solomon M, Wagner SL, Goes J. Effects of a Web-based intervention for adults with chronic conditions on patient activation: online randomized controlled trial. J Med Internet Res 2012;14(1):e32 [FREE Full text] [doi: 10.2196/jmir.1924] [Medline: 22353433]
5. Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. J Med Internet Res 2008;10(3):e22 [FREE Full text] [doi: 10.2196/jmir.1030] [Medline: 18725354]
6. Greene JA, Kesselheim AS. Pharmaceutical marketing and the new social media. N Engl J Med 2010 Nov 25;363(22):2087-2089. [doi: 10.1056/NEJMp1004986] [Medline: 21105789]
7. Webb S. Drug marketing and the new media. Nat Biotechnol 2010 May;28(5):396-398. [doi: 10.1038/nbt0510-396] [Medline: 20458296]
8. Liang BA, Mackey TK. Prevalence and Global Health Implications of Social Media in Direct-to-Consumer Drug Advertising. J Med Internet Res 2011;13(3):e64 [FREE Full text] [doi: 10.2196/jmir.1775]
9. Smith R. Online marketing of medical procedures needs better regulation. BMJ 2012;344:e1399. [Medline: 22378929]
10. Immunization Safety Review Committee, Board on Health Promotion and Disease Prevention. In: Stratton K, Almario DA, Wizeman TM, McCormick MC, editors. Immunization Safety Review: Vaccinations and Sudden Unexpected Death in Infancy. Washington, DC: The National Academies Press; 2003.
11. Wakefield AJ, Murch SH, Anthony A, Linnell J, Casson DM, Malik M, et al. Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children. Lancet 1998 Feb 28;351(9103):637-641. [Medline: 9500320]
12. Centers for Disease Control and Prevention. Morbidity and Mortality Weekly Report. 2011. Increased transmission and outbreaks of measles, European Region URL: http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6047a1.htm [accessed 2013-04-22] [WebCite Cache ID 6G4bn28rh]
13. Keelan J, Pavri-Garcia V, Tomlinson G, Wilson K. YouTube as a source of information on immunization: a content analysis. JAMA 2007 Dec 5;298(21):2482-2484. [doi: 10.1001/jama.298.21.2482] [Medline: 18056901]
14. Keelan J, Pavri V, Balakrishnan R, Wilson K. An analysis of the Human Papilloma Virus vaccine debate on MySpace blogs. Vaccine 2010 Feb 10;28(6):1535-1540. [doi: 10.1016/j.vaccine.2009.11.060] [Medline: 20003922]
15. Beard L, Wilson K, Morra D, Keelan J. A survey of health-related activities on second life. J Med Internet Res 2009;11(2):e17 [FREE Full text] [doi: 10.2196/jmir.1192] [Medline: 19632971]
16. Zhou F, Santoli J, Messonnier ML, Yusuf HR, Shefer A, Chu SY, et al. Economic evaluation of the 7-vaccine routine childhood immunization schedule in the United States, 2001. Arch Pediatr Adolesc Med 2005 Dec;159(12):1136-1144. [doi: 10.1001/archpedi.159.12.1136] [Medline: 16330737]
17. Syed-Abdul S, Fernandez-Luque L, Jian WS, Li YC, Crain S, Hsu MH, et al. Misleading health-related information promoted through video-based social media: anorexia on YouTube. J Med Internet Res 2013;15(2):e30 [FREE Full text] [doi: 10.2196/jmir.2237] [Medline: 23406655]
18. Singh AG, Singh S, Singh PP. YouTube for information on rheumatoid arthritis--a wakeup call? J Rheumatol 2012 May;39(5):899-903. [doi: 10.3899/jrheum.111114] [Medline: 22467934]
19. Eysenbach G. Infodemiology: The epidemiology of (mis)information. Am J Med 2002 Dec 15;113(9):763-765. [Medline: 12517369]
20. Wilson K, Brownstein JS. Early detection of disease outbreaks using the Internet. CMAJ 2009 Apr 14;180(8):829-831 [FREE Full text] [doi: 10.1503/cmaj.090215] [Medline: 19364791]
21. US Centers for Disease Control. 2010. Social Media Tools URL: http://www.cdc.gov/SocialMedia/Tools/ [WebCite Cache ID 6EwakENYm]

Edited by G Eysenbach; submitted 22.10.12; peer-reviewed by B Boateng, AM Auvinen, T Biswas, G Kok; comments to author 13.02.13; revised version received 07.03.13; accepted 28.03.13; published 28.05.13.

Please cite as:
Wilson K, Keelan J
Social Media and the Empowering of Opponents of Medical Technologies: The Case of Anti-Vaccinationism
J Med Internet Res 2013;15(5):e103
URL: http://www.jmir.org/2013/5/e103/
doi:10.2196/jmir.2409
PMID:23715762

Original Paper

Crowdsourcing a Normative Natural Language Dataset: A Comparison of Amazon Mechanical Turk and In-Lab Data Collection

Daniel R Saunders[1], PhD; Peter J Bex[2], PhD; Russell L Woods[1], PhD

[1]Schepens Eye Research Institute, Boston, MA, United States

[2]Schepens Eye Research Institute, Massachusetts Eye and Ear, Boston, MA, United States

Corresponding Author:
Daniel R Saunders, PhD
Schepens Eye Research Institute
20 Staniford Street
Boston, MA, 02114
United States
Phone: 1 617 912 2590
Fax: 1 617 912 0112
Email: daniel_saunders@meei.harvard.edu

Abstract

Background: Crowdsourcing has become a valuable method for collecting medical research data. This approach, recruiting through open calls on the Web, is particularly useful for assembling large normative datasets. However, it is not known how natural language datasets collected over the Web differ from those collected under controlled laboratory conditions.

Objective: To compare the natural language responses obtained from a crowdsourced sample of participants with responses collected in a conventional laboratory setting from participants recruited according to specific age and gender criteria.

Methods: We collected natural language descriptions of 200 half-minute movie clips, from Amazon Mechanical Turk workers (crowdsourced) and 60 participants recruited from the community (lab-sourced). Crowdsourced participants responded to as many clips as they wanted and typed their responses, whereas lab-sourced participants gave spoken responses to 40 clips, and their responses were transcribed. The content of the responses was evaluated using a take-one-out procedure, which compared responses to other responses to the same clip and to other clips, with a comparison of the average number of shared words.

Results: In contrast to the 13 months of recruiting that was required to collect normative data from 60 lab-sourced participants (with specific demographic characteristics), only 34 days were needed to collect normative data from 99 crowdsourced participants (contributing a median of 22 responses). The majority of crowdsourced workers were female, and the median age was 35 years, lower than the lab-sourced median of 62 years but similar to the median age of the US population. The responses contributed by the crowdsourced participants were longer on average, that is, 33 words compared to 28 words ($P<.001$), and they used a less varied vocabulary. However, there was strong similarity in the words used to describe a particular clip between the two datasets, as a cross-dataset count of shared words showed ($P<.001$). Within both datasets, responses contained substantial relevant content, with more words in common with responses to the same clip than to other clips ($P<.001$). There was evidence that responses from female and older crowdsourced participants had more shared words ($P=.004$ and .01 respectively), whereas younger participants had higher numbers of shared words in the lab-sourced population ($P=.01$).

Conclusions: Crowdsourcing is an effective approach to quickly and economically collect a large reliable dataset of normative natural language responses.

(J Med Internet Res 2013;15(5):e100) doi:10.2196/jmir.2620

KEYWORDS

Internet; web; crowdsourcing; free recall

Introduction

Internet-based crowdsourcing of medical studies has had a number of successes in recent years [1]. Using open calls on the Web, researchers have been able to recruit large, and sometimes specialized, populations to contribute data, with low expenditure of resources. For example, 20,000 members of the 23andMe genome-sequencing community responded to a detailed survey about their phenotype [2], over 500 individuals with developmental prosopagnosia were identified through self-testing on the research group's website [3], and thousands of online participants contributed information about their off-label drug use [4]. Traditional recruiting and testing to collect these datasets would have been expensive—in some cases prohibitively so—whereas in these cases, data were contributed freely.

In most uses of crowdsourcing in medical research to date, the primary data consist of categorical responses. However, for many purposes it would be valuable to quickly and inexpensively collect large natural language datasets in response to an open-ended question or prompt. Such a process could be used to norm projective psychological tests or to compile qualitative descriptions of disease symptoms or commonly experienced side effects of treatment. In one recent application of crowdsourcing, workers gave qualitative, free-text feedback on different approaches to communicating oral health messages, in addition to quantitative feedback [5]. Saunders et al [6] recently described the use of free-text responses to evaluate the viewer's acquisition of information from video clips. Rather than scoring text passages manually, using heuristic marking or a rubric, this approach scores them automatically relative to a large body of normative responses. An objective measure of information acquisition such as this has a number of potential applications, including, in our research, quantifying the benefit of video enhancements for people with low vision. In the present study, we examine whether crowdsourcing is an effective way to collect the required normative dataset. We test whether crowdsourced responses have substantial content and whether the responses, as well as the participants giving the responses, are similar to those seen in a supervised lab setting.

Crowdsourcing, first named by Howe [7], refers to the practice of advertising small self-contained tasks on the Web, usually to be worked on via the Internet, such as within a Web browser. Workers are typically compensated on the basis of the work they complete, rather than by a contract for a fixed amount of work. For the employer, the absence of the traditional relationship with employees, in many cases not knowing their identities or qualifications, is balanced by the speed and cheapness with which a large number of tasks can be completed. Often little time investment is required for data collection beyond the initial setup. The volume of data can compensate for potential inconsistency in quality: several studies have shown that combining the responses of nonexpert workers, whether by averaging or by using majority answers to screen out low-quality answers, can equal the quality of expert work, at a much lower cost [8-10]. The present study is based on the crowdsourcing website Mechanical Turk administered by Amazon, chosen because of its advertised worker base of over 500,000 individuals and because of the convenient infrastructure it provides for posting and paying for small jobs (typically requiring between 1 minute and 1 hour) to be completed over the Web. Because of the presence of an intermediary, workers can remain anonymous while receiving payments from experimenters.

Mechanical Turk and other crowdsourcing tools are particularly well suited for the task of collecting nonspecific normative datasets. Besides the speed and low cost of data collection, the population is relatively heterogenous, typically spanning a range of ages, educational backgrounds, and geographic locations that is greater than can be easily accessed by conventional methods [11,12]. Although it is difficult to control the demographic composition in crowdsourcing, this limitation is less serious when a general normative dataset sampling from the population at large is required. However, there is still concern about whether datasets collected in this way would have low quality responses or other distinctive characteristics that limit their usefulness. Some reasons why data obtained through recruiting and testing participants over the Internet might be less valuable [13,14] include potential sampling bias in recruiting only Internet users; that the experimental setting and display conditions cannot be controlled; greater chance of distractions and interruptions; and the possibility of worse compliance or motivation because of the lack of the presence of an experimenter. The question of the quality of more complex responses in light of these issues has not previously been addressed.

We compared a normative natural language dataset that was collected over the Web from participants recruited using Mechanical Turk (crowdsourced), with a dataset collected in the lab with participants recruited using conventional means (lab-sourced). As discussed in Saunders et al[6], the responses consisted of short descriptions of 30-second movie clips. We compared the results of the two recruiting processes, as well as the properties of the responses that the two groups produced. In addition to simple metrics such as the lengths of the responses, we used a take-one-out procedure to evaluate the quality of the content. The text of each response was compared to the text of all other responses in the same normative dataset, taking note of whether it was more similar to the responses to the same movie clip than to the responses to other movie clips, using a simple count of shared words. We also performed this procedure crossing the two normative datasets to test whether the content was similar.

Methods

Recruitment

Crowdsourced participants (workers) were recruited through postings on Amazon Mechanical Turk and were limited to workers who were registered as living in the United States. Demographic information was requested from each worker before they completed any tasks. At the end of the demographic survey, workers were informed about what they would be asked to do and actively consented by selecting a check box. Workers were known to us only by an ID assigned by Amazon. They were paid on a per-response basis, with Amazon as an intermediary. Workers were paid US$0.25 per response contributed, with a one-time $0.25 bonus for filling out the demographic survey and a $0.25 bonus for every 25 responses contributed and approved.

Lab-sourced participants were recruited from the community in and near Boston, Massachusetts, using a contact list or by being referred by participants in this and other studies. There was a target number of 60 participants divided equally into three age groups: under 60 years, 60-70 years, and greater than 70 years, each with equal numbers of men and women. The age stratification ensured responses from older participants, to investigate a possible age effect and because the visual disorders addressed in our other research, such as macular degeneration, are more prevalent in older people. Other criteria for the lab-sourced participants included a normal appearance of retina, no ocular conditions in self-reported ophthalmologic history, binocular visual acuity better than 20/32, and a Montreal Cognitive Assessment [15] score of at least 20. Informed consent was obtained from each participant prior to data collection, and they received a vision assessment and a cognitive assessment. Participants were shown the clips wearing habitual, not necessarily optimal, optical correction. They were compensated at a rate of $10 per hour, including the time for the clinical assessment, with the average time taken being approximately 2.5 hours.

Video Clips

There were 200 video clips selected from 39 different films and TV programs, chosen to represent a range of genres and types of depicted activities. The genres included nature documentaries (eg, BBC's Deep Blue), cartoons (eg, Shrek Forever After), and dramas (eg, The Hurt Locker). The clips were 30 seconds long and were selected from parts of the films that had relatively few scene cuts, which was reflected in the average number of cuts per minute in our clips being 9, as compared to approximately 12 per minute in contemporary films [16]. The clips included conversation, indoor and outdoor scenes, action sequences, and wordless scenes where the relevant content was primarily the facial expressions and body language of one or more actors. Although all participants heard audio in addition to viewing video, they were instructed to report only on the visual aspects of the clip.

Data Collection

Crowdsourced Participants

Crowdsourced participants viewed the video clips within a Web browser, on a local computer of their choice. Therefore the size of the monitor, their distance from the monitor, and other display characteristics were not fixed. The clips were shown within the frame of the Mechanical Turk interface (Figure 1), with each clip representing a separate HIT (Human Interface Task, the unit of paid work on the Mechanical Turk website). Below the clip, there were two text boxes in which to answer two movie description prompts, "Describe this movie clip in a few sentences as if to someone who hasn't seen it" and "List several additional visual details that you might not mention in describing the clip to someone who hasn't seen it." Text entry into these boxes was disabled until the clip had finished playing. Workers could complete as many video clip description tasks as they wanted while more clips were available, at any time of day. It was not possible to guarantee that each worker would complete a certain number of these tasks. The $0.25 bonus for every 25 responses was included as an inducement to complete more clips. Workers were prevented from seeing any clip more than once. Across all crowdsourced participants, 20 responses were collected for each clip, for a total of 4000 responses.

Lab-Sourced Participants

Lab-sourced participants viewed the video clips on an iMac i7 at a fixed distance of 100 cm. The videos were 33 degrees of visual angle wide. The clips were displayed by a MATLAB program using the Psychophysics Toolbox [17]. An experimenter gave the instructions and was in the room during data collection, but the MATLAB program automatically displayed the prompts after viewing a clip. The prompts were the same as for the crowdsourced participants. The spoken responses to each prompt were recorded using a headset microphone and later transcribed using MacSpeech Pro to produce the initial (automated) transcript, and then a separate group of Mechanical Turk workers verified and corrected the automated transcript [8]. Each lab-sourced participant viewed and responded to a different set of 40 clips selected from the set of 200 clips, for a total of 2400 responses (exactly 12 per clip). Equal numbers of responses to each video were collected for each of the six age-stratification by gender groups.

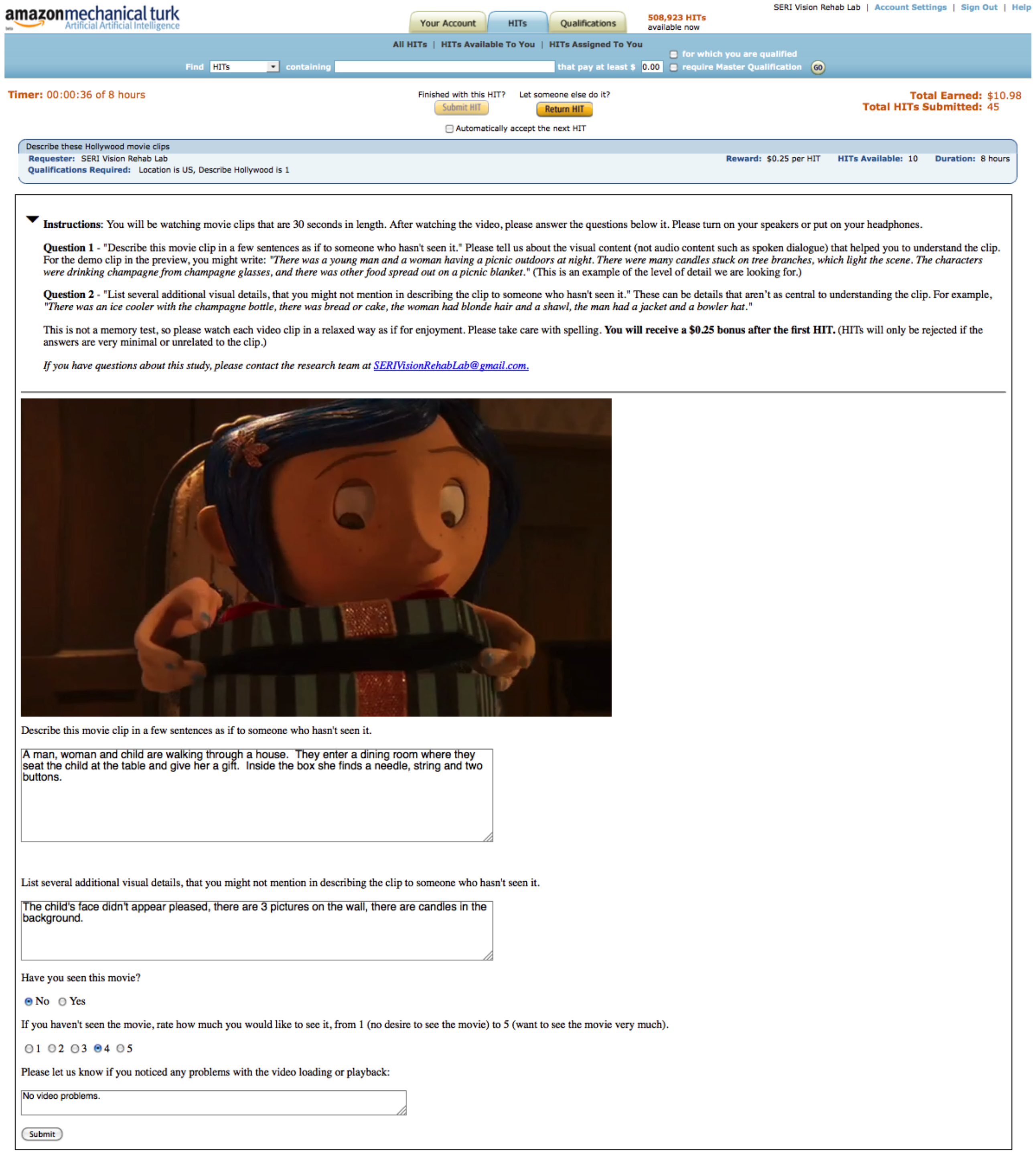
Natural Language Processing

We processed the text of responses with the Text to Matrix Generator toolbox for MATLAB [18], which included a step that deleted a list of stopwords. Stopwords are words that carry little information on their own, such as "the" and "but". To the default stopword list, we added verbal interjections that might have been transcribed from the lab-sourced verbal responses, such as "yeah" and "um". The toolbox converted the compiled responses to term-document matrices for numerical analysis. We used the matrices to compute the number of words in responses and the relationship between demographics and number of words in responses. In addition, we evaluated the content by comparing responses to other responses that were made to the same video clip or to responses to other video clips. We reasoned that if a response contains accurate content about the clip, then on average it should be more similar to the responses to the same video clip than it is to responses to other video clips.

The method we used to compare responses was to count the number of words that two responses shared (after removing stopwords), disregarding repeated instances of the word in either response. More sophisticated approaches, for example that took into account synonyms, did not score as well in our validity benchmarks [6]. Since longer responses have an advantage as far as including words that might be found in normative dataset responses, the total number of words in a response (after removing stopwords) has a strong correlation with its shared word score, r=.63, across all the data we collected. However, the word count does not explain all the variance in the shared word score, and several composite scores, such as the ratio of shared words to total words, performed no better, so we used the simple shared word count as our metric of quality of responses.

This analysis was carried out within the lab-sourced and crowdsourced datasets. The similarity of the two response datasets was then evaluated by crossing the datasets: comparing responses from one dataset to the responses of the other dataset that originated from the same video clip. The mean of the resulting similarity scores should reflect the overall similarity in how the two populations described a clip. Finally, the two datasets were pooled and the mean shared words for each response, for the same clip and other clips, was computed relative to this pooled dataset.

Figure 1. Example screenshot of Web forms used for data collection from crowdsourced participants, as hosted by Amazon Mechanical Turk.



Timer: 00:00:36 of 8 hours

Finished with this HIT? Let someone else do it?

Total Earned: $10.98
Total HITs Submitted: 45

☐ Automatically accept the next HIT

Describe these Hollywood movie clips
Requester: SERI Vision Rehab Lab
Qualifications Required: Location is US, Describe Hollywood is 1
Reward: $0.25 per HIT **HITs Available:** 10 **Duration:** 8 hours

Instructions: You will be watching movie clips that are 30 seconds in length. After watching the video, please answer the questions below it. Please turn on your speakers or put on your headphones.

Question 1 - "Describe this movie clip in a few sentences as if to someone who hasn't seen it." Please tell us about the visual content (not audio content such as spoken dialogue) that helped you to understand the clip. For the demo clip in the preview, you might write: "*There was a young man and a woman having a picnic outdoors at night. There were many candles stuck on tree branches, which light the scene. The characters were drinking champagne from champagne glasses, and there was other food spread out on a picnic blanket.*" (This is an example of the level of detail we are looking for.)

Question 2 - "List several additional visual details, that you might not mention in describing the clip to someone who hasn't seen it." These can be details that aren't as central to understanding the clip. For example, "*There was an ice cooler with the champagne bottle, there was bread or cake, the woman had blonde hair and a shawl, the man had a jacket and a bowler hat.*"

This is not a memory test, so please watch each video clip in a relaxed way as if for enjoyment. Please take care with spelling. **You will receive a $0.25 bonus after the first HIT.** (HITs will only be rejected if the answers are very minimal or unrelated to the clip.)

If you have questions about this study, please contact the research team at SERIVisionRehabLab@gmail.com.

Describe this movie clip in a few sentences as if to someone who hasn't seen it.

A man, woman and child are walking through a house. They enter a dining room where they seat the child at the table and give her a gift. Inside the box she finds a needle, string and two buttons.

List several additional visual details, that you might not mention in describing the clip to someone who hasn't seen it.

The child's face didn't appear pleased, there are 3 pictures on the wall, there are candles in the background.

Have you seen this movie?

● No ○ Yes

If you haven't seen the movie, rate how much you would like to see it, from 1 (no desire to see the movie) to 5 (want to see the movie very much).

○ 1 ○ 2 ○ 3 ● 4 ○ 5

Please let us know if you noticed any problems with the video loading or playback:

No video problems.

Results

Participants

Data collection for the 60 lab-sourced participants (median age 64, range 23-85 years) required 13 months of active recruiting. Examination showed small subclinical cataracts in 6 participants: one case of red-green color vision deficiency, one case of dry eye, and one case of a detachment of the peripheral retina in the right eye, which had been repaired with laser surgery and should not have affected the ability to watch the video clips.

Data collection for the crowdsourced responses took place during 34 days of active data collection (over a 38-day period). Responses were contributed by 99 distinct Mechanical Turk worker IDs, which we assume corresponds to 99 individuals (median age 35, range 20-66 years). However, it is possible for a worker to create multiple accounts with the use of additional credit cards and email addresses (see Discussion). The number of responses contributed by crowdsourced participants ranged between 1 and 188, median 22, with the most prolific 20% of the workers contributing 60% of the responses. Responses were usually contributed over the course of multiple working sessions. The only eye condition reported by the crowdsourced workers that could have affected viewing was one case of cataracts (“not significant enough for surgery yet”). The same worker also reported having severe dry eyes. This worker contributed 39 responses.

The demographics of the two samples are presented in Table 1. The crowdsourced sample was skewed towards women, whereas equal numbers of men and women were recruited for the lab-sourced sample (by study design). The crowdsourced sample distribution had a younger median age, but a long tail of older workers (skewness=0.65). There was no evidence for a significant difference in the racial makeup of the two groups, although none of the lab-sourced sample reported their ethnicity as “Multiple”, in contrast to 8% of the crowdsourced sample. Similarly, there was not a significant difference in the number of people who reported themselves as “Hispanic”, although the proportion was higher in the crowdsourced sample. The lab-sourced sample was more highly educated, with a greater proportion of people with bachelor’s degrees and postgraduate degrees as their maximum attainment and a smaller proportion with a maximum attainment of “Associate degree” or “Some college”.

Table 1 also compares the demographics of the two samples to the population of the United States as a whole. The median age of the lab-sourced sample was older (by design), whereas the median age of the crowdsourced sample was 35 years, which is 2 years younger than the median age of the population of the country (2010 census [19]). Both samples resembled the United States in their racial and ethnic makeup to some degree, with the greatest discrepancy from the country as a whole being in fewer Asian people and fewer Hispanic-identified people. More people reported their race as “Multiple” in the crowdsourced population than in the United States as a whole. Both of our population samples had achieved a higher level of education on average than the population of the United States (based on people 18 years and over in the 2011 Current Population Survey[21]): there was a higher rate of bachelor’s degrees and a lower proportion who had attained only high school diplomas. This could have been partly due to the greater concentration of older adults in the two samples, with few participants falling in the 18-22 year range.

Table 1. Self-reported demographic characteristics of participants.

		Crowdsourced (N=99)	Lab-sourced (N=60)	Test for difference (*P* value)	US population
Gender				.14	
	Male	37 (37%)	30 (50%)		49% [a]
	Female	62 (63%)	30 (50%)		51%
Age (median, min–max)		35y (20–66y)	64y (23–85y)	<.001	37y[a]
Race/Ethnicity				.18	
	Black	6 (6%)	5 (8%)		13% [a]
	White	81 (82%)	54 (90%)		72%
	Asian	3 (3%)	1 (2%)		5%
	American Indian/Alaska Native	1 (1%)	0 (0%)		1%
	Multiple	8 (8%)	0 (0%)		3%
Hispanic				.09	
	Hispanic	8 (8%)	1 (2%)		16%[a]
	Not Hispanic	91 (92%)	59 (98%)		84%
Highest education				<.001	
	High school	11 (11%)	5 (8%)		35% [b]
	Some college	16 (16%)	6 (10%)		23%
	Associate degree	32 (32%)	2 (3%)		10%
	Bachelor's degree	28 (28%)	20 (33%)		21%
	Postgraduate degree	12 (12%)	27 (45%)		11%

[a] 2010 United States Census [19,20].

[b] 2011 US Current Population Survey, 18 years and over [21].

Finally, the self-reported demographics of our Mechanical Turk sample were similar to those found in a survey of Mechanical Turk workers taken in 2009 [22]. Like our workers, the workers in that study who were located in the United States had a mean age of approximately 35 years, were mostly women, and consisted of approximately 40% bachelor's degree holders, with approximately 15% holding a postgraduate degree. Therefore, our sample represented a typical pool of American workers that are available for recruitment through Mechanical Turk for studies of this nature.

We compared survey answers about TV and movie viewing habits between the two sets of participants. We also asked about difficulties in viewing different display devices, with questions such as "Do you find it difficult to see details or feel that you miss important information when watching TV or movies on the TV?" A linear regression showed that crowdsourced participants watched more hours of TV, $t=2.2$, $P=.03$, with 38% reporting 3 or more hours a week compared to 25% in the lab-sourced sample, and 8% reporting 0-1 hours a week compared to 22% in the lab-sourced sample. Crowdsourced participants reported less difficulty with watching television, $X^2_3=10.5$, $P=.01$, with 84% answering "never" or "rarely" to the difficulty question, compared to 73% of the lab-sourced participants. Far more crowdsourced participants reported having watched TV or movies on portable devices, such as a smartphone, than lab-sourced participants: 50% compared to 17%, $X^2_2=18.2$, $P<.001$. However, for those individuals who did view media on portable devices, the level of difficulty reported was not significantly different between the groups, $X^2_3=1.5$, $P=.67$. There was weak evidence of crowdsourced participants watching movies in the theater more often, $X^2_6=11.5$, $P=.07$, although only 3% reported watching movies "never", compared to 15% of the lab-sourced participants. There was no significant difference in the reported difficulty of watching movies, $X^2_3=5.0$, $P=.17$, with most crowdsourced and lab-sourced participants (85% and 90% respectively) reporting difficulties "never" or "rarely".

Comparison of Lab-sourced and Crowdsourced Responses

The distribution of response lengths, after removing stopwords, between the lab-sourced and crowdsourced responses had a large overlap (Figure 2). The means were significantly different: $t_{6398}=15.1$, $P<.001$, with the lab-sourced responses having 5 fewer words on average (mean 33 vs mean 28, medians 31 and 26). This difference could not fully be explained by differences in the demographics of the populations, as demonstrated by a mixed model analysis [23] with dataset, age, highest education level, and gender as predictors, and participant and video as fully crossed random factors. The lab-sourced dataset had shorter responses on average: $P=.003$, even when controlling for these demographic factors.

The total vocabulary used in the crowdsourced responses, after removal of words on the stoplist, was 8512 distinct words for 4000 responses, whereas the lab-source participants used 7356 words for 2400 responses. However, when we controlled for different dataset sizes, the lab-sourced participants had a more varied vocabulary. We randomly sampled 2400 responses from the crowdsourced responses, to match the lab-sourced dataset size, and computed the number of distinct words among those responses. From 1000 such samples, the average vocabulary size was 6904, compared to the lab-sourced vocabulary size of 7356, and this difference was significant: $t_{999}=319$, $P<.001$. Using the same procedure to control for dataset size, we also compared the number of words that occurred once only in each dataset and found that there were 17% more in the lab-sourced dataset (3240 lab-sourced, 2770 crowdsourced), further supporting the idea that participants in the lab used a more varied vocabulary. The two complete datasets had 4875 words in common, with 3637 words appearing in the crowdsourced dataset but not the lab-sourced dataset, and 2481 words appearing in the lab-sourced dataset but not the crowdsourced dataset. Table 2 shows the most frequently used words in these two categories. Excluding stopwords, the mean word length was 4.1 letters for the crowdsourced data and 4.2 letters for the lab-sourced data.

We used a take-one-out procedure to test the validity of the datasets and the scoring method. We compared each response to the remaining responses to the same clip, and to responses to other clips, using the same procedure of counting the non-repeating words shared between the two responses after removal of stopwords. In Figure 3, panel A illustrates that for both datasets, the average similarity to responses to the same movie clip was far greater than to responses to other movie clips: $F_{1,12796}=18,492$, $P<.001$. There was also a difference due to the dataset, with the crowdsourced dataset having larger shared word scores on average than the lab-sourced dataset: $F_{1,12796}=3894$, $P<.001$. There was an interaction between same/other comparisons and dataset, $F_{1,12796}=1580$, $P<.001$, with the difference between the shared words with the same clip and other clips being larger in the lab-sourced condition, although the ratios between the same and other mean number of shared words were similar (4.0 in the crowdsourced dataset and 3.8 in the lab-sourced dataset).

We evaluated the similarity of the two datasets by performing the same response comparisons between datasets. Responses from the lab-sourced dataset were compared to the responses to the same movie clip in the crowdsourced dataset and to responses to other movie clips in the crowdsourced dataset. Panel B in Figure 3 demonstrates that the responses to the same clips were much more similar on average: $t_{4646.5}=120$, $P<.001$ (Welch's t test). Similarly, responses in the crowdsourced dataset were compared to responses to the same and other clips in the lab-sourced dataset, and the responses to the same clip were much more similar: $t_{2833.2}=71$, $P<.001$ (Welch's t test). Therefore we pooled the two datasets, and as panel C in Figure 3 shows, responses were much more similar to responses to the same clip than they were to responses to other clips, $F_{1,12796}=19263$, $P<.001$. Additionally, crowdsourced responses had higher numbers of shared words on average, $F_{1,12796}=1363$, $P<.001$, and a larger difference between same-clip and other-clip shared words, $F_{1,12796}=513$, $P<.001$. The difference between crowdsourced and lab-sourced dataset shared word scores was not only due to demographic differences between the populations, as was shown by a mixed model with age, education, and gender as additional predictors, since the lab-sourced dataset still had significantly lower shared-word scores, $P<.001$.

Finally, we examined whether the average shared word score within a dataset for a particular clip (which reflects the homogeneity of responses to a clip) was similar between the two normative datasets. There was a significant correlation, $r=.69$, $P<.001$, between the mean of a video clip's shared word scores in the crowdsourced dataset and in the lab-sourced dataset, indicating that clips that elicited a large amount of common vocabulary across respondents did so in both datasets.

Demographic Effects

We conducted an analysis to determine whether age, gender, or maximum education level had an effect on average number of shared words within each normative dataset (that is, comparing responses to responses within the same dataset) or on the total number of words in responses (after removal of stopwords). We used mixed models with participant and video as fully crossed random factors. In the crowdsourced dataset, there was strong evidence that gender predicted shared word score, $P=.004$, with men having a shared word score that was 0.61 lower on average. Age was also a significant predictor of shared-word score, $P=.01$, with age positively related to shared-word score with coefficient=0.027 shared-words per year. Education level did not significantly predict shared-word score, $P=.14$. The relationship between demographic factors and total number of words approached significance for gender, $P=.08$; age, $P=.07$; and education, $P=.06$.

In the lab-sourced dataset, age predicted shared-word score, $P=.01$, but with a negative coefficient: –0.013 shared words per year. Gender and education did not significantly predict shared word score for the lab-sourced responses, ie, $P=.53$ and .24 respectively. Education significantly predicted the total number of words, $P=.03$, with a positive coefficient=2.3 words per education level, but gender and age did not: $P=.38$ and .11 respectively.

Figure 2. Distribution of number of words in responses in crowdsourced data (top) and lab-sourced data (bottom), after removal of stopwords.

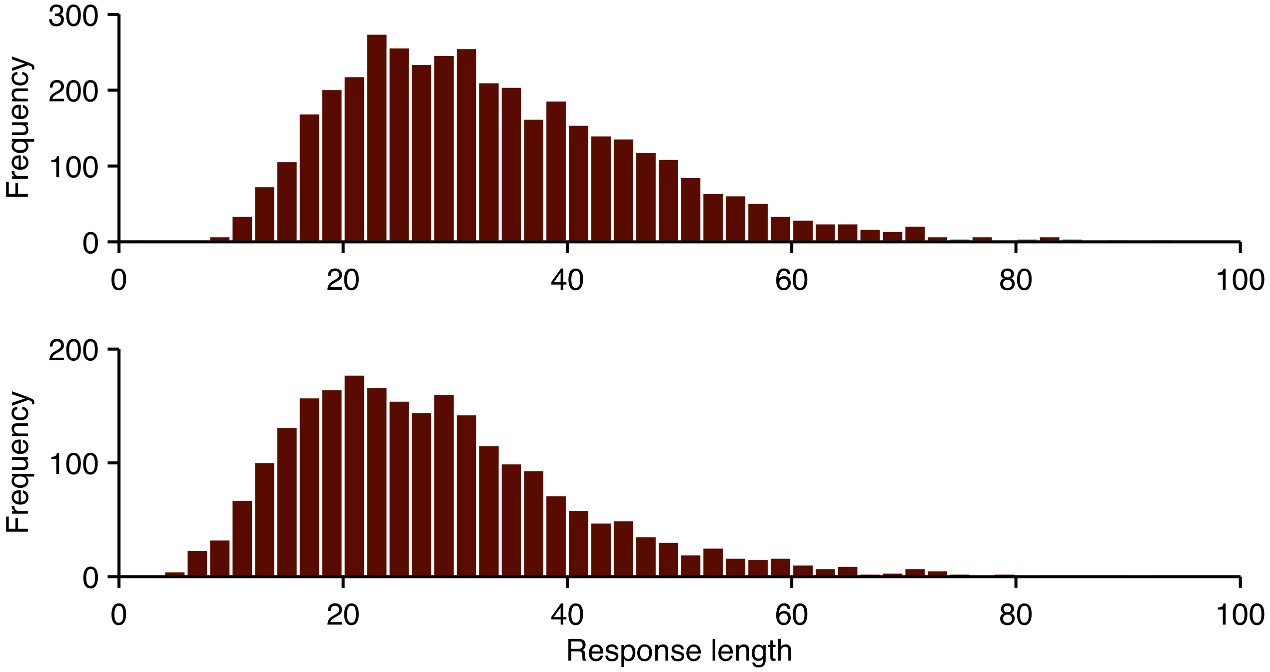
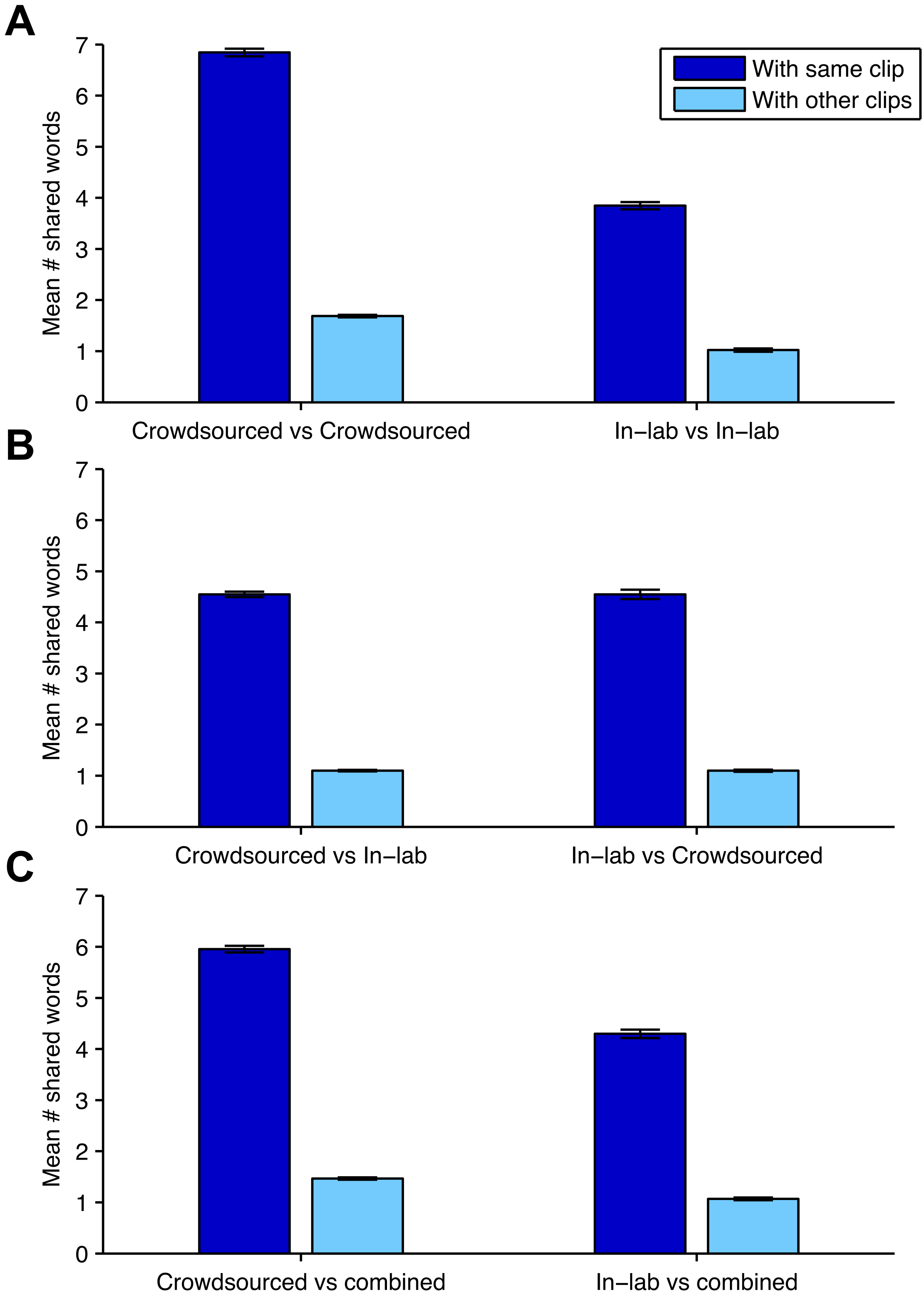


Table 2. Comparison of crowdsourced and lab-sourced vocabulary.

	Frequency
Words that appeared in crowdsourced but not lab-sourced responses	
teen	36
reveal	36
raises	28
cgi	28
pony	23
sleeves	22
sheets	22
listens	20
maroon	19
framed	18
driveway	18
storage	17
whilst	16
slicked	16
rail	16
Words that appeared in lab-sourced but not crowdsourced responses	
involves	15
encampment	12
drama	12
beautifully	12
recording	11
movies	11
jell-o	11
report	10
photographer	10
fiction	10
fella	10
scenario	9
involving	9
impress	9
disney	9

Figure 3. Mean number of words shared by responses with responses to the same clip, and with responses to other clips (error bars indicate 95% CI).



Discussion

This study has shown that crowdsourced natural language data can have substantial content and be similar to data obtained in the laboratory. Although the demographic characteristics were somewhat different between the two samples, with the crowdsourced population being younger, less educated, and more female than the makeup of the lab-sourced population (which was selected for age and gender), there was a large overlap in the lengths of responses that participants provided, and in the vocabulary they used to describe specific movie clips. This makes crowdsourcing a feasible approach for collecting a large normative free-text dataset, such as is needed for an automated natural language scoring method [6]. Unlike previous applications of crowdsourcing to medical natural language processing (eg [24]), our method does not use worker qualification tests or “gold standard” responses created by experts to screen out low-quality answers. Instead, the large volume of free-text data compensates for potential inconsistency in the quality.

A consequence of this finding is that experiments using natural language responses can be conducted quickly using Web-based crowdsourcing, with the dependent measure being the scores obtained through automatic comparison to a normative dataset. These scores are taken to reflect the amount of valid content in the response. We are taking this approach to evaluate the benefits of image enhancement to acquiring information from video clips [25]. Furthermore, panel B in Figure 3 and the associated analysis demonstrate that a crowdsourced normative dataset can be used to effectively score free-text responses obtained in the lab. This makes it possible to use this approach to score a relatively small dataset obtained in a lab-based study, for example with a special population that would be hard to recruit online, against a large dataset of normative responses to the same query obtained through Mechanical Turk or a similar crowdsourcing service.

The crowdsourced sample resembled previous descriptions of the American Mechanical Turk population and resembled the population of the United States as a whole. The most discrepant feature of the crowdsourced population was the 2:1 gender imbalance towards female participants. This could help to account for the higher average shared word score in the crowdsourced sample because responses contributed by women received higher scores in general. Although the effect is relatively small, with average shared word score about 9% higher for women, it suggests that gender should always be included as a predictor in analyses of the scores produced by this method.

The crowdsourced participants also watched more television and movies and far more video on handheld devices. Since amount of TV watched, difficulties watching TV, frequency of watching movies, and likelihood of watching video on a handheld device have been found to be related to age [26], we conducted post hoc logistic and linear regressions that included age as a predictor. The difference in age distribution fully explained the difference in amount of handheld video watching and frequency of moviegoing. However, the difference in the number of hours of TV remained, so this was the only viewing habit difference between the populations that would remain if the samples were age-matched. There were only limited differences in the difficulty the two population samples reported in viewing video on different display devices, with both reporting the most difficulty with viewing on handheld devices and the least difficulty with viewing movies in the theater.

Besides the difference in the length of responses, the content of responses was more consistent in the crowdsourced dataset, indicated by the larger number of words shared between responses to the same clip. There were at least two major differences in the creation of the datasets that could have contributed: first, the crowdsourced responses were typed whereas the lab-sourced responses were spoken and then transcribed; and second, the lab-sourced population had a greater diversity, particularly in terms of age. Of the lab-sourced sample, 45% (27/60) was over 66 years, the age of the oldest crowdsourced participant. Examination of the words that appeared in one sample but not the other (Table 2) showed likely age-related vocabulary differences [27], such as “fella” in the lab-sourced sample and “cgi” in the crowdsourced sample. A more varied vocabulary in older participants would also explain the inverse relationship between age and shared word score in the lab-sourced dataset. However, as described in the results, a difference between the shared word scores of the datasets remained even when controlling for age. Whatever the cause, our results showed strong evidence for a more varied vocabulary in the lab-sourced dataset. However, despite this difference in word use, the shared word score differentiated within-clip responses from between-clip responses just as effectively when the lab-sourced normative dataset was used (panel A in Figure 3), so we saw no evidence that the scores, though lower on average, were less sensitive to semantic differences between the contents of clips.

Our comparison of crowdsourced and lab-sourced data collection focused on a specific type of natural language data, short descriptions of movie clips. One limitation is that, depending on the purpose of the data, responses may require different analysis techniques, which could increase the weight of the differences due to crowdsourcing that we found. For example, if responses are to be automatically scanned for a predefined list of keywords, then the increased probability of spelling errors when responses are typed could affect the results, as could the different vocabularies of the two populations. The fact that the two datasets differed both in their participant populations and in the manner of data input (typed or spoken) meant that differences could not be conclusively attributed to one or the other cause. However, our results show that neither difference led to a drastic change in the lengths or vocabulary of the responses. Another limitation is that we only report a simple method of scoring responses by counting the mean shared vocabulary with other responses to the same clip. Although this method had the best performance of the algorithms we evaluated [6], more sensitive methods of scoring responses might reveal more subtle differences between the datasets.

Data collection using Web-based crowdsourcing took only a fraction of the time it took us to recruit the target number of lab-sourced participants and was considerably less expensive, particularly when experimenter hours are taken into account. Including the time to identify, contact, and brief participants, we estimate an average of more than 3 hours per additional lab-sourced participant, compared to only a few minutes per additional crowdsourced participant. There is an investment of time and technical expertise to prepare a Mechanical Turk task, and data collection is not entirely automated, since it is necessary to review and approve submitted work and to answer worker queries [28]. There are also issues that arise that require time to resolve, such as one case we detected in a related study where an individual had set up two Mechanical Turk worker accounts (in violation of the website's terms of service). Apart from this incident, we found little evidence of cheating, and along with the quantitative evidence of quality of responses, our observation was that the majority of the workers took a conscientious and thoughtful approach to answering our query. Although we had a mechanism for blocking particular workers from our jobs, we did not need to use it and had to reject only a tiny percentage of submissions (no more than 10 in the course of collecting 4000 responses).

There were several factors that may have contributed to our success with Mechanical Turk, given the conditions of the American worker pool at the time of data collection, August and September 2011. We were careful to stay in communication with the worker population, by offering an email address that we monitored closely and by introducing ourselves and responding to posts on the "turkernation" forums [28]. This helped to build our reputation as trustworthy employers and alerted us to problems and potential improvements in the Mechanical Turk task during the data collection period. Our task involved watching clips from entertaining films, which may have helped us attract more workers, led to more return visits, and helped to ensure engagement throughout the task. The free-text format of the response also allowed for a limited amount of creativity and self-expression. Other researchers [29,30] have noted the importance of fun in designing tasks for Internet users who have many competing options for how to spend their time, and this remains important even with financial incentives. However, we also had good results with a less stimulating task, correcting automated transcripts of the spoken lab-sourced responses. In both cases, each job was relatively short, approximately 2 minutes including the time for the clip to play, and we checked work and awarded payments frequently, typically every weekday. For the video description task, we offered a small bonus for every 25 responses contributed, but we did not see reliable evidence that this motivated workers to complete more tasks (ie, there were not noticeable spikes in the histogram of number of responses completed by workers just after 25, 50, or 75). We restricted the listings to workers registered in the United States, which some investigators have suggested might improve average submission quality[24], and we reasoned that focusing on predominantly English-speaking countries could be particularly helpful for natural language data collection (at the time of data collection it was only possible to restrict the task to workers from a single country).

Based on our experience, when might crowdsourcing not be a suitable replacement for lab-based data collection? Unlike in the lab-based data collection, we did not have control over the sample demographics. It might be possible to address this within Mechanical Turk, for example by rejecting workers who do not meet certain criteria [11], but this poses additional challenges because of lack of representation of some demographics in the pool of workers (in particular, older and lower income) [14] and in the difficulty of verifying self-reported demographic information. Our results suggest it would be difficult to obtain a target number of responses from all workers, which would be necessary for a balanced within-subject design (although see [31] for an example of this being achieved). However, the use of a mixed-model analysis can compensate for the lack of equal combinations of conditions and stimuli for each worker. Although we overcame most of the technical challenges inherent in presenting video clips to workers via the Web, the heterogeneity of hardware and software configurations meant that a few workers still experienced problems with the video playback, ranging from stuttering to a refusal to play. It was clear, too, that the exact color, contrast, and visual angle of the video would vary between participants, which was acceptable for a task evaluating high-level vision such as ours but could pose problems when low-level control of the stimuli is necessary. Nevertheless, we have demonstrated that it is feasible to crowdsource not only questionnaires or static images, but also multimedia. Finally, we observed that workers do not always read instructions carefully or else do not adhere to all the details consistently, which could make crowdsourcing unsuitable for experiments where manipulation of the instructions is a critical part of the experiment. As an example, our instructions stated that information from the soundtrack of the video clip should not be used in the description, but auditory information (including dialogue) was mentioned in a number of responses. To ensure the instructions are read and comprehended, a short quiz, as was recommended by Crump, McDonnell, and Gureckis [31], could be used.

In conclusion, crowdsourcing is an effective way to obtain natural language data quickly and inexpensively, both for collecting normative datasets and for conducting experiments. With respect to the concerns raised by the APA Board of Scientific Affairs [14], we found that using the crowdsourcing methodology we chose, the population sample resembled the population of the United States in several key demographic factors and that responses were of a high quality. Crowdsourcing can provide a valuable complement to more narrowly-targeted traditional recruiting and data collection methods and even substitute for them in some studies.

Acknowledgments

Supported by grant R01EY019100 from the National Eye Institute. All research received ethics approval from the Massachusetts Eye and Ear Infirmary Human Subjects Committee. We thank Rachel Berkowitz for preparing the video clips and Dylan Rose for collecting the lab-sourced data.

Conflicts of Interest

The method used in this paper for scoring natural language responses relative to a normative dataset is part of a provisional patent naming the 3 authors and submitted by Massachusetts Eye and Ear Infirmary.

References

1. Swan M. Crowdsourced health research studies: An important emerging complement to clinical trials in the public health research ecosystem. J Med Internet Res 2012;14(2):e46 [FREE Full text] [doi: 10.2196/jmir.1988] [Medline: 22397809]
2. Tung JY, Do CB, Hinds DA, Kiefer AK, Macpherson JM, Chowdry AB, et al. Efficient replication of over 180 genetic associations with self-reported medical data. PLoS One 2011;6(8):e23473 [FREE Full text] [doi: 10.1371/journal.pone.0023473] [Medline: 21858135]
3. Duchaine BC, Nakayama K. Developmental prosopagnosia: A window to content-specific face processing. Curr Opin Neurobiol 2006 Apr;16(2):166-173. [doi: 10.1016/j.conb.2006.03.003] [Medline: 16563738]
4. Frost J, Okun S, Vaughan T, Heywood J, Wicks P. Patient-reported outcomes as a source of evidence in off-label prescribing: Analysis of data from PatientsLikeMe. J Med Internet Res 2011;13(1):e6 [FREE Full text] [doi: 10.2196/jmir.1643] [Medline: 21252034]
5. Turner AM, Kirchhoff K, Capurro D. Using crowdsourcing technology for testing multilingual public health promotion materials. J Med Internet Res 2012;14(3):e79 [FREE Full text] [doi: 10.2196/jmir.2063] [Medline: 22664384]
6. Saunders DR, Bex PJ, Rose DJ, Woods RL. Measuring information acquisition from sensory input using automated scoring of natural-language descriptions. Manuscript submitted for publication 2013 (forthcoming).
7. Howe J. The rise of crowdsourcing. Wired Magazine 2006 Jun;14.
8. Marge M, Banerjee S, Rudnicky AI. Using the Amazon Mechanical Turk for transcription of spoken language. 2010 Presented at: IEEE Conference on Acoustics, Speech and Signal Processing; March 25-30, 2010; Dallas, TX p. 14-19. [doi: 10.1109/icassp.2010.5494979]
9. Snow R, O'Connor B, Jurafsky D, Ng AY. Cheap and fast - but is it good? Evaluating non-expert annotations for natural language tasks. 2008 Presented at: Conference on Empirical Methods in Natural Language Processing; Oct. 25-27, 2008; Honolulu, Hawaii.
10. Alonso O, Mizzaro S. Can we get rid of TREC assessors? Using Mechanical Turk for relevance assessment. 2009 Presented at: SIGIR 2009 Workshop on the Future of IR Evaluation; July 23, 2009; Boston, MA.
11. Paolacci G, Chandler J, Ipeirotis PG. Running experiments on Amazon Mechanical Turk. Judg Dec Mak 2010;5(5):411-419.
12. Behrend TS, Sharek DJ, Meade AW, Wiebe EN. The viability of crowdsourcing for survey research. Behav Res Methods 2011 Sep;43(3):800-813. [doi: 10.3758/s13428-011-0081-0] [Medline: 21437749]
13. Nosek BA, Banaji MR, Greenwald AG. E-Research: Ethics, security, design, and control in psychological research on the Internet. J Soc Issues 2002;58(1):161-176. [doi: 10.1111/1540-4560.00254]
14. Kraut R, Olson J, Banaji M, Bruckman A, Cohen J, Couper M. Psychological research online: Report of Board of Scientific Affairs' Advisory Group on the Conduct of Research on the Internet. Am Psychol 2004;59(2):105-117. [doi: 10.1037/0003-066X.59.2.105] [Medline: 14992637]
15. Nasreddine ZS, Phillips NA, Bédirian V, Charbonneau S, Whitehead V, Collin I, et al. The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. J Am Geriatr Soc 2005 Apr;53(4):695-699. [doi: 10.1111/j.1532-5415.2005.53221.x] [Medline: 15817019]
16. Cutting JE, DeLong JE, Nothelfer CE. Attention and the evolution of Hollywood film. Psychol Sci 2010 Mar;21(3):432-439. [doi: 10.1177/0956797610361679] [Medline: 20424081]
17. Brainard DH. The Psychophysics Toolbox. Spat Vis 1997;10(4):433-436. [Medline: 9176952]
18. Zeimpekis D, Gallopoulos E. Design of a MATLAB toolbox for term-document matrix generation. : SIAM; 2005 Presented at: Workshop on Clustering High Dimensional Data and its Applications; April 20-23, 2005; Newport Beach, CA p. 38-48.
19. U.S. Census Bureau. Age and Sex Composition 2010. 2011. URL: http://www.census.gov/prod/cen2010/briefs/c2010br-03.pdf [accessed 2013-03-14] [WebCite Cache ID 6F7WG1fqR]
20. U.S. Census Bureau. Overview of Race and Hispanic Origin 2010. 2011. URL: http://www.census.gov/prod/cen2010/briefs/c2010br-02.pdf [accessed 2013-03-14] [WebCite Cache ID 6F7WpfJsj]
21. U.S. Census Bureau. Educational Attainment of the Population 18 Years and Over, by Age, Sex, Race, and Hispanic Origin 2011. 2012. URL: http://www.census.gov/hhes/socdemo/education/data/cps/2011/tables.html [accessed 2013-03-14] [WebCite Cache ID 6F7WeVZUT]
22. Ross J, Irani L, Silberman M, Zaldivar A, Tomlinson B. Who are the crowdworkers? Shifting demographics in Mechanical Turk. 2010 Presented at: ACM SIGCHI Conference on Human Factors in Computing Systems; April 10-15, 2010; Atlanta, GA.
23. Janssen DP. Twice random, once mixed: Applying mixed models to simultaneously analyze random effects of language and participants. Behav Res Methods 2012 Mar;44(1):232-247. [doi: 10.3758/s13428-011-0145-1] [Medline: 21858733]

24. Zhai H, Lingren T, Deleger L, Li Q, Kaiser M, Stoutenborough L, et al. Web 2.0-based crowdsourcing for high-quality gold standard development in clinical natural language processing. J Med Internet Res 2013;15(4):e73 [FREE Full text] [doi: 10.2196/jmir.2426] [Medline: 23548263]
25. Saunders DR, Bex PJ, Woods RL. A novel, objective measure of information acquisition from video is correlated with blur. 2012 Presented at: The Association for Research in Vision and Ophthalmology Annual Meeting; May 6-10, 2012; Fort Lauderdale, FL.
26. Woods RL, Satgunam P. Television, computer and portable display device use by people with central vision impairment. Ophthalmic Physiol Opt 2011 May;31(3):258-274 [FREE Full text] [doi: 10.1111/j.1475-1313.2011.00833.x] [Medline: 21410501]
27. Griffin ZM, Spieler DH. Observing the what and when of language production for different age groups by monitoring speakers' eye movements. Brain Lang 2006 Dec;99(3):272-288. [doi: 10.1016/j.bandl.2005.08.003] [Medline: 16290041]
28. Mason W, Suri S. Conducting behavioral research on Amazon's Mechanical Turk. Behav Res Methods 2012 Mar;44(1):1-23. [doi: 10.3758/s13428-011-0124-6] [Medline: 21717266]
29. Von Ahn L. Games with a purpose. Computer 2006;39(6):92-94.
30. Luengo-Oroz MA, Arranz A, Frean J. Crowdsourcing malaria parasite quantification: An online game for analyzing images of infected thick blood smears. J Med Internet Res 2012;14(6):e167 [FREE Full text] [doi: 10.2196/jmir.2338] [Medline: 23196001]
31. Crump MJ, McDonnell JV, Gureckis TM. Evaluating Amazon's Mechanical Turk as a tool for experimental behavioral research. PLoS One 2013;8(3):e57410 [FREE Full text] [doi: 10.1371/journal.pone.0057410] [Medline: 23516406]

Edited by G Eysenbach; submitted 18.03.13; peer-reviewed by Q Zhang; comments to author 11.04.13; revised version received 25.04.13; accepted 25.04.13; published 20.05.13.

Please cite as:
Saunders DR, Bex PJ, Woods RL
Crowdsourcing a Normative Natural Language Dataset: A Comparison of Amazon Mechanical Turk and In-Lab Data Collection
J Med Internet Res 2013;15(5):e100
URL: http://www.jmir.org/2013/5/e100/
doi:10.2196/jmir.2620
PMID:23689038

Original Paper

Online Social Network Use by Health Care Providers in a High Traffic Patient Care Environment

Erik Black[1], PhD; Jennifer Light[1], MD; Nicole Paradise Black[1], MD, MEd; Lindsay Thompson[1], MD, MS

[1]University of Florida, Gainesville, FL, United States

Corresponding Author:
Erik Black, PhD
University of Florida
1701 SW 16th Ave #2113
Gainesville, FL,
United States
Phone: 1 352 334 1340
Fax: 1 352 334 0245
Email: ewblack@peds.ufl.edu

Abstract

Background: The majority of workers, regardless of age or occupational status, report engaging in personal Internet use in the workplace. There is little understanding of the impact that personal Internet use may have on patient care in acute clinical settings.

Objective: The objective of this study was to investigate the volume of one form of personal Internet use—online social networking (Facebook)—generated by workstations in the emergency department (ED) in contrast to measures of clinical volume and severity.

Methods: The research team analyzed anonymous network utilization records for 68 workstations located in the emergency medicine department within one academic medical center for 15 consecutive days (12/29/2009 to 1/12/2010). This data was compared to ED work index (EDWIN) data derived by the hospital information systems.

Results: Health care workers spent an accumulated 4349 minutes (72.5 hours) browsing Facebook, staff cumulatively visited Facebook 9369 times and spent, on average, 12.0 minutes per hour browsing Facebook. There was a statistically significant difference in the time spent on Facebook according to time of day (19.8 minutes per hour versus 4.3 minutes per hour, $P<.001$). There was a significant, positive correlation between EDWIN scores and time spent on Facebook ($r=.266$, $P<.001$).

Conclusions: Facebook use constituted a substantive percentage of staff time during the 15-day observation period. Facebook use increased with increased patient volume and severity within the ED.

(J Med Internet Res 2013;15(5):e94) doi:10.2196/jmir.2421

KEYWORDS

social networking; emergency medicine; Internet

Introduction

There is an ever-increasing amount and diversity of online recreational opportunities available to Internet users, including online videogames, gambling, and social networking sites such as Facebook. Previous research has indicated that a majority of workers, regardless of age or occupational status, report engaging in personal Internet use in the workplace and misuse, such as this personal Internet use during work hours as well as more serious actions such as illegal downloading, accessing unauthorized information, and interpersonal aggression via email or other online communications, is increasingly prevalent [1-3]. Less is known about Internet use and misuse in medical settings and the potential impact on patient care.

Research by Morris-Docker et al showed that health professionals in patient care settings access the Internet during quiet periods throughout day and night for both work and non-work related activities without interfering with patient care or workload [4]. Since this study has been conducted, the Internet and the manner in which it is used has changed dramatically, particularly with the increased prevalence of social networking applications and websites and the prevalence of handheld access to the Internet. In this complex and rapidly developing technology landscape, online social networking applications have emerged as the significant Internet traffic destination. Previous research has established that health care professionals regularly use social networking applications to create and maintain relationships with friends, family, and coworkers [5-10]. While no known empirical study of social network use during clinical work hours has been conducted, studies of non-clinical workplace behavior and misbehavior have been a cornerstone of organizational behavior research [11].

Anecdotal evidence implied that Internet use, especially that associated with online social networking sites (such as Facebook), was common among individuals working in a level 4 trauma center and emergency department (ED) at an academic medical center in the Southeastern United States. Given Facebook's increase in membership, coupled with the opportunity for access to the Internet on hospital workstations, this study aimed to investigate the volume of Facebook traffic generated by workstations in the ED in contrast to measures of its clinical volume and severity.

Methods

Sample Computers

The Institutional Review Board at the University of Florida approved this study. We analyzed network utilization records for 68 workstations located in the ED within one medical center for 15 consecutive days (12/29/2009 to 1/12/2010). These records were anonymous and no user information was available such as job description (physicians, resident, non-physician extender, nurse, clerical, or other staff) or personal demographics. The workstations were all Internet accessible and did not restrict access to popular social networking destinations (including Facebook), and all were located in open physician and staff workspaces within the ED. Workstations associated with designated break rooms were excluded from the study.

Utilization and Volume/Severity Calculations

To calculate Facebook use, network utilization records for each workstation were obtained from the academic medical center's SurfControl Web filtering software, which allows information technology administrators to categorize, track, and potentially limit user access to websites. SurfControl data yielded cumulative Facebook time from selected computers in one second increments. To control for instances in which an individual may have logged onto Facebook and then left the computer idle, SurfControl browse sensitivity was set at a maximum of 3 continuous minutes which roughly equates to the length of time a user is presumably actively engaged with a site. This conservatively takes into account "multi-tasking", or being emergently needed in a different location, instead of counting the entire amount of time a webpage is open, which would likely over-estimate actual use. However, any true engagement with a webpage will only be counted as 3 minutes even if longer. To calculate how busy the ED was during the study, hourly ED work index (EDWIN) scores were calculated according to ED patient volume reports. An EDWIN score is a valid and reliable index that quantifies both the value and severity of ED admissions [12]. EDWIN is calculated using the following formula: $n(i)t(i)/N(a)[B(T)-B(A)]$, where $n(i)$ = the number of patients in the ED in triage category, $t(i)$ = triage category, $N(a)$ = number of attending physicians on duty, $B(T)$ = number of treatment bays, and $B(A)$ = number of admitted patients in the ED. The triage system recommended, the emergency severity index (ESI), was modified by reversing the ranking of triage categories; that is, an ESI score of 1 represented the least acute patient and 5 the most acute [13]. Data were analyzed using IBM SPSS PASW v.20, and included descriptive statistics and analysis of variance procedures with a $P<.05$ as considered significant.

Results

In a 15-day period, health care workers spent an accumulated 4349 minutes (72.5 hours) browsing Facebook on workstations in one ED. ED staff cumulatively visited 9369 Facebook pages and spent, on average, 12.0 minutes per hour browsing Facebook.

There was a statistically significant difference in the amount of time spent on Facebook according to time of day. During the night shift, (7pm-7am), workers cumulatively spent an average of 19.8 minutes per hour browsing Facebook, yet during the day shift (7am-7pm) workers cumulatively spent an average of 4.3 minutes per hour browsing Facebook ($P<.001$). Of note, the ED was busiest during night shift hours (7pm-7am), with mean EDWIN ratings at 0.51 during night shifts versus 0.29 during day ($P<.001$). Importantly, there was a significant, positive correlation between EDWIN scores and time spent on Facebook ($r=.266$, $P<.001$), indicating that as the ED became busier, more time was spent browsing Facebook. (See Figure 1). The relationship between ED business and time on Facebook became more pronounced when averaged across the 15-day period ($r=.757$, $P<.001$, Figure 2).

Figure 1. The relationship between Facebook use and ED business.

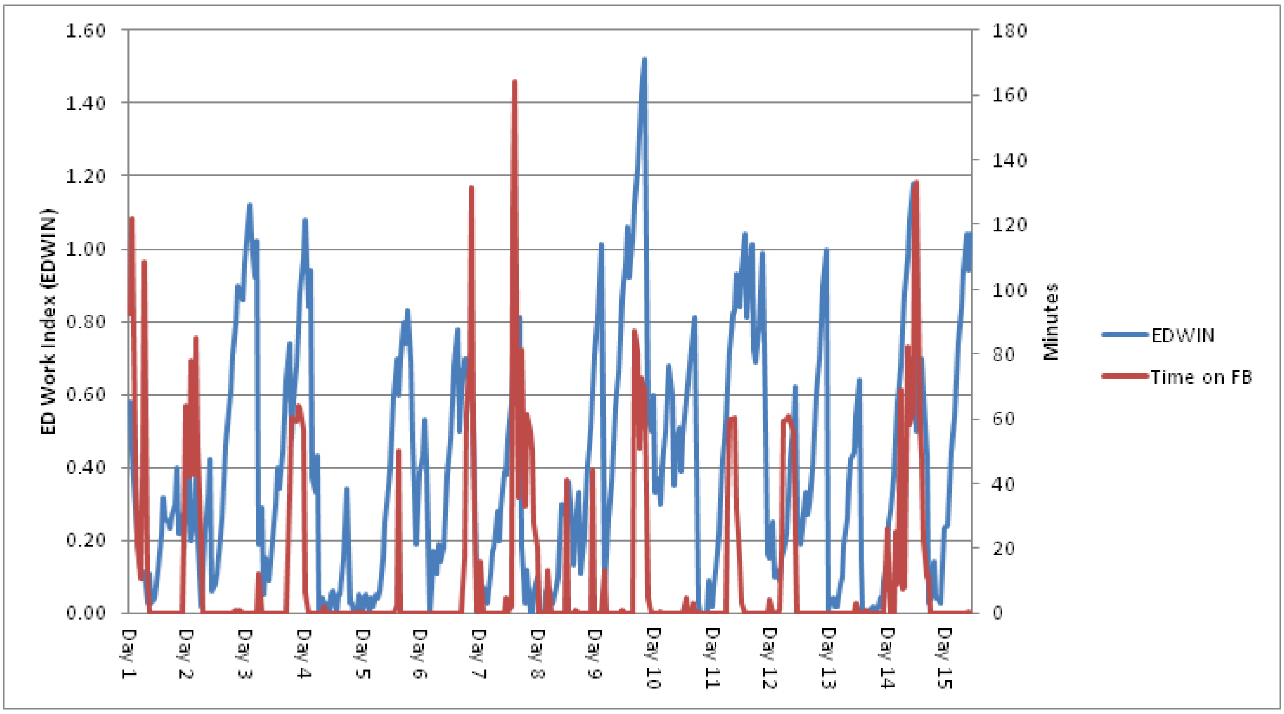
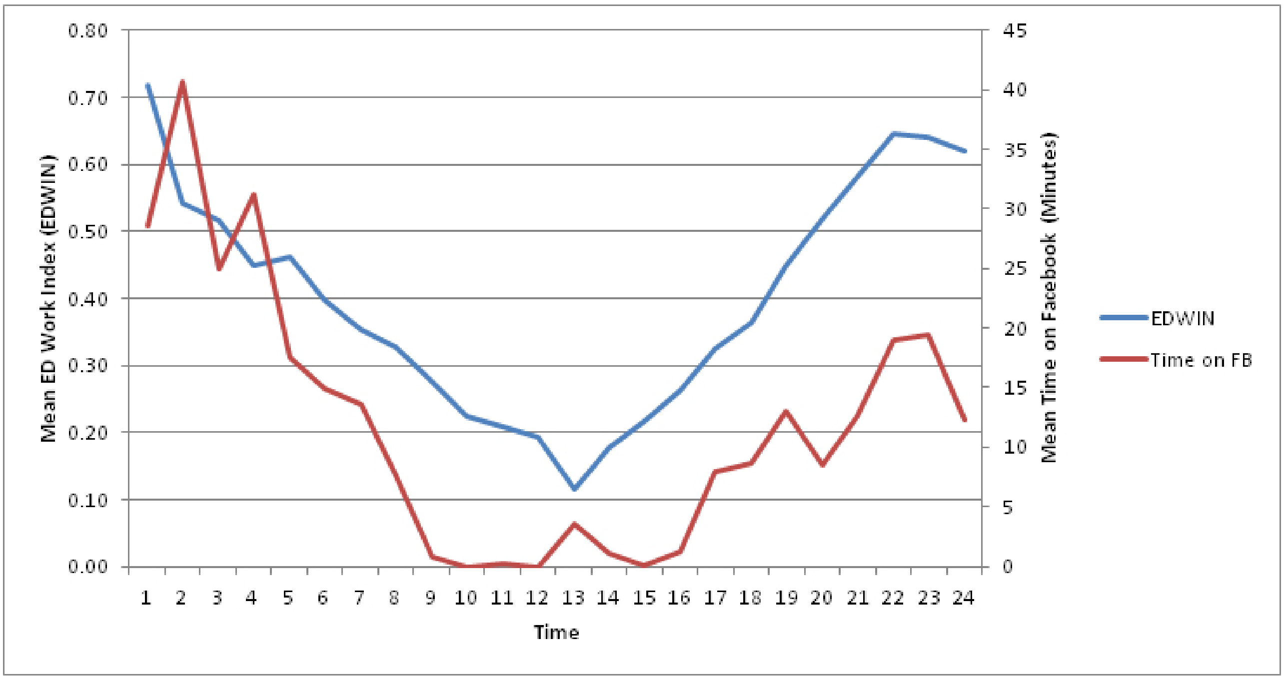


Figure 2. Average time on Facebook and average ED business across 24 hours.



Discussion

Principal Findings

Facebook use constituted a substantive percentage of staff time during the 15-day observation period, and Facebook use increased with increased patient volume and severity within the ED. It is understood that the near ubiquity of online entertainment, including social networking applications, can influence productivity, and, to the best of our knowledge, this study represented the first investigation of online social network use in an acute patient setting [2]. The results of the study provided evidence that social network use in the ED is common, which was expected, but also that it increased as patient volumes and acuity increased, which was unexpected. This unanticipated finding warrants further investigation since increased patient volume and acuity seemed to prompt health care workers to seek distractions or opportunities for cognitive time-outs, which is something that social networks provide. It is possible that these time-outs lead to improved worker functioning, but of more concern is that it may also represent a compromise of patient care. It could be argued that workers need to have the autonomy and authority to take breaks and relax while on the job. This notion is supported by research by Greenfield et al and Reinecke who found that engaging in brief tasks unrelated to work may have positive effects on worker fatigue and stress, yet promote increased worker productivity and happiness [14,15]. However, in specific care environments, such as EDs, individual, organizational, and environmental factors interact in a complex manner that could specifically impact patient health outcomes [16]. Future studies should examine if in acute environments, access to applications like Facebook should be relegated to break rooms or other designated spaces for non-work functions. While such a study would not and could not control access to online applications using mobile or cellular devices, which increasingly account for increasing amounts of traffic to social networking and other sites, it could send a message to health care workers that judicious use of accessing Internet sites is important for high quality care [17].

Limitations

There are several limitations associated with this study that are worth noting. While the results indicated a significant amount of time was spent accessing Facebook, especially during times of increased patient acuity and volume, the study had no comparison to other non-Internet, non-clinical activities that staff may engage in during clinical shifts. Data collected from this study does not account for Internet use from personal mobile devices such as cell phones, where it is estimated that approximately 40% access the Internet or email [16]. Finally, Internet use of other Internet sites was not presented.

Conclusions

Online social networking is an important and worthwhile activity to engage friends, family, and acquaintances, but as with other distractions, electronic or not, should be used cautiously in the workplace. It is our opinion that this level of Facebook use is unacceptably high in clinical spaces, and as such, computer workstations in patient-care space should limit access to online social networking and other forms of entertainment. Such limitations could be externally enforced through Web filters, such as SurfControl. However, internal regulation, such as encouraged by simple reminders like screensaver reminding staff about appropriate use during business hours, may better limit misuse. Given that many individuals now access online entertainment applications via mobile phones, the development and implementation of a comprehensive workplace Internet use policy, one that includes the use of personal mobile devices, should be considered.

Conflicts of Interest

None declared.

Multimedia Appendix 1

The relationship between Facebook use and ED business (with SD).

[JPG File, 132KB - jmir_v15i5e94_app1.jpg]

References

1. Garrett RK, Danziger JN. On cyberslacking: workplace status and personal internet use at work. Cyberpsychol Behav 2008 Jun;11(3):287-292. [doi: 10.1089/cpb.2007.0146] [Medline: 18537498]
2. Vitak J, Crouse J, LaRose R. Personal Internet use at work: understanding cyberslacking. Computers in Human Behavior 2011 Sep;27(5):1751-1759. [doi: 10.1016/j.chb.2011.03.002]
3. Weatherbee TG. Counterproductive use of technology at work: information & communications technologies and cyberdeviancy. Human Resource Management Review 2010 Mar;20(1):35-44. [doi: 10.1016/j.hrmr.2009.03.012]
4. Morris-Docker SB, Tod A, Harrison JM, Wolstenholme D, Black R. Nurses' use of the Internet in clinical ward settings. J Adv Nurs 2004 Oct;48(2):157-166. [doi: 10.1111/j.1365-2648.2004.03183.x] [Medline: 15369496]
5. Black EW, Thompson LA, Duff WP, Dawson KD, Saliba HS, Black NM. Revisiting social network utilization by physicians-in-training. J Grad Med Educ 2010 Jun;2(2):289-293 [FREE Full text] [doi: 10.4300/JGME-D-10-00011.1] [Medline: 21975635]
6. Chretien KC, Greysen SR, Chretien JP, Kind T. Online posting of unprofessional content by medical students. JAMA 2009 Sep 23;302(12):1309-1315. [doi: 10.1001/jama.2009.1387] [Medline: 19773566]
7. Cain J, Scott DR, Akers P. Pharmacy students' Facebook activity and opinions regarding accountability and e-professionalism. Am J Pharm Educ 2009 Oct 1;73(6):104 [FREE Full text] [Medline: 19885073]
8. Thompson LA, Dawson K, Ferdig R, Black EW, Boyer J, Coutts J, et al. The intersection of online social networking with medical professionalism. J Gen Intern Med 2008 Jul;23(7):954-957 [FREE Full text] [doi: 10.1007/s11606-008-0538-8] [Medline: 18612723]
9. Skiba D. Nursing education 2.0: Poke me. Where's your face in space? Nurs Educ Perspect 2007;28(4):214-216. [Medline: 17715807]
10. Ferdig RE, Dawson K, Black EW, Paradise-Black NM, Thompson LA. Medical students' and residents' use of online social networking tools: Implications for teaching professionalism in medical education. First Monday 2008;13(9):1-11 [FREE Full text] [doi: 10.5210/fm.v13i9.2161]

11. Richards J. The many approaches to organisational misbehaviour: a review, map and research agenda. Employee Relations 2008 2008;30(6):653-678. [doi: 10.1108/01425450810910046]
12. McCarthy ML, Aronsky D, Jones ID, Miner JR, Band RA, Baren JM, et al. The emergency department occupancy rate: a simple measure of emergency department crowding? Ann Emerg Med 2008 Jan;51(1):15-24, 24.e1. [doi: 10.1016/j.annemergmed.2007.09.003] [Medline: 17980458]
13. Bernstein SL, Verghese V, Leung W, Lunney AT, Perez I. Development and validation of a new index to measure emergency department crowding. Acad Emerg Med 2003 Sep;10(9):938-942. [Medline: 12957975]
14. Greenfield DN, Davis RA. Lost in cyberspace: the web @ work. Cyberpsychol Behav 2002 Aug;5(4):347-353. [Medline: 12216699]
15. Reinecke L. Games at work: the recreational use of computer games during working hours. Cyberpsychol Behav 2009 Aug;12(4):461-465. [doi: 10.1089/cpb.2009.0010] [Medline: 19619038]
16. Schaefer HG, Helmreich RL, Scheidegger D. Human factors and safety in emergency medicine. Resuscitation 1994 Dec;28(3):221-225. [Medline: 7740192]
17. Smith A. Pew Internet & American Life Project. Washington, DC; 2010 Jul 7. Mobile access 2010 URL: http://www.pewinternet.org/Reports/2010/Mobile-Access-2010.aspx [accessed 2013-04-24] [WebCite Cache ID 6G7oAmKVS]

Abbreviations

ED: emergency department
EDWIN: emergency department work index
ESI: emergency severity index

Edited by G Eysenbach; submitted 02.11.12; peer-reviewed by R Van Deusen; comments to author 24.01.13; revised version received 20.03.13; accepted 28.03.13; published 17.05.13.

Please cite as:
Black E, Light J, Paradise Black N, Thompson L
Online Social Network Use by Health Care Providers in a High Traffic Patient Care Environment
J Med Internet Res 2013;15(5):e94
URL: http://www.jmir.org/2013/5/e94/
doi:10.2196/jmir.2421
PMID:23685530

Original Paper

Predictors of Participant Retention in a Guided Online Self-Help Program for University Students: Prospective Cohort Study

Magdalena Wojtowicz[1], BSc (Hons); Victor Day[2], PhD; Patrick J McGrath[3,4], OC, PhD, FRSC

[1]Department of Psychology and Neuroscience, Dalhousie University, Halifax, NS, Canada

[2]Dalhousie Counselling Centre, Dalhousie University, Halifax, NS, Canada

[3]Department of Psychology and Neuroscience, Psychiatry, & Pediatrics, Dalhousie University, Halifax, NS, Canada

[4]IWK Health Centre, Halifax, NS, Canada

Corresponding Author:
Magdalena Wojtowicz, BSc (Hons)
Department of Psychology and Neuroscience
Dalhousie University
1355 Oxford Street, Life Sciences Centre
Halifax, NS, B3H 4J1
Canada
Phone: 1 902 473 2581
Fax: 1 902 473 4873
Email: m.wojtowicz@dal.ca

Abstract

Background: Attrition is a persistent issue in online self-help programs, but limited research is available on reasons for attrition or successful methods for improving participant retention. One potential approach to understanding attrition and retention in such programs is to examine person-related variables (eg, beliefs and attitudes) that influence behavior. Theoretical models, such as the Theory of Planned Behavior, that describe conditions influencing human behavior may provide a useful framework for predicting participant retention in online-based program.

Objective: We examined predictors of participant retention in a guided online anxiety, depression, and stress self-help program for university students using the theory of planned behavior. We also explored whether age, symptom severity, and type of coaching (ie, email vs phone) affected participant retention.

Methods: 65 university students with mild to moderate depression, anxiety, and stress were enrolled in this prospective cohort study. Participants completed a questionnaire based on the theory of planned behavior prior to commencing the online-based program and the Depression Anxiety and Stress Scale (DASS) during the assessment module of the program. Participant retention was operationalized as the number of program modules completed.

Results: Perceived control over completing the online program significantly predicted intention to complete the program ($F_{3,62}$=6.7; P=.001; adjusted R^2=.2; standardized beta=.436, P=.001). Age (standardized beta=.319, P=.03) and perceived behavioral control (standardized beta=.295, P=.05) predicted the number of program modules completed ($F_{3,61}$=3.20, P=.03, adjusted R^2 =.11). Initial level of distress (ie, symptom severity) did not predict participant retention (P=.55). Participants who chose phone-based coaching completed more program modules than participants who chose email-based coaching (Mann-Whitney's U=137; P=.004).

Conclusions: Participants' age, level of perceived behavioral control, and choice of interaction (ie, phone-based or email-based coaching) were found to influence retention in this online-based program.

(J Med Internet Res 2013;15(5):e96) doi:10.2196/jmir.2323

KEYWORDS

self-help; online treatment; Web-based; retention; dropouts; theory of planned behavior

Introduction

Online self-help programs designed to assist individuals with mental health concerns have been demonstrated to be effective at improving mental health outcomes [1,2]. Despite the noted efficacy of such programs, participant dropout is a persistent issue, with reported attrition rates reaching between 50-83% [3-5]. Few studies have formally investigated factors contributing to participant attrition from Internet-based programs, yet such research would provide crucial information towards improving participant retention and, therefore, improve mental health outcomes.

There is currently little known about successful approaches for improving retention in online programs. Studies using guided Internet programs (eg, coach-assisted) have reported relatively lower dropout rates compared to unguided programs (eg, [6]). However, direct comparisons of retention in guided and unguided programs are currently not available. One recent pilot study evaluated whether the addition of a program coach would increase participation in an online program for promoting self-management in bipolar disorder [7]. The authors found that participants who were given an online coach were more likely to return to the program after registration (71% initial retention) and continue in the program after 3 weeks (38% retention) compared to participants without a program coach (44% and 9% retention, respectively) [7]. Some studies have also investigated the use of phone support in improving participant retention. Kenwright and colleagues found that participants who received phone support during a computer-guided self-help program for obsessive-compulsive disorder were less likely to drop out than those who did not receive phone support [8]. In contrast, Anderson and colleagues did not observe a decrease in dropout rates from participants receiving weekly telephone calls compared to those who received only the online-based program [9]. However, some research suggests that receiving reminders, regardless of the type (eg, phone, in person, postcard), has a positive effect on increasing retention [10,11].

There is limited research available on predictors of attrition from online programs. The few studies examining this issue have focused primarily on sociodemographic factors (eg, age, sex, years of education), disorder characteristics (eg, symptom severity and duration), and/or treatment-related variables (eg, treatment setting) [4,12-15]. To date, discrepant relationships have been reported between all of these variables and attrition, with the exception of the symptom severity [4]. Studies exploring the influence of symptom severity on dropout rates have found that individuals with less severe difficulties were more likely to drop out of online-based programs [12-14]. These findings suggest that individuals with less severe distress may be either less motivated or may benefit less from treatment and, therefore, be more likely to drop out. Although this research provides some insight into reasons for participant dropout, further research is necessary to better understand factors contributing to participant attrition and retention.

An alternative approach to understanding attrition is to examine person-related factors (eg, beliefs, attitudes) that influence the behavior. One theory that attempts to identify predictors of behavior is the Theory of Planned Behavior [16,17]. This theory stipulates a person's (1) attitudes towards the behavior, (2) subjective normative beliefs (ie, perception of what other people think about the behavior and how much they are influenced by others' beliefs), and (3) perceived behavioral control (ie, how much control they believe they have over completing the behavior) drive the person's intention to complete the behavior. Intention and perceived behavioral control, in turn, predict the likelihood the person will engage in the behavior. The theory of planned behavior has been used extensively to investigate and predict changes in health behaviors, including increasing physical activity, reducing risk-taking behavior (eg, speeding, drinking alcohol, using drugs), and dietary changes [18,19]. This theory may provide a useful framework for investigating person-related factors that influence retention in online-based self-help programs.

The present study aimed to investigate predictors of participant retention using the theory of planned behavior. We prospectively examined how participants' attitudes, subjective normative beliefs, and perceived behavior control predict intention to complete a guided online anxiety, depression, and stress self-help program for university students. We then examined whether intention and perceived behavior control successfully predict participant retention in the program. Finally, given the literature examining sociodemographic, disorder characteristics, and treatment-related variables on attrition, we explored whether age, symptom severity, and type of coaching (ie, email vs phone) affected participant retention.

Methods

Participants and Recruitment

Participants were recruited from Dalhousie University, the University of King's College, and Nova Scotia College of Art and Design, in Halifax, Canada. Recruitment for the study began in 2010. Participants were recruited primarily via emails, advertisements in a campus newspaper, and recruitment posters. Interested individuals contacted the primary program coach through email and were provided with information regarding the study. The study protocol was initially presented to participants on the website's consent form page. Interested participants signed up for the program online and received a phone call from the primary program coach, who reviewed the consent form with the participant and assessed their eligibility for the study. Participants who provided verbal and written informed consented and met study criteria were included in the study.

All participants provided informed consent following procedures approved by the Dalhousie University Research Ethics Board. Eligible participants met the following criteria: (1) experiencing mild to moderate levels of anxiety, depression, or stress, (2) not experiencing suicidal thoughts, (3) not experiencing symptoms of bipolar disorder, an eating disorder, an addiction, or psychosis, and (4) not receiving psychological counseling. Eligibility for the study was assessed through a phone conversation with the participant and the program coach. In total, 68 university students attending the aforementioned postsecondary institutes were assessed for eligibility. Three were excluded due to not meeting eligibility criteria (ie, decided to seek personal counseling), and 65 were enrolled to participate in the study. From this sample, 48 subjects were also participants in a controlled clinical trial of the online self-help program, and for this reason, 24 participants experienced a 6-week delay in accessing the program due to being randomly assigned to a delayed access control condition. However, all participants, regardless of assignment, completed all measures (ie, the Theory of Planned Behavior Questionnaire and Depression Anxiety Stress Scale-21) immediately prior to commencing the program (see Figure 1).

Measures

Theory of Planned Behavior Questionnaire

The Theory of Planned Behavior Questionnaire (see Multimedia Appendix 1) is a brief 10-item questionnaire designed to quantitatively measure participants' attitudes, subjective normative beliefs, perceived behavioral control, and intention to complete the guided online self-help program. This questionnaire was developed using guidelines outlined by Fishbein & Ajzen [20] and Francis and colleagues [21].

Depression Anxiety Stress Scale-21 (DASS-21)

The DASS-21 [22] is an abbreviated version of the original 42-item DASS. It is composed of three 7-item subscales measuring symptoms of depression, anxiety, and stress. Participants are asked to rate the degree to which they endorse each item on a 4-point Likert scale. The DASS-21 has been found to be a valid measure of depression, anxiety, and stress [23].

Study Design

All participants who met eligibility criteria and provided written consent were asked to complete the Theory of Planned Behavior Questionnaire via email prior to commencing the guided online self-help program. For participants who received immediate access to the program, the questionnaire was collected immediately prior to beginning the program modules. Participants who were given delayed access to the program, as part of the randomized control trial, completed the questionnaire 6-weeks post assignment (ie, immediately prior to beginning the program modules). Hence all participants completed the questionnaire immediately prior to commencing the program. The DASS-21 was completed as part of the Introduction and Assessment Module. Delayed access participants completed the DASS-21 for a second time (6-weeks post assignment) as part of the first module (ie, Introduction and Assessment Module).

Online Self-Help Program

This is a cognitive-behavior therapy-oriented online self-help program developed at Dalhousie University to assist students experiencing mild to moderate anxiety, depression, and stress. It consists of 5 core modules (Introduction and Assessment, Activity and Mood, Motivation, Thoughts and Feelings, and Advanced Thoughts and Feelings; see Table 1 for description of each module). Each module is organized in a workbook format that includes psychoeducation, real-life examples, videos, and activities (see Figure 2). This program has been demonstrated to reduce self-reported symptoms in depression, anxiety, and stress in participants who complete the program compared with wait-list controls [24].

Program Coaches

Participants were assigned to a program coach (ie, a trained graduate or undergraduate student), who contacted them via telephone or email (based on the participants' preference) on a weekly basis. On average, contact with a coach involved one phone call or one email a week. Phone calls were on average 15-20 minutes in duration, while emails were on average 250-500 words in length. Participants were informed during the consent process that the program coaches were not professional counselors. Program coaches did not function as individual therapists; rather, they provided motivational support to participants and clarified information contained within the program. Coaches also monitored participant progress and reviewed activities completed by participants to ensure the correct applications of the techniques.

Program coaches were trained on the online self-help program by the primary investigator, Dr. Victor Day, as well as the head program coach. The majority of the training involved reviewing the online program materials in order to adequately address participant questions and provide assistance with module activities, when necessary. Program coaches were supervised by the head program coach and the primary investigator in order to assure fidelity to the coaching model.

Data Analysis

The data were analyzed using the statistical software package SPSS 17.0. A planned multiple regression was conducted to investigate whether participants' attitudes, subjective normative beliefs, and perceived behavioral control predicted their intention to complete the online-based program. A planned hierarchical regression was conducted to investigate whether intention, perceived behavioral control, and age predicted participant retention (ie, the number of modules completed). These analyses were conducted in accordance to the methods utilized by Azjen [16,17], Fishbein & Ajzen [20], and those outlined by Francis and colleagues [21]. Nonparametric Mann-Whitney tests were used to investigate differences between immediate and delayed access participants as well as participants who chose phone-based or email-based coach contact.

Figure 1. Flowchart of participant recruitment.

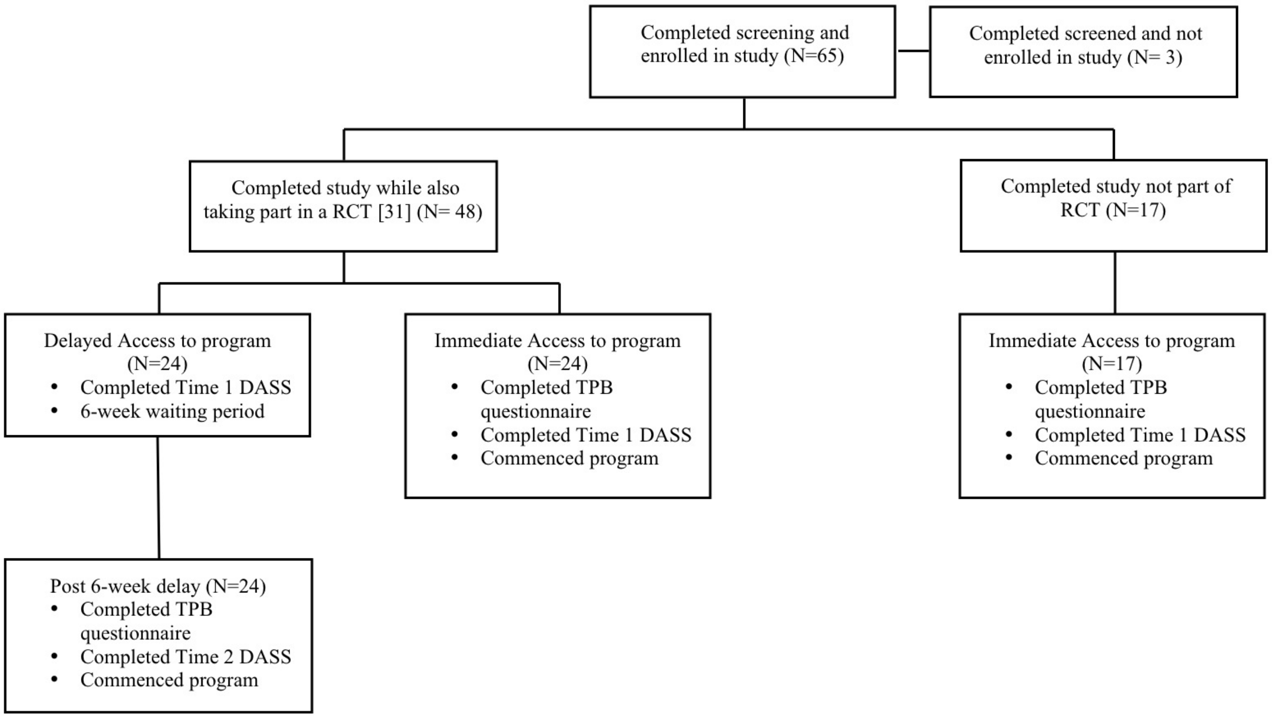
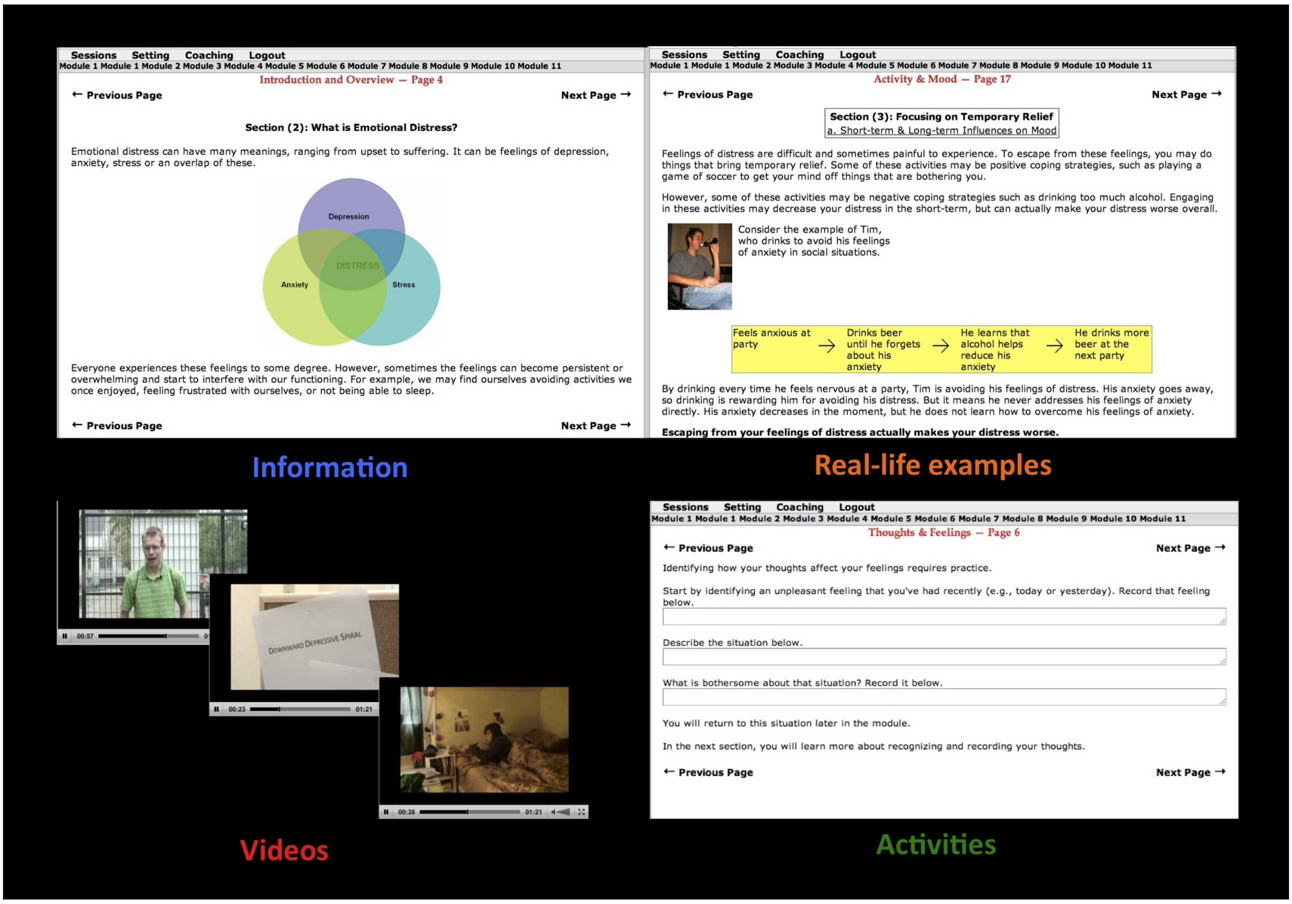


Table 1. Description of core modules.

Core modules	Topics	Exercises
1. Introduction	Introduction to program features. Description of emotional distress.	Depression, Anxiety, and Stress Questionnaire. Suicidal Ideation screener.
2. Activity and Mood	Relationship between activity and mood.	Identifying goals for change. Decisional balancing chart.
3. Motivation	Building motivation for change.	Identifying steps to achieve goals. Identifying and planning for barriers to change.
4. Thoughts and Feelings	How thoughts affect feelings. Identifying and challenging thoughts.	Thought records. Labeling common cognitive distortions. Challenging negative thoughts.
5. Advanced Thoughts and Feelings	Challenging more persistent thoughts and core beliefs.	More practice of challenging thoughts. Identifying automatic thoughts and core beliefs. Challenging automatic thoughts and core beliefs. Depression, Anxiety, and Stress Questionnaire.

Figure 2. Screenshots of the online-based program.



Section (2): What is Emotional Distress?

Emotional distress can have many meanings, ranging from upset to suffering. It can be feelings of depression, anxiety, stress or an overlap of these.

Everyone experiences these feelings to some degree. However, sometimes the feelings can become persistent or overwhelming and start to interfere with our functioning. For example, we may find ourselves avoiding activities we once enjoyed, feeling frustrated with ourselves, or not being able to sleep.

Section (3): Focusing on Temporary Relief
a. Short-term & Long-term Influences on Mood

Feelings of distress are difficult and sometimes painful to experience. To escape from these feelings, you may do things that bring temporary relief. Some of these activities may be positive coping strategies, such as playing a game of soccer to get your mind off things that are bothering you.

However, some of these activities may be negative coping strategies such as drinking too much alcohol. Engaging in these activities may decrease your distress in the short-term, but can actually make your distress worse overall.

Consider the example of Tim, who drinks to avoid his feelings of anxiety in social situations.

Feels anxious at party → Drinks beer until he forgets about his anxiety → He learns that alcohol helps reduce his anxiety → He drinks more beer at the next party

By drinking every time he feels nervous at a party, Tim is avoiding his feelings of distress. His anxiety goes away, so drinking is rewarding him for avoiding his distress. But it means he never addresses his feelings of anxiety directly. His anxiety decreases in the moment, but he does not learn how to overcome his feelings of anxiety.

Escaping from your feelings of distress actually makes your distress worse.

Identifying how your thoughts affect your feelings requires practice.

Start by identifying an unpleasant feeling that you've had recently (e.g., today or yesterday). Record that feeling below.

Describe the situation below.

What is bothersome about that situation? Record it below.

You will return to this situation later in the module.

In the next section, you will learn more about recognizing and recording your thoughts.

Results

Participant Characteristics

See Table 2 for a summary of participant characteristics. All participants endorsed moderate levels of depression, anxiety, and stress prior to commencing the guided online self-help program.

Delayed Access Versus Immediate Access

A proportion of the sample (24/65, 37%) completed the questionnaires and online program 6 weeks after enrolling into the study; thus, the potential effect of delayed access on participant retention was examined using a nonparametric Mann-Whitney test. Participants who experienced delayed access completed a similar number of program modules (mean 2.79, SD 1.44; median 2.5). This was compared to participants who received immediate access (mean 4.33, SD 3.22; median 3.0; *U*=439; *P*=.46). A larger proportion of delayed access participants discontinued the program (ie, did not complete all 5 modules; 19/24, 80%) compared to immediate access participants (23/41, 56%). However, this difference was found to be only marginally significant when examined using a chi-square test (χ^2_1=3.38; *P*=.068; N=65). When comparing only the subjects who were also enrolled in the concurrent randomized controlled clinical trial, 62.5% (15/24) of immediate access subjects completed all 5 modules, while 20.8% (5/24) of the delayed access subjects completed all 5 modules (χ^2_1=8.57; *P*=.003; N=48).

Factors Predicting Intention

To examine whether attitudes, subjective normative beliefs, and perceived behavioral control predict participants' intention to complete the guided online-based program, these variables were entered into a simultaneous multiple regression (see Table 3). The model was significant ($F_{3,62}$=6.7; *P*=.001; adjusted R^2 =.21), however, only perceived behavioral control was found to significantly predict participants' intention to complete the guided online self-help program (standardized beta=.436, *P*=.001). Thus, participants who endorsed higher perceived behavioral control over completing the online program also endorsed higher intention to complete the program.

Table 2. Description of participant characteristics.

Participant characteristics	Total N=65
Age, mean (SD)	23.2 (5.0)
Males (Females)	9 (56)
Dropout[a], n	42
Modules completed, mean (SD)	3 (1.6)
Initial Depression Score, mean (SD)	19.4 (11.7)
Initial Anxiety Score, mean (SD)	12.5 (9.0)
Initial Stress Score, mean (SD)	21.5 (8.9)

[a] Dropout was defined as an individual who did not complete all 5 modules.

Table 3. Multiple regression predicting intention to complete the online-based program.

	B	SE[a] B	Standardized beta
Attitude	.072	.078	.126
Subjective norms	-.013	.013	-.128
Perceived behavioral control	.325	.090	.436[b]

[a] SE=standard error.

[b] *P*=.001

Factors Predicting Program Completion

A hierarchical multiple regression was employed to examine factors that may affect participant retention, defined as the number of program modules completed. Intention and perceived behavioral control were entered in the first model since these two variables are proposed to predict behavior (ie, the number of modules completed) according to the theory of planned behavior [17]. Age was then entered into the second model because previous literature on attrition from online-based programs has found that age can influence program adherence [12,15,25]. Model 1 was not found to significantly predict the number of modules completed (Model 1: $F_{2,62}$=1.29, *P*=.28 adjusted R^2 =.01; see Table 4). Rather, the best fitting model for predicting participant retention was the combination of perceived behavioral control, intention, and age (Model 2: $F_{3,61}$=3.20, *P*=.03, delta R^2 =.10). In this combined model, perceived behavioral control (standardized beta=.295, *P*=.038) and age (standardized beta=.319, *P*=.012) significantly predicted the number of modules completed (see Table 4). A follow-up analysis was conducted to examine whether moderation was occurring between perceived behavior control and age. The moderation analysis was nonsignificant (*P*=.78), suggesting that the presence of age did not moderate the relationship between perceived behavioral control and participant retention. Instead, these two variables in conjunction predict participant retention.

Table 4. Hierarchical multiple regression predicting retention (ie, the number of modules completed) in the online-based program.

		B	SE[a] B	Standardized beta
Model 1				
	Intention	-.058	.214	-.038
	Perceived behavioral control	.242	.160	.215
Model 2				
	Intention	-.182	.210	-.120
	Perceived behavioral control	.332	.157	.295[b]
	Age	.105	.040	.319[c]

[a] SE=standard error.

[b] *P*=.038.

[c] *P*=.012.

Initial Distress

Initial level of distress (ie, severity of depression, anxiety, and stress symptoms), as measured by DASS scores, did not predict the number of modules completed: $F_{3,61}$=7.14, P=.55, adjusted R^2 =-.01.

Phone-Based Versus Email-Based Coaching

The effect of the type of contact with the program coach on participant retention was examined using a Mann-Whitney test because of unequal group *N* s; 83% (54/65) of participants chose primarily email-based contact with the program coach. Participants who chose phone-based coaching completed more program modules (mean 4.36, SD 1.12; median 5.0). This was compared to participants who chose email-based coaching (mean 2.81, SD 1.61; median 2.0; U=137; P=.004). Participants who chose phone-based coaching did not differ from participants who chose email-based contact on any of the theory of planned behavior variables (ie, attitudes, subjective normative beliefs, perceived behavioral control, and intention) or on DASS scores, as examined by a series of Mann-Whitney tests (P>.05).

Discussion

The purpose of this study was to investigate predictors of participant retention in a guided online program for anxiety, depression, and stress in university students through the use of the theory of planned behavior. Within our sample, 65 % (42/65) of participants did not complete all 5 core modules of the program. Although this represents a large proportion of noncompleters, the percentage of dropouts fell within previously reported ranges [3,4] and may have been, in part, influenced by the fact that some participants were also enrolled in a randomized control trial of the program [5]. Overall, attrition rates have been found to be lower in randomized control trials than in open access Web-based studies, with lower completion rates for individuals in the experimental intervention group than those in the control group [3,5]. In our study, we found that participants who were given delayed access completed a similar number of program modules compared with those who were given immediate access. The proportion of participants who did not complete all of the modules appeared to be larger in delayed access participants (19/24, 80%) than immediate access participants (23/41, 56%). However, this difference was only marginally significant (P=.068) and was likely influenced by an unequal number of individuals who experienced delayed access versus immediate access (24 versus 44, respectively). To examine this further, we compared the completion rates of only the subjects who were concurrently enrolled in the randomized controlled trial (N=48). We found that, in this instance, a greater proportion of immediate access participants (15/24, 62.5%) completed all 5 program modules compared to delayed access participants (5/24, 4.17%; P<.01). The result of this subanalysis contradicts previous findings of lower completion rates for individuals in experimental conditions compared with control conditions (eg, [3]) and suggests that delayed access in randomized controlled trials may negatively affect participant retention.

According to the theory of planned behavior [16,17], a person's attitudes, subjective normative beliefs, and perceived behavioral control influence their intention to engage in a behavior. We examined how these variables influenced participants' intention to complete the online self-help program. We found that the participants' perceived control over completing the online self-help program significantly predicted self-reported intention to complete the program. Thus, university students who endorsed greater perceived control over their behavior also endorsed greater intention to complete the online program. This finding is consistent with previously reported research on health behaviors, which has shown that perceived behavioral control is an important predictor of behavioral intention as well as actual behavioral change [19,26].

Ajzen [17] asserts that intention to complete a behavior and perceived control over the behavior predict whether a person will engage in the behavior. We did not find that these two variables alone (ie, intention and perceived behavioral control) significantly predicted the number of modules completed. Instead, we found that age and perceived behavioral control significantly predicted participant retention. Older university students, who endorsed more perceived control over completing the online-based program, actually completed more program modules. Previous studies have found that younger participants are more likely to drop out than older participants, though these studies included adults with a broad range of ages [12,15,25]. Our study found that even in young adulthood (ages 19-28), relatively older participants were more likely to complete online self-help programs. As mentioned above, we also found that when age was entered into the model, greater perceived behavioral control was also found to predict the number of modules completed. The concept of perceived behavior control is closely related to self-efficacy (ie, a person's judgment of how successfully they can complete a behavior) [17]. Our findings are consistent with health psychology research demonstrating that those with high perceived behavioral control (ie, high self-efficacy) are more likely to adhere to exercise programs [27,28]. Promoting self-efficacy within this target group (ie, university students) may help improve participant retention. Suggested methods for improving self-efficacy include motivation interviewing [29], focusing on the students' previous successes, vicarious experience (ie, the successes and failures of their peers), and verbal praise [30,31]. These strategies have been demonstrated to improve academic self-efficacy and performance in university students [32,33]. Identifying participants with low self-efficacy and attempting to foster this self-efficacy through the aforementioned strategies may potentially improve adherence and retention in online-based programs for this population. For example, this could be done during an initial phone conversation by reviewing the costs and benefits of changing the participant's current behavior, discussing when participants can work on the program on a weekly basis, examining past successful life changes, and praising module completion in weekly email or phone conversations. Further research in this area is warranted.

Of note is the absence of a predictive relationship between participants' intention to complete the online program and the number of modules completed. Consistent with this finding, a recent study investigating attrition from an online treatment for chronic insomnia also failed to find a relationship between intention to complete the program and attrition [26]. The lack of a relationship between intention and behavior may be affected by the study design. Few studies using the theory of planned behavior include prospective designs or objectively measure behavior. When behavior is measured, it is generally done through self-report [18,19]. Within the theory of planned behavior literature, prediction of observable behavior has been found to be more modest than prediction of self-reported behavior [18]. The lack of relationship between self-reported intention and behavior in our study may, in part, be due to the fact that we employed a prospective design and objectively measured behavior. Our relatively modest sample size may have also contributed to the absence of this relationship.

Previous literature on attrition from online-based programs has examined sociodemographic, symptom severity, and treatment characteristics. Some studies have found consistent relationships between the degree of symptom severity and participant dropout [4]. In particular, participants with less severe symptoms have been found to be more likely to drop out from online programs for chronic insomnia, posttraumatic stress, phobia, and panic disorders [12-14,26]. In our study, we did not find that severity of depression, anxiety, and/or stress predicted participant retention. However, unlike many of the aforementioned studies, participants in our study were not required to meet diagnostic criteria for a psychological disorder. Rather, the majority of our sample included university students with subclinical levels of anxiety, depression, and stress. The absence of a predictive relationship between symptom severity and participant retention may have been due to our subclinical sample.

Guided Internet programs for anxiety and depression have been found to be more efficacious than interventions without treatment support [34]. These benefits are obtained even when the individuals providing treatment support are not professionally trained therapists [35,36]. Our program included nontherapist coaches who provided encouragement and support to participants via telephone or email, based on participant preference. The majority of participants chose primarily email-based contact (83%). Yet, participants who chose phone-based coaching completed significantly more modules (on average 4.36 modules) than students who chose email-based coaching (on average 2.8 modules). Given that participants were provided with the option to receive phone- or email-based coaching, this finding might represent a self-selection bias (ie, participants who were more likely to complete the program selected to receive phone-based coaching). However, Kenwright and colleagues found that participants who were randomized to receive scheduled clinician-directed phone calls were less likely to drop out from a computer-aided intervention for obsessive compulsive disorder [8]. Phone-based support may facilitate engagement and rapport, enhancing the participants' experience in the online-based program, thus improving participant retention. Future research should examine the utility of phone-support as a strategy to improve participant retention in online-based programs.

Limitations

Our study utilized a questionnaire based on the theory of planned behavior, which was designed to be brief and to address our specific hypotheses (ie, predicting participant retention in the online-based program). Further research is necessary to establish the reliability and internal validity of the items in this questionnaire. In addition, the university students who enrolled in the study were primarily female, and hence gender differences in participant retention could not be examined.

Conclusions

This study contributed to the limited literature on predictors of participant attrition and retention in online-based programs. Age, perceived control over completing the program, and the type of coach contact (ie, phone) were found to be important factors in increasing participant retention. Further research is necessary to examine the potential influence of phone-based support versus email support on participant retention. Interventions exploring potential approaches for fostering participants' perceived behavioral control (ie, self-efficacy) may also be helpful in developing strategies to improve participant retention in online programs.

Acknowledgments

This research was funded by a grant received from the Nova Scotia Health Research Foundation. The authors wish to thank Melissa Kervin for her assistance with data collection.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Theory of planned behavior questionnaire.

[PDF File (Adobe PDF File), 23KB - jmir_v15i5e96_app1.pdf]

References

1. Andersson G, Cuijpers P. Internet-based and other computerized psychological treatments for adult depression: a meta-analysis. Cogn Behav Ther 2009;38(4):196-205. [doi: 10.1080/16506070903318960] [Medline: 20183695]

2. 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 Jul 2008;26(2-4):109-160. [doi: 10.1080/15228830802094429]
3. Christensen H, Griffiths KM, Farrer L. Adherence in internet interventions for anxiety and depression. J Med Internet Res 2009;11(2):e13 [FREE Full text] [doi: 10.2196/jmir.1194] [Medline: 19403466]
4. Melville KM, Casey LM, Kavanagh DJ. Dropout from Internet-based treatment for psychological disorders. Br J Clin Psychol 2010 Nov;49(Pt 4):455-471. [doi: 10.1348/014466509X472138] [Medline: 19799804]
5. Eysenbach G. The law of attrition. J Med Internet Res 2005;7(1):e11 [FREE Full text] [doi: 10.2196/jmir.7.1.e11] [Medline: 15829473]
6. Carrard I, Crépin C, Rouget P, Lam T, Golay A, Van der Linden M. Randomised controlled trial of a guided self-help treatment on the Internet for binge eating disorder. Behav Res Ther 2011 Aug;49(8):482-491. [doi: 10.1016/j.brat.2011.05.004] [Medline: 21641580]
7. Simon GE, Ludman EJ, Goodale LC, Dykstra DM, Stone E, Cutsogeorge D, et al. An online recovery plan program: can peer coaching increase participation? Psychiatr Serv 2011 Jun;62(6):666-669. [doi: 10.1176/appi.ps.62.6.666] [Medline: 21632737]
8. Kenwright M, Marks I, Graham C, Franses A, Mataix-Cols D. Brief scheduled phone support from a clinician to enhance computer-aided self-help for obsessive-compulsive disorder: randomized controlled trial. J Clin Psychol 2005 Dec;61(12):1499-1508. [doi: 10.1002/jclp.20204] [Medline: 16173084]
9. Andersson G, Lundström P, Ström L. Internet-based treatment of headache: does telephone contact add anything? Headache 2003 Apr;43(4):353-361. [Medline: 12656706]
10. 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] [doi: 10.2196/jmir.6.4.e46] [Medline: 15631970]
11. 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] [doi: 10.2196/jmir.7.2.e16] [Medline: 15998607]
12. Lange A, Rietdijk D, Hudcovicova M, van de Ven JP, Schrieken B, Emmelkamp PM. 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. [doi: 10.1037/0022-006X.71.5.901] [Medline: 14516238]
13. Ström L, Pettersson R, Andersson G. Internet-based treatment for insomnia: a controlled evaluation. J Consult Clin Psychol 2004 Feb;72(1):113-120. [doi: 10.1037/0022-006X.72.1.113] [Medline: 14756620]
14. Schneider AJ, Mataix-Cols D, Marks IM, Bachofen M. Internet-guided self-help with or without exposure therapy for phobic and panic disorders. Psychother Psychosom 2005;74(3):154-164. [doi: 10.1159/000084000] [Medline: 15832066]
15. Nicholas J, Proudfoot J, Parker G, Gillis I, Burckhardt R, Manicavasagar V, et al. The ins and outs of an online bipolar education program: a study of program attrition. J Med Internet Res 2010;12(5):e57 [FREE Full text] [doi: 10.2196/jmir.1450] [Medline: 21169169]
16. Ajzen I. From intentions to actions: A theory of planned behavior. In: Kuhl J, Beckmann J, editors. Action control: From cognition to behavior. Heidelberg: Springer; 1985:11-39.
17. Ajzen I. The Theory of Planned Behavior. Organizational Behavior and Human Decision Processes 1991;50(2):179-211.
18. McEachan RRC, Conner M, Taylor NJ, Lawton RJ. Prospective prediction of health-related behaviours with the Theory of Planned Behaviour: a meta-analysis. Health Psychology Review 2011;5(2):97-144. [doi: 10.1080/17437199.2010.521684]
19. Armitage CJ, Conner M. Efficacy of the Theory of Planned Behaviour: a meta-analytic review. Br J Soc Psychol 2001 Dec;40(Pt 4):471-499. [Medline: 11795063]
20. Fishbein M, Ajzen I. Predicting and changing behavior: the reasoned action approach. New York: Psychology Press; 2010.
21. Francis J, Eccles M, Johnston M, Walker A, Grimshaw J, Foy R, et al. Constructing questionnaires based on the Theory of Planned Behaviour. In: A manual for health services researchers. Newcastle upon Tyne, UK: Centre for Health Services Research; 2004.
22. Lovibond, SH, Lovibond, PF. Manual for the depression anxiety stress scale. Sydney: Psychology Foundation; 1995.
23. Henry JD, Crawford JR. The short-form version of the Depression Anxiety Stress Scales (DASS-21): construct validity and normative data in a large non-clinical sample. Br J Clin Psychol 2005 Jun;44(Pt 2):227-239. [doi: 10.1348/014466505X29657] [Medline: 16004657]
24. Day V, McGrath P, Wojtowicz M. Internet-based guided self-help for university students with anxiety, depression and stress: A randomized controlled clinical trial. Behav Res Ther 2013 Mar 28;51(7):344-351. [doi: 10.1016/j.brat.2013.03.003] [Medline: 23639300]
25. Postel MG, de Haan HA, ter Huurne ED, van der Palen J, Becker ES, de Jong CA. Attrition in web-based treatment for problem drinkers. J Med Internet Res 2011;13(4):e117 [FREE Full text] [doi: 10.2196/jmir.1811] [Medline: 22201703]
26. Hebert EA, Vincent N, Lewycky S, Walsh K. Attrition and adherence in the online treatment of chronic insomnia. Behav Sleep Med 2010;8(3):141-150. [doi: 10.1080/15402002.2010.487457] [Medline: 20582757]

27. Cardinal BJ, Sachs ML. Effects of mail-mediated, stage-matched exercise behavior change strategies on female adults' leisure-time exercise behavior. J Sports Med Phys Fitness 1996 Jun;36(2):100-107. [Medline: 8898515]
28. Conn VS, Tripp-Reimer T, Maas ML. Older women and exercise: theory of planned behavior beliefs. Public Health Nurs 2003;20(2):153-163. [Medline: 12588432]
29. Miller WR, Rollnick S. Motivational Interviewing: Preparing People for Change. New York: The Guilford Press; 2002.
30. Bandura A. Self-efficacy: toward a unifying theory of behavioral change. Psychol Rev 1977 Mar;84(2):191-215. [Medline: 847061]
31. Zimmerman BJ. Self-Efficacy: An Essential Motive to Learn. Contemp Educ Psychol 2000 Jan;25(1):82-91. [doi: 10.1006/ceps.1999.1016] [Medline: 10620383]
32. Pintrich PR, Schunk DH. Motivation in education: Theory, research and applications (3rd ed.). Merril, New Jersey: Prentice Hall; 2007.
33. Pintrich PR. The role of motivation in promoting and sustaining self-regulated learning. International Journal of Educational Research 1999;31(6):459-470. [doi: 10.1016/S0883-0355(99)00015-4]
34. 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. [doi: 10.1017/S0033291706008944] [Medline: 17112400]
35. Titov N, Andrews G, Davies M, McIntyre K, Robinson E, Solley K. Internet treatment for depression: a randomized controlled trial comparing clinician vs. technician assistance. PLoS One 2010;5(6):e10939 [FREE Full text] [doi: 10.1371/journal.pone.0010939] [Medline: 20544030]
36. Titov N, Andrews G, Schwencke G, Solley K, Johnston L, Robinson E. An RCT comparing effect of two types of support on severity of symptoms for people completing Internet-based cognitive behaviour therapy for social phobia. Australian and New Zealand Journal of Psychiatry 2009;43(10):920-926. [doi: 10.1080/00048670903179228]

Edited by G Eysenbach; submitted 24.08.12; peer-reviewed by E Murray, K Kaipainen; comments to author 08.02.13; revised version received 04.03.13; accepted 26.03.13; published 22.05.13.

Please cite as:
Wojtowicz M, Day V, McGrath PJ
Predictors of Participant Retention in a Guided Online Self-Help Program for University Students: Prospective Cohort Study
J Med Internet Res 2013;15(5):e96
URL: http://www.jmir.org/2013/5/e96/
doi:10.2196/jmir.2323
PMID:23697614

Original Paper

Web-Based Counseling for Problem Gambling: Exploring Motivations and Recommendations

Simone Rodda[1,2], BSc (Hons); Dan I Lubman[1,2], PhD, FRANZCP, FAChAM; Nicki A Dowling[3], PhD; Anna Bough[1], BSW; Alun C Jackson[3], PhD

[1]Turning Point Alcohol and Drug Centre, Fitzroy, Australia
[2]Eastern Health Clinical School, Monash University, Melbourne, Australia
[3]Problem Gambling Research and Treatment Centre, University of Melbourne, Victoria, Australia

Corresponding Author:
Simone Rodda, BSc (Hons)
Turning Point Alcohol and Drug Centre
54-62 Gertrude Street
Fitzroy, 3065
Australia
Phone: 61 0384138433
Fax: 61 0394181012
Email: simoner@turningpoint.org.au

Abstract

Background: For highly stigmatized disorders, such as problem gambling, Web-based counseling has the potential to address common barriers to treatment, including issues of shame and stigma. Despite the exponential growth in the uptake of immediate synchronous Web-based counseling (ie, provided without appointment), little is known about why people choose this service over other modes of treatment.

Objective: The aim of the current study was to determine motivations for choosing and recommending Web-based counseling over telephone or face-to-face services.

Methods: The study involved 233 Australian participants who had completed an online counseling session for problem gambling on the Gambling Help Online website between November 2010 and February 2012. Participants were all classified as problem gamblers, with a greater proportion of males (57.4%) and 60.4% younger than 40 years of age. Participants completed open-ended questions about their reasons for choosing online counseling over other modes (ie, face-to-face and telephone), as well as reasons for recommending the service to others.

Results: A content analysis revealed 4 themes related to confidentiality/anonymity (reported by 27.0%), convenience/accessibility (50.9%), service system access (34.2%), and a preference for the therapeutic medium (26.6%). Few participants reported helpful professional support as a reason for accessing counseling online, but 43.2% of participants stated that this was a reason for recommending the service. Those older than 40 years were more likely than younger people in the sample to use Web-based counseling as an entry point into the service system (P=.045), whereas those engaged in nonstrategic gambling (eg, machine gambling) were more likely to access online counseling as an entry into the service system than those engaged in strategic gambling (ie, cards, sports; P=.01). Participants older than 40 years were more likely to recommend the service because of its potential for confidentiality and anonymity (P=.04), whereas those younger than 40 years were more likely to recommend the service due to it being helpful (P=.02).

Conclusions: This study provides important information about why online counseling for gambling is attractive to people with problem gambling, thereby informing the development of targeted online programs, campaigns, and promotional material.

(J Med Internet Res 2013;15(5):e99) doi:10.2196/jmir.2474

KEYWORDS

Internet; motivation; gambling; counseling; Web-based interventions; health services accessibility

Introduction

Internet interventions have the potential to cover large geographical areas at low cost and reach marginalized and difficult-to-reach populations [1]. Their potential for anonymity and convenience has increased access to information and counseling to groups such as young men [2], in addition to attracting new treatment seekers [3]. Particularly relevant to highly stigmatized disorders, such as problem gambling, Web-based (online) counseling has the potential to address common barriers to treatment, including shame and stigma [4,5]. Indeed, shame has been identified as a significant barrier to help seeking for problem gambling, as well as a reason for gamblers wanting to recover without formal assistance and not wanting others to know about the problem [6-8]. Research on Internet interventions and problem gambling has included investigating the effectiveness of self-directed Internet therapies [9], online peer-support groups and message boards [10,11], and tailored feedback on assessment [12]. With the exception of an evaluation of a UK program which provided the first publicly funded synchronous real-time chat intervention for problem gambling [13], no further research has been published on online counseling (ie, synchronous real-time chat) and problem gambling.

Research conducted in online counseling environments has typically attempted to identify similarities and differences to the therapeutic alliance found in face-to-face or telephone counseling [14]. Online counseling shares similarities with these other forms of counseling in that it is synchronous and involves at least 2 parties, but the lack of verbal, aural, and physical cues, argued to be critically important to the development of therapeutic alliance, is absent. Indeed, the disadvantages of online counseling have been well documented, and include a lack of audio and visual cues, limited capacity to develop a therapeutic alliance, and modality issues, such as typing speed, consent, privacy, and comfort with the medium [4,15,16]. Although legitimate concerns, it is possible that some clients find these issues attractive and as perceived benefits of online counseling.

The motivations of people involved in ongoing online treatment were captured in a small study by Cook and Doyle [17], who interviewed clients in their third or later session of predominately email counseling for a range of issues, including mental health and relationships. They found motivations for using email and chat included viability (believing this mode would be effective), disinhibition (lowered embarrassment or fear of judgment), cost, travel, the ease of developing an honest client-therapist relationship, and confidentiality/flexibility. In addition, clients said the benefits of a documented written text meant there was the capacity to read over and reflect on counseling sessions. This study has been used extensively as the basis for why people access online counseling, but the themes were based on the responses of only 9 participants, with just 3 engaged in real-time chat. Since this time, multiple studies have examined motivations of those engaged in appointment-based (often involving a cost) services and identified a number of additional motivators, including convenience, privacy and anonymity, face-to-face wait times, and access to specialized services [3,17-19]. To date, Leibert et al [18] conducted the only study to consider motivations as well as perceived advantages and disadvantages of using online counseling. This study found the reasons for using online counseling were similar to the perceived advantages (ie, anonymity, flexibility, emotional expression).

There is minimal research involving free online counseling without an appointment. However, investigations of motivations for using real-time chat provided without appointment have been conducted with clients and counselors of the Kids Helpline, an Australian telephone and online service providing counseling to young people. One of these studies attempted to identify the motivation for using online counseling over telephone or face-to-face counseling by recruiting young people waiting for a real-time chat counseling session into online focus groups [19]. A range of motivational factors emerged, including privacy and an emotionally safe environment (eg, reduced exposure, privacy, control), and issues around time (more time to reflect).

Although these studies are important in identifying why people use online counseling, there are several constraints that may limit their generalization to immediate interventions. These include relatively small sample sizes (some as low as 9 participants), as well as a lack of clarity on the modality of service offered (ie, typically email rather than chat). Studies have also tended to focus on the lack of face-to-face elements rather than possible benefits associated with their absence, and only 1 study involving adolescents directly asked about motivations for accessing counseling online over telephone or face-to-face services [19]. In addition, participants in these studies have predominately been drawn from ongoing appointment-based counseling, with limited research into the experiences of those accessing free services without appointment. Lastly, few studies have sought to explore motivations for using online counseling as well as the impact of their experience on reasons for recommending that modality to other people with a similar problem.

The aim of the current study was to determine reasons for choosing and recommending online counseling. Based on previous research examining ongoing clients involved in a range of online modalities (eg, chat, email), as well as young people engaged in brief interventions provided via real-time chat, we expected themes to emerge associated with anonymity, confidentiality, flexibility, and factors associated with the modality (ie, record of session). We did not expect that cost, therapeutic alliance, and counselor credentials, which are similar to telephone and face-to-face services, would be a reason for using or recommending online counseling over other options. In addition, recent research on barriers to help seeking for problem gambling [8] indicate shame and stigma to be barriers to engaging in professional and nonprofessional help among younger people (18-39 years of age). As such, we expected motivations for accessing online counseling would differ by age, with younger clients (<40 years) being more likely to endorse factors around shame and embarrassment than older clients.

Method

Participants

There were 241 participants with concerns about their own gambling, who accessed online counseling offered by the Australian national online counseling site Gambling Help Online [20] between November 2010 and February 2012. Six participants left both open-ended questions blank and were removed, leaving a final sample of 235 participants. Participants were more often male (57.4%) than female (42.6%), and ages ranged from younger than 30 years (30.6%), between 30 to 39 years (29.8%), between 40 to 49 years (20.9%), to older than 50 years (18.8%). Participants were most often engaged in nonstrategic forms of gambling, including electronic gaming machines, lotteries, bingo, and Keno (70.6%), than strategic forms of gambling, such as wagering, casino gambling, and sports betting (29.4%). A preference to gamble online was reported by 16.9% of participants. All participants were classified as problem gamblers as measured by the Problem Gambling Severity Index (PGSI) of the Canadian Problem Gambling Index (CPGI) [21] (mean 21.6, SD 4.0, range 8-27). Almost two-thirds of participants (62.1%) were new treatment seekers for problem gambling, with 33.6% having received counseling previously and 3.8% currently seeking treatment at another service. Participants with previous help seeking had accessed face-to-face (68.8%), telephone (15.1%), chat or email help from Gambling Help Online (9.7%) or other sources, such as international websites (6.5%). Most sessions occurred outside traditional business hours, including evenings and weekends (69.8%), and participants represented all states across Australia, except the Northern Territory.

Participants were offered an electronic exit survey at the completion of an online counseling session. The survey was provided as a link when a counseling session was terminated and was not promoted by the counselor or pop-up technology. The response rate for completing the exit survey was 17.1%. This response rate is comparable to online surveys that do not involve follow-up reminders, pop-ups, or other methods to increase participation [22,23].

To determine the representativeness of the current sample, the demographics of participants were compared with the total population of 1219 clients who completed a real-time chat counseling session with Gambling Help Online between November 2010 and February 2012. Chi-square (χ^2) analysis indicated that there were fewer participants younger than 40 years ($\chi^2_1 = 27.1$, $P<.001$), and significantly more participants who had previously sought counseling online, via telephone or face-to-face ($\chi^2_2 = 12.3$, $P=.002$), in the research sample than the total client group. There were no significant differences between groups in terms of gender, ethnicity, severity, type, or mode of gambling.

Procedure

Participants were offered an exit survey at completion of a counseling session via Gambling Help Online. This service provides real-time chat and email support to approximately 1500 people affected by problem gambling each year. Gamblers, family, and friends can access the service anonymously by completing a brief demographic survey and registering with an email address. Available 24/7, this service provides immediate free access to professional counselors without an appointment [24].

The service primarily provides counseling, information, and referrals for a range of gambling concerns. Brief interventions via reactive (inbound) helplines typically include brief assessment, feedback, and advice (eg, limiting time and money, scheduling alternative activities). Provided as single sessions, counselors responding to chat requests have qualifications in psychology or social work with training and expertise in the area of problem gambling. A typical session is delivered over a 45-minute period, although the amount of content covered online is approximately half of that discussed in face-to-face or telephone environments.

As part of a larger study, ethics approval was granted from the University of Melbourne’s Human Research Ethics Committee (ID: 1034028) and the Department of Justice’s Human Research Ethics Committee (JHREC) CF/10/17108. The exit survey was delivered at the end of the counseling session and contained 2 open-ended questions designed to elicit the motivations for choosing online counseling over other modalities. These included (1) What made you decide to use online counseling over other types of assistance (eg, telephone helpline, face-to-face counseling)? and (2) Would you recommend online counseling to someone concerned about a gambling issue (yes/no)? Why is that? The overall survey included a range of post-session indicators and took between 10 and 15 minutes to complete. On completion, participants saved the survey, which was stored in a secure online database.

Data Analysis

The open-ended responses pertinent to this study were analyzed using content analysis [25]. This method was chosen because client responses were diverse (ie, 1 word to full-sentence responses) and we were interested in capturing novel and new themes as well as the extent of similarity of experience. In addition, this method of analysis allowed us to examine responses against previously developed categories and use an inductive approach to expand these new categories to represent the motivations of participants engaged in online counseling. Responses were capped at 200 characters and ranged between 1 and 52 words. Responses were typically brief, with participants responding with an average 11 words (median 8, IQR 4-15). When new categories emerged that were distinctly different to those previously reported, the researchers developed new labels and descriptions for these categories that were added to the dataset. Two of the researchers developed categories independently that captured all of the data (SR and ND), with a third researcher arbitrating differences and contributing toward the final category development (DL). To ensure categories were mutually exclusive, a number of categories were combined (eg, privacy and confidentiality) and subcategories developed.

Once initial categories were established, 2 researchers coded the entire sample and continuously checked categories with each other to ensure consistency (SR and AB). Responses varied from 1-word descriptions to sentences involving multiple reasons for using online counseling. As such, the unit of analysis was ideas or themes. For example, responses such as “access” and “I find it easier to access” were coded as *accessibility*. Responses including multiple ideas were coded into multiple categories. For example, the response “easy to use in comfort of home, safe, less confrontational” was coded into 2 categories, *access from home* and *comfortable*. Items that were ambiguous or not relevant to the motivation for treatment seeking were excluded from analysis (eg, “I have a gambling problem”). Participant quotes reported in this paper have been provided verbatim except with minor alterations to spelling. Words added to assist readability are indicated within parentheses.

Following the initial analysis to identify themes and develop categories, 2 raters undertook 3 hours of training in the application of the data dictionary (ie, definitions of categories and subcategories). They each coded 30 responses for the 2 open-ended questions (13% of the sample). As described by Neuendorf [25], the results of pilot testing were used to improve and adapt the coding dictionary before final coding and items with low responses were collapsed into single categories. Items were checked for interrater reliability using Cohen’s kappa (κ), which calculates percent agreement while correcting for chance. Scores of .41 to .60 indicate moderate agreement, .61 to .80 substantial agreement, and .81 to 1 almost perfect agreement [26]. A high interrater agreement was achieved ranging between .89 and .98. Eleven items were then resolved via consensus between the 2 raters, with a third researcher (DL) providing arbitration where consensus was unable to be reached.

To determine whether participants experienced online counseling differently according to age, gender, gambling type, and previous treatment experiences, data were analyzed via a series of chi-square procedures or *t* tests where data were continuous. A McNemar nonparametric test was used to determine change in reasons for use over reasons for recommending across the sample. Proportions reported throughout the results relate to the number of participants who freely reported each item rather than how many of the sample agreed with that reason.

Results

Participants

There were 222 participants who provided 351 reasons for using online counseling (13 participants did not respond to this question). Reasons reported by participants fell into 4 broad categories: (1) confidentiality and anonymity, (2) convenience and accessibility, (3) service system access, and (4) therapeutic medium. The same 4 broad themes emerged as to why people recommended online counseling, with the addition of access to helpful professional support. A total of 229 participants provided 311 reasons for recommending the service (6 participants were excluded due to insufficient information for classification).

Confidential and Anonymous

Over one-quarter (27.0%) of participants mentioned issues around confidentiality and privacy as reasons for choosing online counseling over telephone or face-to-face counseling, and 21% stated that this was a reason for recommendation. For some participants, online counseling provided a discrete option that could be engaged in without others knowing. This may be due to the gambling itself being hidden from others or the act of seeking help being hidden. For some, online counseling provided a safe, private, and secure option where family, friends, or coworkers would not overhear the individual discussing the problem: “My phone bills are viewable by work or family; I don’t wish to be traced to calling for help” (male, 30-34 age group).

Anonymity was described as “not as daunting,” “not exposed,” and “not sharing problems with people you know.” It was viewed as an enabling factor to speaking about the problem, often for the first time: “It enabled me to face up to the fact that I have a gambling problem and talk to someone anonymously. It is the first time I have spoken to anyone about my despair over not being able to control my gambling” (female, 55-59 age group).

There was concern about being judged and embarrassment about having a gambling problem. Some participants described their experiences of having a gambling problem as a “disgrace,” and that they were “ashamed” and frequently embarrassed. For some, help seeking was “demeaning,” with 1 participant saying that they were able to admit the problem, but not accept the embarrassment of disclosure. For others, embarrassment had prevented exploration of phone or face-to-face options: “I feel very embarrassed about even ringing making an appointment and/or meeting someone face to face. After tonight I have more confidence about eventually consulting with a counselor; in the meantime, I feel it’s given me an avenue of help” (female, 60-64 age group).

Again, anonymity appeared to be an enabling factor for overcoming embarrassment and talking to a counselor online. Some participants separately related embarrassment to the benefits of anonymity and privacy. Indeed, when exploring why they would recommend the service, participants discussed feeling less judged and having increased control over the session: “It’s easy to be honest about feelings when anonymous. It is very difficult to talk about the extent that problem gambling affects all areas of life. Online appears less judgmental and the option is always there to switch off and run away if need be” (female, 55-59 age group).

Convenience and Accessibility

Over half of participants (50.9%) stated that the reason they chose online counseling over telephone or face-to-face counseling was due to convenience, although only one-quarter (25.8%) cited convenience as a reason they would recommend online counseling to others.

Almost one-quarter (24.3%) of participants said they chose online counseling because it was easy, simple, flexible, convenient, and accessible. For some, easy access referred to being able to reach the service when experiencing difficulty: “The least effort to get counseling when you feel really down” (male, 30-34 age group).

Two time factors emerged, one around immediacy and the other around 24-hour access. Participants said they were attracted by the immediate and quick access to a counselor. In this situation, contact was typically in response to distress related to gambling behavior and wanting to speak with someone immediately. For others, accessing online counseling was a spontaneous decision that was facilitated by the absence of an appointment process: “It was available; I saw the literature at the club earlier tonight and thought I’d give it a go” (female, 40-44 age group, 3:14 am).

Similarly, 24-hour access was attractive as it provided a help-seeking option at a convenient time, including evenings, overnight, and weekends. A small number of participants described a preference for accessing online counseling from home. For these participants, the physical comfort and not having to go to an office was attractive. For others, online counseling provided a low cost option in which a landline was not available to call a helpline (mobile telephone calls to helplines are charged at standard call rate).

Service System Access

Approximately one-third (34.2%) of participants stated the reason for using online counseling was related to service system access, although only 17.3% cited service system access as a reason for recommending online counseling to others. Specifically, 16.7% of participants identified online counseling as a good first step in both disclosing the gambling problem for the first time and accessing counseling: “I thought that it was a good place to start to get a feel for what I should and may expect from going to see a counselor face to face. It was a good first step and the online counselor provided information for me to go see a counselor” (male, 30-34 age group).

Sixteen participants cited dissatisfaction with other help (7.2%). This included a range of issues, such as wait lists or helplines not answering and unsatisfying interactions with counselors from other services. Some participants said they had tried everything else and were seeking a different perspective. In addition, 4 participants said that they did not know what other services were available or were not able to find any information on other options.

Referral to online counseling via advertising, word of mouth, and referral from other services was stated as a reason for using online counseling by 16 participants. Advertising and word of mouth were the reasons 11 participants came to the site, and included online and television advertising, as well as information found via search engines, gambling venues, or other websites. Two participants said that they chanced across the site and decided to “give it a go.” For 5 participants, online counseling provided a referral to other forms of help: “Initially did online counseling to enquire about face-to-face counseling. It was also an opportunity to experience it for the first time” (male, 35-39 age group).

Only 3 participants stated they used online counseling as an adjunct to other treatment. For these participants, it was a method of accessing support between counseling appointments, for relapse prevention, or when their counselor was unavailable.

Therapeutic Medium

Thirty-three participants (26.6%) reported that they preferred online counseling to face-to-face or telephone counseling because of modality-specific features, with 17.9% citing these factors as a reason for recommendation. This included a preference to talk to, or through, a computer rather than face to face. For these participants, the experience of chatting online was viewed as easier than talking face to face or via the telephone: “It’s easier to talk to a screen” (female, 25-29 age group).

Participants identified a range of online counseling features as attractive, including the extended delivery time (ie, time to think and reflect), the capacity to review and save transcripts, as well as the act of writing over speaking. One participant also suggested this was a reason for recommending online counseling: “It’s less pressure. Writing actually makes you think about the situation in a logical [way]. Helps make order out of chaos” (male, 40-44 age group).

Eight participants reported that it was easier to express emotions using online counseling compared to telephone or face-to-face counseling. This was particularly the case where there was extreme distress and associated embarrassment: “It was late at night and I was very upset and crying so I would not have made any sense trying to talk to anyone” (female, 35-39 age group); “I do not like talking on phones and I prefer to cry without anyone seeing me” (female, 30-34 age group).

A few participants (4.5%) specifically stated that online counseling was more relaxed, comfortable, and less confronting than telephone or face-to-face counseling: “Less confronting at the moment, it’s easier when things are so bad to be anonymous” (female, 60-64 age group).

Lastly, 6 participants reported that the online platform facilitated more open and honest communication than phone or face-to-face modalities. This was also the case when participants reflected on why they would recommend online counseling: “It is discreet and allows for complete honesty with the anonymous counselor and yourself” (male, 30-34 age group).

In this case, the participant identified anonymity of the counselor as important. Indeed, a range of factors described previously, including anonymity, lack of physical presence, and the perception that they felt less judged appeared to facilitate honest communication.

Helpful Professional Support

Few participants stated that they used online counseling because they thought it would provide access to professional and helpful support, but almost half of participants (43.2%) stated that this was a reason to recommend online counseling. Helpful professional support was highlighted as helpful for improving mood (eg, emotional regulation), confidence in resisting urges (eg, awareness of triggers), and addressing gambling cognitions (eg, alteration of gambling-related cognitions about winning): “I gained useful facts that opened my eyes and helped me realize that the machine is designed to make money and for you to lose it” (male, 20-24 age group).

Eighteen participants reported that they experienced the relationship with the online counselor as nonjudgmental and understanding, and indicated that the counselor knew what they were going through. Participants said counselors provided "thought-provoking questions" without "sugar-coating it." Being able to access an independent/neutral professional was viewed as helpful in problem solving. In this situation, the counselor was viewed as empathic, expert, and credible: "Because I feel much better in myself and I didn't feel judged in any way" (female, 30-34 age group).

Online counseling was recommended as a source of information and/or strategies. This included referral to other services and exploration of treatment options. Some participants described online counseling as "putting them in the right direction" and helping them to find the right resources: "They helped me out. They came back with answers; phone numbers, just general help. It was just nice to know there was someone on the other side, reading your problems and telling you their opinion" (female, 25-29 age group).

Overall, 87.7% of participants said that they would recommend online counseling to someone with a gambling problem. Fourteen participants (6.3%) stated that they did not like the medium or that it was generally unhelpful. Ten participants (4.5%) had specific issues with the counselor, involving miscommunication, a perceived lack of listening skills, or the delivery of empathy. Lastly, a small number of participants (2.1%) experienced problems with the technology itself, premature disconnection, or service dropout.

Differences in Reported Motivations by Key Demographic and Help-Seeking Variables

We found few demographic differences between gender, age, gambling type (strategic and nonstrategic), preferred modality (face-to-face, online, or phone), severity of problem gambling, help-seeking experiences (new, current, or previous treatment seeking), time of contact, and reasons for using online counseling. However, those older than 40 years were more likely to use online counseling as an entry point into the service system (38.7%) compared with those under 40 years (26.1%; $\chi^2_1 = 4.2$, $P=.045$), whereas those engaged in nonstrategic betting (eg, electronic gaming machines) were more likely to be motivated to use online counseling as an entry point into the service system (36.0%) compared with strategic gamblers (19.3%; $\chi^2_1 = 6.8$, $P=.01$). Those older than 40 years were more likely to recommend it because of its privacy and potential for anonymity (25.8%) compared with those younger than 40 years (14.8%; $\chi^2_1 = 4.4$, $P=.04$), whereas those younger than 40 years (47.2%) were more likely than those older than 40 years (31.2%) to recommend online counseling because it was helpful ($\chi^2_1 = 5.9$, $P=.02$).

Given the similarities of response between motivations and recommendations, we were interested in the degree of movement between these 2 variables. In terms of movement between motivations for use and reasons for recommending, 84 (35.7%) participants changed their initial response about convenience when asked why they would recommend online counseling. Of these, 18 (7.7%) participants changed their response to convenience (from another motivation), whereas 66 (28.1%) did the reverse ($\chi^2_1 = 26.3$, $P<.001$). For service access, 67 (28.5%) participants changed their initial response, with 49 (21.0%) participants subsequently not identifying it as a reason for recommendation, whereas 18 (7.7%) did the reverse ($\chi^2_1 = 13.4$, $P<.001$). There was also a significant change in the proportion of participants endorsing helpful professional advice, with 93 (39.6%) participants subsequently endorsing helpfulness as a reason for recommendation, and only 3 the reverse ($\chi^2_1 = 82.5$, $P<.001$). There was no significant change in the proportion of those endorsing anonymity/privacy or therapeutic medium. That is, those who endorsed these reasons did not significantly alter their response when asked why they would recommend online counseling.

Discussion

Principal Findings

This exploratory study provides a first look at the reasons why people choose online counseling over telephone or face-to-face counseling and why they would recommend it to someone else with a gambling problem. As expected, themes around anonymity and confidentiality emerged, as well as flexibility, albeit within the larger theme of convenience and accessibility. Openness of expression overlapped with a range of factors associated with the therapeutic modality, including a preference for writing instead of talking. Therapeutic alliance and counselor credentials, which are similar to telephone and face-to-face services, were not a reason for using online counseling, but access to helpful professional support as well as the development of a therapeutic alliance was a reason to recommend online counseling. The hypothesis that younger people would endorse more factors around shame and stigma than older people was not supported.

The findings of this study indicate that motivations for using online counseling over telephone or face-to-face counseling is in response to barriers, such as shame and stigma, and accessibility [7,27], but there are important differences, such as being able to easily reach help when experiencing distress or when highly motivated. Although our findings on age and gender by shame or stigma differed to those reported by Hing et al [8], we did find that males were more motivated than females by convenience and less by the immediacy the medium provided. In addition, younger people were also more likely to recommend online counseling due to its convenience than people older than 40 years. Clearly, the environment in which counseling is accessed is increasingly relevant in online counseling, where privacy is of concern during business hours, possibly when the individual is help seeking from a place of employment.

Congruent with previous research involving those engaged in a range of Internet interventions, concerns around anonymity and privacy, as well as easy and convenient access, emerged [10]. Anonymity in previous studies has been related to "perceived anonymity" [17], anonymity such that others are not aware of their treatment seeking [3], and being physically unseen by the counselor [18]. We found that anonymity was typically associated with an absence of identifying personal information (eg, their name), as well as both theirs and/or the counselor's physical presence. Adolescents contacting the Australian Kids

Helpline reported that the privacy of being online involved not wanting others to know that counseling was being sought at that moment (eg, late at night when others are asleep, or being overheard on the phone) [19]. These findings are also consistent with previous research, with online clients reporting greater concerns about their own physical environment (eg, being heard by someone else in the house) than helpline callers, who reported fears of the Internet being unsafe [28].

In addition to differences between face-to-face, telephone, and online environments, the current research identified important differences between immediate and appointment-based online interventions. Our study involved those accessing a free service that provided an immediate intervention. The intervention typically involves motivational interviewing and/or behavioral strategies [29] following a brief screen of gambling severity and the immediate impact of problem gambling (ie, level of distress). Although these therapeutic interventions have been found effective for problem gambling, there has been almost no research on the effectiveness of these interventions delivered at a time when the participant is eager, ready, and willing to talk. Indeed, participants talked about being highly motivated to act, which was often in response to distress, anger, or anxiety. A desire for emotional relief may partially account for the speed of immersion found in this and other studies [18,19], whereby the participant is already thinking about their concern prior to the counseling session commencing.

Despite participant uptake of anonymous online counseling, there is scant research on the clinical benefits of providing an immediate intervention. It is perhaps surprising given widespread funding for helpline and online services across most areas of mental health, that minimal research exists on the impact of providing an intervention at the moment the person is experiencing harm. Over the past 3 years, the advent of smartphones and other mobile devices has significantly increased the frequency of interventions occurring at the time of the event (eg, low mood) [30,31] rather than at some future time (ie, akin to appointment-based services). In addition, the utility of immediate interventions have also been explored in the context of emergency departments versus primary care, suggesting 85% of presentations relate to non-life-threatening issues [32]. In this setting, the presentation is not related to an accident or emergency, but patients present because of a range of factors, including convenience and access. A model by Padgett and Brodsky [33] of accident and emergency presentations suggests an interaction of predisposing issues (eg, social support), enabling factors (eg, accessibility), and perceived need (eg, level of distress), and partially explains why our participants would choose online over telephone or face-to-face services.

Few participants chose online counseling because it would provide helpful professional support, but when asked why they would recommend it to someone with a gambling concern, the fact that the intervention helped became important. Previous research involving clients in ongoing treatment indicated viability was a reason for choosing online counseling [17]. Although a few participants mentioned service viability as a motivator, the main theme that emerged in our study was related to helpfulness of professional support. Given that it could be expected that telephone and face-to-face services also provide helpful professional support, we suspect that the immediacy of the intervention, that is at the right time and right place, was important.

Participants were primarily asked the reasons for recommending online counseling to obtain additional information related to their motivations. Indeed, responses were similar across motivations and recommendations, except for the emergence of helpful professional support. Understanding the characteristics and experiences in relation to movement between these variables could have practical implications in terms of clinician training and evaluating service effectiveness. For example, shame and embarrassment is repeatedly reported as a concern for highly stigmatized conditions, but there is minimal literature describing how interventions and services best address this issue. In practical terms, it would be helpful to know whether it is clinically more important to address the reason for presenting to a service (ie, anonymity) or to provide an intervention that addresses the presenting issue (ie, gambling). Indeed, our study indicated that some participants did not shift perspective (ie, were motivated by anonymity and also provided this as a reason for recommendation), whereas others did shift (ie, motivated by anonymity and would recommend online counseling because it helped).

Limitations

This research is the first to explore motivations of an adult population accessing immediate, online counseling for problem gambling. However, there are several limitations that need to be considered. First, participants in this sample were older than the population from which they were drawn and more often had sought help previously. Individual experiences combined with a slightly older demographic may mean that the motivations of some groups, including younger people, were underrepresented. In addition, we had expected issues around shame and stigma to be more frequently reported by younger than older participants. Our sample was slightly older than the total online counseling population, but still younger than other research involving adult gamblers (ie, 61% of our sample was younger than 40 years of age). It is possible that stigma is an issue for any age group or that issues such as access and convenience are more relevant for this population.

Second, surveys of help-seeking motivations are bound by the context and source of participants. As with the current study, they are typically cross-sectional, not capturing shifting motivations to change or motivations or readiness to seek treatment (eg, influence of gambling harms, social pressure, and time since last bet). Indeed, most previous surveys have involved clients of face-to-face or helpline counseling services, or identified perceived barriers of individuals not currently seeking help. Typically, these surveys have not been offered at the time the help was being sought and were retrospective reports. Although our study examined motivations at the time the decision was made, it is possible these reports were biased by their experiences of accessing the service.

Third, whether motivations are better identified via open-ended questioning or rating scales needs further investigation. As suggested by Pulford et al [7], many barriers to help seeking for gambling are not identified until prompted. Our study found approximately half of the sample were motivated by convenient and easy access, but it is possible that this was important to a larger proportion of the sample. In addition, the use of qualitative research methods allows us to be fairly confident that we are representing the views of participants, but there are issues with drawing conclusions related to the impact of motivations on recommendations. For example, we found significant movement between motivations and recommendations on convenience, service access, and helpfulness, but no significant change in anonymity/confidentiality and therapeutic medium. It is possible experiences, including the degree to which participant expectations are met, influence reasons for recommendation. Often client surveys include a question about whether the service would be recommended, typically as an indicator of satisfaction or rates of referral. However, responses may well be a better indicator of what happened in the intervention and whether they met participant expectations, rather than as an indicator of referral, which is possibly unrealistic when highly stigmatized conditions are involved. Indeed, service usage statistics for Gambling Help Online indicate that fewer than 10% of clients state their knowledge of the service was derived via a referral from a family member, friend, or professional.

Conclusions

In summary, we found that reasons for choosing online counseling over telephone or face-to-face services include issues of confidentiality/anonymity, accessibility, service system access, a preference for features of the therapeutic medium, and professional support. Given the rapid expansion of service systems in response to the opportunities presented by technology, it is timely to identify the motivations for using services so that they can be better targeted, promoted, and configured. Most front-end gambling services, including telephone and online, are established at least in part to refer people to face-to-face services, but our research suggests referral to services that cannot be accessed at a convenient time or place, or where a referral is deemed unnecessary, requires further investigation. Ultimately, this would require the development of an evidence base, which demonstrates the uptake, usage, focus, and effectiveness of all clinical interventions on offer. This should also identify the dimensions of the counseling session that contributes toward perceived helpfulness, including the impact of counselor qualifications and counseling methods (including session focus, therapeutic techniques, and mechanics of online counseling) on client outcomes. Given many online clients indicate that online counseling was not just a first step, but the only step in changing behavior, there is an urgent need to develop and evaluate online single session interventions. To do this effectively, the reasons people are drawn to different services need to be further examined.

Acknowledgments

The authors would like to acknowledge the efforts by states and territories in forming a collaborative funding agreement for Gambling Help Online and in particular the Victorian Responsible Gambling Foundation as contract managers. We would also like to thank all the counselors involved in providing the Gambling Help Online service, as well as Orson Rapose for his assistance in data extraction. Lastly, this work would not be possible without the willingness of people affected by problem gambling to access this new modality.

Conflicts of Interest

None declared.

References

1. 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 Jul 2008;26(2-4):109-160. [doi: 10.1080/15228830802094429]
2. Ellis LA, Collin P, Davenport TA, Hurley PJ, Burns JM, Hickie IB. Young men, mental health, and technology: implications for service design and delivery in the digital age. J Med Internet Res 2012;14(6):e160 [FREE Full text] [doi: 10.2196/jmir.2291] [Medline: 23171827]
3. Young KS. An empirical examination of client attitudes towards online counseling. Cyberpsychol Behav 2005 Apr;8(2):172-177. [doi: 10.1089/cpb.2005.8.172] [Medline: 15938657]
4. Griffiths M, Cooper G. Online therapy: implications for problem gamblers and clinicians. British Journal of Guidance & Counselling 2003 Feb 2003;31(1):113-135. [doi: 10.1080/0306988031000086206]
5. Cooper G, Doucet G. Online help for problem gambling: Why it is and is not being considered. Journal of Gambling Issues 2002 Dec 2002;7:1-10 [FREE Full text] [doi: 10.4309/jgi.2002.7.1]
6. Hodgins DC, el-Guebaly N. Natural and treatment-assisted recovery from gambling problems: a comparison of resolved and active gamblers. Addiction 2000 May;95(5):777-789. [Medline: 10885052]
7. Pulford J, Bellringer M, Abbott M, Clarke D, Hodgins D, Williams J. Barriers to help-seeking for a gambling problem: the experiences of gamblers who have sought specialist assistance and the perceptions of those who have not. J Gambl Stud 2009 Mar;25(1):33-48. [doi: 10.1007/s10899-008-9113-9] [Medline: 19050995]

8. Hing N, Nuske E, Gainsbury S. Gamblers at-risk and their help-seeking behaviour. Lismore, Australia: Gambling Research Australia; 2011. URL: http://www.gamblingresearch.org.au/resources/4edd7f4d-ed5c-43d0-a8f7-af2490695d7a/toc-abstract.pdf [accessed 2013-04-29] [WebCite Cache ID 6GFEjlDXw]
9. Carlbring P, Smit F. Randomized trial of internet-delivered self-help with telephone support for pathological gamblers. J Consult Clin Psychol 2008 Dec;76(6):1090-1094. [doi: 10.1037/a0013603] [Medline: 19045977]
10. Wood RT, Wood SA. An evaluation of two United Kingdom online support forums designed to help people with gambling issues. Journal of Gambling Issues 2009 Jun 2009;23:5-30. [doi: 10.4309/jgi.2009.23.1]
11. Cooper G. Exploring and understanding online assistance for problem gamblers: The pathways disclosure model. International Journal of Mental Health and Addiction 2004;1(2):32-38.
12. Cunningham JA, Hodgins DC, Toneatto T, Murphy M. A randomized controlled trial of a personalized feedback intervention for problem gamblers. PLoS One 2012;7(2):e31586 [FREE Full text] [doi: 10.1371/journal.pone.0031586] [Medline: 22348112]
13. Wood RTA, Griffiths MD. Online guidance, advice, and support for problem gamblers and concerned relatives and friends: an evaluation of the pilot service. British Journal of Guidance & Counselling 2007 Nov 2007;35(4):373-389. [doi: 10.1080/03069880701593540]
14. Sucala M, Schnur JB, Constantino MJ, Miller SJ, Brackman EH, Montgomery GH. The therapeutic relationship in e-therapy for mental health: a systematic review. J Med Internet Res 2012;14(4):e110 [FREE Full text] [doi: 10.2196/jmir.2084] [Medline: 22858538]
15. Mallen MJ. The practical aspects of online counseling: ethics, training, technology, and competency. The Counseling Psychologist 2005 Nov 2005;33(6):776-818 [FREE Full text] [doi: 10.1177/0011000005278625] [Medline: 22973420]
16. Haberstroh S, Duffey T, Evans M, Gee R, Trepal H. The experience of online counseling. Journal of Mental Health Counseling 2007;29(3):269-282 [FREE Full text]
17. Cook JE, Doyle C. Working alliance in online therapy as compared to face-to-face therapy: preliminary results. Cyberpsychol Behav 2002 Apr;5(2):95-105. [Medline: 12025884]
18. Leibert T, Archer JJ, Munson J, York G. An exploratory study of clients perceptions of internet counseling and the therapeutic alliance. Journal of Mental Health Counseling 2006;28(1):69-83 [FREE Full text]
19. King R, Bambling M, Lloyd C, Gomurra R, Smith S, Reid W, et al. Online counselling: The motives and experiences of young people who choose the Internet instead of face to face or telephone counselling. Counselling and Psychotherapy Research 2006 Sep 2006;6(3):169-174. [doi: 10.1080/14733140600848179]
20. Gambling Help Online. URL: http://www.gamblinghelponline.org.au/ [accessed 2013-04-24] [WebCite Cache ID 6G77UHebl]
21. Ferris J, Wynne H. The Canadian Problem Gambling Index. Ottawa, ON: Canadian Centre on Substance Abuse; 2001. URL: http://www.ccsa.ca/2003%20and%20earlier%20CCSA%20Documents/ccsa-008805-2001.pdf [accessed 2013-04-29] [WebCite Cache ID 6GFFBkJ0S]
22. Sheehan KB. Email survey response rates: A review. Journal of Computer-Mediated Communication 2001;6. [doi: 10.1111/j.1083-6101.2001.tb00117.x]
23. Powell J, McCarthy N, Eysenbach G. Cross-sectional survey of users of Internet depression communities. BMC Psychiatry 2003 Dec 10;3:19 [FREE Full text] [doi: 10.1186/1471-244X-3-19] [Medline: 14664725]
24. Rodda S, Lubman DI. Characteristics of gamblers using a national online counselling service for problem gambling. J Gambl Stud 2013 Jan 8. [doi: 10.1007/s10899-012-9352-7] [Medline: 23297169]
25. Neuendorf KA. The Content Analysis Guidebook. Thousand Oaks, CA: Sage Publications; 2002.
26. Hallgren KA. Computing inter-rater reliability for observational data: an overview and tutorial. Tutor Quant Methods Psychol 2012;8(1):23-34 [FREE Full text] [Medline: 22833776]
27. Suurvali H, Hodgins DC, Toneatto T, Cunningham JA. Motivators for seeking gambling-related treatment among Ontario problem gamblers. J Gambl Stud 2012 Jun;28(2):273-296. [doi: 10.1007/s10899-011-9268-7] [Medline: 21932112]
28. Fukkink RG, Hermanns JM. Children's experiences with chat support and telephone support. J Child Psychol Psychiatry 2009 Jun;50(6):759-766. [doi: 10.1111/j.1469-7610.2008.02024.x] [Medline: 19207634]
29. Cowlishaw S, Merkouris S, Dowling N, Anderson C, Jackson A, Thomas S. Psychological therapies for pathological and problem gambling. Cochrane Database Syst Rev 2012;11:CD008937. [doi: 10.1002/14651858.CD008937.pub2] [Medline: 23152266]
30. Baribeau JM, Braun CM, Dubé R. Effects of alcohol intoxication on visuospatial and verbal-contextual tests of emotion discrimination in familial risk for alcoholism. Alcohol Clin Exp Res 1986 Oct;10(5):496-499. [Medline: 3541672]
31. Harrison V, Proudfoot J, Wee PP, Parker G, Pavlovic DH, Manicavasagar V. Mobile mental health: review of the emerging field and proof of concept study. J Ment Health 2011 Dec;20(6):509-524. [doi: 10.3109/09638237.2011.608746] [Medline: 21988230]
32. Dent AW, Phillips GA, Chenhall AJ, McGregor LR. The heaviest repeat users of an inner city emergency department are not general practice patients. Emerg Med (Fremantle) 2003 Aug;15(4):322-329. [Medline: 14631698]
33. Padgett DK, Brodsky B. Psychosocial factors influencing non-urgent use of the emergency room: a review of the literature and recommendations for research and improved service delivery. Soc Sci Med 1992 Nov;35(9):1189-1197. [Medline: 1439937]

Abbreviations

CPGI: Canadian Problem Gambling Index
PGSI: Problem Gambling Severity Index

Edited by G Eysenbach; submitted 19.12.12; peer-reviewed by R King, S Gainsbury, M Krausz; comments to author 21.01.13; revised version received 14.03.13; accepted 07.04.13; published 24.05.13.

Please cite as:
Rodda S, Lubman DI, Dowling NA, Bough A, Jackson AC
Web-Based Counseling for Problem Gambling: Exploring Motivations and Recommendations
J Med Internet Res 2013;15(5):e99
URL: http://www.jmir.org/2013/5/e99/
doi:10.2196/jmir.2474
PMID:

Original Paper

Internet-Delivered Interpersonal Psychotherapy Versus Internet-Delivered Cognitive Behavioral Therapy for Adults With Depressive Symptoms: Randomized Controlled Noninferiority Trial

Tara Donker[1], PhD; Kylie Bennett[2], BA(Hons), BSC; Anthony Bennett[2], BAppSc; Andrew Mackinnon[3], PhD; Annemieke van Straten[4,5], PhD; Pim Cuijpers[4,5], PhD; Helen Christensen[1], PhD; Kathleen M Griffiths[2], PhD

[1]Black Dog Institute, University of New South Wales, Sydney, Australia
[2]Centre for Mental Health Research, The Australian National University, Canberra, Australia
[3]Orygen Youth Health, University of Melbourne, Melbourne, Australia
[4]Clinical Psychology, Department of Psychology and Education, VU University of Amsterdam, Amsterdam, Netherlands
[5]EMGO Institute for Health and Care Research, VU University and VU University Medical Center Amsterdam, Amsterdam, Netherlands

Corresponding Author:
Tara Donker, PhD
Black Dog Institute
University of New South Wales
Hospital Road
Sydney, 2031
Australia
Phone: 61 2 9382 4522
Fax: 61 29382 8208
Email: t.donker@unsw.edu.au

Abstract

Background: Face-to-face cognitive behavioral therapy (CBT) and interpersonal psychotherapy (IPT) are both effective treatments for depressive disorders, but access is limited. Online CBT interventions have demonstrated efficacy in decreasing depressive symptoms and can facilitate the dissemination of therapies among the public. However, the efficacy of Internet-delivered IPT is as yet unknown.

Objective: This study examines whether IPT is effective, noninferior to, and as feasible as CBT when delivered online to spontaneous visitors of an online therapy website.

Methods: An automated, 3-arm, fully self-guided, online noninferiority trial compared 2 new treatments (IPT: n=620; CBT: n=610) to an active control treatment (MoodGYM: n=613) over a 4-week period in the general population. Outcomes were assessed using online self-report questionnaires, the Center for Epidemiological Studies Depression scale (CES-D) and the Client Satisfaction Questionnaire (CSQ-8) completed immediately following treatment (posttest) and at 6-month follow-up.

Results: Completers analyses showed a significant reduction in depressive symptoms at posttest and follow-up for both CBT and IPT, and were noninferior to MoodGYM. Within-group effect sizes were medium to large for all groups. There were no differences in clinical significant change between the programs. Reliable change was shown at posttest and follow-up for all programs, with consistently higher rates for CBT. Participants allocated to IPT showed significantly lower treatment satisfaction compared to CBT and MoodGYM. There was a dropout rate of 1294/1843 (70%) at posttest, highest for MoodGYM. Intention-to-treat analyses confirmed these findings.

Conclusions: Despite a high dropout rate and lower satisfaction scores, this study suggests that Internet-delivered self-guided IPT is effective in reducing depressive symptoms, and may be noninferior to MoodGYM. The completion rates of IPT and CBT were higher than MoodGYM, indicating some progress in refining Internet-based self-help. Internet-delivered treatment options available for people suffering from depression now include IPT.

Trial Registration: International Standard Randomized Controlled Trial Number (ISRCTN): 69603913; http://www.controlled-trials.com/ISRCTN69603913 (Archived by WebCite at http://www.webcitation.org/6FjMhmE1o)

(J Med Internet Res 2013;15(5):e82) doi:10.2196/jmir.2307

KEYWORDS

interpersonal relations; cognitive behavior therapy; depressive disorder; Internet; randomized controlled trial

Introduction

Depression is a highly prevalent mental disorder [1] and it is expected to rank as the leading cause of burden of disease in high-income countries by 2030 [2]. Depression is associated with serious disability [3], loss in quality of life [4], and substantial economic costs both at an individual and a societal level [5,6]. Both pharmacological and psychological treatments for depressive disorders are effective in reducing symptoms [7]. Clinical practice guidelines recommend cognitive behavior therapy (CBT) and interpersonal psychotherapy (IPT) as options for psychological treatment [8-10]. CBT is based on the cognitive theory that negative automatic thoughts, maladaptive information processing, and avoidance behavior play a key role in the development and maintenance of depression [11]. IPT originates from interpersonal theory [12]. It links stressful life events and insufficient social support to the development and maintenance of depressive symptoms [13]. Both psychotherapies are brief, highly structured, and can be manualized. CBT and IPT have shown to be effective in reducing depression symptoms compared to treatment as usual [7,14,15]. Meta-analyses show that, when compared head-to-head, CBT and IPT do not differ significantly from one another in their effectiveness [7,14,15].

Both CBT and IPT require significant therapist time. Long waiting lists caused by low workforce numbers are common [16]. Perceived social stigma, which hinders help seeking [17], and high costs [18] may discourage individuals with a psychiatric disorder from seeking professional help. Internet-based self-help interventions offer potential solutions to these barriers. Immediately accessible and less costly, online interventions may offer a valuable alternative to face-to-face therapy. Previous studies and meta-analyses have demonstrated unguided Internet-based self-help interventions to be effective for common mental disorders, with a pooled effect size of 0.28, but dropout rates are high [8]. CBT programs have been successfully delivered on the Internet [19,20]. However, to our knowledge, no study has examined the effectiveness of Internet-based IPT.

The present study examined the effectiveness of Internet-delivered IPT and a new Internet-delivered CBT module (from e-couch [21]) compared to an online CBT intervention (MoodGYM). MoodGYM was originally developed for youth, but has known efficacy in reducing depressive symptoms in adults [22-24]. The trial was designed within a noninferiority framework. Noninferiority trials are used when there is clear evidence of efficacy for an existing standard treatment, such that it is ethically unacceptable to employ a placebo or inactive control group [25] and when a new treatment is hypothesized to have comparable, but not necessarily superior, effectiveness to the established intervention [26]. We hypothesized that the new Internet-delivered modules of IPT and CBT would be noninferior to a CBT module (MoodGYM) in reducing symptoms of depression and anxiety. We also predicted that the Internet-delivered IPT module would be rated by its users as being as feasible, acceptable, and satisfactory as MoodGYM.

Method

Participants and Procedure

This automated, 3-arm, fully self-guided, online noninferiority trial compared 2 new treatments (IPT and CBT) to an active control treatment (MoodGYM) for depressed individuals. The Internet-delivered CBT and IPT interventions (from e-couch) were developed at the Centre for Mental Health Research (CMHR) at the Australian National University (ANU). The e-couch program targets a range of conditions currently (depression, generalized anxiety disorder, social anxiety disorder) with other conditions to be added in the future. It also provides modules for bereavement and loss, as well as divorce and separation. It comprises a mental health literacy component and psychotherapeutic components for each condition (eg, CBT, IPT, applied relaxation, physical activity, and behavioral activation for depression). This study compared the IPT and CBT components with the 4-module version of MoodGYM. To increase external validity, there was no specific promotion for the trial. Spontaneous visitors from around the world who registered on the e-couch Internet website [21] between October 2009 and October 2010 and who showed interest in participating in the research trial (by clicking a “I want more information about the trial” button), were given information about the study. Those who provided both informed consent to participating in the trial (by clicking on the “I agree” button on the webpage) and an email address were then asked to complete an online baseline screening survey. Individuals who were 18 years of age or older and not currently receiving treatment for depression by a mental health specialist were eligible for inclusion in the study. Individuals with suicide intention, as measured with a suicidal ideation screening item on the Web Screening Questionnaire (WSQ) [27], or those who scored above 27 (95th percentile or higher) on the Center for Epidemiological Studies Depression scale (CES-D) at baseline, were immediately provided with an information page containing advice about obtaining appropriate professional help, including emergency help. They could, however, continue to participate in the study. Excluded were individuals who were health professionals treating people with depression or anxiety, researchers reviewing depression or anxiety sites, or students studying anxiety or depression as part of a college or university course. Individuals who did not meet the inclusion criteria were directed to the public version of the e-couch program, which provides interventions for depression, generalized anxiety disorder, and social phobia. Individuals were not required to provide their real names, but were asked to use a pseudonym instead. Ethical approval for the study was provided by the Human Research Ethics Committee of the ANU (protocol number 2008/269).

Participants were randomly assigned to MoodGYM, CBT, or IPT, stratified by sex, age, and presenting depression symptom severity. The randomization schedule for participant allocation to condition groups was prepared by using an automated system built into the trial software, and randomization occurred automatically. The allocation sequence was concealed from the researchers. Participants randomized to the intervention groups were aware of the allocated arm. Following randomization, an automated email containing log-in details for the assigned program was sent to each participant, at which point the intervention could be accessed immediately.

Interventions

All programs were offered over 4 weeks. Users were required to complete the modules in order. Participants were able to revisit previous pages of the modules and scores of previous assessments, but were not able to repeat the assessments. Each week an automated email was sent to advise participants of the availability of their new module. Participants were always offered the option to pause and restart at their chosen time. See Figures 1-3 for screenshots of the 3 programs.

Internet-Delivered Cognitive Behavioral Therapy (CBT e-couch)

The Internet-delivered CBT intervention comprised 1 component of the depression stream of e-couch [21] and is based on the principles of CBT [11]. In addition to an explanation of the rationale of CBT, the program consisted of 3 major modules: identifying negative thoughts, tackling negative thoughts, and undertaking behavioral activation (based on activity scheduling developed by Lewinsohn [28]). The program contained 18 exercises and assessments in total, which were saved in a personal workbook.

Internet-Delivered Interpersonal Psychotherapy (IPT e-couch)

The Internet-delivered form of IPT comprised 1 component of the depression stream of e-couch [21]. It consisted of 4 modules (grief, role disputes, role transition, and interpersonal deficits) and a personal workbook (containing 13 exercises and assessments). The IPT program was based on the IPT clinician manual of Weissman et al [13], with each of the 4 IPT areas constructed to reflect the areas and topics relevant to each area. Interactive exercises reflected the topics and questions described in the Interpersonal Inventory. Participants did not choose IPT areas, but could decide the order in which they were completed; exercises within each of the IPT areas were not compulsory.

Internet-Delivered CBT (MoodGYM)

The online CBT package comprised a 4-module version of MoodGYM [29] delivered over 4 weeks. The details of the program are described elsewhere [30,31]. In this trial, a set of 4 of the CBT modules, a personal workbook (containing 22 exercises and assessments), and a feedback evaluation form were used. The modules cover the identification of and behavioral methods to overcome dysfunctional thinking, assertiveness, and self-esteem training. Each module takes approximately 20 to 40 minutes to complete [31]. The relaxation module was removed from the program for this study to match the time length of the other 2 programs. Previous research has demonstrated that this component is not needed for efficacy [31].

Measures

All questionnaires comprised online standard self-report measures taken at baseline (pretest), immediately after the intervention (posttest), and 6 months after the intervention (follow-up). Measures of participant characteristics were collected at baseline, symptoms measures were administered at all 3 time points, and user satisfaction was collected at posttest.

Participant Characteristics

The survey included questions concerning sociodemographic characteristics (age, gender, country of origin, location, and education level), previous history of depression, previous use of treatments for depression, marital status, preference for randomization condition, perceived need for treatment, and current medication.

Primary Outcome Measures: Depressive Symptoms

Center for Epidemiological Studies Depression Scale

The 20-item self-report CES-D was used to assess depressive symptoms (item score: 0-3; total score range: 0-60) [32]. The Internet CES-D is reliable and valid with a cut-off score of 22 (sensitivity: 0.94; specificity: 0.62) [33]. The Cronbach alpha in this study was .90. Because the CES-D was administered online, a cut-off score of 22 is used in this study.

Secondary Outcomes: Satisfaction, User-Perceived Benefits, and Adherence

Client Satisfaction Questionnaire

The Client Satisfaction Questionnaire (CSQ-8) assesses global client satisfaction with treatments [34]. The 8-item self-report questionnaire uses scale response options from 1 to 4, with total score ranges from 8 to 32. Previous research has reported that the CSQ-8 has high internal consistency [35] and was comparable to the Cronbach alpha in this study (Cronbach alpha=.90).

Treatment Preference

Preference for randomization condition was assessed by asking the question “Do you have a preference to be in one of the programs?” at baseline. Participants replied with no preference or “yes, program 1, 2, 3.” These data were included in the analyses (no preference, preference: match/no match).

Adherence

Adherence was measured in 2 ways for each individual: (1) completion of posttest surveys (all groups), and (2) the number of IPT, CBT, or MoodGYM modules completed.

Statistical Analysis

Noninferiority trials require the a priori specification of a noninferiority margin. We used the confidence interval (CI) approach [36] to define the noninferiority margin for this study. The noninferiority margin of the primary outcome measure CES-D was set at a lower-bound 95% CI pre-post within-group effect size of 0.33, which was based on the lower-bound 95%

CI margin of the pre-post within-group effect size of 0.56 (95% CI 0.33-0.79) of MoodGYM [24]. To decrease the risk of type 1 error (false acceptance of an ineffective treatment), the standard deviation (SD) of the pretest was used in calculating the lower-bound 95% CI margin of the effect size of 0.56; this yields a conservative estimate of benefit. For noninferiority trials, the null is E-S≤-delta and the alternative hypotheses (1-sided) is E-S>-delta, where *E* is the experimental treatment and *S* is the standard treatment. Figure 4 shows the formula for calculating the *t* test statistic when testing noninferiority (using the formula of Mascha and Sessler [26]).

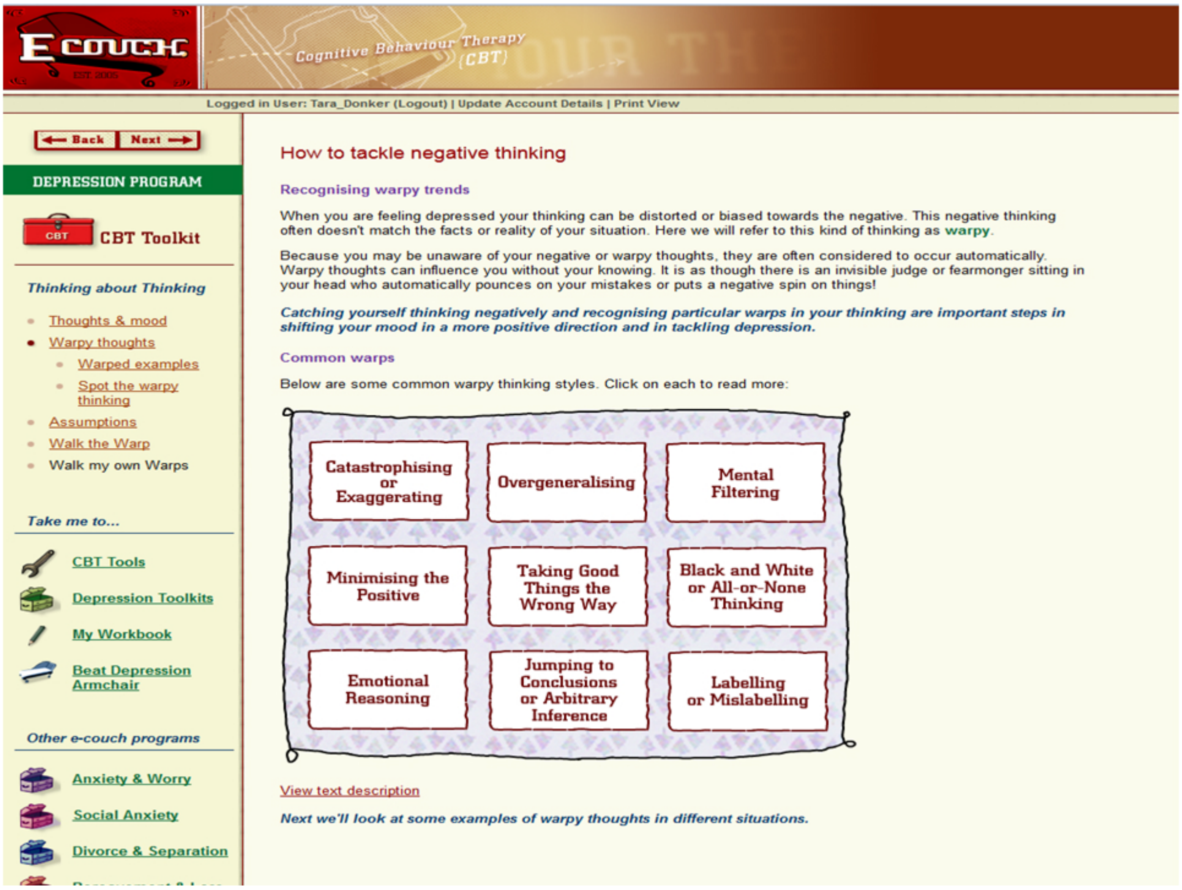
The null hypothesis is rejected to claim noninferiority of the standard control treatment and the new treatment, if *T* is larger than the value of *T* from a *t* distribution with n_E–n_S–2df at 1–alpha. The *P* value is the probability of observing a larger value of *T*l, if the null hypothesis (ie, inferiority) were true in the population sampled from. For a *P* value less than alpha, we reject the null hypothesis and conclude noninferiority [26]. As this was a noninferiority trial, this criterion did not apply for the upper bound of the CI. Using 1-beta=.90 and alpha=.05 (2-sided), we needed at least 150 participants in each condition at posttest (a total sample of 450 participants) to reach sufficient statistical power.

Data integrity (distribution, outliers, skewness, and kurtosis) tests were conducted. Measures of skewness and kurtosis indicated deviations from normality for baseline CES-D scores because of some extreme responses. The Box-Cox model omitting the pretest scores was fitted and the transformed data were compared with the raw data using mixed model analyses. For ease of interpretation of the test results, only raw data are reported because the conclusions were the same. The baseline characteristics of the 3 groups were compared by using 1-way analysis of variance (ANOVA), and Kruskal-Wallis and Mann-Whitney U tests for continuous measures and chi-square (χ^2) tests for categorical variables.

In noninferiority trials, intention-to-treat (ITT) analysis will often increase the risk of falsely claiming noninferiority (type I error) [37]. Non-ITT analyses are preferred as a protection from ITTs increase of type I error risk [38]. Therefore, the effects of the interventions were analyzed by using both ITT analyses and per-protocol approaches as recommended for noninferiority trials by Piaggio et al [38]. There is greater confidence in results when the conclusions are consistent [38].To conduct the per-protocol analysis, 2 groups were created: those who returned the posttest and follow-up surveys (completers), and those who completed half or more of the treatment modules and returned the surveys (adherent completers). Linear mixed models (LMM) were used for both types of analyses. Restricted maximum likelihood estimation was used with an unstructured covariance structure accommodation with participant effects. The LMM gives unbiased estimates of ITT effect under the assumption that data from participants who withdrew were missing at random (MAR). Test time was treated as a categorical variable because we were interested in the differences between groups on each occasion of measurement.

Between-group and within-group effect sizes were calculated according to Cohen’s *d* (standardized mean difference) [39]. Clinically meaningful changes on the CES-D were assessed using the clinically significant change (CSC) formula (with a CES-D score <22) and the reliable change index (RCI) [40]. The RCI reflects the degree of change that occurred beyond the fluctuations of an imprecise measuring instrument, with values greater than 1.96 representing statistically significant change [41]. In the present study, pretest SD scores of the CES-D with a reliability of 0.90 were used in the RCI formula. In addition, analyses were also undertaken for the subsample of participants who had symptoms severe enough to be considered clinical cases at baseline (score ≥22 on the CES-D). Chi-square tests and 1-way ANOVA tests with Bonferroni correction at posttest were used to examine differences in treatment completers and noncompleters (those who completed less than half of the modules). Statistical analyses were conducted using SPSS version 19.0, except for the Box-Cox transformation procedures, which were conducted using Stata 9.

Figure 1. Screenshot of e-couch cognitive behavior therapy (CBT) website.



How to tackle negative thinking

Recognising warpy trends

When you are feeling depressed your thinking can be distorted or biased towards the negative. This negative thinking often doesn't match the facts or reality of your situation. Here we will refer to this kind of thinking as warpy.

Because you may be unaware of your negative or warpy thoughts, they are often considered to occur automatically. Warpy thoughts can influence you without your knowing. It is as though there is an invisible judge or fearmonger sitting in your head who automatically pounces on your mistakes or puts a negative spin on things!

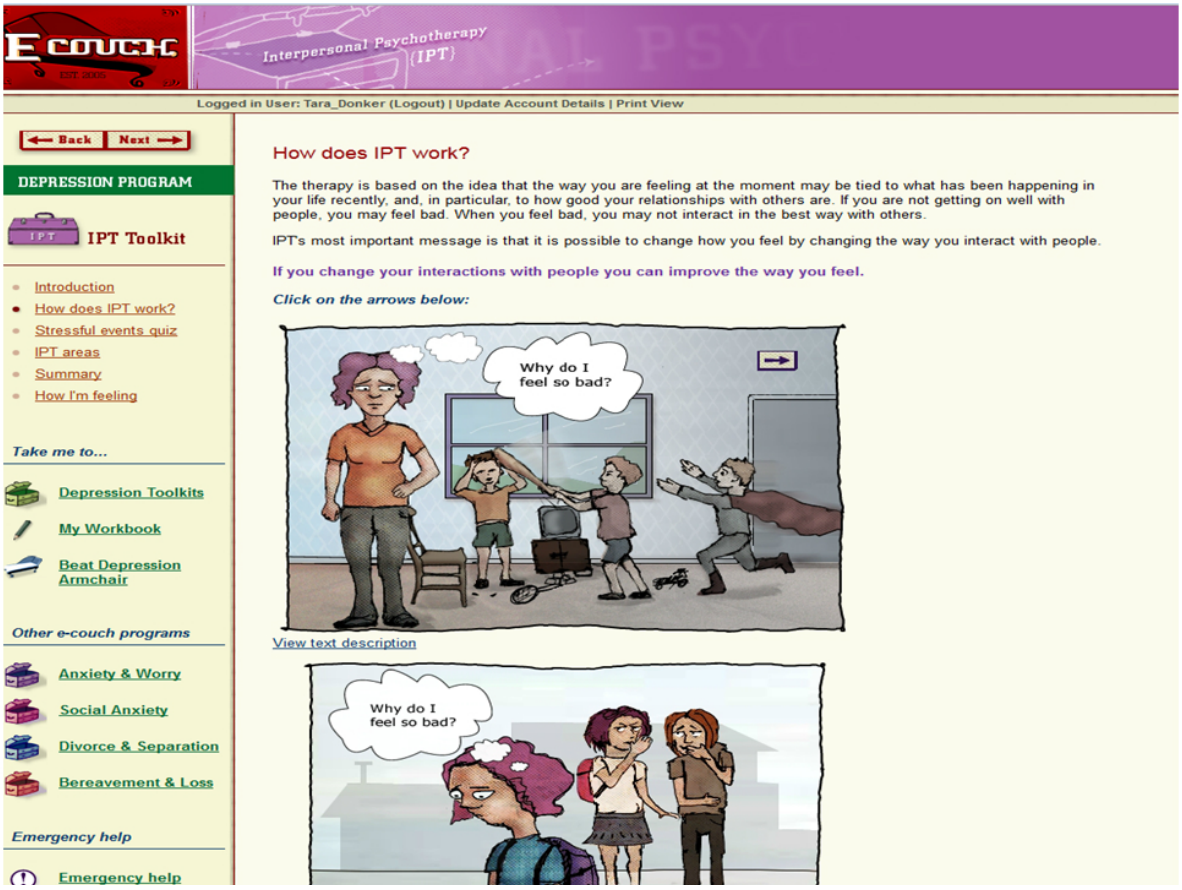
Catching yourself thinking negatively and recognising particular warps in your thinking are important steps in shifting your mood in a more positive direction and in tackling depression.

Common warps

Below are some common warpy thinking styles. Click on each to read more:

Next we'll look at some examples of warpy thoughts in different situations.

Figure 2. Screenshot of e-couch interpersonal psychotherapy (IPT) website.



How does IPT work?

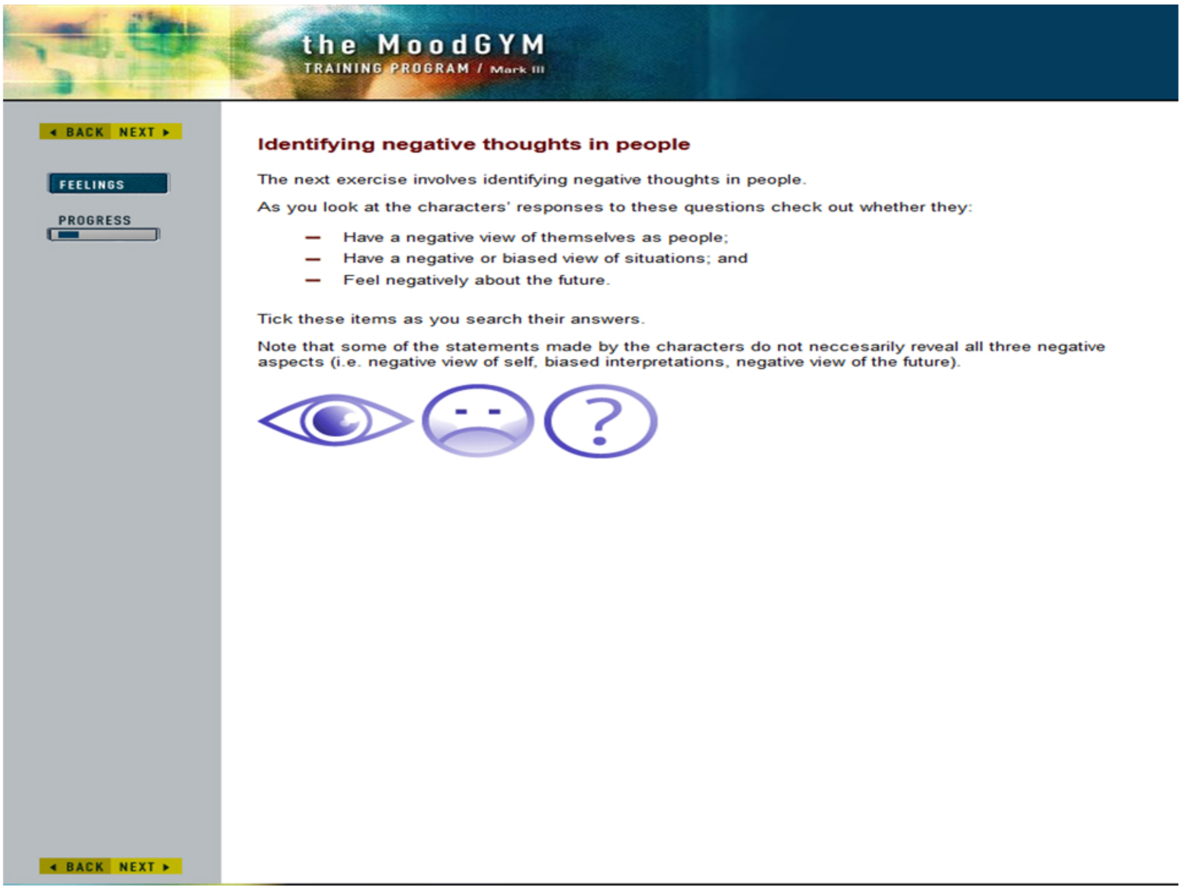
The therapy is based on the idea that the way you are feeling at the moment may be tied to what has been happening in your life recently, and, in particular, to how good your relationships with others are. If you are not getting on well with people, you may feel bad. When you feel bad, you may not interact in the best way with others.

IPT's most important message is that it is possible to change how you feel by changing the way you interact with people.

If you change your interactions with people you can improve the way you feel.

Click on the arrows below:

Figure 3. Screenshot of MoodGYM website.



Identifying negative thoughts in people

The next exercise involves identifying negative thoughts in people.

As you look at the characters' responses to these questions check out whether they:

- Have a negative view of themselves as people;
- Have a negative or biased view of situations; and
- Feel negatively about the future.

Tick these items as you search their answers.

Note that some of the statements made by the characters do not neccesarily reveal all three negative aspects (i.e. negative view of self, biased interpretations, negative view of the future).

Figure 4. Formula of Mascha and Sessler.

$$T = \frac{(\mu_E - \mu_s) + \delta}{\sqrt{s_p^2\left(\frac{1}{n_E} + \frac{1}{ns}\right)}}$$

Results

Participants

Of the 10,598 individuals who registered on e-couch during the trial period, 5796 expressed interest in the trial and proceeded to screening. Of these, 3166 did not meet the eligibility criteria (eg, under 18 years of age or currently receiving treatment for depression by a mental health specialist) and were excluded from the study. Of the remaining 2630 participants, 2045 provided informed consent; however, 116 of these did not subsequently verify their email address. Accordingly, a total of 1929 participants were randomized to 1 of the 3 conditions. However, 66 of these participants were excluded after randomization because it became apparent that they were ineligible at baseline for participation (eg, being a researcher or a student, n=21). In addition, 45 randomized participants did not complete the baseline assessment. This was missed at first screening because of a technical fault, but was picked up subsequently. Figure 5 shows the flowchart of participants (CONSORT-EHEALTH checklist [42] presented in Multimedia Appendix 1).

Of the total sample (N=1843), 543 (29.46%) were aged between 25 to 29 years, and most were female, (1334/1843, 72.38%). Participants were primarily Australian or New Zealand residents (751/1843, 40.75%) and most were well educated, having completed postsecondary education (1606/1843, 87.14%). The mean CES-D baseline score was 36 (SD 11.52). There were no significant differences between the groups at baseline with respect to depressive symptoms (χ^2_2= 3.1, *P*=.21), demographic characteristics (see Table 1), or treatment preference before randomization (*P*=.73).

Treatment Adherence and Attrition

In total, 30% (549/1843) of participants completed the posttest assessment and 28% (336/1843) completed the follow-up assessment. Of participants who were adherent to the program (completed 50% or more of the modules), 25.8% (476/1843) and 16% (294/1843) completed posttest and follow-up assessments, respectively. Of the IPT participants, 49.5% (307/620) completed at least half of the intervention (≥2 modules) and 27.3% (169/620) completed all modules. For the CBT participants, 37.7% (230/610) finished 2 or more modules and 14.4% (88/610) completed all modules. A total of 195 of 613 participants (31.8%) finished half or more of the MoodGYM program. Of these, 10.9% (67/613) finished the whole program. Reasons given for dropout included technical problems, personal issues (lack of time), disease-specific barriers (feeling too depressed to work on the program or not convinced that the program would help), general intervention problems (programs was taking too long, too much text to read, boring, or too repetitive), specific intervention issues (the examples were not relevant to the participant), or engagement issues (preferred to obtain help from somewhere other than a computer). However, most participants (1248/1294, 96%) did not provide any reason for dropout. Those who dropped out of treatment had significantly higher scores on the CES-D (χ^2_1=4.3, *P*=.04), but differences were small (mean difference 1.26). Furthermore, dropout rates were significantly higher for participants assigned to MoodGYM (451/613, 74%) compared with IPT (414/620, 67%) or CBT (429/610, 70%; χ^2_2= 6.8, *P*=.03). Those who dropped out of treatment were more likely to be female (914/1294, 71%; χ^2_1= 6.6, *P*=.01), and under 50 years of age (1090/1294, 84%; χ^2_1=21.6, *P*<.001). No significant differences were found for medication use (*P*=.73), treatment preference (*P*=.14), or marital status (*P*=.60).

Effectiveness and Noninferiority

Results are presented for 3 groups: all participants (all those enrolled in the trial, ITT), completers (those completing online surveys at posttest and at 6-month follow-up), and adherent completers (those completing ≥50% of the modules).

For completers, the within-group effect sizes on the primary outcome measure CES-D were large for all treatments at posttest (IPT *d*=0.76 vs CBT *d*=0.87) and follow-up (IPT *d*=1.02 vs CBT *d*=1.44). Between-group effect sizes were small (posttest: IPT vs MoodGYM *d*=0.14, 95% CI –0.06 to 0.35; CBT vs MoodGYM *d*=0.05, 95% CI –0.17 to 0.26; follow-up: IPT vs MoodGYM *d*=0.18, 95% CI –0.09 to 0.45; CBT vs MoodGYM *d*=0.12, 95% CI –0.15 to 0.39). Within-group effect sizes for adherent completers ranged from *d*=0.74 to *d*=0.90 at posttest and *d*=1.02 to *d*=1.33 at follow-up. The between-group effect size for IPT vs MoodGYM was higher (posttest: *d*=0.23, 95% CI 0.0-0.46; follow-up: *d*=0.31, 95% CI 0.02-0.60) than that for CBT vs MoodGYM (posttest: *d*=0.02, 95% CI –0.25 to 0.22; follow-up: *d*=0.04, 95% CI –0.26 to 0.34). The ITT analyses yielded medium within-group effect sizes (*d*=0.59 to *d*=0.67 at posttest and *d*=0.66 to *d*=0.80 at follow-up). Between-group effect sizes were small (posttest: IPT vs MoodGYM *d*=0.09, 95% CI–0.02 to 0.21); CBT vs MoodGYM *d*=0.01, 95% CI –0.10 to 0.12; follow-up: IPT vs MoodGYM *d*=0.09, 95% CI –0.02 to 0.21; CBT vs MoodGYM *d*=0.03, 95% CI –0.08 to 0.14). See Table 2 and Multimedia Appendix 2.

The previously determined noninferiority margin (*d*=0.33) was converted to delta=3.795 points differences on the CES-D (based on a SD of 11.5). Using the formula of Mascha and Sessler [26], a completers analysis indicated that IPT compared to MoodGYM was found to be noninferior at posttest (t_{366}=4.046, *P*<.001, 95% CI –0.89 to 4.73). The mean difference between IPT and MoodGYM on the CES-D for completers at posttest was 1.92 points (95% CI –0.86 to 4.70, *P*=.17). MoodGYM participants scored nonsignificantly lower at posttest. CBT completers were also found to be noninferior to MoodGYM (t_{341}=2.142, *P*=.02; 95% CI –3.57 to 2.33), with a mean difference at posttest of 0.62 points (lower for CBT) which was not statistically significant (95% CI –2.30 to 3.54, *P*=.68). For adherent completers, results were similar (IPT vs MoodGYM posttest: t_{316}=4.506, *P*<.001; CBT vs MoodGYM posttest: t_{282}=2.246, *P*<.001; 95% CI –3.39 to 2.91). There was a nonsignificant mean difference between IPT and MoodGYM on the CES-D for adherent completers at posttest of 3.05 which was higher for IPT (95% CI 0.06-6.04, *P*=.05), but not for CBT vs MoodGYM (mean difference: 0.24; 95% CI –2.88 to 3.36, *P*=.88, lower for CBT). An ITT analysis also indicated that IPT and CBT were found to be noninferior to MoodGYM (IPT: t_{1231}=4.769, *P*<.001, 95% CI –0.41 to 4.43; CBT: t_{1221}=3.207, *P*<.001, 95% CI –2.27 to 2.71). Mean depression scores were not significantly different across the 3 programs at posttest (IPT vs MoodGYM: 2.01, 95% CI –0.32 to 4.34, *P*=.09, higher for IPT; CBT vs MoodGYM: 0.22, 95% CI: –2.17 to 2.61, *P*=.86, higher for CBT).

Table 2 presents the means and SDs for completers, adherent completers, and the ITT sample as produced by the LMM procedure. Because LMM does not yield SDs, we calculated them manually by using the formula SD=SEM×√N. For the completers of posttest and/or follow-up, there was a significant overall improvement over time for all groups on the CES-D ($F_{2,434.0}$=290.309, *P*<.001). There was no significant group×time interaction effects on the CES-D at posttest ($F_{4,436.3}$=1.15, *P*=.33). Results were similar for the ITT sample and the adherent completers (see Table 3).

Residuals of the models were inspected and showed nonnormality. Therefore, to be thorough, power transforms were estimated fitted using a Box-Cox model that included the same terms as the mixed model omitting the pretest scores. The test of deviations of residuals from normality was significant for just the IPT group at posttest ($t_{386.273}$=2.36, *P*=.02). We compared the contrast results by using the transformed data to the raw data, indicated that they have the same pattern of significance. Because the normality violation was not profound and because it is easier to interpret raw data (and retransformation of model estimates is not always appropriate), we have presented raw data in this paper.

Table 1. Baseline demographic, socioeconomic, and clinical characteristics of participants for the e-couch cognitive behavioral therapy (CBT), the e-couch interpersonal psychotherapy (IPT), and the MoodGYM website.

Condition	All participants	MoodGYM	CBT	IPT
n/N (%)	1843 (100)	613 (33.26)	610 (33.10)	620 (33.64)
Female, n (%)	1334 (72.38)	438 (71.45)	445 (72.95)	451 (72.74)
Age group (years), n (%)				
18-24	307 (16.66)	100 (16.31)	92 (15.08)	115 (18.55)
25-34	543 (29.46)	181 (29.52)	188 (30.82)	174 (28.06)
35-44	470 (25.50)	145 (23.65)	164 (26.88)	161 (25.97)
45-55	338 (18.34)	111 (18.11)	113 (18.52)	114 (18.39)
>55	185 (10.04)	76 (12.39)	53 (8.69)	56 (9.03)
Country of residence, n (%)				
Australia and New Zealand	751 (40.75)	254 (41.44)	239 (39.18)	258 (41.61)
United Kingdom	454 (24.63)	148 (24.14)	157 (25.73)	149 (24.03)
United States	350 (18.99)	112 (18.27)	115 (18.85)	123 (19.84)
Canada	100 (5.43)	28 (4.57)	36 (5.90)	36 (5.81)
Other	188 (10.20)	71 (11.58)	63 (10.32)	54 (8.71)
Spouse	914 (49.59)	301 (49.10)	310 (50.82)	303 (48.87)
Education				
None, or primary	21 (1.13)	11 (1.79)	4 (0.66)	6 (0.97)
Secondary	216 (11.72)	70 (11.42)	67 (10.98)	79 (12.74)
Postsecondary	1606 (87.14)	532 (86.79)	539 (88.36)	535 (86.29)
Baseline CES-D[a], mean (SD)	36.01 (11.52)	35.34 (11.61)	36.29 (11.04)	36.38 (11.86)
Current medication[b], n (%)	754 (40.91)	253 (41.27)	255 (41.80)	246 (39.68)

[a] CES-D: Center for Epidemiological Studies Depression scale.

[b] Any prescribed current medication.

Figure 5. Flowchart of participants.

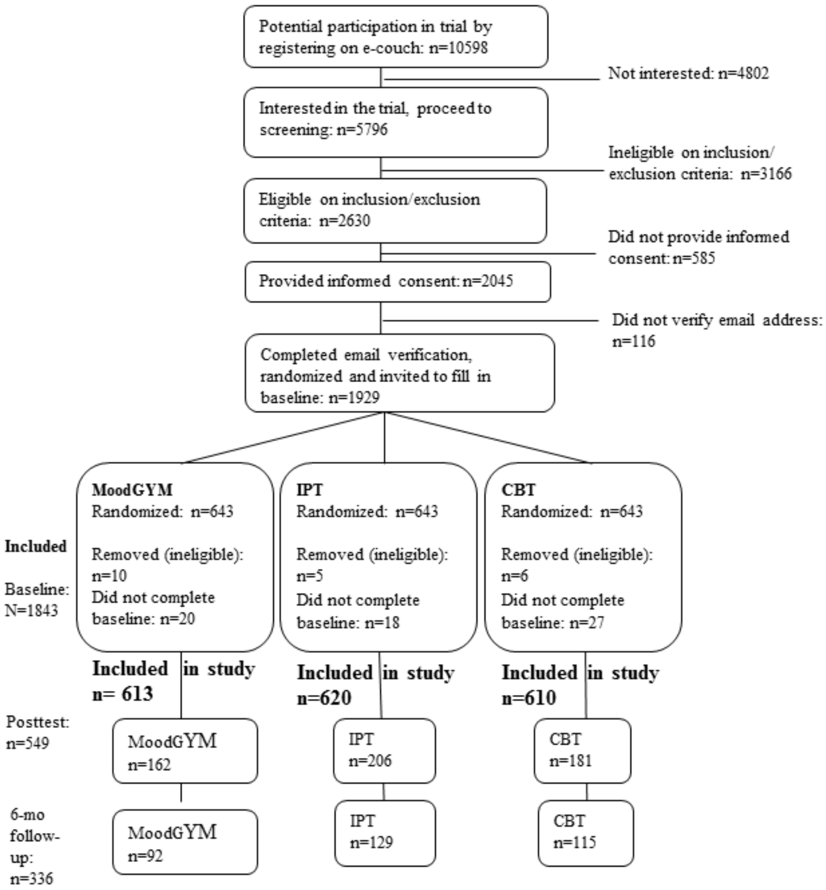


Table 2. Results and effect sizes (Cohen's *d*) for the Center for Epidemiological Studies Depression scale (CES-D) for completers and adherent completers, and for intention-to-treat (ITT) analyses.

Program	Test time, n; mean (SD)			Within-group effect size, *d* (95% CI)		Between-group effect size, *d* (95% CI)		
	Pretest	Posttest	Follow-up	Pre-post	Pre–follow-up[a]	Program	Posttest	Follow-up (95% CI)
Completers of posttest (n=549) and/or follow-up (n=336)								
IPT	206; 35.65 (11.85)	206; 26.22 (12.92)	129; 22.41 (13.84)	0.76 (0.56,0.96)	1.02 (0.76,1.28)	IPT vs MoodGYM	0.14 (–0.06,0.35)[b]	0.18 (–0.09,0.45)[b]
CBT	181; 34.46 (11.31)	181; 23.68 (13.34)	115; 18.17 (12.15)	0.87 (0.65,1.09)	1.44 (1.15,1.72)	CBT vs MoodGYM	0.05 (–0.17,0.26)[c]	0.12 (–0.15,0.39)[c]
MoodGYM	162; 35.19 (12.44)	162; 24.30 (14.10)	92; 19.79 (14.92)	0.82 (0.59,1.04)	1.04 (0.72,1.34)			
Adherent completers of posttest (n=476) and/or follow-up (n=294)								
IPT	192; 35.60 (11.79)	192; 26.38 (13.25)	119; 22.50 (13.55)	0.74 (0.53,0.94)	1.02 (0.74,1.28)	IPT vs MoodGYM	0.23 (0.0,0.46)[b]	0.31 (0.02,0.60)[b]
CBT	158; 34.30 (11.79)	158; 23.09 (13.25)	101; 17.75 (13.55)	0.89 (0.65,1.11)	1.33 (1.02,1.63)	CBT vs MoodGYM	0.02 (–0.25,0.22)[c]	0.04 (–0.26,0.34)[c]
MoodGYM	126; 34.41 (11.32)	126; 23.33 (13.25)	74; 18.30 (13.55)	0.90 (0.64,1.16)	1.21 (0.86,1.56)			
ITT posttest and follow-up (N=1843)								
IPT	620; 36.38 (11.51)	620; 26.59 (20.27)	620; 23.17 (25.60)	0.59 (0.48,0.71)	0.67 (0.55,0.78)	IPT vs MoodGYM	0.09 (–0.02,0.21)[b]	0.09 (–0.02,0.21)[b]
CBT	610; 36.29 (11.51)	610; 24.80 (21.34)	610; 19.68 (26.85)	0.67 (0.55,0.79)	0.80 (0.69,0.92)	CBT vs MoodGYM	0.01 (–0.10,0.12)[b]	0.03 (–0.08,0.14)[c]
MoodGYM	613; 35.34 (11.52)	613; 24.58 (22.43)	613; 20.56 (29.69)	0.60 (0.49,0.72)	0.66 (0.54,0.77)			

[a] Within-group follow-up effect size for completers is based upon the following pretest scores: IPT (n=129, mean 35.66, SD 12.05); CBT (n=115, mean 34.89, SD 11.05); MoodGYM (n=92, mean 34.13, SD 12.65); within-group follow-up effect size for adherent completers is based upon the following pretest scores: IPT (n=119, mean 35.48, SD 11.91); CBT (n=101, mean 34.68, SD 11.90); MoodGYM (n=74, mean 33.77, SD 11.92).

[b] In favor of MoodGYM.

[c] In favor of CBT.

Table 3. Effectiveness of Internet-delivered programs with depression score (CES-D) as dependent variable.

Depression score	Posttest				Follow-up			
	Time		Group×time		Time		Group×time	
	F (df)	*P*	*F* (df)	*P*	*F* (df)	*P*	*F* (df)	*P*
Total sample								
Completers	290.309 (2,434.0)	<.001	1.15 (4,436.3)	.33	237.187 (2,315.1)	<.001	1.20 (4,315.3)	.31
Adherent completers	260.021 (2,386.7)	<.001	1.52 (4,388.3)	.20	216.083 (2,284.1)	<.001	1.426 (4,284.5)	.23
Intention-to-treat	382.60 (2,484.155)	<.001	1.45 (4,483.246)	.22		<.001		
Clinical cases								
Completers	306.190 (2,368.8)	<.001	.976 (4,369.4)	.42	223.572 (2,242)	<.001	0.824 (4,242)	.51
Adherent completers	275.800 (2,327.7)	<.001	1.39 (4,328.3)	.24	230.990 (2,242.9)	<.001	1.056 (4,243.1)	.38
Intention-to-treat	306.190 (2,368.8)	<.001	0.976 (4,451.2)	.42				

Clinically Significant Change and Reliable Change Index for Completers

For completers, no significant differences in CSC were found between the 3 programs at posttest (χ^2_2=1.78, P=.41) and follow-up (χ^2_2=3.70, *P*=.16). The number of participants showing CSC at posttest were n=61 for IPT, n=65 for CBT, and n=52 for MoodGYM. For adherent completers, results were similar. Using the formula of Jacobson and Truax [40] for RCI (the degree of change that occurred beyond the fluctuations of an imprecise measuring instrument) with a Cronbach alpha of .90, all programs reached the RCI critical value of 1.96 at posttest (IPT: 2.01; CBT: 2.41; MoodGYM: 2.21) and follow-up (IPT: 2.78; CBT: 3.82; MoodGYM: 2.86). The RCI results were similar for adherent completers at posttest (IPT: 1.97; CBT: 2.40; MoodGYM: 2.47) and follow-up (IPT: 2.76; CBT: 3.59; MoodGYM: 3.28; see Table 4).

Clinical Cases

Analyses were also undertaken for the subsample of participants who had symptoms severe enough to be considered clinical cases at baseline. A CES-D value of ≥22 is considered to indicate clinical caseness [31]. For the ITT sample scoring ≥22 on the CES-D, analyses showed a significant overall improvement over time for all groups on the CES-D ($F_{2,368.8}$=306.190, *P*<.001). No differences between the treatments over time were found on the CES-D ($F_{4,451.2}$=0.976, *P*=.42). Within-group effect sizes on the primary outcome measure CES-D were small for all treatments at posttest (IPT *d*=0.55; CBT and MoodGYM *d*=0.56) and medium at follow-up (CBT *d*=0.65; MoodGYM *d*=0.61) except for IPT, which was small (IPT *d*=0.58). The RCI was below the critical value of 1.96 at posttest for all programs. At follow-up, all programs reached the critical value of 1.96 (IPT: 2.26; CBT: 2.51; MoodGYM: 2.46). For completers and adherent completers scoring ≥22 on the baseline CES-D, results were similar (see Table 3). RCI for completers was above 1.96 for all programs at posttest (IPT: 2.93; CBT: 3.26; MoodGYM: 3.47) and follow-up (IPT: 3.84; CBT: 4.80; MoodGYM: 4.97). RCI for adherent completers was above 1.96 for all programs at posttest (IPT: 2.95; CBT: 3.40; MoodGYM: 3.57) and follow-up (IPT: 4.00; CBT: 4.93; MoodGYM: 4.77, see Multimedia Appendix 3).

Treatment Satisfaction

There was a significant difference between the 3 interventions in treatment satisfaction scores at posttest for completers as measured with the CSQ-8 ($F_{2,535}$=18.75, *P*<.001). Post hoc analyses using Tukey's honestly significant difference (HSD) test showed that participants randomized to IPT (n=201) had a significantly lower total satisfaction score (mean 20.55, SD 4.80) compared to MoodGYM (n=158; mean 22.81, SD 4.58) with a mean difference of 2.26 (SD 0.49, *P*<.001) and CBT (n=179; mean 23.26, SD 4.47) with a mean difference of 2.71 (SD 0.48, *P*<.001).

Table 4. Proportion of participants reaching the criteria for clinically significant change (score <22) on the Center for Epidemiological Studies Depression scale (CES-D).

Treatment condition	Baseline caseness, n (%)	Clinically significant change			
		Posttest n (%)		6-month follow-up n (%)	
		Completers[a]	Adherent completers[b]	Completers[c]	Adherent completers[d]
IPT (n=610)	581 (95.2)	61 (32.0)	55 (32.7)	54 (43.5)	49 (48.0)
CBT (n=620)	581 (93.7)	65 (38.2)	61 (43.6)	63 (57.3)	32 (36.0)
MoodGYM (n=613)	575 (93.8)	52 (34.7)	41 (39.4)	42 (51.2)	36 (59.0)

[a] Completers posttest IPT (n=194), CBT (n=170), MoodGYM (n=150).

[b] Adherent completers posttest IPT (n=168), CBT (n=140), MoodGYM (n=104).

[c] Completers 6-month follow-up IPT (n=124), CBT (n=110), MoodGYM (n=82).

[d] Adherent completers IPT (n=102), CBT, MoodGYM (n=61).

Discussion

Principal Results: Noninferiority, Effectiveness, and Efficacy

The present study is the first to show that Internet-delivered IPT can be effective in the treatment of depressive symptoms at posttest and at 6-month follow-up. Both the IPT and the CBT online interventions employed in the trial showed significant medium to large within-group effect sizes on the CES-D for completers and adherent completers. For the ITT sample, effect sizes were smaller, but still moderate in size. Of the clinical cases, completers and adherent completers showed medium to large effect sizes on posttest and follow-up ratings. We found that IPT and CBT were noninferior compared to MoodGYM for those who returned posttest, and between-group effect sizes were small. Although recent MoodGYM studies report similar effect sizes to our study, our conclusions need to be taken with some caution given that the effect size found in this study differed from the effect size from the initial study, and therefore might hamper assay sensitivity. Furthermore, the new CBT program reached consistently higher, but not significant, effect sizes compared to the IPT and the standard MoodGYM program. Overall, the between-group effect sizes were larger for IPT versus MoodGYM compared to CBT versus MoodGYM.

Comparison With Prior Work

Our findings of the equivalent effectiveness of CBT and IPT are concordant with previous research on face-to-face interventions [7]. The within-group effect size for completers of MoodGYM found in our study was similar to that of 2 recently published studies of unguided MoodGYM [23,43], but was considerably higher than the trial conducted by its originators in 2004 [22,24]. To be able to draw reliable conclusions of noninferiority, it is important to establish effect sizes of similar size to prior trials. To minimize bias, it is important to replicate the conditions under which the control treatment was previously examined (eg, the same population sample, outcome measures, assessment time points, and delivery of treatment). MoodGYM is automated and has fidelity as an intervention. We have no reason to assume that omission of the MoodGYM relaxation module accounts for the difference in the effect size found in this study, because removal did not affect treatment effectiveness in a previous dismantling study [31]. The most likely cause of the observed differences lies in the different samples recruited. The present study recruited participants directly from those visiting a self-help website, whereas the original study consisted of a sample of participants selected randomly from the Australian electoral roll. The present sample had higher depression scores at baseline compared to the original trial [22,24]. The difference in dropout rate (42% in the original study vs 70% in our study) might also account for the higher effect size we found for our completer analysis, because the effect size in our ITT sample (MoodGYM *d*=0.66) is more similar to the effect size of the completers in the originators study (MoodGYM *d*=0.56) [22,24]. Lower dropout rates in the original study may have arisen from the addition of weekly phone calls by lay interviewers, which might be considered as minimal contact therapy [44] and might affect the dropout rate [45]. However, a recent study by Farrer et al [23] found no significant difference in dropout between participants receiving weekly telephone calls in addition to MoodGYM and those receiving only self-guided MoodGYM. This aside, we can conclude that Internet-delivered IPT is likely to be an effective treatment for depressive symptoms, and thereby offers people with depression another online treatment option

The CSC rates in the current study were lower than those reported in other online studies [46,47]. One explanation for this finding might be that those studies incorporated guidance, whereas this study was fully automated. Another explanation might be that the baseline CES-D scores were higher in this study than typically found in other studies [47]. Hence, the drop in CES-D score required to achieve a score in the nonclinical range (ie, a CSC) is more difficult to reach. Clinical cases of the ITT samples showed no reliable change. However, completers of clinical cases showed reliable change for all programs at posttest and follow-up. CBT reached consistently higher RCI rates. CBT might be superior to IPT and/or MoodGYM. However, as we did not set our hypothesis a priori to test noninferiority between IPT and CBT, or superiority between CBT and the other programs, conclusions cannot be drawn because of insufficient power.

Feasibility and Satisfaction

There was no significant difference in treatment preference at baseline before randomization. This lack of preference for treatment condition is important, because it suggests that a disparity between the preferred and allocated conditions was unlikely to negatively impact disproportionately on the findings. However, treatment satisfaction ratings were significantly lower for the IPT program compared with MoodGYM and CBT. One explanation for these findings may be related to what people were looking for in an online intervention. Also, although there were no patient program preferences before randomization, it is unknown how participants felt about being randomized to IPT immediately postrandomization but before exposure to the treatment. Online CBT is widely known, whereas fewer individuals know about IPT. To the extent that the social psychological literature has demonstrated that familiarity breeds liking, it may be possible that differences in satisfaction in treatment were driven in part by differences in familiarity with each treatment. Another explanation may be that the IPT program was too brief. Adherence to the treatment was considerably lower than the original MoodGYM trial [22]. As mentioned earlier, the influence of weekly telephone calls in the original study might have influenced the dropout rate, as might the source of participants from among spontaneous visitors to a self-help website. Some studies of unguided self-help have reported similar dropout rates [43,48,49], but others have not [7,50]. Completion rates for the new IPT and CBT programs were significantly higher than for MoodGYM. This could suggest that the new programs are more acceptable, particularly to adults. Within a noninferiority framework, this finding is very important, because newer implementations of e-therapy were at least as effective as MoodGYM, whereas completion rates—a key problem in this field [51]—were higher. However, MoodGYM is a well-known open-access program. Some participants assigned to MoodGYM could have undertaken the program previously, and if so may have been less willing to finish the intervention.

Limitations

This study has several limitations. First, as mentioned previously, the effect size found in this study differs from that on which we based the noninferiority margin and power calculation. Second, the noninferiority margin of the primary outcome measure is usually based on the lower-bound CI of the between-group effect size of the traditional treatment [36]. In our case, this would be an effect size of 0.33 and a lower-bound 95% CI of 0.11 [24]. To reach sufficient statistical power to be able to detect a significant difference, we would need at least 14,000 participants per condition. Therefore, we used an alternative approach to calculate the lower-bound noninferiority margin. Based on the study of Mackinnon et al [24] we used the within-group effect size of 0.56 instead. This resulted in a noninferiority margin of an effect size of 0.33, which is a 3.795 difference on the CES-D. Although this difference is still liberal, an effect size of 0.30 is considered as the minimum for clinically meaningful change [52]. Third, LMM is based on the MAR assumption, while dropout rates were very high. It is widely recognized that the MAR assumption is untestable. MAR assumes that the pattern of missing data does not depend on the unobserved data. This is a substantially weaker assumption than missing completely at random (MCAR), in which the data are missing independent of values of the observed and unobserved data. Therefore, LMM is the most robust of the methods for analyzing the data.

Low adherence, however, could underestimate differences between groups, and therefore increase the likelihood of finding noninferiority. However, our completer analyses revealed no statistical differences in effectiveness between the 3 programs. Nevertheless, our conclusions need to be taken with caution given the high dropout rates. One possible explanation of the difference in attrition rates across the programs might be that MoodGYM takes longer to complete compared with the other programs, and lengthier programs might be associated with greater attrition [31]. Although MoodGYM had the highest dropout rate, dropout was high among all conditions, a finding that is common for Internet interventions. High dropout rates are likely with minimal exclusion criteria, unguided interventions [44,45], and little or no financial commitment [51]. However, a recent study by Hilvert-Bruce et al [53] showed that noncompleters derive benefit before dropping out. Also, there were significant baseline differences (CES-D score, gender, age) between participants who completed the programs and those who did not, which might indicate selection bias. The ITT analyses demonstrated effects nevertheless. In addition, it was unknown whether participants used other treatments during the study. This could mask real differences between groups if this use of additional treatments was more prevalent for 1 group compared with the others. Because we did not measure additional use of other treatments, we cannot rule this possibility out entirely. Finally, in face-to-face IPT, one focus is chosen, whereas in the Internet-delivered IPT, all modules were undertaken by the participant.

Future research is needed to replicate IPT noninferiority compared to CBT programs, to test whether the new CBT program is superior to other programs, to examine whether guided Internet-delivered IPT is as effective as face-to-face IPT, to investigate methods to improve adherence, to investigate whether IPT would also be effective outside of a randomized controlled trial setting, and whether Internet-delivered IPT is also effective in the treatment of other disorders, such as social phobia or panic disorder. It is important that future research investigates individual characteristics, such as recent life events, that predict treatment response for IPT. There will also be value in investigating whether a planned extended version of e-couch IPT will yield higher satisfaction ratings.

Conclusions

Although a firm conclusion regarding the noninferiority of IPT and the sustainability of results compared to CBT cannot be drawn yet, we can conclude that Internet-delivered IPT is an effective treatment for depressive symptoms, and thereby offers those with depression another online treatment option. An Internet-accessed IPT program could potentially be more appealing to IPT-trained therapists than a CBT-based one, perhaps making such clinicians more likely to recommend it to their clients. In the United Kingdom, the first wave of the Increasing Access to Psychological Therapies (IAPT) initiative was CBT only, but recently it has been expanded to other approaches, including IPT. Given that MoodGYM is already a resource used within IAPT (mostly without support), Internet-delivered IPT could well be a feasible option in second-wave IAPT services. Furthermore, the new e-couch CBT program was shown to be noninferior to the active CBT-based control program and thus may provide an open-access alternative to MoodGYM. Another important finding is that the completion rates of the new treatments were higher, indicating some progress in refining Internet-based self-help.

Acknowledgments

This study was funded by the Faculty of Psychology and Education of the VU University, Amsterdam, and the Center for Mental Health Research at The Australian National University. HC is supported by NHMRC Fellowship 525411. KG is supported by an NHMRC Senior Research Fellowship No 525413. We wish to thank Ada Tam, Philip Batterham, Jos Twisk, Bob Forrester, Filip Smit, and Lisanne Warmerdam for their helpful comments and participation in the project.

Conflicts of Interest

The interventions investigated in the current study were developed at the Centre for Mental Health Research, The Australian National University. HC and KG are authors and developers of the MoodGYM and e-couch websites, but derive no personal or financial benefit from their operation.

Multimedia Appendix 1

CONSORT-EHEALTH checklist V1.6.2 [42].

[PDF File (Adobe PDF File), 996KB - jmir_v15i5e82_app1.pdf]

Multimedia Appendix 2

Mean depression scores over time for interpersonal psychotherapy (IPT), cognitive behavior therapy (CBT), and MoodGYM (intention-to-treat, N=1843).

[PDF File (Adobe PDF File), 11KB - jmir_v15i5e82_app2.pdf]

Multimedia Appendix 3

Results and effect sizes (Cohen's *d*) for Center for Epidemiological Studies Depression scale (CES-D) per protocol and intention-to-treat (ITT) analyses for clinical cases (≥22 on the CES-D).

[PDF File (Adobe PDF File), 48KB - jmir_v15i5e82_app3.pdf]

References

1. Kruijshaar ME, Barendregt J, Vos T, de Graaf R, Spijker J, Andrews G. Lifetime prevalence estimates of major depression: an indirect estimation method and a quantification of recall bias. Eur J Epidemiol 2005;20(1):103-111. [Medline: 15756910]
2. Mathers CD, Loncar D. Projections of global mortality and burden of disease from 2002 to 2030. PLoS Med 2006 Nov;3(11):e442 [FREE Full text] [doi: 10.1371/journal.pmed.0030442] [Medline: 17132052]
3. van Schaik DJ, van Marwijk HW, Beekman AT, de Haan M, van Dyck R. Interpersonal psychotherapy (IPT) for late-life depression in general practice: uptake and satisfaction by patients, therapists and physicians. BMC Fam Pract 2007;8:52 [FREE Full text] [doi: 10.1186/1471-2296-8-52] [Medline: 17854480]
4. Cuijpers P, de Graaf R, van Dorsselaer S. Minor depression: risk profiles, functional disability, health care use and risk of developing major depression. J Affect Disord 2004 Apr;79(1-3):71-79. [doi: 10.1016/S0165-0327(02)00348-8] [Medline: 15023482]
5. Kessler RC, McGonagle KA, Zhao S, Nelson CB, Hughes M, Eshleman S, et al. Lifetime and 12-month prevalence of DSM-III-R psychiatric disorders in the United States. Results from the National Comorbidity Survey. Arch Gen Psychiatry 1994 Jan;51(1):8-19. [Medline: 8279933]
6. Smit F, Cuijpers P, Oostenbrink J, Batelaan N, de Graaf R, Beekman A. Costs of nine common mental disorders: implications for curative and preventive psychiatry. J Ment Health Policy Econ 2006 Dec;9(4):193-200. [Medline: 17200596]
7. Cuijpers P, Andersson G, Donker T, van Straten A. Psychological treatment of depression: results of a series of meta-analyses. Nord J Psychiatry 2011 Dec;65(6):354-364. [doi: 10.3109/08039488.2011.596570] [Medline: 21770842]
8. Practice guideline for the treatment of patients with major depressive disorder (revision). American Psychiatric Association. Am J Psychiatry 2000 Apr;157(4 Suppl):1-45. [Medline: 10767867]
9. Ellis P, Royal Australian and New Zealand College of Psychiatrists Clinical Practice Guidelines Team for Depression. Australian and New Zealand clinical practice guidelines for the treatment of depression. Aust N Z J Psychiatry 2004 Jun;38(6):389-407. [doi: 10.1111/j.1440-1614.2004.01377.x] [Medline: 15209830]
10. National Institute for Clinical Excellence (NICE). Depression: management of depression in primary and secondary care (amended). In: NICE Clinical Practice Guideline 23. London: NICE; 2007.
11. Beck AT, Rush AJ, Shaw BF, Emery G. Cognitive Therapy of Depression. New York: Guilford Press; 1979.
12. Klerman GL, Budman S, Berwick D, Weissman MM, Damico-White J, Demby A, et al. Efficacy of a brief psychosocial intervention for symptoms of stress and distress among patients in primary care. Med Care 1987 Nov;25(11):1078-1088. [Medline: 3695638]
13. Weissman MM, Markowitz JC, Klerman GL. Clinician's Quick Guide to Interpersonal Psychotherapy. New York: Oxford University Press; 2007.
14. Cuijpers P, Geraedts AS, van Oppen P, Andersson G, Markowitz JC, van Straten A. Interpersonal psychotherapy for depression: a meta-analysis. Am J Psychiatry 2011 Jun;168(6):581-592. [doi: 10.1176/appi.ajp.2010.10101411] [Medline: 21362740]
15. Jakobsen JC, Hansen JL, Simonsen S, Simonsen E, Gluud C. Effects of cognitive therapy versus interpersonal psychotherapy in patients with major depressive disorder: a systematic review of randomized clinical trials with meta-analyses and trial sequential analyses. Psychol Med 2012 Jul;42(7):1343-1357. [doi: 10.1017/S0033291711002236] [Medline: 22051174]
16. Cameron PA, Thompson DR. Changing the health-care workforce. Int J Nurs Pract 2005 Feb;11(1):1-4. [doi: 10.1111/j.1440-172X.2005.00499.x] [Medline: 15610338]
17. Barney LJ, Griffiths KM, Jorm AF, Christensen H. Stigma about depression and its impact on help-seeking intentions. Aust N Z J Psychiatry 2006 Jan;40(1):51-54. [doi: 10.1111/j.1440-1614.2006.01741.x] [Medline: 16403038]
18. Palmqvist B, Carlbring P, Andersson G. Internet-delivered treatments with or without therapist input: does the therapist factor have implications for efficacy and cost? Expert Rev Pharmacoecon Outcomes Res 2007 Jun;7(3):291-297. [doi: 10.1586/14737167.7.3.291] [Medline: 20528315]
19. Andrews G, Cuijpers P, Craske MG, McEvoy P, Titov N. Computer therapy for the anxiety and depressive disorders is effective, acceptable and practical health care: a meta-analysis. PLoS One 2010;5(10):e13196 [FREE Full text] [doi: 10.1371/journal.pone.0013196] [Medline: 20967242]
20. Griffiths KM, Farrer L, Christensen H. The efficacy of internet interventions for depression and anxiety disorders: a review of randomised controlled trials. Med J Aust 2010 Jun 7;192(11 Suppl):S4-11. [Medline: 20528707]
21. e-couch. URL: https://www.ecouch.anu.edu.au/welcome [accessed 2013-01-22] [WebCite Cache ID 6DsCazg8z]

22. 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] [doi: 10.1136/bmj.37945.566632.EE] [Medline: 14742346]
23. Farrer L, Christensen H, Griffiths KM, Mackinnon A. Internet-based CBT for depression with and without telephone tracking in a national helpline: randomised controlled trial. PLoS One 2011;6(11):e28099 [FREE Full text] [doi: 10.1371/journal.pone.0028099] [Medline: 22140514]
24. 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] [doi: 10.1192/bjp.bp.106.032078] [Medline: 18245031]
25. Pocock SJ. The pros and cons of noninferiority trials. Fundam Clin Pharmacol 2003 Aug;17(4):483-490. [Medline: 12914552]
26. Mascha EJ, Sessler DI. Equivalence and noninferiority testing in regression models and repeated-measures designs. Anesth Analg 2011 Mar;112(3):678-687 [FREE Full text] [doi: 10.1213/ANE.0b013e318206f872] [Medline: 21304155]
27. Donker T, van Straten A, Marks I, Cuijpers P. A brief Web-based screening questionnaire for common mental disorders: development and validation. J Med Internet Res 2009;11(3):e19 [FREE Full text] [doi: 10.2196/jmir.1134] [Medline: 19632977]
28. Lewinsohn PM. The behavioral study and treatment of depression. In: Hersen M, Eisler RM, Miller PM, editors. Progress in Behavioral Modification, 1st ed. New York: Academic; 1975:19-65.
29. MoodGYM. URL: https://moodgym.anu.edu.au/welcome [accessed 2013-01-22] [WebCite Cache ID 6DsCeWxBr]
30. 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 Mar;4(1):e3 [FREE Full text] [doi: 10.2196/jmir.4.1.e3] [Medline: 11956035]
31. 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. [doi: 10.1017/S0033291706008695] [Medline: 16938144]
32. Radloff LS. The CES-D Scale: a self-report depression scale for research in the general population. Appl Psychol Meas 1977;1(3):385-401.
33. Donker T, van Straten A, Marks I, Cuijpers P. Brief self-rated screening for depression on the Internet. J Affect Disord 2010 May;122(3):253-259. [doi: 10.1016/j.jad.2009.07.013] [Medline: 19679358]
34. Nguyen TD, Attkisson CC, Stegner BL. Assessment of patient satisfaction: development and refinement of a service evaluation questionnaire. Eval Program Plann 1983;6(3-4):299-313. [Medline: 10267258]
35. Attkisson CC, Zwick R. The client satisfaction questionnaire. Psychometric properties and correlations with service utilization and psychotherapy outcome. Eval Program Plann 1982;5(3):233-237. [Medline: 10259963]
36. Hwang IK, Morikawa T. Design issues in noninferiority equivalence trials. Drug Inform J 1999;33:1205-1218 [FREE Full text]
37. Jones B, Jarvis P, Lewis JA, Ebbutt AF. Trials to assess equivalence: the importance of rigorous methods. BMJ 1996 Jul 6;313(7048):36-39 [FREE Full text] [Medline: 8664772]
38. Piaggio G, Elbourne DR, Altman DG, Pocock SJ, Evans SJ, CONSORT Group. Reporting of noninferiority and equivalence randomized trials: an extension of the CONSORT statement. JAMA 2006 Mar 8;295(10):1152-1160. [doi: 10.1001/jama.295.10.1152] [Medline: 16522836]
39. Cohen J. Statistical Power Analysis for the Behavioral Sciences. Hillsdale, NJ: L Erlbaum Associates; 1988.
40. 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]
41. McGlinchey JB, Atkins DC, Jacobson NS. Clinical significance methods: Which one to use and how useful are they? Behavior Therapy 2002 Sep 2002;33(4):529-550. [doi: 10.1016/S0005-7894(02)80015-6]
42. Eysenbach G, CONSORT-EHEALTH Group. CONSORT-EHEALTH: improving and standardizing evaluation reports of Web-based and mobile health interventions. J Med Internet Res 2011;13(4):e126 [FREE Full text] [doi: 10.2196/jmir.1923] [Medline: 22209829]
43. Lintvedt OK, Griffiths KM, Sørensen K, Østvik AR, Wang CE, Eisemann M, et al. Evaluating the effectiveness and efficacy of unguided internet-based self-help intervention for the prevention of depression: a randomized controlled trial. Clin Psychol Psychother 2013 Sep;20(1):10-27. [doi: 10.1002/cpp.770] [Medline: 21887811]
44. Newman MG, Erickson T, Przeworski A, Dzus E. Self-help and minimal-contact therapies for anxiety disorders: Is human contact necessary for therapeutic efficacy? J Clin Psychol 2003 Mar;59(3):251-274. [doi: 10.1002/jclp.10128] [Medline: 12579544]
45. Andersson G. Using the Internet to provide cognitive behaviour therapy. Behav Res Ther 2009 Mar;47(3):175-180. [doi: 10.1016/j.brat.2009.01.010] [Medline: 19230862]
46. Hedman E, Andersson G, Ljótsson B, Andersson E, Rück C, Mörtberg E, et al. Internet-based cognitive behavior therapy vs. cognitive behavioral group therapy for social anxiety disorder: a randomized controlled non-inferiority trial. PLoS One 2011;6(3):e18001 [FREE Full text] [doi: 10.1371/journal.pone.0018001] [Medline: 21483704]

47. 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] [doi: 10.2196/jmir.1094] [Medline: 19033149]
48. de Graaf LE, Huibers MJ, Riper H, Gerhards SA, Arntz A. Use and acceptability of unsupported online computerized cognitive behavioral therapy for depression and associations with clinical outcome. J Affect Disord 2009 Aug;116(3):227-231. [doi: 10.1016/j.jad.2008.12.009] [Medline: 19167094]
49. Melville KM, Casey LM, Kavanagh DJ. Dropout from Internet-based treatment for psychological disorders. Br J Clin Psychol 2010 Nov;49(Pt 4):455-471. [doi: 10.1348/014466509X472138] [Medline: 19799804]
50. 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. [doi: 10.1017/S0033291706008944] [Medline: 17112400]
51. Eysenbach G. The law of attrition. J Med Internet Res 2005;7(1):e11 [FREE Full text] [doi: 10.2196/jmir.7.1.e11] [Medline: 15829473]
52. Wilson DB, Lipsey MW. The role of method in treatment effectiveness research: evidence from meta-analysis. Psychol Methods 2001 Dec;6(4):413-429. [Medline: 11778681]
53. Hilvert-Bruce Z, Rossouw PJ, Wong N, Sunderland M, Andrews G. Adherence as a determinant of effectiveness of internet cognitive behavioural therapy for anxiety and depressive disorders. Behav Res Ther 2012 Aug;50(7-8):463-468. [doi: 10.1016/j.brat.2012.04.001] [Medline: 22659155]

Abbreviations

ANU: The Australian National University
CBT: cognitive behavioral therapy
CES-D: Center for Epidemiological Studies Depression scale
CMHR: Centre for Mental Health Research
CSC: clinically significant change
CSQ-8: Client Satisfaction Questionnaire
IAPT: Increasing Access to Psychological Therapies
IPT: interpersonal psychotherapy
ITT: intention-to-treat
LMM: linear mixed model
MAR: missing at random
RCI: reliable change index
WSQ: Web Screening Questionnaire

Edited by G Eysenbach; submitted 11.08.12; peer-reviewed by L Palmili, H O'Mahen; comments to author 29.12.12; revised version received 31.01.13; accepted 15.02.13; published 13.05.13.

Please cite as:
Donker T, Bennett K, Bennett A, Mackinnon A, van Straten A, Cuijpers P, Christensen H, Griffiths KM
Internet-Delivered Interpersonal Psychotherapy Versus Internet-Delivered Cognitive Behavioral Therapy for Adults With Depressive Symptoms: Randomized Controlled Noninferiority Trial
J Med Internet Res 2013;15(5):e82
URL: http://www.jmir.org/2013/5/e82/
doi:10.2196/jmir.2307
PMID:23669884

Original Paper

Cost-Utility Analysis of the EVOLVO Study on Remote Monitoring for Heart Failure Patients With Implantable Defibrillators: Randomized Controlled Trial

Paolo Zanaboni[1], PhD; Maurizio Landolina[2], MD; Maurizio Marzegalli[3], MD; Maurizio Lunati[4], MD; Giovanni B Perego[5], MD; Giuseppe Guenzati[6], MD; Antonio Curnis[7], MD; Sergio Valsecchi[8], PhD; Francesca Borghetti[8], MS; Gabriella Borghi[9], MS; Cristina Masella[10], MS

[1]Norwegian Centre for Integrated Care and Telemedicine, University Hospital of North Norway, Tromsø, Norway
[2]Cardiology Department, Fondazione Policlinico S Matteo IRCCS, Pavia, Italy
[3]Cardiology Department, S Carlo Borromeo Hospital, Milan, Italy
[4]Cardiovascular Department, Niguarda Hospital, Milan, Italy
[5]Cardiology Division, Istituto Auxologico S Luca Hospital, Milan, Italy
[6]Cardiology Department, S. Carlo Borromeo Hospital, Milan, Italy
[7]Cardiology Unit, Ospedali Civili, Brescia, Italy
[8]Clinical Department, Medtronic Italia, Rome, Italy
[9]CEFRIEL, Regione Lombardia, Milan, Italy
[10]Department of Management, Economics and Industrial Engineering, Politecnico di Milano, Milan, Italy

Corresponding Author:
Paolo Zanaboni, PhD
Norwegian Centre for Integrated Care and Telemedicine
University Hospital of North Norway
PO Box 35
Tromsø, N-9038
Norway
Phone: 47 41409600
Fax: 47 77754098
Email: paolo.zanaboni@telemed.no

Abstract

Background: Heart failure patients with implantable defibrillators place a significant burden on health care systems. Remote monitoring allows assessment of device function and heart failure parameters, and may represent a safe, effective, and cost-saving method compared to conventional in-office follow-up.

Objective: We hypothesized that remote device monitoring represents a cost-effective approach. This paper summarizes the economic evaluation of the Evolution of Management Strategies of Heart Failure Patients With Implantable Defibrillators (EVOLVO) study, a multicenter clinical trial aimed at measuring the benefits of remote monitoring for heart failure patients with implantable defibrillators.

Methods: Two hundred patients implanted with a wireless transmission–enabled implantable defibrillator were randomized to receive either remote monitoring or the conventional method of in-person evaluations. Patients were followed for 16 months with a protocol of scheduled in-office and remote follow-ups. The economic evaluation of the intervention was conducted from the perspectives of the health care system and the patient. A cost-utility analysis was performed to measure whether the intervention was cost-effective in terms of cost per quality-adjusted life year (QALY) gained.

Results: Overall, remote monitoring did not show significant annual cost savings for the health care system (€1962.78 versus €2130.01; *P*=.80). There was a significant reduction of the annual cost for the patients in the remote arm in comparison to the standard arm (€291.36 versus €381.34; *P*=.01). Cost-utility analysis was performed for 180 patients for whom QALYs were available. The patients in the remote arm gained 0.065 QALYs more than those in the standard arm over 16 months, with a cost savings of €888.10 per patient. Results from the cost-utility analysis of the EVOLVO study show that remote monitoring is a cost-effective and dominant solution.

Conclusions: Remote management of heart failure patients with implantable defibrillators appears to be cost-effective compared to the conventional method of in-person evaluations.

Trial Registration: ClinicalTrials.gov NCT00873899; http://clinicaltrials.gov/show/NCT00873899 (Archived by WebCite at http://www.webcitation.org/6H0BOA29f).

(J Med Internet Res 2013;15(5):e106) doi:10.2196/jmir.2587

KEYWORDS

telemedicine; heart failure; implantable defibrillators; cost-effectiveness

Introduction

Recent guidelines based on the evidence from randomized controlled trials recommend the use of implantable cardioverter defibrillators (ICD) and defibrillators for cardiac resynchronization therapy (CRT-D) for the management of chronic heart failure (HF) patients [1]. The conventional approach to cardiac device follow-up consists of scheduled in-office visits at intervals ranging from 3 to 6 months [2]. Because of increasing patient volumes, routine follow-up contributes a significant burden to already overstrained clinics in terms of time, capital, and human resources required, and to patients and caregivers in terms of travel and time. Remote monitoring allows assessment of device function [3] and patients' HF-related parameters at home [4], and may represent a safe, effective, and cost-saving way to significantly reduce in-office follow-up visits that are a burden for both hospitals and patients [5].

Cost-effectiveness and cost-utility analyses are scientific approaches that can help justify the value of new interventions and, thus, informs both medical decision making and public policy [6]. Remote monitoring programs for HF have shown a positive effect on clinical outcomes [7]. However, the evidence for cost-effectiveness is limited and does not include the full range of perspectives [8]. In 2002, a systematic review of cost-effectiveness studies of telemedicine interventions concluded that there was no good evidence that telemedicine is a cost-effective means of delivering health care, but none of the studies used cost-utility [9]. In a recent systematic review of 47 economic evaluations of telemedicine interventions from 2004 to 2010, 11 were cost-effective analyses and 7 were cost-utility analyses [10]. In a meta-analysis of 14 randomized clinical trials of remote monitoring for patients with HF, only 4 studies using structured telephone support examined health care costs [11].

Thus, prospective health-economic studies are needed to correctly determine the clinical and economic benefits of systematic remote monitoring in patients with ICD and CRT-D [5,12]. We conducted a multicenter clinical trial, the Evolution of Management Strategies of Heart Failure Patients With Implantable Defibrillators (EVOLVO) study (ClinicalTrials.gov NCT00873899), aimed at measuring the benefits of remote monitoring of chronic HF patients implanted with wireless transmission-enabled ICD/CRT-D endowed with specific diagnostic features for HF [13]. The primary clinical endpoint of the EVOLVO study was to determine whether remote monitoring was associated with different rates of emergency department (ED) and urgent in-office visits for HF, arrhythmias, or ICD-related events compared to patients in the standard-treatment arm. Details of primary and secondary clinical endpoints are published elsewhere [14]. This paper focuses on the economic evaluation of the intervention and its cost utility. We hypothesized that remote device monitoring represents a cost-effective approach.

Methods

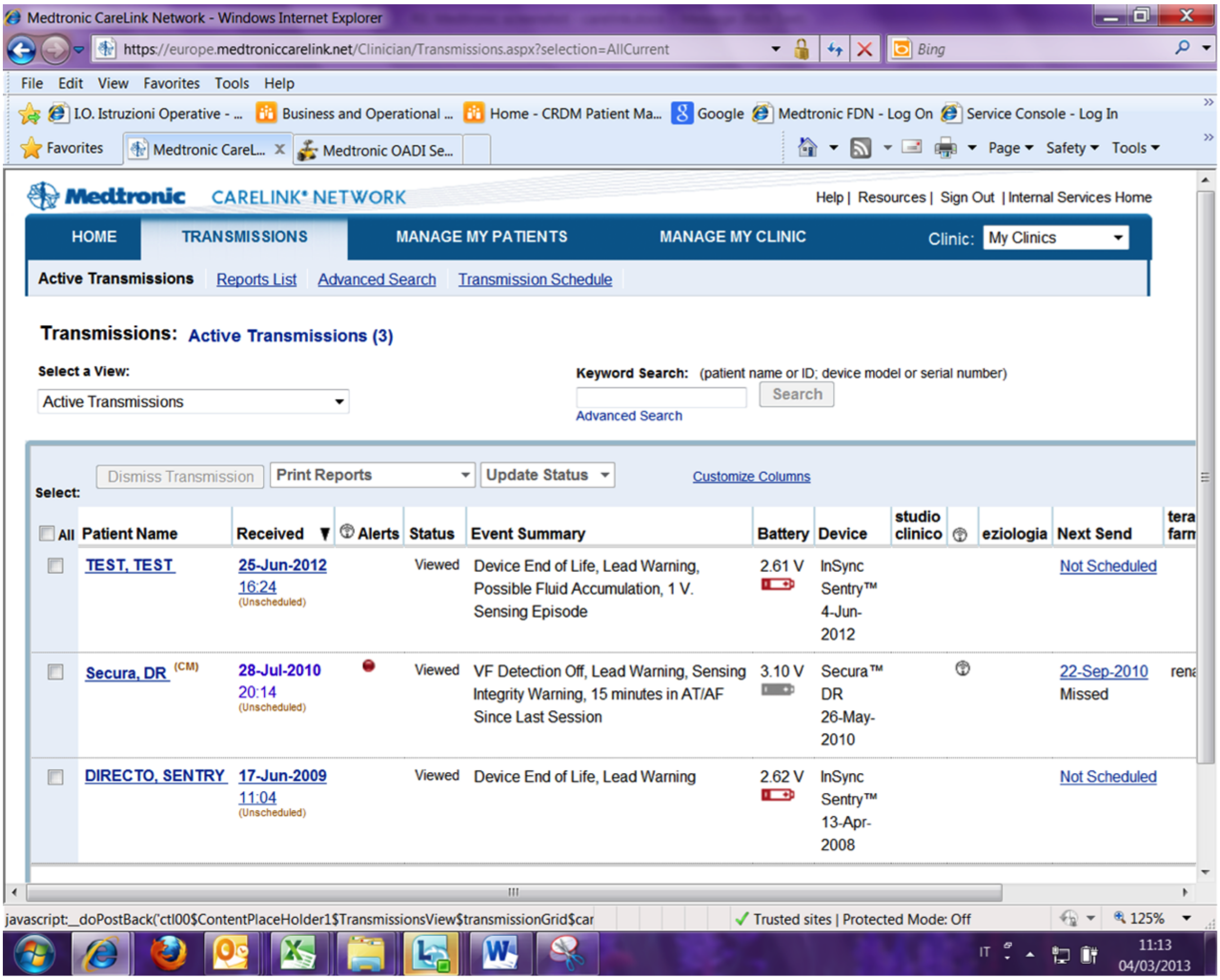
Study Design

The study design is described in detail elsewhere [13]. Briefly, the EVOLVO study is a prospective, randomized, open, multicenter clinical trial designed to compare remote monitoring of chronic HF patients with ICD/CRT-D (remote arm) to the current standard of care (standard arm; ClinicalTrials.gov NCT00873899). Two hundred patients implanted with a Medtronic (Minneapolis, MN, USA) wireless transmission-enabled ICD/CRT-D were enrolled by 6 Italian hospitals and randomized to receive either the Medtronic CareLink Home Monitor for remote transmission [15] (Figure 1) or the conventional method of in-person evaluations. Patients in the standard arm were followed for a 16-month period with scheduled in-office visits at 4, 8, 12, and 16 months. For the remote arm, patients had in-office visits at 8 and 16 months, but remote transmissions replaced their in-office visits at 4 and 12 months. In the remote arm, all alerts regarding clinical management (intrathoracic impedance for fluid accumulation monitoring, atrial arrhythmias, and ICD shocks delivered) were turned on for wireless notification through the CareLink Home Monitor, but no audible alerts were used. Hospital staff accessed patients' data via the Web-based Medtronic CareLink Network (Figure 2). In the standard arm, patients did not have access to the CareLink Network, and the alerts were turned on for audible notification only. All system-integrity alerts were turned on for both wireless and audible notification in the remote arm and for only audible notification in the standard arm. Management strategies and data collection were predefined and have been previously described [13].

The research protocol of this study was approved by the Institutional Review Boards of the 6 participating hospitals (4 hospitals in Milan, 1 in Pavia, and 1 in Brescia). The investigation conforms to the principles outlined in the Declaration of Helsinki. All patients gave written informed consent. This trial is reported in accordance with the Consolidated Standards of Reporting Trials of Electronic and Mobile Health Applications and Online Telehealth (CONSORT-EHEALTH) [16].

Figure 1. Medtronic CareLink home monitor.

Figure 2. Medtronic Carelink Network.



Transmissions: Active Transmissions (3)

Select a View: Active Transmissions

Keyword Search: (patient name or ID; device model or serial number)

javascript:__doPostBack('ctl00$ContentPlaceHolder1$TransmissionsView$transmissionGrid$car

☐ All	Patient Name	Received	Alerts	Status	Event Summary	Battery	Device	studio clinico		eziologia	Next Send	tera farn
☐	TEST, TEST	25-Jun-2012 16:24 (Unscheduled)		Viewed	Device End of Life, Lead Warning, Possible Fluid Accumulation, 1 V. Sensing Episode	2.61 V	InSync Sentry™ 4-Jun-2012				Not Scheduled	
☐	Secura, DR (CM)	28-Jul-2010 20:14 (Unscheduled)	●	Viewed	VF Detection Off, Lead Warning, Sensing Integrity Warning, 15 minutes in AT/AF Since Last Session	3.10 V	Secura™ DR 26-May-2010				22-Sep-2010 Missed	rena
☐	DIRECTO, SENTRY	17-Jun-2009 11:04 (Unscheduled)		Viewed	Device End of Life, Lead Warning	2.62 V	InSync Sentry™ 13-Apr-2008				Not Scheduled	

Objectives

This paper summarizes the economic evaluation of the intervention. The analysis was conducted with the perspectives of the health care system and the patient. A cost-utility analysis was performed to measure whether the intervention was cost-effective in terms of cost per quality-adjusted life year (QALY) gained.

Health Care System Perspective

The objective of this analysis was to determine whether the total costs incurred by the health care authority for the patients in the remote arm were different from those in the standard arm. Costs included urgent and nonurgent in-office visits, scheduled and unscheduled remote follow-ups, ED visits, hospitalizations, and diagnostic examinations. All costs are expressed in Euro (€) and refer to the fiscal year 2010. A top-down approach was used for in-office visits, ED visits, hospitalizations, and diagnostic examinations. These costs, therefore, correspond to the specific public tariffs from the diagnosis-related group (DRG) system offered by the regional health care authority. Remote follow-ups were not covered by an official reimbursement scheme in Italy at the time this study was conducted, as in other European countries [17]. However, the attribution of an economic value to remote follow-ups was necessary to properly include their cost for the health care system and to compare remote to standard management. In the countries where a reimbursement for remote follow-ups is recognized, this is in-line with that of in-office visits [15,18,19]. Thus, the cost of a remote follow-up was assumed to be equal to that of an in-office visit, and reduced by 50% if not followed with a phone call to the patient. In Italy and other countries, the use of the technology (the remote monitoring device, network server, and website) is included in the initial cost of the ICD without any adjunctive fee [20], thus it does not represent a marginal cost in the economic evaluation.

However, the introduction of a yearly fee to device manufacturers covering the use of technology is a current topic of debate [21]. France is the only European country where the service is covered by the national health care insurance, with an average fee of €900 for the life of the device [22]. Therefore, a different scenario was included assuming a fee of €900 per patient for renting the remote monitoring device, the network server, and the website. An average device life span of 5 years was assumed according to recent studies [23,24]. In the EVOLVO study, the patients in both study arms were implanted with the same devices (ie, remote monitoring capabilities were available for both the intervention arm and the control arm). Therefore, the cost of the device was not included in the economic evaluation because it did not represent a marginal cost. All Medtronic ICDs currently sold in the Italian market have remote monitoring capabilities, as do most ICDs sold in Italy. Moreover, the tariff received by the hospitals for an ICD implantation is fixed and it does not vary according to the type of device implanted. New hardware investments were not requested for remote monitoring in the hospitals because the existent information technology services of the hospitals were sufficient to support the transmissions. Transportation costs were included in the patient perspective only because they are not reimbursed by the health care system. Data regarding the number of activities provided and events occurring to patients during the study period were systematically collected in an electronic database.

Patient Perspective

The objective of this analysis was to determine whether the costs for in-office and ED visits incurred by patients and their caregivers in the remote arm were different from those in the standard arm. The cost of each visit was related to out-of-pocket expenses, including transportation, room and board, and wages lost by patients and family caregivers. Because the newest generation of Medtronic devices are able to automatically transmit data wirelessly, the time used by patients for remote follow-ups was null. These data were collected through questionnaires administered to patients at baseline. Fares of €0.47 per kilometer and €25.67 per hour were used for travel by car and by taxi, respectively. Patient-reported costs were used for other means of transportation and room and board. National wage data were used to calculate wages lost by patients and family caregivers. Hourly wages of €7.82, €10.19, €18.99, €15.06, and €10.40 were used for workers, employees, managers, entrepreneurs, and other self-employed workers, respectively.

Cost-Utility Analysis

A cost-utility analysis was conducted using the costs assessed with the health care system perspective and QALYs. QALYs were calculated based on the answers of the EQ-5D questionnaires submitted by each patient at baseline and at 16 months. Utility values (from 0 to 1) were calculated using the European EQ-net VAS set [25]. Utility values were calculated only if all 5 of the EQ-5D dimensions were answered. Moreover, missing utility values at the study exit were imputed using regression models [26], in which the dependent variable was the utility value at 16 months, and the independent variable was the baseline value. Finally, the cost-utility ratio was computed as differential costs between remote arm and standard arm over 16 months, and differential QALYs. Because of the presence of a baseline imbalance in mean utility values between the study arms, a regression-based adjustment was applied to calculate differential QALYs controlling for baseline utility values [27].

Statistical Analysis

Descriptive statistics were reported as mean and standard deviation (SD) for normally distributed continuous variables or median and interquartile range (IQR) in the case of skewed distributions. Normality of distribution of statistics was tested by means of the nonparametric Kolmogorov–Smirnov test. Differences between mean data were compared by using *t* tests. A Mann–Whitney nonparametric test was used to compare non-Gaussian variables. Differences in proportions were compared by using chi-square (χ^2) tests.

Cost data are typically highly skewed because a few patients incur particularly high costs. Despite the usual skewness in the distribution of costs, statistical analysis comparing medians and using standard nonparametric methods may provide misleading conclusions [28]. The arithmetic mean is the most informative measure for policy decisions, and the *t* test on untransformed data is appropriate for costs because it is the only method addressing a comparison of arithmetic means [29]. Moreover, the *t* test is considered reliable for moderately large sample sizes. Therefore, the *t* test was used for cost analyses. A *P* value <.05 was considered significant. All statistical analyses were performed by using IBM SPSS Statistics version 19 (IBM SPSS, New York, NY, USA).

Results

Baseline Characteristics and Summary of Clinical Endpoints

Table 1 summarizes the baseline characteristics of patients. Ninety-nine patients were randomly assigned to the remote arm and 101 patients to the standard arm. Demographic and clinical parameters were similar between the study arms. Fifteen patients died during the course of the study (7 in the remote arm and 8 in the standard arm), and 9 patients were withdrawn (3 patients in the remote arm and 6 in the standard arm) (Figure 3). Table 2 summarizes the results of the primary and secondary clinical endpoints, expressed as number of events and annualized rates per patient-year. A detailed analysis of the baseline characteristics of patients and the clinical endpoints is published elsewhere [14].

Health Care System Costs

The cost of in-office visits was €23.75, the mean cost of ED visits was €28.91 (range €22.38-€29.69), the mean cost of hospitalizations was €3865.45 (range €213.61-€25,727.70), and the mean cost of diagnostic examinations was €17.71 (range €3.95-€102.93). The mean annual cost for the management of the patients in the remote arm was lower than that in the standard arm (€1962.78 versus €2130.01; *P*=.80), although statistical significance was not reached (Table 3). Overall, remote monitoring of HF patients with implantable defibrillators did not show significant annual cost savings for the health care system. Focusing on the cost components, remote monitoring implied, on average, a lower cost for protocol-defined clinic visits than the standard management, since 2 of 4 in-office visits were replaced by scheduled remote follow-ups. According to the primary clinical endpoint, the cost of ED visits and urgent in-office visits was statistically significantly lower in the remote arm (*P*=.04). But remote monitoring required higher costs for nonurgent in-office visits, and an additional cost to perform unscheduled remote follow-ups as a consequence of automatic wireless remote notifications via CareLink. Most of the annual cost savings (€223.80) were from hospitalizations, which represents the main cost component (91% of the annual cost in the standard arm). Specifically, some of the patients in the standard arm experienced a higher number of HF-related hospitalizations compared to the patients in the remote arm. However, no statistically significant difference was detected between the 2 groups. Finally, the cost of diagnostic examinations was similar between the 2 groups.

Table 1. Demographics and baseline clinical characteristics of patients at the time of enrollment (N=200).

Patient characteristics	Standard arm (n=101)	Remote arm (n=99)	*P* value
Male gender, n (%)	76 (75.2)	81 (81.9)	.34
Age (years), median (IQR)	69 (60-73)	66 (60-72)	.14
New York Heart Association (NYHA) class, n (%)			.80
Class I	13 (12.9)	11 (11.1)	
Class II	68 (67.3)	71 (71.7)	
Class III	20 (19.8)	17 (17.2)	
Primary prevention, n (%)	95 (94.1)	87 (87.9)	.20
Time since implantation >6 months, n (%)	46 (45.5)	45 (45.5)	.90
Comorbidities, n (%)			
Hypertension	52 (51.5)	46 (46.5)	.57
Diabetes	26 (25.7)	22 (22.2)	.68
Chronic kidney disease	22 (21.8)	21 (21.2)	1.00
COPD	15 (14.9)	19 (19.2)	.50
LV ejection fraction (%), median (IQR)	30 (25-34)	31 (25-35)	.39

Table 2. Summary of the clinical endpoints expressed as number of events (annualized rate per patient-year).

Clinical endpoints	Events, n (annualized rate per patient-year)		*P* value
	Standard arm (n=101)	Remote arm (n=99)	
Primary endpoint			
ED/urgent in-office visits for HF, arrhythmias, or ICD-related events	117 (0.93)	75 (0.59)	.005
Secondary endpoints			
ED/urgent in-office visits for HF	92 (0.73)	48 (0.38)	<.001
ED/urgent in-office visits for arrhythmias or ICD-related events	25 (0.20)	27 (0.21)	.65
Total health care utilizations	726 (5.76)	559 (4.40)	<.001

Figure 3. Consolidated Standards of Reporting Trials (CONSORT) diagram of the study.

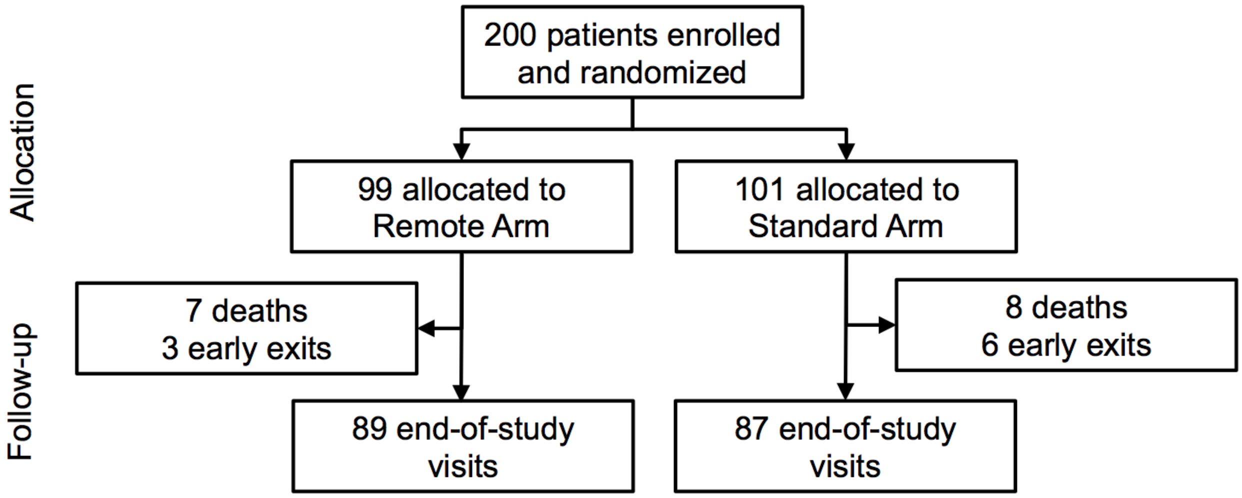


Table 3. Comparison of health care system costs.

Health care system costs	Costs (€), mean (SD)		Mean difference (95% CI)	*P* value
	Standard arm (n=101)	Remote arm (n=99)		
Protocol-defined clinic visits	90.29 (38.58)	56.63 (38.64)	33.66 (22.89, 44.43)	<.001
ED visits and urgent in-office visits	23.60 (33.68)	14.80 (24.71)	8.81 (0.56, 17.06)	.04
Nonurgent in-office visits	20.13 (38.71)	30.81 (72.13)	–10.68 (–26.78, 5.42)	.19
Scheduled remote follow-ups	0.00 (0.00)	32.50 (9.20)	–32.50 (–34.34, –30.67)	<.001
Unscheduled remote follow-ups	0.00 (0.00)	56.42 (58.95)	–56.42 (–68.18, 44.67)	<.001
Hospitalizations	1945.82 (5247.62)	1722.02 (4106.00)	223.80 (–1091.83, 1539.44)	.74
Diagnostic examinations	50.16 (73.23)	49.60 (77.80)	0.56 (–20.50, 21.63)	.96
Mean annual cost per patient	2130.01 (5251.33)	1962.78 (4185.61)	167.23 (–1158.61, 1493.06)	.80

Patient Costs

The mean cost of in-hospital visits was €68.37 (range €0-€1720). Results summarized in Table 4 show a statistically significant reduction of the annual cost for the patients in the remote arm in comparison to that in the standard arm (€291.36 versus €381.34; *P*=.01). Remote monitoring of HF patients with implantable defibrillators, therefore, implied cost savings to patients of 24% of their total annual cost. In particular, cost savings are because of a reduction in the number of protocol-defined clinic visits, replaced by remote follow-ups for the patients in the remote arm, together with a reduction of ED visits and urgent in-office visits.

Cost-Utility

The EQ-5D scores at baseline and 16 months were complete for 144 patients. Fifteen patients died during the study period; therefore, a 0 utility value was assigned at the study exit. By using imputed utility missing values for 21 patients with incomplete data at 16 months, QALYs were available for 180 patients, 91 in the standard arm and 89 in the remote arm. Cost data were available for all those patients. Results from the cost-utility analysis are summarized in Table 5.

Mean utility values at baseline were slightly imbalanced between the remote arm and standard arm, but not significantly different (0.793 versus 0.737; *P*=.08). Controlling for baseline, there was a differential QALY of 0.065 between the study arms (1.032 versus 0.966; *P*=.03). The mean cost for the patients in the remote arm was lower than that in the standard arm (€2074.70 versus €2962.80; *P*=.33), although statistical significance was not reached. Therefore, patients in the remote arm gained 0.065 QALYs more than those in the standard arm, with a cost savings of €888.10 per patient over the 16-month study period. The cost-utility ratio was negative. As a consequence, the cost-utility analysis showed that remote monitoring is cost-effective compared to the conventional follow-up, representing a dominant solution. Assuming a fee of €900 per patient for using the technology over 5 years, the mean cost for the patients in the remote arm was still lower than that in the standard arm (€2304.95 versus €2962.80), with a negative cost-utility ratio.

Table 4. Comparison of patient costs.

Patient costs	Costs (€), mean (SD)		Mean difference (95% CI)	*P* value
	Standard arm (n=101)	Remote arm (n=99)		
Protocol-defined clinic visits	259.91 (111.07)	163.01 (111.23)	96.90 (65.90, 127.90)	<.001
ED visits and urgent in-office visits	63.48 (87.29)	39.68 (66.31)	23.81 (2.16, 45.45)	.03
Nonurgent in-office visits	57.93 (111.44)	88.67 (207.63)	–30.74 (–77.08, 15.60)	.19
Mean annual cost per patient	381.34 (202.98)	291.36 (305.53)	89.97 (17.78, 162.17)	.01

Table 5. Utility values, quality-adjusted life years (QALYs), and cost per patient over the 16-month study period.

Cost-utility variables	Value, mean (SD)		Mean difference (95% CI)	*P* value
	Standard arm (n=91)	Remote arm (n=89)		
Mean utility value at baseline	0.737 (0.234)	0.793 (0.179)	–0.055 (–0.117, 0.006)	.08
Mean utility value at 16 months	0.711 (0.305)	0.754 (0.275)	–0.043 (–0.128, 0.043)	.32
QALYs (controlling for baseline)	0.966 (0.231)	1.032 (0.177)	–0.066 (–0.126, –0.005)	.03
Mean cost per patient (€)	2962.80 (7323.93)	2074.70 (4581.30)	–888.10 (–906.75, 2682.95)	.33

Discussion

Principal Findings

The results from the cost-utility analysis of the EVOLVO study show that chronic HF patients wearing ICD/CRT-D followed with remote monitoring gained 0.065 QALYs more than those in the standard arm over the 16-month study period, with a cost savings of €888.10 per patient. Remote monitoring, therefore, appears to be a cost-effective and dominant solution compared to conventional in-office follow-up. The cost-effectiveness ratio remains negative even including a fee for the use of technology in the analysis, currently adopted only in France. These results are in-line with a meta-analysis in which cost savings from remote monitoring in HF in comparison to usual care ranged from €300 to €1000, with a QALY gain of 0.06 [30]. Results from cost-utility analyses have clear implications to inform policy makers and payers. Cost per QALY of new health interventions are often grouped in league tables, in which interventions at the top should take priority. Decisions regarding implementation can then be based on threshold values for the cost per QALY, which represents the willingness of society to pay for additional QALYs. For instance, the National Institute for Clinical Excellence (NICE) has set a range of acceptable cost-effectiveness from £20,000 to £30,000 per QALY [31], and a US $50,000 per QALY threshold has been widely used in the United States for renal dialysis [5,32]. Remote monitoring of HF patients with implantable defibrillators could be taken into consideration for large-scale implementation.

Mean costs for the health care system provide another informative measure for policy decisions and confirm that the remote device monitoring might become an institutionalized service [33]. Our analysis showed that the mean annual cost for the management of the patients in the remote arm was €167.23 lower than that in the standard arm (€1962.78 versus €2130.01; *P*=.80). The cost of scheduled and unscheduled remote follow-ups, assuming a hypothetical tariff in-line with that of in-office visits, accounted for €68.92. Therefore, according to the specific results from the EVOLVO study, the maximum value that could be allocated by the health care authority to remote monitoring of HF patients implanted with ICD/CRT-D without increasing the total budget is €256.15 per patient per year. In the Clinical Evaluation of Remote Notification to Reduce Time to Clinical Decision (CONNECT) trial, the estimated mean cost per hospitalization was significantly lower because of the shorter hospital length of stay for the remote arm. However, more detailed cost data were not collected [34]. The EVOLVO study confirms that remote monitoring implies major cost savings for hospitalizations, ED visits, and urgent in-office visits, which balance the additional cost to perform unscheduled remote follow-ups as a consequence of automatic wireless remote notifications. Moreover, as compared with standard management, remote monitoring increases the rate of appropriate in-hospital visits for clinically relevant device alerts, allows early detection of worsening symptoms [35], and decreases the time from the alert condition to the data review [14].

Implications for patients are positive and confirm the findings from previous studies. Remote monitoring has been demonstrated to be highly accepted and time saving for patients with ICD [20]. Transportation costs are a major component of the overall costs of follow-up, and the potential savings have been previously estimated [36]. The EVOLVO study provides new evidence of the economic benefits for patients and caregivers. The automatic data transmission eliminates the cost normally incurred to attend in-office visits. In our clinical protocol, 2 of 4 in-office visits were replaced by remote transmissions, with consequent savings. Additional benefits would clearly emerge if a higher number of in-office visits were replaced by remote follow-ups.

Limitations

We acknowledge 2 methodological limitations in the economic evaluation of the EVOLVO study. First, to include the cost of remote device monitoring in the absence of a reimbursement scheme, we assumed the cost of a remote follow-up based on the tariff of an in-office visit. In a European survey, 82% of the hospitals had no established reimbursement mechanism for remote follow-up. For cases in which reimbursement was present, this was established as a tariff per visit, an annual fee per patient, or charged as a service by private companies [20]. In a Finnish study, the cost of a routine follow-up, including clinical and device evaluation by a cardiologist, was €210, whereas the fee per transmission evaluation was €55 [19]. In a US study, the cost of device interrogation in-office and by remote monitoring were US $86.92 and US $102.79, respectively [18]. The introduction of a reimbursement mechanism for remote ICD follow-up is currently under discussion in different Italian regions. The second limitation concerns the study design and the different management strategies for alerts in the 2 arms. The cost of protocol-defined clinic visits was lower in the intervention arm because, in this group, patients had remote transmissions replacing their in-office visits at 4 and 12 months, which are more costly than remote follow-ups. Moreover, the protocol imposed, for the standard arm, urgent visits for audible alerts.

Conclusions

The results from the cost-utility analysis of the EVOLVO study demonstrate that remote management of chronic HF patients with implantable defibrillators appears to be a cost-effective solution compared to the conventional method of in-person evaluations. Remote monitoring also implies significant cost savings for the patients. Today, an increasing number of outpatient clinics are already implementing remote monitoring in daily practice [4]. Thus, a large-scale adoption could be supported.

The EVOLVO study summarizes the benefits of remote monitoring for a subgroup of the HF population, namely those patients with an implantable defibrillator. This is in-line with a recent Cochrane systematic literature review [7], in which implications for research include the need for cost-effectiveness and the stratification of the benefits across the HF patient population. Future research should focus on intervention intensity and economic evaluations of large-scale studies to tailor remote monitoring for HF patients with implantable defibrillators to the population’s needs and resources, to the geography of the population, and to patient preferences [7].

Acknowledgments

We are grateful to all investigators (physicians, nurses, and administrative staff) who have enthusiastically worked in the EVOLVO study. We also thank S Rusconi for his support in the analyses. The EVOLVO study was supported by the Italian Ministry of Health (grant RFPS-2006-2-335243) and by Regione Lombardia. Medtronic Italia provided technical support.

Conflicts of Interest

Dr Landolina has speakers’ bureau appointments and an advisory board relationship with Medtronic and other device companies. Valsecchi and Borghetti are employees of Medtronic Inc. The other authors report no conflicts.

Multimedia Appendix 1

CONSORT-EHEALTH checklist V1.6.2 [16].

[PDF File (Adobe PDF File), 989KB - jmir_v15i5e106_app1.pdf]

References

1. Dickstein K, Vardas PE, Auricchio A, Daubert JC, Linde C, McMurray J, ESC Committee for Practice Guidelines (CPG). 2010 Focused Update of ESC Guidelines on device therapy in heart failure: an update of the 2008 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure and the 2007 ESC guidelines for cardiac and resynchronization therapy. Developed with the special contribution of the Heart Failure Association and the European Heart Rhythm Association. Eur Heart J 2010 Nov;31(21):2677-2687 [FREE Full text] [doi: 10.1093/eurheartj/ehq337] [Medline: 20801924]
2. Wilkoff BL, Auricchio A, Brugada J, Cowie M, Ellenbogen KA, Gillis AM, Heart Rhythm Society (HRS), European Heart Rhythm Association (EHRA), American College of Cardiology (ACC), American Heart Association (AHA), European Society of Cardiology (ESC), Heart Failure Association of ESC (HFA), Heart Failure Society of America (HFSA). HRS/EHRA Expert Consensus on the Monitoring of Cardiovascular Implantable Electronic Devices (CIEDs): description of techniques, indications, personnel, frequency and ethical considerations: developed in partnership with the Heart Rhythm Society (HRS) and the European Heart Rhythm Association (EHRA); and in collaboration with the American College of Cardiology (ACC), the American Heart Association (AHA), the European Society of Cardiology (ESC), the Heart Failure Association of ESC (HFA), and the Heart Failure Society of America (HFSA). Endorsed by the Heart Rhythm Society, the European Heart Rhythm Association (a registered branch of the ESC), the American College of Cardiology, the American Heart Association. Europace 2008 Jun;10(6):707-725 [FREE Full text] [doi: 10.1093/europace/eun122] [Medline: 18480075]
3. Maass AH, van Veldhuisen DJ. Remote monitoring via implanted devices in heart failure: rising star or lame duck? Eur J Heart Fail 2011 Sep;13(9):925-926. [doi: 10.1093/eurjhf/hfr096] [Medline: 21852310]

4. de Vries AE, van der Wal MH, Nieuwenhuis MM, de Jong RM, van Dijk RB, Jaarsma T, et al. Health professionals' expectations versus experiences of internet-based telemonitoring: survey among heart failure clinics. J Med Internet Res 2013;15(1):e4 [FREE Full text] [doi: 10.2196/jmir.2161] [Medline: 23305645]
5. Heidbüchel H, Lioen P, Foulon S, Huybrechts W, Ector J, Willems R, et al. Potential role of remote monitoring for scheduled and unscheduled evaluations of patients with an implantable defibrillator. Europace 2008 Mar;10(3):351-357 [FREE Full text] [doi: 10.1093/europace/eun010] [Medline: 18245771]
6. Winkelmayer WC, Cohen DJ, Berger ML, Neumann PJ. Comparing cost-utility analyses in cardiovascular medicine. In: Weintraub WS, editor. Cardiovascular Health Care Economics. Totowa, NJ: Humana Press; 2003:329-356.
7. Inglis SC, Clark RA, McAlister FA, Ball J, Lewinter C, Cullington D, et al. Structured telephone support or telemonitoring programmes for patients with chronic heart failure. Cochrane Database Syst Rev 2010(8):CD007228. [doi: 10.1002/14651858.CD007228.pub2] [Medline: 20687083]
8. McLean S, Protti D, Sheikh A. Telehealthcare for long term conditions. BMJ 2011;342:d120. [Medline: 21292710]
9. Whitten PS, Mair FS, Haycox A, May CR, Williams TL, Hellmich S. Systematic review of cost effectiveness studies of telemedicine interventions. BMJ 2002 Jun 15;324(7351):1434-1437 [FREE Full text] [Medline: 12065269]
10. Mistry H. Systematic review of studies of the cost-effectiveness of telemedicine and telecare. Changes in the economic evidence over twenty years. J Telemed Telecare 2012 Jan;18(1):1-6. [doi: 10.1258/jtt.2011.110505] [Medline: 22101609]
11. Clark RA, Inglis SC, McAlister FA, Cleland JG, Stewart S. Telemonitoring or structured telephone support programmes for patients with chronic heart failure: systematic review and meta-analysis. BMJ 2007 May 5;334(7600):942 [FREE Full text] [doi: 10.1136/bmj.39156.536968.55] [Medline: 17426062]
12. van Veldhuisen DJ, Maass AH. Telemonitoring of outpatients with heart failure: a search for the holy grail? Circulation 2012 Jun 19;125(24):2965-2967. [doi: 10.1161/CIRCULATIONAHA.112.118141] [Medline: 22626742]
13. Marzegalli M, Landolina M, Lunati M, Perego GB, Pappone A, Guenzati G, et al. Design of the evolution of management strategies of heart failure patients with implantable defibrillators (EVOLVO) study to assess the ability of remote monitoring to treat and triage patients more effectively. Trials 2009;10:42 [FREE Full text] [doi: 10.1186/1745-6215-10-42] [Medline: 19538734]
14. Landolina M, Perego GB, Lunati M, Curnis A, Guenzati G, Vicentini A, et al. Remote monitoring reduces healthcare use and improves quality of care in heart failure patients with implantable defibrillators: the evolution of management strategies of heart failure patients with implantable defibrillators (EVOLVO) study. Circulation 2012 Jun 19;125(24):2985-2992. [doi: 10.1161/CIRCULATIONAHA.111.088971] [Medline: 22626743]
15. Burri H, Senouf D. Remote monitoring and follow-up of pacemakers and implantable cardioverter defibrillators. Europace 2009 Jun;11(6):701-709 [FREE Full text] [doi: 10.1093/europace/eup110] [Medline: 19470595]
16. Eysenbach G, CONSORT-EHEALTH Group. CONSORT-EHEALTH: improving and standardizing evaluation reports of Web-based and mobile health interventions. J Med Internet Res 2011;13(4):e126 [FREE Full text] [doi: 10.2196/jmir.1923] [Medline: 22209829]
17. Sticherling C, Kühne M, Schaer B, Altmann D, Osswald S. Remote monitoring of cardiovascular implantable electronic devices: prerequisite or luxury? Swiss Med Wkly 2009 Oct 17;139(41-42):596-601 [FREE Full text] [Medline: 19918698]
18. Al-Khatib SM, Piccini JP, Knight D, Stewart M, Clapp-Channing N, Sanders GD. Remote monitoring of implantable cardioverter defibrillators versus quarterly device interrogations in clinic: results from a randomized pilot clinical trial. J Cardiovasc Electrophysiol 2010 May;21(5):545-550. [doi: 10.1111/j.1540-8167.2009.01659.x] [Medline: 20021522]
19. Raatikainen MJ, Uusimaa P, van Ginneken MM, Janssen JP, Linnaluoto M. Remote monitoring of implantable cardioverter defibrillator patients: a safe, time-saving, and cost-effective means for follow-up. Europace 2008 Oct;10(10):1145-1151 [FREE Full text] [doi: 10.1093/europace/eun203] [Medline: 18703585]
20. Halimi F, Cantù F, European Heart Rhythm Association (EHRA) Scientific Initiatives Committee (SIC). Remote monitoring for active cardiovascular implantable electronic devices: a European survey. Europace 2010 Dec;12(12):1778-1780 [FREE Full text] [doi: 10.1093/europace/euq399] [Medline: 21097482]
21. Moving towards good practice in reimbursement of CIED telemonitoring. Germany: PricewaterhouseCoopers; 2012. URL: http://www.eucomed.org/uploads/Modules/Publications/whitepaper_reimbursementciedtelemonitoring.pdf [accessed 2013-04-08] [WebCite Cache ID 6Fj5doQQa]
22. Ministère du Travail de l'Emploi et de la Santé. Journal Officiel De La République Francaise. 2012 Jan 24. Avis et communications URL: http://www.legifrance.gouv.fr/jopdf/common/jo_pdf.jsp?numJO=0&dateJO=20120124&numTexte=137&pageDebut=01355&pageFin=01355 [WebCite Cache ID 6GmUKScRz]
23. Biffi M, Ziacchi M, Bertini M, Sangiorgi D, Corsini D, Martignani C, et al. Longevity of implantable cardioverter-defibrillators: implications for clinical practice and health care systems. Europace 2008 Nov;10(11):1288-1295 [FREE Full text] [doi: 10.1093/europace/eun240] [Medline: 18772164]
24. Biffi M, Ziacchi M, Bertini M, Gardini B, Mazzotti A, Massaro G, et al. How to truly value implantable cardioverter-defibrillators technology: up-front cost or daily cost? Int J Technol Assess Health Care 2011 Jul;27(3):201-206. [doi: 10.1017/S0266462311000183] [Medline: 21756409]

25. Kind P. Guidelines for value sets in economicnon-economic studies using EQ-5D. In: Brooks R, Rabin R, de Charro F, editors. The Measurement and Valuation of Health Status Using EQ-5D: A European Perspective. Dordrecht, Netherlands: Kluwer Academic Publishers; 2003.
26. Williams NH, Edwards RT, Linck P, Muntz R, Hibbs R, Wilkinson C, et al. Cost-utility analysis of osteopathy in primary care: results from a pragmatic randomized controlled trial. Fam Pract 2004 Dec;21(6):643-650 [FREE Full text] [doi: 10.1093/fampra/cmh612] [Medline: 15531626]
27. Manca A, Hawkins N, Sculpher MJ. Estimating mean QALYs in trial-based cost-effectiveness analysis: the importance of controlling for baseline utility. Health Econ 2005 May;14(5):487-496. [doi: 10.1002/hec.944] [Medline: 15497198]
28. Barber JA, Thompson SG. Analysis and interpretation of cost data in randomised controlled trials: review of published studies. BMJ 1998 Oct 31;317(7167):1195-1200 [FREE Full text] [Medline: 9794854]
29. Thompson SG, Barber JA. How should cost data in pragmatic randomised trials be analysed? BMJ 2000 Apr 29;320(7243):1197-1200 [FREE Full text] [Medline: 10784550]
30. Klersy C, De Silvestri A, Gabutti G, Raisaro A, Curti M, Regoli F, et al. Economic impact of remote patient monitoring: an integrated economic model derived from a meta-analysis of randomized controlled trials in heart failure. Eur J Heart Fail 2011 Apr;13(4):450-459. [doi: 10.1093/eurjhf/hfq232] [Medline: 21193439]
31. Devlin N, Parkin D. Does NICE have a cost-effectiveness threshold and what other factors influence its decisions? A binary choice analysis. Health Econ 2004 May;13(5):437-452. [doi: 10.1002/hec.864] [Medline: 15127424]
32. Diamond GA, Kaul S. Cost, effectiveness, and cost-effectiveness. Circ Cardiovasc Qual Outcomes 2009 Jan;2(1):49-54 [FREE Full text] [doi: 10.1161/CIRCOUTCOMES.108.793406] [Medline: 20031812]
33. Zanaboni P, Lettieri E. Institutionalizing telemedicine applications: the challenge of legitimizing decision-making. J Med Internet Res 2011;13(3):e72 [FREE Full text] [doi: 10.2196/jmir.1669] [Medline: 21955510]
34. Crossley GH, Boyle A, Vitense H, Chang Y, Mead RH, CONNECT Investigators. The CONNECT (Clinical Evaluation of Remote Notification to Reduce Time to Clinical Decision) trial: the value of wireless remote monitoring with automatic clinician alerts. J Am Coll Cardiol 2011 Mar 8;57(10):1181-1189. [doi: 10.1016/j.jacc.2010.12.012] [Medline: 21255955]
35. Paré G, Moqadem K, Pineau G, St-Hilaire C. Clinical effects of home telemonitoring in the context of diabetes, asthma, heart failure and hypertension: a systematic review. J Med Internet Res 2010;12(2):e21 [FREE Full text] [doi: 10.2196/jmir.1357] [Medline: 20554500]
36. Fauchier L, Sadoul N, Kouakam C, Briand F, Chauvin M, Babuty D, et al. Potential cost savings by telemedicine-assisted long-term care of implantable cardioverter defibrillator recipients. Pacing Clin Electrophysiol 2005 Jan;28 Suppl 1:S255-S259. [doi: 10.1111/j.1540-8159.2005.00071.x] [Medline: 15683509]

Abbreviations

CONSORT: Consolidated Standards of Reporting Trials
CRT-D: cardiac resynchronization therapy defibrillators
DRG: diagnosis-related group
ED: emergency department
EVOLVO: Evolution of Management Strategies of Heart Failure Patients With Implantable Defibrillators
HF: heart failure
ICD: implantable cardioverter defibrillators
NICE: National Institute for Clinical Excellence
NYHA: New York Heart Association
QALY: quality-adjusted life year

Edited by G Eysenbach; submitted 25.02.13; peer-reviewed by P Raatikainen, G Boriani; comments to author 21.03.13; revised version received 25.04.13; accepted 09.05.13; published 30.05.13.

Please cite as:
Zanaboni P, Landolina M, Marzegalli M, Lunati M, Perego GB, Guenzati G, Curnis A, Valsecchi S, Borghetti F, Borghi G, Masella C
Cost-Utility Analysis of the EVOLVO Study on Remote Monitoring for Heart Failure Patients With Implantable Defibrillators: Randomized Controlled Trial
J Med Internet Res 2013;15(5):e106
URL: http://www.jmir.org/2013/5/e106/
doi:10.2196/jmir.2587
PMID:23722666

Original Paper

The Digital Divide Among Low-Income Homebound Older Adults: Internet Use Patterns, eHealth Literacy, and Attitudes Toward Computer/Internet Use

Namkee G Choi[1], PhD; Diana M DiNitto[1], PhD

The University of Texas at Austin, Austin, TX, United States

Corresponding Author:
Namkee G Choi, PhD
The University of Texas at Austin
1925 San Jacinto Blvd
Austin, TX, 78712-0358
United States
Phone: 1 512 232 9590
Fax: 1 512 471 9600
Email: nchoi@austin.utexas.edu

Abstract

Background: Internet technology can provide a diverse array of online resources for low-income disabled and homebound older adults to manage their health and mental health problems and maintain social connections. Despite many previous studies of older adults' Internet use, none focused on these most vulnerable older adults.

Objective: This study examined Internet use patterns, reasons for discontinued use, eHealth literacy, and attitudes toward computer/Internet use among low-income homebound individuals aged 60 and older in comparison to their younger counterparts—homebound adults under age 60.

Methods: Face-to-face or telephone surveys were conducted with 980 recipients of home-delivered meals in central Texas (78% were age 60 years and older and 22% under age 60). The eHealth Literacy Scale (eHEALS) and the efficacy and interest subscales of the Attitudes Toward Computer/Internet Questionnaire (ATC/IQ) were used to measure the respective constructs. Age groups were compared with chi-square tests and *t* tests. Correlates of Internet use were analyzed with multinomial logistic regression, and correlates of eHEALS and ATC/IQ scores were analyzed with OLS regression models.

Results: Only 34% of the under-60 group and 17% of the 60 years and older group currently used the Internet, and 35% and 16% of the respective group members reported discontinuing Internet use due to cost and disability. In addition to being older, never users were more likely to be black (OR 4.41; 95% CI 2.82-6.91, *P*<.001) or Hispanic (OR 4.69; 95% CI 2.61-8.44, *P*<.001), and to have lower incomes (OR 0.36; 95% CI 0.27-0.49, *P*<.001). Discontinued users were also more likely to be black or Hispanic and to have lower incomes. Among both age groups, approximately three-fourths of the current users used the Internet every day or every few days, and their eHEALS scores were negatively associated with age and positively associated with frequency of use. Among the 60 and older group, a depression diagnosis was also negatively associated with eHEALS scores. ATC/IQ efficacy among never users of all ages and among older adults was positively associated with living alone, income, and the number of medical conditions and inversely associated with age, Hispanic ethnicity, and Spanish as the primary language. Although ATC/IQ interest among older adults was also inversely associated with age, it was not associated with Hispanic ethnicity and Spanish as the primary language.

Conclusions: This study is the first to describe in detail low-income disabled and homebound adults' and older adults' Internet use. It shows very low rates of Internet use compared to the US population, either due to lack of exposure to computer/Internet technology; lack of financial resources to obtain computers and technology; or medical conditions, disabilities, and associated pain that restrict use. Recommendations to reduce the digital divide among these individuals are provided.

(J Med Internet Res 2013;15(5):e93) doi:10.2196/jmir.2645

KEYWORDS

homebound older adults; housebound older adults; Internet; eHealth literacy; attitudes toward Internet

Introduction

With the unprecedented growth of the aging population, the number of disabled and homebound older adults continues to increase. Census data for 2009 show that 23.5% of the 40 million noninstitutionalized adults aged 65 years and older in the United States had an ambulatory disability and 15.8% had an independent living disability [1]. The Centers for Medicare and Medicaid Services also report that in 2011, 3.3 million Medicare or Medicaid recipients aged 65 and older received home health care services [2]. Of disabled and homebound older adults, the oldest, poorest, and physically and mentally most vulnerable tend to receive home-delivered meals (HDM, commonly known as “Meals on Wheels”) funded under Title III of the Older Americans Act [3]. In 2009, a little over 880,000 older adults (9%, 60-64 years old; 22%, 65-70 years old; 40%, 75-84 years old; and 30%, 85 years old and up) received HDM [4,5]. These low-income homebound older adults, who often have multiple chronic medical conditions and disabilities, face daunting tasks maintaining their independent living status. Their mobility impairments and lack of financial resources are significant barriers to conducting basic activities of daily living and instrumental activities of daily living (ADLs/IADLs) and remaining socially engaged, and as a result, they also become highly vulnerable to depression [6-8].

Internet technology can provide a diverse array of online resources for homebound older adults to manage their health and mental health problems and ADLs/IADLs. For example, they can use the Internet to search for health information; participate in freely available online chronic disease self-management programs, health and mental health support groups, and exercise programs; and order medications, make appointments, and communicate with their health care providers. Homebound older adults may also be able to stay connected to their close social support networks and the larger community via emails and video calls and by visiting religious sites, social networking sites, chat/discussion groups, interest/hobby groups, and news and blog sites. They may also take advantage of online shopping, banking, and bill paying to take more control of their daily lives. Furthermore, Internet access can allow them to benefit from the growing number of telehealth and telemental health interventions [9-11].

Older-adult Internet users indeed report multiple benefits of using this technology including convenience of accessing health-and nonhealth-related information; increased communication and social connections with family, friends, and others regardless of geographical distance; keeping abreast of news and other happenings in their immediate and global communities; participating in a variety of online educational, social, and recreational activities; and convenience of online shopping, banking, and travel arrangements [12-18]. Internet technology and web-based resources may likewise promote homebound older adults’ physical and mental health and reduce their social isolation and dependence on informal and formal support systems.

Although older adults are the fastest growing group of Internet users, their use still lags behind all other age groups. In April 2012, the Pew Internet and American Life Project found that among a nationally representative sample of Americans, 53% of those aged 65 and older, but only 34% of those aged 76 and older, used the Internet or email, in contrast to 97% of the 18-29 age group, 91% of the 30-49 age group, and 77% of the 50-64 age group [19]. Given their advanced age, high degree of functional impairment, limited financial resources, and social isolation, Internet use among low-income homebound older adults is likely to be even lower than that among general older adults. In fact, previous studies found that older adults who did not use the Internet or email tended to be older and of racial/ethnic minority status and had less education, worse physical and functional health, fewer social and financial resources, and greater loneliness/perceived social isolation [20-25]. Other studies also report that the most powerful predictors of not using information technology among older adults are cognitive decline associated with aging processes and attitudes such as anxiety about computer use and the perception that the technology was not useful for them [14,25,26]. Previous studies have not found consistent evidence about depressive symptoms as a correlate of older adults’ computer/Internet use. One study found depressive symptoms to be negatively associated with Internet use [27]; another found no relationship [25].

Older adults themselves report the following reasons for not using computer/Internet technology: the cost of the computer/other equipment and Internet access, functional impairments such as arthritis and joint pain that interfere with typing, visual deficits, ergonomic barriers (eg, small font sizes), lack of computer knowledge, lack of computer-efficacy (beliefs about their ability to use computers/Internet technology) and general self-efficacy (eg, “too old to learn new things”), and mistrust of Internet systems and privacy-related concerns [15,21,28]. However, previous studies also found that experience with computers/Internet reduced anxiety and increased self-confidence and positive attitudes about computers/Internet use in older adults regardless of income and educational levels [18,29-32].

For older adults in general and for low-income, disabled, homebound older adults in particular, eHealth literacy, along with Internet access, is an important dimension of the digital divide, ie, those who use versus those who do not use this technology. eHealth literacy is “the ability to seek, find, understand and appraise health information from electronic sources and apply knowledge gained to addressing or solving a health problem” and is composed of basic literacy, health literacy, scientific literacy, media literacy, and computer literacy [33]. Previous studies show that (1) eHealth literacy is lower among older adults, those with lower socioeconomic status, and those with less computer experience, and (2) higher eHealth literacy is associated with more positive outcomes from Internet searches in three domains: cognitive (eg, health knowledge/information gathering), instrumental (eg, self-management of health needs and health behaviors), and interpersonal (eg, interactions with physicians) [34-36]. Studies also find that health information technology training among older adults results in significant gains in eHealth literacy and ability to navigate complex health websites [18,34]. Government agencies and many private nonprofit and for-profit sector organizations now make prodigious amounts of health and mental health information and resources available online. Given vulnerable low-income homebound older adults' substantial health and mental needs, examining their ability to search for high-quality health information/resources and make informed decisions about applying the information to improve their quality of life may be particularly useful. This examination could identify their training needs to help close the digital divide and allow them to reap the multiple benefits of Internet and computer technology use.

Given that no study has examined Internet use patterns, eHealth literacy, and attitudes toward computer/Internet among low-income homebound older adults (aged 60 and older), we did so by comparing them with their younger counterparts—low-income homebound adults under age 60. The research questions in the present study were: Compared to their younger counterparts, (1) What are the rates of current Internet use, previous use, and never use among older adults?, (2) Among current users, what is the frequency of Internet use, types of Internet activities in which they engage, physical and functional difficulties using the Internet, and their comfort level in joining online health discussion groups and exchanging emails with other participants?, (3) Among previous users, what are the reasons for discontinued use?, and (4) Among never users, what is their level of willingness and comfort to engage in conducting health-information searches and joining online health discussion groups and exchanging emails with other participants? In addition, we tested the following hypotheses: Controlling for age, (H1) Never users and previous users will be more likely than current users to be black or Hispanic, lack English proficiency, have lower income, have more chronic medical conditions and ADL/IADL impairments, and have self-reported diagnoses of depression and anxiety, (H2) Among current users, eHealth literacy will be lower among those with self-reported diagnoses of depression and anxiety and lower frequency of Internet use, and (H3) Among never users, attitudes toward computer/Internet use (efficacy and interest) will be positively associated with higher income and living alone and negatively associated with lack of English proficiency and self-reported diagnoses of depression and anxiety.

Methods

Participants and Procedures

The data are from a survey of 980 HDM recipients residing in central Texas. The HDM program is operated by a multipurpose aging-service agency that serves about 2100 low-income, disabled, and homebound adults (80% were 60 years and older, and 20% under age 60) daily. The agency receives partial funding for HDM and case management services for clients aged 60 and older under Title III of the Older American Act and partial funding for the same services for persons under age 60 from the state Medicaid program and the Social Services Block Grant. The computer/Internet use survey was conceived as part of the agency's strategic exploration of the potential for using emails as part of its communication with clients and for providing case management services via videoconferencing in the future. Through an academic and community collaborative partnership, one of the authors helped the agency develop the survey questionnaire and trained the HDM program's 12 full-time case managers to conduct the survey with their clients. Most surveys were done between November 2012 and February 2013, either in person using the paper form survey questionnaire or by telephone using the electronic form survey questionnaire. The Spanish version of the survey was used for the clients who spoke Spanish only (< 3% of respondents). Clients assessed as having moderate to severe cognitive impairment based on the 4-item (memory, concentration, orientation, and decision-making) cognition test contained in the HDM program's intake and recertification assessments were excluded from the survey. Clients unable to participate in the survey due to severe mental illness and those who refused to participate for any reason were also excluded. All survey data were entered in the agency's centralized electronic client data management system and linked with each respondent's intake or most recent recertification assessment data. With approval from the University of Texas at Austin's Institutional Review Board, the de-identified data were analyzed in March 2013.

Measures

Internet Use

Internet use was measured with the question, "Have you ever used the Internet?" The answer categories were (1) No, I have never used it (never user), (2) I have used it before but not currently (previous user), and (3) Yes, I am a current user. The previous users (n=75 adults under age 60 and n=120 adults aged 60 or older) were asked the reasons for discontinuation (no computer or Internet connection at home because of cost, it is not helpful, I do not need it, cannot use computer because of disability or pain, and other—specify).

Internet Use Patterns and Activities

Patterns and activities in Internet use among current users (n=73 adults under age 60 and n=128 adults aged 60 or older) were ascertained with the following items: (1) location of Internet connection (at home, apartment complex, family/friend's home, and other—specify) and frequency of Internet use (at least once a day, every few days, once a week, a few times a month, once a month or less often), (2) type of activities conducted on the Internet (research health-related information, research information about other topics or issues of interest, send/receive email, buy products online, do banking online and/or pay bills, read news, papers, magazines, and books online, play games online, watch videos (including YouTube), use social networking or dating site (eg, Facebook, Match.com), and other—specify, (3) ease/difficulty of locating websites the user was looking for and finding the information that he/she needed within that site (on a 5-point Likert scale: 1="always easy" to 5="very difficult"), and (4) any physical/functional problem that made it harder for the respondent to use the Internet (pain in the limbs, unsteady hands, difficulty concentrating for long periods of time, difficulty sitting for long periods, eyes that tire easily, and other—specify).

eHealth Literacy

eHealth Literacy among current Internet users was measured by the 8-item eHealth Literacy Scale (eHEALS) with each item scored on a 5-point Likert scale. The eHEALS measures the concept of eHealth literacy as defined as a set of skills required to effectively engage information technology for health and has shown high levels of internal consistency and good test-retest reliability [33]. The items are: (1) I know *what* health resources are available on the Internet, (2) I know *where* to find helpful health resources on the Internet, (3) I know *how* to find helpful health resources on the Internet, (4) I know *how to use* the Internet to answer my questions about health, (5) I know how to use *the health information* I find on the Internet to help me, (6) I have the skills I need to *evaluate* the health resources I find on the Internet, (7) I can tell *high-quality* health resources from *low-quality* health resources on the Internet, and (8) I feel *confident* in using information from the Internet to make health decisions. The final eHEALS score is the average of all 8 items, with higher scores suggesting higher eHealth literacy. The internal consistency reliability in the original eHEALS validation study with a sample of 664 individuals aged 13-21 was Cronbach alpha=.88, and the principal components analysis produced a single factor solution (factor loadings ranging from .60 to .84 among 8 items; eigenvalue=4.479; and 56% of the variance explained). Item-scale correlations ranged from *r*=.51 to *r*=.76, and test-retest reliability showed modest stability over a 6-month period (*r*=.49 to *r*=.68) [33]. Although the eHEALS was originally validated with adolescents and young adults, it has been used to measure eHealth literacy among older adults [37]. In the present study, internal consistency reliability coefficient for the 8-item eHEALS for current Internet users was Cronbach alpha=.93 for both the younger (under age 60) group (n=73) and the older (60 years and up) group (n=128) adults.

In addition to these 8 items, two eHEALS supplemental items were used to measure (1) perceived usefulness of the Internet in helping make health decisions, and (2) perceived importance of being able to access health resources on the Internet. Both items were scored on a 5-point Likert scale with higher scores suggesting higher levels of perception. eHEALS developers recommend using these two supplemental items along with the 8 items.

Attitudes Toward Computer/Internet

Among never users (n=69 adults under age 60 and n=515 adults aged 60 or older), attitudes toward computers/Internet were measured with the 5-item computer efficacy subscale and the 5-item computer interest subscale of the Attitudes Toward Computers Questionnaire (ATCQ), with each item scored on a 1-5 point Likert scale. The ATCQ was originally validated to measure seven dimensions of attitudes toward computers (comfort, efficacy, gender equality, control, dehumanization, interest, and utility) among 398 students in Grades 4 through 12 [38]. It was later validated with 420 older adults and used to assess older adults' attitudes toward computers in previous studies [30,37,39,40]. In the present study, the original wording "computer" was changed to "computer/Internet" in each item (ATC/IQ hereafter) to emphasize the Internet. The efficacy items were (1) I know that if I worked hard to learn about computers/Internet, I could do well, (2) Computers/Internet are *not* too complicated for me to understand (*italics* in original), (3) I think I am the kind of person who would learn to use a computer/Internet well, (4) I think I am capable of learning to use a computer/Internet, and (5) Given a little time or training, I know I could learn to use a computer/Internet. The interest items were (1) Learning about computers/Internet is a worthwhile and necessary subject, (2) Reading or hearing about computers/Internet would be (is) boring, (3) I don't care to know more about computers/Internet, (4) Computers/Internet would be (are) fun to use, and (5) Learning about computers/Internet is a waste of time. For both efficacy and interest subscales, the final score is the average of all 5 items, and higher scores suggest higher computer/Internet efficacy or interest. In the present study, the internal consistency reliability coefficients for the efficacy subscale were Cronbach alpha=.85 for those under age 60 and .92 for those age 60 and up. The internal consistency reliability coefficients for the interest subscale were .88 for those under age 60 and .84 for those age 60 and up.

Willingness to Use Online Health Information

Among never users, willingness to use online health information was measured with one item, "If someone can teach me how to use the Internet to look for health information, I am willing to try" and scored on a 1-5 point Likert scale. Higher scores suggest greater willingness.

Comfort With Joining Online Health Discussion Groups and Exchanging Emails With Other Participants

*A*mong both current and never users, comfort with joining online health discussions and exchanging emails with other participants was measured with one item, "I would be comfortable joining an online health discussion group and exchanging emails with other participants" and scored on a 1-5 point Likert scale. Higher scores suggest greater levels of comfort.

Sociodemographics

Sociodemographics included age in years, gender, race/ethnicity (nonHispanic white—reference category, black/African American, Hispanic, and other), marital status (married, widowed, divorced/separated, and never married), living arrangement (living alone, living with spouse [and any other person], living with another adult, and living with dependent adult child[ren] or minor child[ren] only), income-to-needs ratio (ratio of income to the official poverty line adjusted for the number of family members, with higher ratios indicating higher income/better financial situation), and primary language the respondent speaks at home (English, both English/Spanish, Spanish only). The agency assessment does not include any questions about the client's level of education.

Health, Mental Health, and Disability

Health, mental health, and disability were measured by (1) the number of chronic medical conditions (arthritis, hypertension, diabetes, heart disease, lung disease, kidney disease, stroke, and cancer) that the respondent reported as having been diagnosed by a doctor, (2) diagnoses of depression, anxiety, and severe mental illnesses that the respondent reported (and confirmed by case managers using the respondent's list of medications when possible), and (3) the number of ADL impairments (feeding/eating, bathing, grooming, dressing, toileting, and getting in and out of bed) and IADL impairments (cleaning, preparing meals, doing laundry, grocery shopping, making telephone calls, and taking medications).

Analysis

First, we examined data integrity and missingness using univariate frequency distributions. Of 983 surveys conducted, 3 had incomplete data, leaving 980 usable surveys. Then we examined survey participants' representativeness by comparing their sociodemographic characteristics to those of all HDM clients the agency serves. Despite the exclusion of cognitively impaired and some severely mentally ill clients, survey participants' sociodemographic characteristics did not differ statistically from all HDM clients. Next, we conducted bivariate analyses using chi-square and *t* tests to compare respondents under 60 years of age with respondents 6 years of age and over in terms of their computer/Internet use patterns, reasons for discontinued use, eHealth literacy, attitudes toward computer/Internet use, and their willingness and comfort level regarding joining online health discussion groups and exchanging emails with other participants. Finally, we used multinomial logistic regression models to test H1 (Internet use/previous use/never use) and ordinary least squares (OLS) regression models to test H2 (correlates of eHealth literacy) and H3 (computer/Internet efficacy and interest), with sociodemographic and health/mental health characteristics as covariates. To examine correlates that may be specific to older adults (age 60 and up), we also ran separate multivariate models for them. In the multivariate regression analyses, 12 respondents who were not nonHispanic white, black, or Hispanic were excluded because of their small number. All statistical analyses were conducted with SPSS v.20.

Results

Participant Characteristics

Table 1 shows that the participants consisted of 217 (22.1%) people under age 60 and 763 (77.9%) people aged 60 years or older, 70% were female and 30% male, and 42% were nonHispanic white, 36% black, and 21% Hispanic. (The younger group ranged in age from 30-59 years, with 75% at 50-59. The oldest person in the older age group was 102 years old.) Participants' median income-to-needs ratio was 1.15, they had an average of three chronic illnesses, 42% reported a depression diagnosis, and 23% reported an anxiety diagnosis. Participants were indeed low-income and had high levels of physical, functional, and mental distress. The two age groups did not differ in terms of gender, racial/ethnic distributions, and number of ADL impairments, while the older age group had greater income and higher numbers of chronic illnesses and IADL impairments but lower rates of self-reported diagnoses of depression, anxiety, and severe mental illness. The majority of both groups lived alone, but their living arrangements and marital status differed (eg, the older group was much more likely to be widowed and the younger group never married).

Internet Use and Correlates

Table 2 shows participants' Internet use patterns. Almost 60% of all participants had never used the Internet, 20% had used it before, and 20% were currently using it. Internet use did differ by age, with a higher rate of use for younger adults. For example, 38% of those under age 55 and 28% of those aged 55-59 were current users, while less than 15% of those 70 years and older were current users; however, only 10% of those 75-79 years old were current users while close to 15% of those 80-89 years were current users. As expected, those 90 years and older had the smallest proportion of current users (less than 9%). The proportion of previous users also varied by age but with higher rates of discontinued use among younger than older adults. A majority of previous users (76% of the under age 60 group and 60.8% of the 60 and up group) reported their inability to afford an Internet subscription and/or a new computer. Some reported that their old computers were no longer working/broken. In addition, 13.3% of the younger group and 14.2% of the older group reported they stopped using computers/the Internet because of disability, pain, or vision impairment. 9.3% of the younger group and 18.3% of the older group reported they no longer use the Internet because they do not need it. As well, 1.3% of the younger group and 1.7% of the older group reported discontinuing use because the Internet was not helpful. 5% of the older group reported they just moved and needed to reassemble/reconnect their computer before they could use it again, and one person (77 years old) reported that he did not have enough time for the Internet. Age group differences in reasons for discontinuing use were not significant (Pearson χ^2_4=7.91, *P*=.10)

Table 3 shows the results of multinomial logistic regression analysis. Among all participants, having never used the Internet, as opposed to current use, was significantly associated with older age, being black or Hispanic (as opposed to being nonHispanic white), and having lower income. Odds ratios show that blacks were 4.4 times and Hispanics were 4.7 times more likely than non-Hispanic whites to have never used the Internet (OR 4.41; 95% CI 2.82-6.91, *P*<.001 for blacks and OR 4.69; 95% CI 2.61-8.44, *P*<.001 for Hispanics) when other variables were held constant. The likelihood of having never used the Internet decreased by 36% for every one unit increase in income-to-needs ratio (OR 0.36; 95% CI 0.27-0.49, *P*<.001). Discontinued use, as opposed to current use, was not significantly associated with age; however, it was significantly associated with ethnicity, with blacks almost twice and Hispanics almost three times more likely to have discontinued Internet use (OR 1.79; 95% CI 1.08-2.95, *P*<.05 for blacks and OR 2.86; 95% CI 2.53-5.35, *P*<.001 for Hispanics). In addition, the likelihood of discontinued use decreased by 62% with every one unit increase in income-to-needs ratio (OR 0.62; 95% CI 0.45-0.86, *P*<.001).

Multinomial logistic regression results for older adults only show that the likelihood of having never used the Internet decreased by 62% with a self-reported depression diagnosis (OR 0.62; 95% CI 0.39-0.98, *P*<.05), suggesting that depressed older adults were more likely to have used the Internet than their peers without this diagnosis. The likelihood of discontinued

Internet use decreased by 53% for older adults living alone (OR 0.53; 95% CI 0.31-0.92, *P*<.05), indicating that older adults living alone are more likely than those living with others to use the Internet.

Table 1. Sociodemographic and health and mental health characteristics by age group.

		All (N=980, 100%)	Under 60 (n=217, 22.1%)	60 and older (n=763, 77.9%)	*P* value[d]
Age, mean (SD)		71.31 (13.43)	53.83 (6.04)	76.57 (9.83)	<.001
Gender (%)					.40
	Male	29.5	31.8	28.8	
	Female	70.5	68.2	71.2	
Race/ethnicity (%)					.33
	Non-Hispanic white	41.7	39.6	42.3	
	Black/African American	36.2	38.2	35.6	
	Hispanic	20.8	19.8	21.1	
	Other	1.2	2.3	0.9	
Primary language spoken at home (%)					.24
	English	86.8	89.9	84.9	
	English/Spanish	11.0	8.9	11.7	
	Spanish				
	Other				
Marital status (%)					<.001
	Married	17.7	13.4	18.9	
	Widowed	33.9	6.9	41.5	
	Divorced/separated	34.7	48.4	30.8	
	Never married	13.8	31.1	8.8	
Living arrangement (%)					.02
	Live alone	58.0	56.7	58.3	
	Live with spouse	16.7	12.0	18.1	
	Live with other adult	21.2	24.9	20.2	
	Live with dependent child	4.1	6.5	3.4	
Income-to-needs ratio, mean (SD)		1.15 (0.65)	0.95 (0.51)	1.21 (0.67)	<.001
No. of chronic medical conditions[a], mean (SD)		3.03 (1.54)	2.79 (1.62)	3.10 (1.50)	.01
No. of ADL impairment[b], mean (SD)		1.69 (1.41)	1.68 (1.65)	1.69 (1.34)	.89
No. of IADL impairment[c], mean (SD)		3.26 (1.49)	2.95 (1.58)	3.34 (1.45)	.001
Diagnosis of depression (%)		41.9	63.1	35.9	<.001
Diagnosis of anxiety (%)		23.1	37.8	18.9	<.001
Diagnosis of severe mental illness (%)		12.2	28.2	7.8	<.001

[a] Includes arthritis, hypertension, diabetes, heart disease, lung disease, kidney disease, stroke, and cancer.

[b] Includes moderate to severe impairment in feeding/eating, dressing, grooming, bathing, toileting, and transferring from bed to chair.

[c] Includes moderate to severe impairment in cleaning, doing laundry, preparing meals, shopping, taking medication, and making telephone calls.

[d] *P* denotes difference between the two age groups.

Table 2. Internet use status by age group (%).

Age group		Distribution, n (%)	Never user	Previous user	Current user
All ages		980 (100)	59.6	19.9	20.5
Under 60[a]		217 (22.1)	31.8	34.6	33.6
60 and older		763 (77.9)	67.5	15.7	16.8
Under 55 [b]		118 (12.0)	27.1	34.7	38.1
	55-59	99 (10.1)	37.4	34.3	28.3
	60-64	117 (11.9)	50.4	23.1	26.5
	65-69	118 (12.0)	48.3	27.1	24.6
	70-74	111 (11.3)	67.6	18.0	14.4
	75-79	118 (12.0)	70.3	19.5	10.2
	80-84	121 (12.3)	76.9	8.3	14.9
	85-89	110 (11.2)	80.0	5.5	14.5
90 and older		68 (6.9)	88.2	2.9	8.8

[a] Age group difference in Internet use patterns was significant: Pearson χ^2_2=98.68, P<.001.

[b] Age group difference in Internet use patterns was significant: Pearson χ^2_{14}=153.53, P<.001.

Internet Use Patterns and Activities Among Current Users

Table 4 shows that 86% of the younger group and 95% of the older group had an Internet connection at home, while the rest used an Internet connection available at their apartment complex, family/friends' home, and other places including a store with wireless services. The age groups differed significantly in terms of their Internet connection sites (P=.02), with the older group more likely to connect at home; however, they did not differ in frequency of Internet use. A little more than half of both younger and older groups used the Internet daily, a little over 20% used it every few days, 10-11% used it once a week, and the rest used it less often than weekly. For both groups, sending and receiving email was the most popular Internet activity, followed by research on nonhealth- and health-related information. A little more than 75% of the younger group reported health-related information searches, but only 55% of the older group reported the same (P=.01). Significant age group differences were also found in Internet use for playing games (56% of the younger group vs 39% of the older group, P=.03), watching videos (49% vs 27%, P=.01), and for social network or dating sites (48% vs 20%, P<.001). Although not statistically significant, almost half of the younger group engaged in online goods purchases and banking/bill paying and reading online papers/news, magazines and books, while 35-39% of the older group did the same. "Other" Internet use (not reported in Table 4) included collecting coupons, looking at used car/motorcycle pictures on craigslist, looking at other photos, video chats using "Skype and Tango", checking lottery winning numbers; using it as Yellow pages/directory, listening to the radio, and visiting religious websites. Both age groups reported that they had a relatively easy time finding the information they were looking for on the Internet: mean 2.14 (SD 1.08) for the younger group and mean 2.27 (SD 1.15) for the older group, t=0.82, P=.41), suggesting that they felt confident about their search skills. However, many reported discomfort in using the computer/Internet due to physical, functional, and vision-related limitations. The problems they reported included arthritic pain in the fingers, neck and back pain, neuropathy, difficulty typing due to other disability, chronic fatigue and other medical conditions that interfere with their ability to concentrate and sit for a long period of time, and glaucoma and other vision problems. In addition, a few older adults said they were "too old to learn new things," were fearful of radiation exposure from the computer, and had insufficient reading comprehension to effectively use Internet resources.

Table 3. Correlates of Internet use and nonuse: odds ratios (OR) from multinomial regression results.

	All ages (n=968)		Older adults only (n=756)	
	Never use vs current use OR (95% CI)	Previous use vs current use OR (95% CI)	Never use vs current use OR (95% CI)	Previous use vs current use OR (95% CI)
Age	1.09[a] (1.07-1.11)	1.01 (0.99-1.03)	1.08[a] (1.06-1.11)	0.99 (0.96-1.02)
Male	1.00	1.00	1.00	1.00
Female	1.05 (0.70-1.57)	1.16 (0.74-1.82)	0.94 (0.58-1.53)	1.31 (0.73-2.36)
Non-Hispanic white	1.00	1.00	1.00	1.00
Black	4.4[a] (2.82-6.91)	1.79[c] (1.08-2.95)	5.13[a] (2.96-8.92)	2.12[c] (1.09-4.14)
Hispanic	4.69[a] (2.61-8.44)	2.86[a] (2.53-5.35)	7.63[a] (3.28-17.74)	5.62[a] (2.25-14.06)
English-speaking	1.00	1.00	1.00	1.00
Spanish-speaking	0.77 (0.14-4.16)	0.66 (0.10-4.44)	0.51 (0.06-4.49)	0.38 (0.03-4.97)
Not living alone	1.00	1.00	1.00	1.00
Living alone	0.82 (0.56-1.21)	0.74 (0.48-1.13)	0.78 (0.48-1.24)	0.53[c] (0.31-0.92)
Income-to-needs ratio	0.36[a] (0.27-0.49)	0.62[b] (0.45-0.86)	0.34[a] (0.24-0.48)	0.65 (0.45-0.94)
No depression diagnosis	1.00	1.00	1.00	1.00
Depression diagnosis	0.74 (0.50-1.10)	0.97 (0.63-1.52)	0.62[c] (0.39-0.98)	0.64 (0.37-1.12)
No anxiety diagnosis	1.00	1.00	1.00	1.00
Anxiety diagnosis	0.94 (0.60-1.49)	1.34 (0.83-2.16)	1.11 (0.63-1.96)	1.53 (0.80-2.92)
No. of medical conditions	0.93 (0.83-1.05)	0.88[d] (0.77-1.01)	0.92 (0.79-1.07)	0.83[c] (0.70-0.99)
No. of ADL/IADL impairment	1.07[d] (1.00-1.15)	1.04 (0.96-1.12)	1.08 (0.98-1.17)	1.06 (0.96-1.18)
-2 LL Model χ^2_{22}	307.90		219.02	
P	<.001		<.001	
Pseudo R^2 (Cox and Snell; Nigelkerke)	0.27; 0.32		0.25; 0.31	

[a] *P*<.001.

[b] *P*<.01.

[c] *P*<.05.

[d] *P*<.06.

Table 4. Internet use patterns and activities among current users.

		Under 60 n=217 (22.1%)	60 and older n=763 (77.9%)	*P* value[b]
Location of Internet connection				.02
	At home	86.3	95.2	
	Apartment complex	4.1	4.0	
	Family/friend’s house	2.7	0.8	
	Other (eg, store with Wi-Fi)	6.8	0	
Frequency of use				.97
	Daily	54.8	53.2	
	Every few days	23.3	21.0	
	Once a week	9.6	11.3	
	A few times a month	6.8	7.3	
	Once a month of less often	5.5	7.3	
Type of use				
	Research health-related information	75.3	54.7	.01
	Research information about other topics	76.7	66.4	.15
	Send/Receive email	78.1	76.6	.86
	Buy product online	49.3	35.2	.05
	Do banking /paying bills online	46.6	39.1	.30
	Read papers/news, magazines, and books	50.7	36.7	.07
	Play games	56.2	39.1	.03
	Watch videos (eg, YouTube)	49.3	27.3	.01
	Use social network or dating site (eg, Facebook, Match.com)	47.9	19.5	<.001
Self-reported ease of Internet search[a], mean (SD)		2.14 (1.08)	2.27 (1.15)	.41
Problems causing difficulty using the computer/Internet				
	Pain in the limbs, neck, and back	60.3	39.8	.01
	Unsteady hands	49.3	42.2	.38
	Difficulty concentrating (due to chronic fatigue; recent stroke)	45.2	39.8	.46
	Difficulty sitting for a long period of time	50.7	46.1	.30
	Vision problems (tired eyes, poor vision…)	52.1	46.1	.46
	Other (“too old to learn new things”, fear of radiation exposure, amputated hands, hands not usable, comprehension difficulty)	2.7	4.9	.28

[a] On a scale of 1-5, with lower scores suggesting higher level of ease and lower-level of difficulty.

[b] *P* denotes difference between the two age groups.

eHealth Literacy, Attitudes Toward Computer/Internet, and Correlates

Table 5 shows eHEALS scores for current users and ATC/IQ scores for never users by age group. eHEALS scores suggest that self-rated eHealth literacy for both age groups, on average, are at a neutral (ie, “undecided”) level, although the younger group’s score was significantly higher than the older group’s: mean 3.53 (SD 0.76) vs mean 3.22 (SD 0.85), *t*=2.57, *P*=.01. Both age groups scored slightly higher on the Internet’s usefulness in helping them make decisions about their health (mean 3.67 (SD 1.11) and mean 3.41 (SD 1.28), *t*=1.48, *P*=.14) and about the importance of being able to access health resources on the Internet (mean 3.75 (SD 1.16) and mean 3.43 (SD 1.32), *t*=1.74, *P*=.08). eHEALS scores and supplemental item scores were highly correlated (*r*=0.67, *P*<.001 for eHEALS and perceived usefulness and *r*=0.69, *P*<.001 for eHEALS and perceived importance). Perceived usefulness scores and perceived importance scores were also highly correlated (*r*=0.79, *P*<.001). However, both groups expressed a lower level of certainty/comfort about joining online health discussion groups and exchanging emails with other participants, with less willingness among older adults: mean 2.89 (SD 1.23) for the younger group and mean 2.52 (SD 1.30) for the older group, t=2.01, P=.05.

Both ATC/IQ efficacy and interest scores, on average, suggest a neutral (undecided) level of efficacy and interest. The younger group's efficacy score was slightly and significantly higher than the older group's: mean 3.34 (SD 0.77) vs 3.01 (SD 0.98), t=2.66, P=.01. However, there was no age group difference in interest level: mean 3.33 (SD 0.88) vs 3.23 (SD 0.85), t=0.88, P=.38. Willingness to use online health information (if someone taught them how to use the computer/Internet) was also at a neutral level, with slightly and significantly higher scores for the younger than older group: mean 3.52 (SD 1.05) vs 3.03 (SD 1.22), t=3.18, P=.01. Comfort with joining online health discussion groups and exchanging emails with other participants was also slightly and significantly higher for younger than older adults: mean 2.81 (SD 1.20) vs 2.44 (SD 1.17), t=2.50, P=.01.

Another way to examine eHEALS and ATC/IQ scores is by the proportion of those who agreed (rating of 4) or strongly agreed (rating of 5) with the scale items. Among respondents, 35.7% of the younger group and 29.0% of the older group had an average score of 4+ on the 8-item eHEALS, 65.7% of the younger and 63.3% of the older groups rated perceived usefulness as 4 or 5, 68.5% of the younger and 62.5% of the older groups rated perceived importance 4 or 5, and 39.7% and 31.3% of the respective age groups rated their comfort level with joining online health discussion groups and exchanging emails with other participants as 4 or 5. Further analysis also showed that 40.5% of the younger group and 27.3% of the older group scored 4+ on the ATC/IQ efficacy subscale, 36.2% of the younger group and 28.8% of the older group scored 4+ on the ATC/IQ interest subscale, 68.1% and 48.4% of the respective age groups scored 4 or 5 on their willingness to try accessing online health information, and 40.5% and 25.0% of the respective age groups scored their comfort level with joining online health discussion groups and exchanging emails with other participants as 4 or 5.

As expected, Table 6 shows that eHEALS scores among current Internet users of all ages were inversely associated with age and computer/Internet use frequency, with these variables alone explaining 27% of the variance in eHEALS scores. No other sociodemographic and health/mental health characteristics were associated with eHEALS scores. Among the older age group, however, depression was also inversely associated with eHEALS scores: B=-0.33 (SE 0.14), P=.02. The model adjusted R^2 was .36.

As Table 7 shows, ATC/IQ efficacy among never users of all ages was positively associated with living alone, income-to-needs ratio, and the number of medical conditions and inversely associated with age, Hispanic ethnicity, and Spanish as the primary language spoken at home. Among the older age group, being black was also marginally positively associated with higher efficacy scores: B=0.19 (SE 0.10), P=.057. ATC/IQ interest among never users of all ages was positively associated with being black but inversely associated with age, Hispanic ethnicity (marginally), and Spanish as the primary language spoken at home. Among the older age group, Hispanic ethnicity and Spanish as the primary language were not significant factors, while living alone was marginally positively associated with higher interest scores: B=0.14 (SE 0.07), P=.066. Given the low R^2 statistics (15% for efficacy and 8-10% for interest), it appears that variables not captured by the participants' sociodemographic and health/mental health characteristics may influence ATC/IQ efficacy and interest.

Table 5. eHealth Literacy (eHEALS), Attitudes Toward Computer/Internet (ATC/IQ), and willingness to use health information searches and online health discussion groups: mean and standard deviation of the mean.

	Current User		Never User	
	Under 60 (n=73)	60 and older (n=218)	Under 60 (n=69)	60 and older (n=515)
8-item eHEALS	3.53 (0.76)[b]	3.22 (0.85)[b]		
Perceived usefulness	3.67(1.11)	3.41 (1.28)		
Perceived importance	3.75 (1.16)	3.43 (1.32)		
ATC/IQ efficacy			3.34 (0.77)[a]	3.01 (0.98)[a]
ATC/IQ interest			3.33 (0.88)	3.23 (0.85)
Willingness to try online health information (if someone can teach me how)			3.52 (1.05)[a]	3.03 (1.22)[a]
Comfort with online health discussions groups and email exchanges with other participants	2.89 (1.23)	2.52 (1.30)	2.81 (1.20)[b]	2.44 (1.17)[b]

[a] P<.01.

[b] P<.05; denotes difference between the two age groups.

Table 6. Correlates of eHEALS among current Internet users.

	All ages (n=198) B (SE)	Older adults only (n=128) B (SE)
Age	-0.02 (0.01)[a]	-0.03 (0.01)[a]
Female	0.14 (0.11)	-0.01 (0.14)
Black	0.17 (0.14)	0.13 (0.18)
Hispanic	-0.27 (0.19)	-0.42 (0.29)
Spanish-speaking	-0.03 (0.76)	0.02 (0.78)
Live alone	0.09 (0.11)	0.18 (0.14)
Income-to-needs ratio	0.11 (0.07)	0.11 (0.08)
Diagnosis of depression	-0.17 (0.11)	-0.33 (0.14)[c]
Diagnosis of anxiety	0.11 (0.13)	0.03 (0.17)
No. of medical conditions	0.00 (0.03)	0.01 (0.04)
No. of ADL/IADL impairment	-0.01 (0.02)	0.02 (0.03)
Use Internet a few times a week	-0.44 (0.14)[b]	-0.36 (0.18)[c]
Use Internet once a week or less often	-0.88 (0.13)[a]	-1.01 (0.16)[a]
R^2	0.32	0.40
Adjusted R^2	0.27	0.36
SE	0.71	0.70
df (P)	13 (<.001)	13 (<.001)

[a] $P<.001$.

[b] $P<.01$.

[c] $P<.05$.

Table 7. Correlates of ATC/IQ efficacy and interest among those who never used the Internet.

	ATC/IQ efficacy		ATC/IQ interest	
	All ages (n=577) B (SE)	Older adults only (n=509) B (SE)	All ages (n=577) B (SE)	Older adults only (n=509) B (SE)
Age	-0.02 (0.00)[a]	-0.02 (0.01)[a]	-0.01 (0.00)[b]	-0.02 (0.00)[a]
Female	0.09 (0.08)	0.13 (0.09)	0.11 (0.08)	0.12 (0.08)
Black	0.14 (0.09)	0.19 (0.10)[d]	0.24 (0.08)[b]	0.32 (0.09)[a]
Hispanic	-0.40 (0.11)[a]	-0.34 (0.12)[b]	-0.17 (0.10)[d]	-0.12 (0.10)
Spanish-speaking	-0.68 (0.20)[a]	-0.65 (0.21)[b]	-0.40 (0.19)[c]	-0.31 (0.19)
Living alone	0.15 (0.08)[c]	0.21 (0.08)[c]	0.06 (0.06)	0.14 (0.07)[d]
Income-to-needs ratio	0.15 (0.07)[c]	0.21 (0.07)[b]	0.05 (0.08)	0.11 (0.07)
Diagnosis of depression	-0.07 (0.08)	-0.06 (0.09)	-0.05 (0.08)	-0.04 (0.08)
Diagnosis of anxiety	0.04 (0.10)	0.00 (0.11)	-0.04 (0.09)	-0.03 (0.10)
No. of medical conditions	0.05 (0.03)	0.03 (0.03)	0.03 (0.02)	0.01 (0.03)
No. of ADL/IADL impairment	-0.00 (0.02)	-0.01 (0.02)	-0.01 (0.01)	-0.01 (0.02)
R^2	0.17	0.17	0.10	0.12
Adjusted R^2	0.15	0.15	0.08	0.10
SE	0.87	0.90	0.82	0.81
df (*P*)	11 (<.001)	11 (<.001)	11 (<.001)	11 (<.001)

[a] *P*<.001.

[b] *P*<.01.

[c] *P*<.05.

[d] *P*<.07.

Discussion

Many previous studies describe the digital divide between older and younger people, with the divide being greater for those who are racial/ethnic minorities and of lower socioeconomic status (SES) [19,22,25,28,34]. Much research has also been done regarding the psychological, functional, and educational barriers that prevent many older adults from joining the digital age and taking advantage of the many benefits that Internet technology can offer [18,20,35,36]. Most previous research included older adults with varying degrees of SES and functional abilities, and few focused on those with low-incomes and disabilities. This study examined Internet use patterns, eHealth literacy, and attitudes toward computer/Internet among a large sample of low-income homebound older adults and compared them to a younger group of low-income homebound individuals. Because of their disabilities, none worked for pay and all received home-delivered meals; thus, any computer/Internet use in which they engaged would have been exclusively for their personal use.

As expected, this vulnerable group of individuals had low rates of Internet use—34% of the younger group (under 60 years) and 17% of the older group (60 years and older). For the most part, age was inversely associated with Internet use, with lower use rates among those with more advanced age. However, this study also found that the numbers who had to discontinue Internet use (35% of the younger group and 16% of the older group) were as many as those who were currently using the Internet. The primary reasons for discontinuation were the cost of an Internet connection and/or replacing a nonfunctional computer and disability, pain, and vision problems. For those who could not afford an Internet subscription, computer, or other necessary equipment, it appears that they could have continued using the Internet if affordability was not a barrier.

The study also found that even within this group of low-income homebound persons, racial/ethnic minorities and those with lower income were much less likely to use the Internet, indicating the persistent negative effects of racial/ethnic minority status and low SES on digital inclusion. Multivariate analyses also identified the number of chronic medical conditions and ADL/IADL impairments as marginally significant correlates of Internet use. As expected, ADL/IADL impairments were barriers to Internet use; however, higher numbers of chronic medical conditions were positively associated with current Internet use as opposed to discontinued use. While having chronic medical conditions seems to promote Internet use, it is not clear if this results from the need to obtain medical information or manage ones' health care or whether having more chronic conditions results in greater isolation, making the Internet important in maintaining social connections. Also important was that a self-reported diagnosis of depression or anxiety was not a significant correlate, suggesting that these mental health conditions did not inhibit Internet use. Thus, H1 was partially supported.

Regardless of age, about three-fourths of Internet users went online either daily or every few days, suggesting that a majority of these low-income, homebound Internet users integrated Internet technology in their usual routines. In this respect, they were not different from the general US population. The aforementioned national survey done in 2012 found that 70% of US adults aged 65 and older used the Internet on a typical day and 67% of all American adults aged 18 and older did so [19]. Younger persons in our sample reported utilizing the Internet for a wider variety of activities, taking advantage of the many benefits the Internet offers. Older users were not taking full advantage of the Internet's multiple benefits, as only about 55% did research on health-related information and only one-fifth were using the Internet for social networking purposes. This may reflect their reports that searching and finding the information they needed fell somewhere between “sometimes easy” and “not so easy.” Although most users in the older age group used the Internet daily or almost daily, they appear to have somewhat low levels of confidence in their Internet search skills, which was reflected in their average eHEALS score being significantly lower than in the younger age group. In multivariate analyses, eHEALS scores were negatively associated with age, meaning those of older ages had lower perceptions of their eHealth self-efficacy. Better news is that self-efficacy was significantly determined by the frequency of Internet use, a finding consistent with previous studies that training and practicing Internet skills increases older adults' computer-related self-efficacy [18,29-32]. As hypothesized, eHEALS scores in the older age group were also inversely associated with a depression diagnosis, which may reflect the generally negative self-evaluation among depressed older adults, even though older adults with depression were more likely to use the Internet than those without this diagnosis. These findings support H2. The low-level of eHealth efficacy among both age groups may also have been responsible for respondents' lack of willingness to join online health discussion groups, although the lack of willingness may also have stemmed from privacy concerns related to the exchange of emails with other participants or warnings to avoid being taken advantage of online. Some low-income homebound older adults may have faced discrimination or mistreatment by others throughout their lives, and as a result, they may have been cautious about connecting with strangers online, although they perceived the usefulness and importance of the Internet-based health resources.

Those who never used the Internet did not express aversion to learning to use it and believed they could do so, although older respondents were slightly less confident than their younger counterparts. In addition to age, Hispanics and those who primarily spoke Spanish at home expressed lower levels of computer/Internet efficacy, though it is not clear why Hispanics, even controlling for Spanish speaking, had a lower level of efficacy. Participants who lived alone and participants, including those in the older age group, with higher incomes had higher efficacy levels. Those living alone may have more confidence in general given their ability to live independently and may also feel a greater need to use email and other Internet technology that can connect them to others.

Although bivariate analyses showed that low-income homebound older adults' computer/Internet interest did not differ significantly from their younger counterparts, multivariate analyses again showed that older age was a significant negative factor. Although blacks were less likely to use the Internet than nonHispanic whites, black older adults and older adults who lived alone expressed greater interest in computer/Internet use than their nonHispanic white counterparts and those who lived with someone else. Hispanics were also less likely than nonHispanic whites to use the Internet, but ethnicity and Spanish-language use were not significant factors for older adults' level of interest. Thus, H3 was partially supported.

A few study limitations should be noted. First, despite the large sample size, the survey participants were selected from a geographically limited area, which may limit the findings' generalizability. Second, although case managers confirmed participants' reported health and mental health conditions using medication lists, these diagnoses by themselves may not be equated with symptom manifestations and severity, especially in the case of depression, anxiety, and severe mental illness. Pharmacotherapy may have effectively reduced symptoms for some people. Thus, actual assessment of current symptoms would have allowed more accurate evaluation of their influence. Third, a potentially important omission in the agency assessment dataset was the clients' level of education, which could have provided a more comprehensive picture of participants' sociodemographic characteristics and their level of disadvantage.

Despite its limitations, the present study is the first to provide a detailed description of Internet use and nonuse among low-income, disabled, and homebound older and younger adults. We found very low rates of Internet use compared to the US population, either due to lack of exposure to computer and Internet technology, lack of financial resources to obtain computers and access technology for personal use, or medical conditions, disabilities, and associated pain that restrict use. However, the findings also provide hope for reducing the digital divide because while blacks and Hispanics were less likely to be current Internet users, black older adults expressed greater interest and Spanish-speaking adults were no less interested than nonHispanic whites in computer/Internet use. Internet technology can offer multiple benefits to vulnerable homebound individuals and may contribute to reducing health disparities among other disabled homebound individuals. Thus, improving access to Internet technology that can enhance health and well-being should be viewed as a social justice issue. As health care systems increasingly rely on Internet technology to manage patients' records, communicate with them, and provide care, it will be necessary for patients who want greater involvement in their health care to become proficient in using health information technology. For example, access to one's electronic health records and being able to communicate more readily with health care providers may go a long way in improving patient compliance with treatment regimens, engaging patients in their treatment, and increasing their control over what is happening to them. Those, such as homebound individuals who often have multiple health needs, can benefit the most from becoming well versed at using these tools.

Until the digital divide eventually disappears due to younger Americans' nearly universal exposure to computer use and Internet technology, steps can be taken to increase Internet use among today's older adults, including those who are disadvantaged, through social policy, technology/equipment design, and training/education. First, in the social policy domain, offering low-income persons technology subsidies/allowances may help them join the digital age, and government agencies and nongovernmental organizations (NGOs) could recycle and refurbish the many computers sitting idle or disposed of each year for older adults' use. Such government-provided allowances and NGO efforts may result in cost effectiveness if they enable people to live independently, reduce their dependence on informal and formal support, and increase their quality of life. Second, to encourage Internet use among individuals with substantial disabilities, technology should be designed to be as user-friendly as possible [41]. For example, touch screens tend to be more usable than keyboards for older adults with arthritic pains in their fingers/hands. However, future technology designs should go far beyond many current innovations and provide personalized technology systems to facilitate use even among those with a high degree of disability, such as greater access to voice systems for people with low literacy levels or who are visually impaired. Third, older adults who remain reluctant to use the Internet due to low technology-related self-efficacy may be motivated to embrace its use through demonstrations and education. The present study suggests that exposure and practice (ie, frequent use) increases Internet skill efficacy regardless of income level and disability. Many younger people's computer and Internet skills could be used by employing them through volunteer work or paid employment to teach older adults how to use email, surf the Web, and engage in social networking and health-related tasks. Especially for low-income homebound older adults who have not been exposed to computer/Internet technology but whose needs are substantial, the multiple benefits of computer/Internet use need to be emphasized and equipment and training provided to facilitate their use.

Future studies should test the extent to which providing computer equipment (especially devices that are easiest to use), Internet connections, computer applications, and training to use them increase interest, use, and efficacy and are associated with improved health, mental health, and other well-being outcomes. Studies should also test the types of devices and applications that homebound adults may be most interested in using and the features that facilitate use and better outcomes for this population.

Acknowledgments

The authors are grateful to the HDM program's case managers for data collection, to Linda Perez for her supervision of data collection, and to David Thompson for his data management.

Conflicts of Interest

None declared.

References

1. United States Census Bureau. Statistical Table Based on data from the 2009 American Community Survey. 2009. Table 35, Persons 65 Years and Over - Living Arrangements and Disability Status URL: http://www.census.gov/compendia/statab/2012/tables/12s0035.pdf [accessed 2013-04-01] [WebCite Cache ID 6FYdAECOu]
2. Centers for Medicare and Medicaid Services. Table 7.2, Persons Served, Visits, Total Charges, Visit Charges, and Program Payments for Medicare Home Health Agency Services: Calendar Year 2011. 2012. Medicare and Medicaid Supplemental Statistics URL: http://cms.hhs.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/MedicareMedicaidStatSupp/2012.html [accessed 2013-04-01] [WebCite Cache ID 6FYdVEAGi]
3. Barrett A, Schimmel J. Issue Brief No 2.: Mathematica Policy Research, Inc; 2012 Aug. OAA Title III services target the most vulnerable elderly in the United States URL: http://www.nanasp.org/pdf/vulnerableseniors_ib2.pdf [accessed 2013-04-24] [WebCite Cache ID 6G7am0QLA]
4. Altchuler N, Schimmel J. Issue Brief No. 1.: Mathematica Policy Research, Inc; 2010. Aging in place: Do Older Americans Act Title III services reach those most likely to enter nursing homes? URL: http://www.aoa.gov/aoaroot/program_results/docs/AoA-issue1_Nursing%20Homes.pdf [accessed 2013-04-24] [WebCite Cache ID 6G7asrlAm]
5. Colello KJ. Congressional Research Service Report for Congress. 2011 Jun 17. Older Americans Act Title III Nutrition Services Program URL: http://www.aging.senate.gov/crs/nutrition1.pdf [accessed 2013-04-24] [WebCite Cache ID 6G7b0Ve9C]
6. Choi NG, Teeters M, Perez L, Farar B, Thompson D. Severity and correlates of depressive symptoms among recipients of meals on wheels: age, gender, and racial/ethnic difference. Aging Ment Health 2010 Mar;14(2):145-154. [doi: 10.1080/13607860903421078] [Medline: 19946802]
7. Ell K, Unützer J, Aranda M, Sanchez K, Lee PJ. Routine PHQ-9 depression screening in home health care: depression, prevalence, clinical and treatment characteristics and screening implementation. Home Health Care Serv Q 2005;24(4):1-19 [FREE Full text] [doi: 10.1300/J027v24n04_01] [Medline: 16446263]

8. Sirey JA, Bruce ML, Carpenter M, Booker D, Reid MC, Newell KA, et al. Depressive symptoms and suicidal ideation among older adults receiving home delivered meals. Int J Geriatr Psychiatry 2008 Dec;23(12):1306-1311. [doi: 10.1002/gps.2070] [Medline: 18615448]
9. Grady B, Myers KM, Nelson EL, Belz N, Bennett L, Carnahan L, American Telemedicine Association Telemental Health Standards and Guidelines Working Group. Evidence-based practice for telemental health. Telemed J E Health 2011 Mar;17(2):131-148. [doi: 10.1089/tmj.2010.0158] [Medline: 21385026]
10. van den Berg N, Schumann M, Kraft K, Hoffmann W. Telemedicine and telecare for older patients--a systematic review. Maturitas 2012 Oct;73(2):94-114. [doi: 10.1016/j.maturitas.2012.06.010] [Medline: 22809497]
11. Wilcox ME, Adhikari NK. The effect of telemedicine in critically ill patients: systematic review and meta-analysis. Crit Care 2012 Jul 18;16(4):R127 [FREE Full text] [doi: 10.1186/cc11429] [Medline: 22809335]
12. Internet use among midlife and older adults: an AARP bulletin Poll.: AARP; 2009 Dec. URL: http://assets.aarp.org/rgcenter/general/bulletin_internet_09.pdf [accessed 2013-04-24] [WebCite Cache ID 6G7bFjMQF]
13. Crabb RM, Rafie S, Weingardt KR. Health-related internet use in older primary care patients. Gerontology 2012;58(2):164-170. [doi: 10.1159/000329340] [Medline: 21734360]
14. Czaja SJ, Lee CC. The impact of aging on access to technology. Univ Access Inf Soc 2006 Dec 2006;5(4):341-349. [doi: 10.1007/s10209-006-0060-x]
15. Gatto SL, Tak SH. Computer, Internet, and E-mail Use Among Older Adults: Benefits and Barriers. Educational Gerontology 2008 Aug 2008;34(9):800-811. [doi: 10.1080/03601270802243697]
16. Russell C, Campbell A, Hughes I. Ageing, social capital and the Internet: findings from an exploratory study of Australian 'silver surfers'. Australas J Ageing 2008 Jun;27(2):78-82. [doi: 10.1111/j.1741-6612.2008.00284.x] [Medline: 18713197]
17. Sum S, Mathews RM, Hughes I. Participation of older adults in cyberspace: how Australian older adults use the Internet. Australas J Ageing 2009 Dec;28(4):189-193. [doi: 10.1111/j.1741-6612.2009.00374.x] [Medline: 19951340]
18. Xie B. Effects of an eHealth literacy intervention for older adults. J Med Internet Res 2011 Nov;13(4):e90 [FREE Full text] [doi: 10.2196/jmir.1880] [Medline: 22052161]
19. Zickuhr K, Madden M. Pew Research Center's Internet & American Life Project. Older adults and Internet use URL: http://www.pewinternet.org/Reports/2012/Older-adults-and-internet-use.aspx [accessed 2013-04-24] [WebCite Cache ID 6G7bYAs5A]
20. Adams N, Stubbs D, Woods V. Psychological barriers to Internet usage among older adults in the UK. Med Inform Internet Med 2005 Mar;30(1):3-17. [doi: 10.1080/14639230500066876] [Medline: 16036626]
21. Carpenter BD, Buday S. Computer use among older adults in a naturally occurring retirement community. Computers in Human Behavior 2007 Nov;23(6):3012-3024. [doi: 10.1016/j.chb.2006.08.015]
22. Choi N. Relationship between health service use and health information technology use among older adults: analysis of the US National Health Interview Survey. J Med Internet Res 2011;13(2):e33 [FREE Full text] [doi: 10.2196/jmir.1753] [Medline: 21752784]
23. Dreisbach N, Axler F, Kotranski L, Weingartner RM, Ingerman S, Ramirez N, et al. Assessing the digital divide among older adults residing in an urban and suburban metropolitan area. In: Proceedings of the 139th Annual Meeting of the American Public Health Association. 2011 Presented at: 139th Annual Meeting of the American Public Health Association; Oct. 29 - Nov. 2, 2011; Washington, DC URL: http://www.chdbdata.org/uploads/datareports/Internet&Older%20Adults_10.28.pdf
24. Slegers K, van Boxtel MPJ, Jolles J. Computer use in older adults: determinants and the relationship with cognitive change over a 6 year episode. Comput Hum Behav 2012;28:1-10. [doi: 10.1016/j.chb.2011.08-003]
25. Werner JM, Carlson M, Jordan-Marsh M, Clark F. Predictors of computer use in community-dwelling, ethnically diverse older adults. Hum Factors 2011 Oct;53(5):431-447 [FREE Full text] [Medline: 22046718]
26. Charness N, Boot WR. Aging and information technology use. Curr Dir Psychol Sci 2009;18(5):253-258. [doi: 10.1111/j.1467-8721.2009.01647.x]
27. Choi NG, DiNitto DM. Different types of Internet use among older adults:. Association with health needs, psychological capital, and social capital 2013 (forthcoming). [doi: 10.2196/jmir.2333]
28. Berry R. Older people and the Internet. UK: International Longevity Centre; 2011. URL: http://www.ilcuk.org.uk/images/uploads/publication-pdfs/pdf_pdf_181.pdf [accessed 2013-04-24] [WebCite Cache ID 6G7cjYgyq]
29. Chu A, Huber J, Mastel-Smith B, Cesario S. "Partnering with Seniors for Better Health": computer use and Internet health information retrieval among older adults in a low socioeconomic community. J Med Libr Assoc 2009 Jan;97(1):12-20 [FREE Full text] [doi: 10.3163/1536-5050.97.1.003] [Medline: 19159002]
30. Czaja SJ, Sharit J. Age differences in attitudes toward computers. J Gerontol B Psychol Sci Soc Sci 1998 Sep;53(5):P329-P340. [Medline: 9750571]
31. Wild KV, Mattek NC, Maxwell SA, Dodge HH, Jimison HB, Kaye JA. Computer-related self-efficacy and anxiety in older adults with and without mild cognitive impairment. Alzheimers Dement 2012 Nov;8(6):544-552. [doi: 10.1016/j.jalz.2011.12.008] [Medline: 23102124]
32. Lagana L. Enhancing the Attitudes and Self-Efficacy of Older Adults Toward Computers and the Internet: Results of a Pilot Study. Educ Gerontol 2008 Sep 1;34(9):831 [FREE Full text] [doi: 10.1080/03601270802243713] [Medline: 20148185]

33. Norman CD, Skinner HA. eHEALS: The eHealth Literacy Scale. J Med Internet Res 2006 Nov;8(4):e27 [FREE Full text] [doi: 10.2196/jmir.8.4.e27] [Medline: 17213046]
34. Czaja SJ, Sharit J, Lee CC, Nair SN, Hernández MA, Arana N, et al. Factors influencing use of an e-health website in a community sample of older adults. J Am Med Inform Assoc 2013 Jul;20(2):277-284. [doi: 10.1136/amiajnl-2012-000876] [Medline: 22802269]
35. Jensen JD, King AJ, Davis LA, Guntzviller LM. Utilization of internet technology by low-income adults: the role of health literacy, health numeracy, and computer assistance. J Aging Health 2010 Sep;22(6):804-826. [doi: 10.1177/0898264310366161] [Medline: 20495159]
36. Neter E, Brainin E. eHealth literacy: extending the digital divide to the realm of health information. J Med Internet Res 2012 Jan;14(1):e19 [FREE Full text] [doi: 10.2196/jmir.1619] [Medline: 22357448]
37. Xie B. Older adults, e-health literacy, and collaborative learning: An experimental study. J Am Soc Inf Sci 2011 Mar;62(5):933-946. [doi: 10.1002/asi.21507]
38. Bear GG, Richards HC, Lancaster P. Attitudes Toward Computers: Validation of a Computer Attitudes Scale. Journal of Educational Computing Research 1995 Jan 1995;3(2):207-218. [doi: 10.2190/1DYT-1JEJ-T8J5-1YC7]
39. Jay GM, Willis SL. Influence of direct computer experience on older adults' attitudes toward computers. J Gerontol 1992 Jul;47(4):P250-P257. [Medline: 1624702]
40. Xie B, Bugg JM. Public library computer training for older adults to access high-quality Internet health information. Libr Inf Sci Res 2009 Sep 1;31(3):155 [FREE Full text] [doi: 10.1016/j.lisr.2009.03.004] [Medline: 20161649]
41. Wagner N, Hassanein K, Head M. Computer use by older adults: A multi-disciplinary review. Comput Hum Behav 2010;26:870-882. [doi: 10.1016/j.chb.2010.03-029]

Abbreviations

ADL/IADL: activities of daily living and instrumental activities of daily living
ATC/IQ: Attitudes Toward Computer/Internet Questionnaire
eHEALS: eHealth Literacy Scale
HDM: home-delivered meals
NGOs: nongovernmental organizations
SES: socioeconomic status

Edited by G Eysenbach; submitted 02.04.13; peer-reviewed by B Tennant, L Donelle; comments to author 19.04.13; revised version received 21.04.13; accepted 22.04.13; published 02.05.13.

Please cite as:
Choi NG, DiNitto DM
The Digital Divide Among Low-Income Homebound Older Adults: Internet Use Patterns, eHealth Literacy, and Attitudes Toward Computer/Internet Use
J Med Internet Res 2013;15(5):e93
URL: http://www.jmir.org/2013/5/e93/
doi:10.2196/jmir.2645
PMID:23639979

Original Paper

Internet Access and Use in Adults With Hearing Loss

Elisabet Sundewall Thorén[1,2], MSc; Marie Öberg[1,3], PhD; Gunilla Wänström[3], MSc; Gerhard Andersson[4,5,6], PhD; Thomas Lunner[2,4,5], PhD

[1]Division of Technical Audiology, Department of Clinical and Experimental Medicine, Linköping University, Linköping, Sweden
[2]Eriksholm Research Centre, Oticon A/S, Snekkersten, Denmark
[3]Hearing Clinic, County Council of Östergötland, Linköping, Sweden
[4]The Swedish Institute for Disability Research, Linköping University, Linköping, Sweden
[5]Department of Behavioural Sciences and Learning, Linköping University, Linköping, Sweden
[6]Department of Clinical Neuroscience, Karolinska Institutet, Stockholm, Sweden

Corresponding Author:
Elisabet Sundewall Thorén, MSc
Division of Technical Audiology
Department of Clinical and Experimental Medicine
Linköping University
Sandbäcksgatan 7
Linköping, 581 85
Sweden
Phone: 46 10 103 28 57
Fax: 46 13 14 94 03
Email: elisabet.thoren@liu.se

Abstract

Background: The future rehabilitation of adults with hearing loss is likely to involve online tools used by individuals at home. Online tools could also be useful for people who are not seeking professional help for their hearing problems. Hearing impairment is a disability that increases with age, and increased age is still associated with reduced use of the Internet. Therefore, to continue the research on online audiological rehabilitative tools for people with hearing loss, it is important to determine if and to what extent adults with hearing loss use the Internet.

Objective: To evaluate the use of the Internet and email in a group of adults with hearing loss and to investigate if their use of Internet and email differed between genders, among different age groups, and how it compared with the general population in Sweden.

Methods: Questionnaires containing multiple-choice questions about Internet access, email use, and educational level were mailed to individuals with hearing loss, who were registered as patients at a hearing aid clinic. Out of the 269 invited participants, 158 returned a completed questionnaire, which was a response rate of 58.7%.

Results: The results showed that 60% (94/158) of the participants with hearing loss used computers and the Internet. The degree of hearing loss in the group of participants did not explain the level of Internet usage, while factors of age, gender, and education did ($P<.001$). More men than women used the Internet (OR 2.54, 95% CI 1.32-4.91, $P<.001$). Use of the Internet was higher in the youngest age group (25-64 years) compared to the oldest age group (75-96 years, $P=.001$). A higher usage of the Internet was observed in the participants with hearing loss, especially the elderly, when compared with the general population of Sweden (OR 1.74, 95% CI 1.23-3.17, $P=.04$).

Conclusions: We conclude that the use of computers and the Internet overall is at least at the same level for people with hearing loss as for the general age-matched population in Sweden, but that this use is even higher in specific age groups. These results are important for the future work in developing and evaluating rehabilitative educational online tools for adults with hearing loss.

(J Med Internet Res 2013;15(5):e91) doi:10.2196/jmir.2221

KEYWORDS

hearing loss; hearing rehabilitation; Internet; trends

Introduction

The use of the Internet and communication via email, chat forums, blogs, and instant messaging have increased dramatically in western society during recent years. For groups that are suffering from different disabilities, the Internet and the use of online communication tools can be helpful because they can reach out and contact other people without being identified as disabled [1]. Research shows that people with different kinds of working disabilities benefit from using computers and the Internet, but they still represent a group with less access to these media than persons without disabilities. It has been argued that the low rate of Internet use in persons with disabilities linked to problems at work (eg, chronic pain) may be associated with socioeconomic factors and a lack of knowledge about online resources [2].

One of the most common disabilities is hearing loss, and objectively measured hearing loss often occurs prior to subjective hearing difficulties [3]. People with hearing loss describe difficulties when interacting with friends in daily communication situations. The mixing of speech with different types of background noise represents a challenging situation for hearing-impaired people. This issue is one reason why the Internet is a medium that may suit people with hearing loss and deaf people because they can use it to communicate with people with normal hearing or peers with similar problems [1,4]. The Internet can also be useful as a communication tool for people with hearing loss, eg, the use of Internet telephony, which has been shown to be particularly useful for improving speech perception [5]. Hearing impairment is a disability that increases with age [6]; usually by approximately age 50, 35-45% of adults report some kind of hearing difficulty, and it is therefore an important public health problem [7].

Higher age is typically associated with reduced use of the Internet [8]. For example, data from Europe have shown that a third of those over the age of 54 and 10% of the adults over the age of 65 use the Internet, which can be contrasted with the approximately 75% of individuals aged 16-24 years who use the Internet [9]. Furthermore, a Canadian study showed that fewer than 10% of the elderly used the Internet, with "elderly" being defined as over 65 years old [10]. An observation made in the same study was that older persons with better hearing and hearing aid users use information technology, such as the Internet, more than persons with hearing loss who were not using their prescribed hearing aids. However, the Canadian data [10] were collected in 2000, and a plausible assumption is that Internet usage has increased since then in all age groups, including the elderly [11]. For some of the people who are not using the Internet, however, it is assumed that they could benefit from available online services. Research on 86-year-olds in Sweden showed that 19% owned a computer, but only 10% were connected to the Internet. However, approximately 90% of the respondents expressed that they might benefit from the Internet if they had access to it [12]. In a study published more than 5 years ago [13], the researcher concluded that teaching the elderly how to use computers and the Internet was possible, so that, for example, the elderly could obtain information and health care contacts. In addition, including the elderly in the process of developing computers and Internet tools and adjusting the media to be more useful and attractive for many older adults were important factors [14].

The rehabilitation of people with hearing loss, audiological rehabilitation, is a complex process and not always successful. Audiological rehabilitation for people suffering from hearing loss consists of many elements, but most people with hearing loss are not offered any additional rehabilitation once their hearing aids have been fitted. In fact, a large number of adults with hearing loss are not seeking professional help to overcome their hearing problems.

Currently, approximately 67% of all Internet users use it to search for online health-related information [15]. In a study from the United Kingdom, Henshaw et al concluded that the Internet is a useful medium for offering hearing health care, especially to the adults with hearing loss who are typically not seeking hearing health care [16]. By using the Internet during audiological rehabilitation, relevant elements could be included in the rehabilitation without the inconvenience of traveling to a hearing health center away from home. In the near future, parts of the rehabilitation and contact with the professionals could be expected to occur via the Internet [17,18]. Therefore, to continue the research on online audiological rehabilitative tools for people with hearing loss, it is important to determine if and to what extent adults with hearing loss use the Internet.

The objective of this study was to evaluate the use of the Internet, computers, and email in a group of adults with hearing loss. We also investigated whether the use of the Internet, computers, and email differed between genders and different age groups and to what degree age, gender, education, and hearing loss could explain the amount of Internet usage. The final aim of our study was to investigate whether there was a difference in the use of the Internet, computers, and email between the general population of Sweden [19] and a group of adults with hearing loss.

Methods

Recruitment and Procedure

In this study, we used systematic sampling by inviting a selected group of hearing aid users from the University Hospital in Linköping, Sweden. Every fourth person who had finished hearing-aid rehabilitation at the University Hospital during 2008 and who did not meet our exclusion criteria was asked to participate in the study via invitation letters sent by regular mail. The defined exclusion criteria were if the potential participant was unable to communicate in Swedish (ie, used an interpreter during the hospital visit) or was under the age of 18 years. During 2009, invitation letters were sent by mail to a total of 269 individuals. The average age of the invited participants was 73.4 years (range 20-98 years; SD 13.3). The invited participants included 154 out of 269 men (57.2%) and 115 out of 269 women (42.8%).

Study Participants

Among the invited participants, 173 out of 269 individuals returned their questionnaires (response rate 64.3%), and 158 out of 269 (58.7%) returned a completed questionnaire. We did not send out reminders to the invited participants. The age of the participants who returned a complete questionnaire ranged from 31-96 years (mean 73.6 years; SD 12.2 years). Of the included participants, 96 out of 158 were men (60%) and 62 out of 158 were women (40%). The majority, 85 out of 158 participants (54%), had completed 9 years of elementary school. The lowest number of individuals, 31 out of 158 (20%), had finished 12 years in school and 42 out of 158 (27%) had a university-level degree and therefore more than 12 years in school, as shown in Table 1. Approximately half of the participants (86/158, 54.7%) were urban citizens, living in cities with more than 100,000 residents. The remainder of the participants lived in smaller villages in the countryside. In total, 110 out of 269 (40.9%) invited individuals were counted as nonrespondents because they either did not return the questionnaire or returned an incomplete questionnaire. The mean age of the nonrespondents was 73.2 years (range 20-98, SD 14.9 years). There was no significant difference due to age between the participants who returned a complete questionnaire and those who did not return the questionnaire (*P*=.39).

Hearing Loss

Measurements of the participants' hearing losses, as measured by the pure-tone air-conducted hearing thresholds (ISO 8253-1 1989) were collected from their latest visit to the hearing clinic. The pure tone average of the better ear at the four frequencies of 500, 1000, 2000, and 4000 Hz was, on average, 40 dB HL (SD 15 dB HL; Figure 1). There was a significant correlation between age and the degree of hearing loss (*r*=-0.46, *P*<.001), indicating that the degree of hearing loss increased with increasing age, as expected.

Outcomes

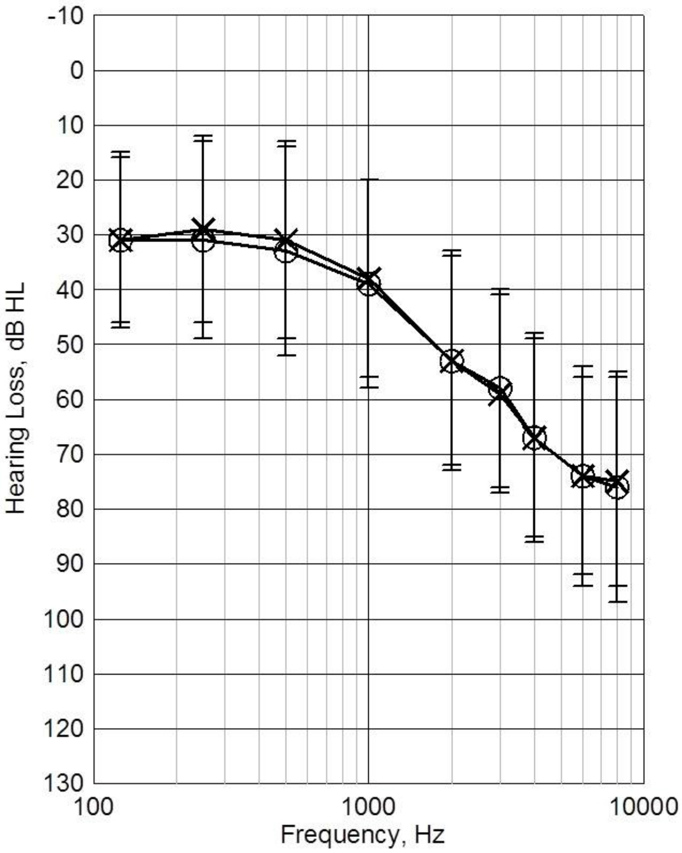
A questionnaire containing multiple-choice questions about Internet access, email use, and educational level was mailed to the invited participants. The questionnaire was sent together with a letter and a pre-paid reply envelope. The questionnaire contained the following questions: (1) Do you have a computer at home?, (2) Do you have access to a computer outside your home?, (3) Do you have access to the Internet?, (4) Do you search for information via the Internet?, (5) How often do you use the Internet?, (6) Do you have an email address?, (7) Do you use your email address?, (8) How often do you use your email address?, and (9) What kind of education do you have? (see Multimedia Appendix 1).

The medical ethical committee in Linköping, Sweden, approved the protocol.

Statistical Analysis

To statistically test the aims of the study, descriptive analysis, Pearson's chi-square test (χ^2), and multiple regression analysis were performed. For all analyses, an alpha level of <.05 was used as statistical significance. A multiple regression analysis was used to investigate whether age, education, gender, or hearing loss could predict Internet use and to investigate how much of the variance in Internet use could be explained by age, education, gender, and hearing loss, as shown. The statistical software package Statistica 10, StatSoft, was used.

Figure 1. Average (SD) hearing loss of the participants (dB HL; right ear points marked with circles and left ear with crosses).



Results

Questionnaires

We were interested in the distribution of use of the Internet, computers, and email in a group of adults with hearing loss. The results are presented in Table 1 for the whole group, for three different age groups, and for men and women in the different age groups. We found that 60% (94/158) of respondents had a computer at home. Out of those who had a computer at home, only 1 participant did not have access to the Internet. Furthermore, out of the participants who used the Internet, a clear majority of 83% (77/93) answered that they used the Internet monthly or more often. Half of the participants (81/158, 51%) had an email address, and all except 7 participants used it daily or multiple days per week.

The second aim was to investigate whether Internet, computer, and email use differed between genders. The results showed that significantly more men than women had a computer (*P*<.001), had access to the Internet (*P*=.01,) and used email (*P*<.001), as shown in Table 2. The results are in agreement with general Internet use in the Swedish population [19], showing significantly higher usage of computers and the Internet by men than women (*P*<.001).

The third aim of the study was to analyze the data with respect to age groups to investigate if Internet use and email use were significantly lower in the elderly compared with the younger participants. We divided the participants into three age groups, as shown in Table 3. The age groups were defined so that the results could be compared with data on Internet use in the general population of Sweden and with respect to the typical correlation between hearing impairment and a gradual acceleration in the age of retirement (65 years). The results showed that there were significantly more participants in the younger age groups that had access to a computer than in the older group (*P*<.001), as shown in Table 3. Similar results were seen with respect to the use of Internet and email, meaning that the use of these services was significantly more common in the younger groups than in the older group (*P*<.001).

Multiple logistic regression analysis was done to investigate whether age, education, gender, or hearing loss could predict Internet use. Multiple logistic regressions were also used to investigate how much of the variance in Internet use could be explained by age, education, gender, and hearing loss, as seen in Table 4. As shown in Table 4, the partial correlations were significant for all factors except for hearing loss. Therefore, the factor of hearing loss was excluded in further analysis. About 14% of the variance in Internet use was explained by age, around 12% was explained by education, and less than 3% was explained by the gender of the participants.

The final aim was to compare the data generated in this study with the data from a typical Swedish population [18] in order to investigate if the group of adults with hearing loss used information technology more than their peers in the general population, as shown in Table 5.

Additionally, each age group from the two datasets was compared, as shown in Table 3. In the youngest age group I (25-64 yrs), we did not find any significant differences in Internet use (*P*=.06) or computer access at home (*P*=.10). In age group II (65-74 yrs), there were no significant differences in computer access at home when comparing the two datasets (*P*=.30), but the participants from the group of adults with hearing loss had significantly more access to Internet than the people in the general population (*P*=.05). In age group III (75-96 yrs), we found significant differences between the two datasets in both computer access (*P*=.004) and Internet use (*P*=.02), which were more common in the group of participants with hearing loss.

Table 1. The collected data (%) on the use of Internet, computers, and email overall and in the different age groups.

		Computer	Internet	Email	Education		
					9 yr	12 yr	>15 yr
Total							
	All (N=158)	59.5	58.9	51.2	50	18.3	24.1
	Men (N=96)	70	67.7	63.5	51	19.8	21.9
	Women (N=62)	43.5	45.2	30.1	48.4	16.1	27.4
Age 25-64							
	All (N=31)	100	100	87.1	25.8	35.5	38.7
	Men (N=20)	100	100	90	25	35	40
	Women (N=11)	100	100	81.8	27.3	36.4	36.4
Age 65-74							
	All (N=41)	75.6	78	65.8	48.8	24.4	26.8
	Men (N=28)	82.1	82.1	78.6	50	25	25
	Women (N=13)	61.5	69.2	38.5	46.2	23.1	30.8
Age 75-96							
	All (N=86)	37.2	34.9	30.2	59.3	9.3	17.4
	Men (N=48)	50	45.8	43.8	62.5	10.4	14.6
	Women (N=38)	21.1	21.1	13.2	55.3	7.9	21.1

Table 2. Results from the chi-square tests (χ^2) and odds ratio (OR) comparing gender and comparing with the dataset from the general population of Sweden (data on email use not collected in the dataset from the general population).

		χ^2	*P* value	OR	Lower 95% CI	Upper 95% CI
Current data (n=158)						
	PC use	10.77	.001	3.03	1.56	5.90
	Internet use	11.52	<.001	2.54	1.32	4.91
	Email use	16.31	<.001	4.04	2.04	8.00
General population (n=6292)						
	PC use	47.09	<.001	1.53	1.35	1.73
	Internet use	35.34	<.001	1.42	1.27	1.59
	Email use	—	—	—	—	—

Table 3. Results from the chi-square tests (χ^2) and odds ratio (OR) comparing age groups (AG) and with the dataset from the general population of Sweden (data on email use not collected in the dataset from the general population).

		AG II					AG III					General population				
		χ^2	OR	Lower, 95% CI	Upper, 95% CI	*P*	χ^2	OR	Lower, 95% CI	Upper, 95% CI	*P*	χ^2	OR	Lower, 95% CI	Upper, 95% CI	*P*
AG I																
	Computer	8.78	[a]	[a]	[a]	.003	38.72	[a]	[a]	[a]	<.001	2.77	[a]	[a]	[a]	.10
	Internet	7.78	[a]	[a]	[a]	.01	36.15	[a]	[a]	[a]	<.001	3.63	[a]	[a]	[a]	.06
	Email	4.25	3.50	1.02	12.01	.04	29.74	15.58	4.95	49.02	<.001	—	—	—	—	—
AG II																
	Computer						18.52	5.79	2.50	13.40	<.001	1.12	1.48	0.71	3.06	.29
	Internet						18.45	6.00	2.54	14.17	<.001	3.95	2.11	0.99	4.48	.05
	Email						14.49	4.45	2.01	9.83	<.001	—	—	—	—	—
AG III																
	Computer											8.29	1.98	1.23	3.17	.004
	Internet											5.62	1.74	1.10	2.77	.02
	Email											—	—		—	—

[a] The value could not be calculated due to few data points in the cell.

Table 4. Multiple logistic regression results for prediction of Internet use.

	b[a]	b	*P* value
Intercept		30.88	<.001
Age	-0.38	-0.02	<.001
Education	-0.34	0.07	<.001
Gender	0.17	0.18	<.01
Hearing loss	0.03	0.07	.64

[a] b=raw coefficients in the multiple regression equation.

Table 5. The use of computers and the Internet (in %) in the general population of Sweden.

		Computer	Internet
Total			
	All (N=6292)	79.7	76.8
	Men (N=3219)	83.2	80.0
	Women (N=3372)	76.4	73.8
Age group I			
	All (N=4829)	91.8	89.4
	Men (N=2441)	92.1	89.5
	Women (N=2388)	91.5	89.4
Age group II			
	All (N=886)	67.7	62.7
	Men (N=425)	72.7	68
	Women (N=460)	63.3	58
Age group III			
	All (N=878)	25.5	21.3
	Men (N=354)	34.2	28.8
	Women (N=524)	19.3	16.2

Discussion

Principal Findings

The aim of this study was to evaluate the use of the Internet, computers, and email in a group of adults with hearing loss. Furthermore, we investigated if the use of Internet, computers, and email differed between genders and different age groups. The results relating to our first objective indicate that the use of Internet and email is high in the total group of adults with hearing loss, even though it is significantly more common in the younger age groups. We interpret our results of computer and Internet use as valid since the participants reported use of email was nearly the same as computer and Internet use, and we therefore expect that the participants in our sample are using both their computers and their Internet connections. These findings were expected based on the results from earlier studies showing that Internet use in the elderly population is low [8,12]. However, Internet use in adults with hearing loss has barely been described in the literature [16].

In this study, we also identified a difference due to gender. Our results showed that it was more common for men than women to use computers, the Internet, and email. These findings were expected in this group of participants due to prior research evaluating how gender differences correlate with Internet usage [16]. Our results are also in line with findings from the general Swedish population, which show a significant difference in the use of the Internet and computers between genders [19].

Because hearing loss increases with age, the final objective in our study was to evaluate the pattern of Internet use among the elderly and compare with data from the general population of Sweden. More specifically, our aim was to evaluate whether we could detect a higher rate of Internet use among adults with hearing loss. In summary, the results from the multiple regression analysis indicate that Internet use in a group of adults with hearing loss can be explained by age, education, and gender. More specifically, the highest usage of the Internet is seen among the youngest age group and males with higher education levels, and the lowest usage is among the elderly and women with less education. These results are consistent with newly reported findings from Henshaw et al [16] who investigated the association between age, socioeconomic status, and gender due to self-reported usage of computers and the Internet. The findings are also in line with reports of general Internet use in the Swedish population [15] showing that age, gender, and education still have a strong association with Internet use, especially among the elderly.

When comparing our data with information technology use in the general Swedish population [19], we found that individuals with hearing loss were more likely to use computers and have Internet access than individuals with normal hearing. Interestingly, a comparison of our data in elderly people with hearing loss with data from Europe [9] showed that approximately 10% of the elderly above 65 years use the Internet, while in our study, 50% of those over 65 use computers and the Internet. Recently reported data show that Sweden represents one of the top five countries with high access and Internet usage [15]. This could explain why our study shows a reasonably higher use of the Internet by elderly persons with hearing loss than a comparable study from United Kingdom [16].

A reasonable overall interpretation of our findings, together with previous findings, is that people with decreasing hearing sensitivity are using computers and the Internet and also that these media can be useful tools to help the elderly with hearing loss get access to rehabilitation from home [2,16,18].

Limitations

In this study, we reported on the use of the Internet, computers, and email in a sample from Sweden, but usage in a similar group in other parts of Europe might be different. The data presented in the study can be seen as a reflection of the present, but the reported use of this type of information technology typically continues to increase over time, especially in elderly people [11]. However, we find the data to be representative as a sample from the population of people with hearing loss recruited at a hearing clinic in the county of Östergötland because all age groups are represented and because we could see the expected increase of hearing loss with increased age. Further analyses of the Internet, computer, and email usage in different groups of individuals with hearing loss and of different ages should involve more participants to investigate if our findings apply to the general population of people with hearing loss. We had a response rate of 59%, without any missing data in the questionnaires, which we consider rather good since the majority of our participants were elderly. Questionnaires mailed to elderly people are not always recommended as the first choice because a high rate of missing data and a lack of willingness to fill out questionnaires have been reported [20]. Determining the use of the Internet, computers, and email in the group of nonrespondents could, however, be interesting.

Future Research

This study was conducted to evaluate whether information technology was used by people with hearing loss in order to explore if developing online rehabilitation tools for them would be fruitful. By using the Internet in the rehabilitation of adults with hearing loss, they could be informed and guided about communication strategies, hearing tactics, ways to handle hearing aids, and other issues in a cost-effective manner. Our results support the idea that, in the near future, the audiological rehabilitation process can be expected to include the Internet and that some elements of rehabilitation and contact with professionals can occur via the Internet using communication tools like email [17,18].

Conclusion

The conclusion from this study is that, in a systematic, selective sample of hearing aid users, the use of computers, Internet, and email are overall at the same level as the general Swedish population, but this use is even higher in some specific age groups. This information is important for future work in developing and evaluating rehabilitative educational online tools for adults with hearing loss.

Acknowledgments

Thanks to Bo Westergård for valuable comments on the manuscript. The Oticon Foundation and the Swedish Hard of Hearing Association (HRF) are acknowledged for funding this study.

Authors' Contributions

The authors collaborated closely on this work. EST initiated and designed the study together with MÖ, GW, GA, and TL. EST coordinated the study and was responsible for the distribution and collection of the questionnaires. EST analyzed the data and drafted the manuscript in close collaboration with MÖ, GW, GA, and TL. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Questionnaire.

[PDF File (Adobe PDF File), 214KB - jmir_v15i5e91_app1.pdf]

References

1. Barak A, Sadovsky Y. Internet use and personal empowerment of hearing-impaired adolescents. Computers in Human Behavior 2008 Sep;24(5):1802-1815. [doi: 10.1016/j.chb.2008.02.007]
2. Kaye S. Computer and Internet Use Among People with Disabilities. In: Disability Statistics Report. Washington, DC: U.S. Department of Education, National Institute on Disability and Rehabilitation Research; 2000.
3. Chia EM, Wang JJ, Rochtchina E, Cumming RR, Newall P, Mitchell P. Hearing impairment and health-related quality of life: the Blue Mountains Hearing Study. Ear Hear 2007 Apr;28(2):187-195. [doi: 10.1097/AUD.0b013e31803126b6] [Medline: 17496670]
4. Pilling D, Barrett P. Text communication preferences of deaf people in the United Kingdom. J Deaf Stud Deaf Educ 2008;13(1):92-103 [FREE Full text] [doi: 10.1093/deafed/enm034] [Medline: 17602163]
5. Mantokoudis G, Kompis M, Dubach P, Caversaccio M, Senn P. How internet telephony could improve communication for hearing-impaired individuals. Otol Neurotol 2010 Sep;31(7):1014-1021. [doi: 10.1097/MAO.0b013e3181ec1d46] [Medline: 20634771]

6. Davis AC. The prevalence of hearing impairment and reported hearing disability among adults in Great Britain. Int J Epidemiol 1989 Dec;18(4):911-917. [Medline: 2621028]
7. Cruickshanks KJ, Tweed TS, Wiley TL, Klein BE, Klein R, Chappell R, et al. The 5-year incidence and progression of hearing loss: the epidemiology of hearing loss study. Arch Otolaryngol Head Neck Surg 2003 Oct;129(10):1041-1046. [doi: 10.1001/archotol.129.10.1041] [Medline: 14568784]
8. Selwyn N, Gorard S, Furlong J, Madden L. Older adults' use of information and communications technology in everyday life. Ageing and Society 2003;23(5):561-582. [doi: 10.1017/S0144686X03001302]
9. Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions. i2010 - Annual Information Society Report 2007. In: SEC(2007) 395, Volumes 1, 2, 3. Luxembourg: Office for Official Publications of the European Communities; 2007.
10. Gonsalves C, Pichora-Fuller MK. The effect of hearing loss and hearing aids on the use of information and communication technologies by community-living older adults. Can J Aging 2008;27(2):145-157. [doi: 10.3138/cja.27.2.145] [Medline: 18845510]
11. Internet World Stats. URL: http://www.internetworldstats.com/ [accessed 2012-06-14] [WebCite Cache ID 68Pqvfh1V]
12. Eek M, Wressle E. Everyday technology and 86-year-old individuals in Sweden. Disabil Rehabil Assist Technol 2011;6(2):123-129. [doi: 10.3109/17483107.2010.507858] [Medline: 20662743]
13. Kiel JM. The digital divide: Internet and e-mail use by the elderly. Med Inform Internet Med 2005 Mar;30(1):19-23. [doi: 10.1080/14639230500066900] [Medline: 16036627]
14. Selwyn N. The information aged: A qualitative study of older adults' use of information and communications technology. Journal of Aging Studies 2004 Nov;18(4):369-384. [doi: 10.1016/j.jaging.2004.06.008] [Medline: 23402809]
15. World Internet Project International Report. URL: http://www.worldinternetproject.net/ [accessed 2012-06-14] [WebCite Cache ID 68PrNjV85]
16. Henshaw H, Clark DP, Kang S, Ferguson MA. Computer skills and internet use in adults aged 50-74 years: influence of hearing difficulties. J Med Internet Res 2012;14(4):e113 [FREE Full text] [doi: 10.2196/jmir.2036] [Medline: 22954484]
17. Andersson G. Using the Internet to provide cognitive behaviour therapy. Behav Res Ther 2009 Mar;47(3):175-180. [doi: 10.1016/j.brat.2009.01.010] [Medline: 19230862]
18. Thorén E, Svensson M, Törnqvist A, Andersson G, Carlbring P, Lunner T. Rehabilitative online education versus internet discussion group for hearing aid users: a randomized controlled trial. J Am Acad Audiol 2011 May;22(5):274-285. [doi: 10.3766/jaaa.22.5.4] [Medline: 21756843]
19. Statistiska Central Byrån.: Sweden Statistics URL: http://www.scb.se/ [accessed 2012-06-14] [WebCite Cache ID 68PtQV8g9]
20. Smeeth L, Fletcher AE, Stirling S, Nunes M, Breeze E, Ng E, et al. Randomised comparison of three methods of administering a screening questionnaire to elderly people: findings from the MRC trial of the assessment and management of older people in the community. BMJ 2001 Dec 15;323(7326):1403-1407 [FREE Full text] [Medline: 11744565]

Edited by G Eysenbach; submitted 25.07.12; peer-reviewed by M Ferguson, H Henshaw; comments to author 25.09.12; revised version received 02.11.12; accepted 26.03.13; published 09.05.13.

Please cite as:
Thorén ES, Öberg M, Wänström G, Andersson G, Lunner T
Internet Access and Use in Adults With Hearing Loss
J Med Internet Res 2013;15(5):e91
URL: http://www.jmir.org/2013/5/e91/
doi:10.2196/jmir.2221
PMID:23659867

Original Paper

Internet Use Among Older Adults: Association With Health Needs, Psychological Capital, and Social Capital

Namkee G Choi[1], PhD; Diana M DiNitto[1], PhD

[1]The University of Texas at Austin, School of Social Work, The University of Texas at Austin, Austin, TX, United States

Corresponding Author:
Namkee G Choi, PhD
The University of Texas at Austin
School of Social Work
The University of Texas at Austin
1925 San Jacinto Blvd
Austin, TX, 78712
United States
Phone: 1 512 232 9590
Fax: 1 512 471 9600
Email: nchoi@austin.utexas.edu

Abstract

Background: Previous studies have identified socioeconomic status and health status as predictors of older adults' computer and Internet use, but researchers have not examined the relationships between older adults' health needs and psychological capital (emotional well-being and self-efficacy) and social capital (social integration/ties and support networks) to different types of Internet use.

Objective: This study examined (1) whether older adults' health conditions and psychological and social capital differentiate Internet users from nonusers, and (2) whether the Internet users differed in their types of Internet use on the basis of their health conditions and psychological and social capital.

Methods: Data for this study came from the National Health and Aging Trends Study, which is based on a nationally representative sample of US Medicare beneficiaries aged 65 years and older. The sample for this study were those who resided in the community in their own or others' homes (N=6680). Binary logistic regression analysis was used to compare health needs, psychological capital, and social capital among (1) any type of Internet users and nonusers, (2) Internet users who engaged in health-related tasks and Internet users who did not, (3) Internet users who engaged in shopping/banking tasks and Internet users who did not, and (4) Internet users only used the Internet for email/texting and all other Internet users.

Results: Depressive and anxiety symptoms, measures of psychological capital, were negatively associated with Internet use among older adults (odds ratio [OR] 0.83, 95% CI 0.70-0.98, *P*=.03 and OR 0.79, 95% CI 0.65-0.97, *P*=.03, respectively), whereas most measures of social capital were positively associated with Internet use. Having more chronic medical conditions and engaging in formal volunteering increased the odds of Internet use for health-related tasks by 1.15 (95% CI 1.08-1.23, *P*<.001) and 1.28 (95% CI 1.05-1.57, *P*=.02), respectively, but anxiety symptoms decreased the odds (OR 0.74, 95% CI 0.55-0.99, *P*=.05). Religious service attendance was negatively associated with Internet use for shopping/banking activities (OR 0.75, 95% CI 0.62-0.91, *P*=.01). Anxiety symptoms increased the odds of using the Internet only for emails/texting (OR 1.75, 95% CI 1.12-2.75, *P*=.02), but formal volunteering decreased the odds (OR 0.63, 95% CI 0.43-0.92, *P*=.02). Other correlates of Internet use solely for emails/texting were older age (80-84 years and ≥85 years), a black or "other" racial/ethnic background, a high school education or less than high school, and lower income.

Conclusions: The findings point to the importance of social capital in facilitating older adults' learning and adoption of Internet technology. Older adults who used the Internet for email/texting purposes only were the most socially and economically disadvantaged group of Internet users. Computer/Internet training for older adults and computer/Internet use for various purposes need to consider the significant role their social capital can play.

(J Med Internet Res 2013;15(5):e97) doi:10.2196/jmir.2333

KEYWORDS

older adults; Internet use; health needs; psychological capital; social capital

Introduction

Over the past 2 decades, Internet technology has increased access to health-related and non-health-related information and facilitated communication and social connections transcending geographic distance at relatively low cost. Almost 3 out of 4 people aged 65 years and older, compared to fewer than 1 out of 5 people aged between 20 and 44 years, have multiple (2 or more) chronic conditions [1]. Older adults are also more likely to feel socially isolated than younger adults, and social disconnectedness and perceived isolation are independently associated with lower levels of self-rated physical health and higher odds of having a mental health problem [2-4]. Older adults who have health problems and feel socially isolated are especially likely to benefit from using Internet technology because it allows them to carry out an increasingly diverse array of tasks, especially when they lack family, friends, and health and social service providers who can help with these tasks. Previous studies have documented the multiple benefits of computer and Internet use training for older adults [5,6]. Older adult Internet users note increased communication with those in their social networks; maintenance of geographically dispersed connections; convenience and benefits of searching for and increased learning from health-related information; increased ability to research non-health-related information, read news/magazines/books, and engage in continuing education activities; increased awareness of and connection to interest/support/hobby groups, events, and resources in their immediate and global communities; convenience of online shopping, banking, travel arrangements, and related information; and use of computer- and Internet-based entertainment [7-13].

Despite their rapidly increasing rate of Internet use, older adults still lag behind younger adults in Internet use in their everyday life [14,15]. An August 2012 Pew Internet Research Center survey found that only 58% of older adults (aged ≥65 years) in the United States are connected to and use the Internet, compared with 85% of those in the 50 to 64 age group and over 90% of those in the 18 to 49 age group [15]. Studies that examined determinants of Internet use found that older adults who were younger, non-Hispanic white, and of higher socioeconomic status (based on education, health literacy, and income) were more likely to use the Internet [14,16-18]. The significance of socioeconomic status as a correlate of Internet use is not surprising, because those of higher socioeconomic status have both the human and financial capital needed for adoption of rapidly changing technology. The cost of computer equipment and Internet connectivity poses a barrier to Internet use among low-income older adults [19].

Previous studies have also found that better overall health is positively associated with older adults' computer and Internet use [14,18,20]. Some physical and functional health problems can pose barriers to computer use, such as difficulty performing activities of daily living (ADL) and instrumental activities of daily living (IADL), motor skills deficit due to arthritis and Parkinson's disease, and vision impairment [21,22]. However, health problems/needs (eg, number of diagnosed chronic medical conditions, diagnosis of dementia/Alzheimer's disease, and the number of ADL/IADL impairments) may also motivate older adults to take advantage of health information technology because some sicker individuals (eg, those with cancer) are more likely than their healthier peers to seek health information online in conjunction with a doctor visit [23]. In addition, older adults with health problems may use the Internet to manage various aspects of health care and address their daily health and disability care needs (eg, ordering/refilling prescriptions and contacting medical providers).

In addition to socioeconomic status and health care needs, psychological capital (eg, depressive symptoms, general anxiety symptoms, and general self-efficacy) and social capital (eg, indicators of social integration/ties and social support) are likely to influence older adults' Internet use. With respect to psychological capital, previous research suggests that older adults are not afraid or unwilling to use technology and can acquire necessary skills; however, many older adults reported usability problems (eg, small fonts, difficulty of navigation) and associated frustration with the systems due in part to the cognitive, perceptual, and motor skill demands they experienced [9,10,24,25]. Older adults often express more anxiety about their ability to use these systems and less confidence in their ability to use them successfully than younger ones [9,26,27]. Older adults who positively perceived the Internet's usefulness, ease of use, and efficacy and were more open to experiencing the Internet were more likely to be Internet users [23,28]. Werner et al [18] also found that older adults with an active coping style or a dispositional proactive approach to challenges (including learning to use technology in later life) were more likely to use a computer. However, they did not find depressive symptoms to be associated with older adults' computer use, although another study found that older caregivers' sense of social isolation and depressive symptoms abated when they participated in an online social interaction intervention [29].

On a macro level, social capital refers to the larger political and societal structures that promote a general sense of social cohesion, embeddedness, and trust, whereas microlevel social capital refers to individual resources that emerge from one's social networks: social integration/ties and social support [30]. An individual's social networks are the conceptual and structural core of his or her social capital. Those with strong and dense social networks have an easier and safer time accessing information because network members provide bridging and bonding support and contribute to boosting confidence and trust. When applied to older adults' Internet use, those with a larger social network (eg, children, friends, volunteering buddies) are more likely to receive encouragement to learn to use the Internet and emotional and instrumental assistance in doing so by their social network members. Participation in activities with family, friends, and other network members is also likely to increase the need for and perceived usefulness of Internet connectivity as a means to maintain social integration and ties. One exploratory qualitative study of social capital and Internet use among older Australians (N=30) found that the most frequent pathways to use were having observed and talked with children and grandchildren about their computer/Internet use and having informal help from family and friends on how to use a computer and the Internet [11]. Study participants also mentioned that the need to use email to communicate with friends and relatives was a major reason for their Internet use, although they noted that online communication did not replace face-to-face contact. Moreover, the participants stated that online communication was responsible for expanding their network of close relationships and often led to face-to-face interactions that would not otherwise have occurred [11]. One study of US older adults in the Detroit area found that older adult computer users, as compared to nonusers, were more likely to be employed, have memberships in community organizations, and do volunteer work [31]. Another study also found that older adults who tended to be actively involved in the community, rather than withdrawn or behaviorally disengaged, were more likely to use computers [18].

A literature review on the determinants of older adults' Internet use reveals gaps in 2 areas. First, although the Internet is used for an increasing variety of tasks including personal communication, commerce, information seeking, social networking, job searches, and entertainment, no studies have examined the factors associated with different types of Internet use. Previous studies did find that Internet use differences are affected by the level of Internet operational and other digital skills (eg, operating an Internet browser; using Internet-based search engines; completing forms on the Internet; navigating various types of websites; locating specific, detailed, or customized information; and evaluating the source and the quality of information), which was positively associated with education, but negatively associated with age [32-34]. A survey of Internet use showed that email and information searches tend to be the most common uses among both older and younger adults [35]. However, because older adults use the Internet for a diverse array of activities, Internet use differences among older adults are likely to be influenced by different characteristics. Second, although some previous studies found that psychological and social resources significantly influenced Internet use, the samples studied tended to be small. The relationships among Internet use and psychological and social capital have not yet been tested with a large, nationally representative sample of older adults. The examination of psychological and social capital on different types of Internet use is especially important given that older adults may require these resources to use the Internet for activities that require advanced skills. Older adults who are disadvantaged in terms of psychological and social capital may be more likely to use the Internet for limited purposes only.

Using a nationally representative sample of older adults aged 65 years and older in the United States, the present study had 2 purposes. The first was to examine whether health conditions and psychological and social capital resources differentiate Internet users from nonusers. The second was to determine whether the subgroup of Internet users differed in their types of Internet use based on their health conditions and psychological and social capital. Controlling for demographic and socioeconomic factors, the study hypotheses were (H1) older adults with symptoms of depression and/or anxiety will be less likely to use the Internet, (H2) older adults with higher levels of general self-efficacy will be more likely to use the Internet, (H3) older adults with at least 1 living child and/or sibling will be more likely to use the Internet, (H4) older adults with a higher level of social integration/ties from engagement in paid work activities, formal volunteer work, informal caregiving, and an active social life will be more likely to use the Internet, (H5) older adult Internet users with a higher levels of physical and functional health needs will be more likely to use the Internet for health-related tasks, (H6) older adult Internet users with higher levels of psychological and social capital will be more likely to use the Internet for health-related tasks and shopping/banking activities, and (H7) older adult Internet users with lower levels of psychological and social capital will be more likely to use the Internet for email/texting only. This is the first study to try to identify characteristics associated with different Internet activities using a nationally representative sample of older adults in the United States. The findings contribute to understanding the role of older adults' psychological and social capital on their Internet use and shed further light on significant disparities in Internet access and use among older adults.

Methods

Data Source and Sample

This study analyzed secondary data drawn from the first interview wave of the National Health and Aging Trends Study (NHATS). The National Institute on Aging supports NHATS under a cooperative agreement with the Johns Hopkins University Bloomberg School of Public Health. Westat, a statistical survey organization headquartered in Rockville, Maryland, collected the data. The NHATS is intended to be a new resource for the scientific study of physical, psychological, and social functioning in later life and is based on a nationally representative sample of US Medicare beneficiaries aged 65 years and older (N=8077) who resided in the community in their own or another's home or in residential care settings, including nursing homes and other facilities [36]. Face-to-face individual interviews, lasting approximately 2 hours, were administered in 2011 by Westat's professionally trained interviewers with sample persons in all settings (except nursing homes) to collect detailed information on activities of daily life, living arrangements, general and technological environment of the home, health conditions, work status and participation in valued activities, mobility and use of assistive devices, cognitive functioning, and help provided with daily activities (self-care, household, and medical), economic status, and well-being. The NHATS sample design was age-stratified so that persons were selected from 5-year age groups between the ages of 65 and 90, and from persons age 90 and older. Persons in older age groups and persons whose race was listed as black on the Center for Medicare and Medicaid Services enrollment file were oversampled [37]. Detailed data collection procedures and variable definitions are described in the NHATS User Guide [38]. The analyses in this study included only those sample persons (N=6680) who resided in their own or another's home, and excluded those in residential care settings, such as nursing homes (n=468) or other such settings (n=412), and those represented by proxy respondents, such as their spouse or child (n=517) due to dementia, illness, hearing impairment, and/or speech impairment. These exclusions were based on both systematic and respondent-level missing data on many variables (eg, psychological and social capital resources) included in this study.

Measures

Internet Use

Each NHATS sample participant was asked if he or she had a working cell phone and a working desktop or laptop computer at home (response categories: yes, no, yes but doesn't know how to use a computer, refused, and don't know). Those who did not have a computer at home were asked if they used a computer anywhere else (eg, in the building where they lived, at a library, and/or at a friend's or family member's home) in the past month. Those with a cell phone and/or who used a computer were asked if they ever (1) sent messages by email or via texting (described as "texting is like email but usually done on a phone"); (2) went on the Internet or online for any other reason than email or texting ("In the last month, besides email or texting, have you ever gone on the Internet or online for any other reason?"); (3) went on the Internet or online to contact a medical provider (to make or change medical appointments, get test results, request referrals or prescriptions, or get advice), handle Medicare or other health insurance matters (going to Medicare's website or another insurer's website to find out what is covered, compare plans or providers, find out about bills, or file a claim), and get information about their health conditions; and (4) went on the Internet or online to shop for groceries or personal items, pay bills or do banking, and order or refill prescriptions. The response categories were yes, no, refused, and don't know. The time frame for the Internet/online use for all health-related tasks, except ordering or refilling prescriptions, was within the past year, and for all other activities was within the past month. Note that NHATS used the term "Internet or online" interchangeably in all questions, without distinguishing between them.

In the present study, Internet use was grouped into 4 types: (1) any health-related tasks (ordering or refilling prescriptions, contacting medical providers, handling Medicare or other health insurance matters, and/or get information on health conditions) with or without other types of Internet use; (2) shopping for groceries or personal items, paying bills, and/or banking (shopping/banking hereafter) with or without other types of Internet use; (3) email/texting with or without other types of Internet use (with the focus of multivariate analysis on email/texting only without any other type of Internet use); and (4) any other tasks that do not fall under any of the other 3 categories of tasks. This fourth category was derived from comparing those who reported Internet use but did not report any email/texting, health-related tasks, or shopping/banking.

Demographic and Socioeconomic Factors

Demographic and socioeconomic variables included age group (65-69 years [reference group], 70-74 years, 75-79 years, 80-84 years, and ≥85 years); gender (female or male); race/ethnicity (non-Hispanic white [reference group], non-Hispanic black, Hispanic, and all others); living arrangement (living with spouse vs all others); level of education (less than high school/don't know/refused, high school diploma or GED, some college or an associate's degree, and bachelor's degree or higher [reference group]); and total income (in units of $10,000 for multivariate analysis). Missing values in education level due to respondents' uncertainty (don't know) or refusal to answer were grouped with the "less than high school" category based on multiple bivariate analyses of other sample characteristics (eg, Internet use, sociodemographics, health conditions, and psychological/social capital) that showed similarities between the don't know or refused to answer group (unweighted n=67) and the less than high school group.

Health Needs

Health needs included the number of chronic medical conditions diagnosed by a doctor (including high blood pressure, heart attack/heart disease, arthritis, osteoporosis, diabetes, lung disease, stroke, and cancer), diagnosis of dementia or Alzheimer's disease (yes vs no), and the number of ADL/IADL impairments. ADLs included eating, bathing, toileting, dressing, getting in and out of bed, getting in and out of a chair, and walking inside. IADLs included preparing meals, doing laundry, doing light housework, shopping for groceries, managing money, taking medication, and making telephone calls. Separate questions were used to collect data on the diagnosis of each medical condition and each ADL/IADL impairment, and the numbers of diagnoses and the functional impairments were added up, respectively. The small number of missing values (don't know or refused to answer) for some of the medical conditions and ADL/IADL variables were treated as an absence of a diagnosis or impairment to arrive at conservative estimates.

Psychological Capital

Psychological capital included symptoms of depression and anxiety and general self-efficacy. For depression, each sample person was asked how often in the past month he or she (1) had little interest or pleasure in doing things, and (2) felt down, depressed, or hopeless. For anxiety, participants were asked how often in the past month he or she (1) felt nervous, anxious, or on edge, and (2) had been unable to stop or control worrying. The response categories were 1=not at all, 2=several days, 3=more than half the days, and 4=nearly every day. In the present study, those who responded with more than half the days to either item for depression or anxiety were categorized as depressed or anxious, respectively. To create a general efficacy score, the responses to the following 4 questions were summed: (1) I feel confident and good about myself, (2) I gave up trying to improve my life a long time ago (reverse-coded), (3) When I really want to do something, I usually find a way to do it, and (4) I have an easy time adjusting to change. The response categories were 1=agree not at all, 2=agree a little, and 3=agree a lot. The Cronbach alpha (internal consistency reliability of the 4 items measuring general efficacy) was low at .57, most likely because of the small number of items in the scale. According to the NHATS User Guide [33], these psychological capital variables draw on items similar to those used in Midlife in the United States: A Study of National Health and Well-being (MIDUS), with changes in the reference period as "last month" and fewer response categories.

Social Capital

Social capital was measured by whether or not the sample person reported (1) having at least 1 living child/stepchild; (2) having at least 1 living sibling; and whether in the past month he or she ever (3) worked for pay or owned a business; (4) did any volunteer work; (5) cared for or looked after an adult or child who could not care for themselves; (6) visited in person with friends or family not living with them either at your home or theirs; (7) attended religious services; (8) participated in clubs, classes, or other organized activities; and (9) went out for enjoyment, including going to dinner, to a movie, to gamble, or to hear music or see a play. Response categories for all these variables were yes, no, refused, and don't know. The small number of missing values (don't know and refused) in any social capital variable were treated as absence of the condition or activity to arrive at conservative estimates.

Analysis Strategy

Univariate frequency analysis was used to examine demographic and socioeconomic characteristics, health needs, psychological capital, social capital, cell phone and computer ownership, and any Internet use among all sample persons, and the type(s) of Internet use among Internet users. Bivariate analyses, using chi-square and *t* tests, were used to compare Internet users and nonusers on relevant variables. Hypothesis testing was conducted by using binary logistic regression analysis to compare (1) any type of Internet users with nonusers, (2) Internet users who engaged in health-related tasks with Internet users who did not, (3) Internet users who engaged in shopping/banking tasks with Internet users who did not, and (4) Internet users whose sole use was for email/texting with all other Internet users. Although users that did not engage in Internet use for health-related tasks, shopping/banking, and email/texting were identified, this group was excluded from the multivariate analysis because of the unspecified and possibly widely varying nature of their Internet activities. Because of the cross-sectional nature of the data, the relationships examined are correlational, not causal. Analyses were conducted with svy commands in Stata 12 (StataCorp LP, College Station, Texas, USA) to account for the NHATS' complex multistage, stratified sampling design [37].

Results

Computer Ownership and Internet Use

As seen in Table 1, 80.19% of the study sample had a working cell phone, 64.4% had a computer at home and knew how to use it, 4.11% had a computer at home but did not know how to use it, and 2.20% did not have a computer at home but used one outside their home. Of the study sample, 50.60% reported that they went on the Internet or online for at least 1 purpose in the past month, whereas 49.40% did not report any Internet/online use, such as email/texting or carrying out other activities. Of the computer users, 25.42% did not go online for email/texting or any other type of Internet use in the past month. Of those who went on the Internet/online for email/texting or any other tasks, only 1.80% reported that they did not use a computer, implying that these people may have relied exclusively on cell phones and/or other devices.

The results also show the prevalence of different kinds of tasks that these community-dwelling older adults conducted on the Internet/online: 43.35% sent emails or text messages, 20.74% paid bills and did banking, 16.83% searched information on health conditions for self or others, 14.9% shopped for groceries or personal items, 8.41% ordered or refilled prescriptions, 7.45% contacted medical providers, and 5.64% handled Medicare or other health insurance matters. Among the Internet/online users, 85.68% sent emails or text messages, 40.99% paid bills and did banking, 33.26% searched information on health conditions for self or others, 29.40% shopped for groceries or personal items, 16.62% ordered or refilled prescriptions, 14.72% contacted medical providers, and 11.15% handled Medicare or other health insurance matters. In summary, 45.15% of the Internet/online users conducted health-related tasks, 51.23% paid bills, did banking, and/or shopped for groceries or personal items—common tasks related to everyday life—and 30.90% conducted activities pertaining to all these categories of Internet use. The findings also show that 8.94% used the Internet/went online solely for sending emails or text messages, and 8.76% used it for purposes/tasks other than emailing/texting, health-related tasks, and the tasks related to everyday life specified previously. The NHATS did not ask about these other Internet/online activities. However, based on a recent Pew survey of the Internet activities in which US adults engage [34], these other activities may include searching for information on a hobby or interest or a map or driving directions, checking weather, making travel reservations, getting news or information about sports, participating in social networking/dating programs, and so forth.

Comparison Between Internet Users and Nonusers

Table 2 shows that the younger age groups (65-69 years and 70-74 years) were disproportionately (more highly) represented among the Internet users, whereas the older age groups (75-79 years, 80-84 years, and ≥85 years) were disproportionately (more highly) represented among the nonusers. Men, non-Hispanic whites, those married and living with their spouse, and those with at least some college education were also overrepresented among the Internet users. The median income of the Internet users was more than twice that of the nonusers. The Internet users were in better health than the nonusers. With respect to psychological capital, the rates of depression and anxiety symptoms among the Internet users were half of those among the nonusers. The Internet users also had higher self-efficacy scores. With respect to social capital, a higher proportion of the Internet users than nonusers had at least 1 child, but the 2 groups were equally likely to have at least 1 sibling. The Internet users were significantly more advantaged than nonusers in all other indicators of social integration/ties and social support.

Table 1. Cell phone and computer ownership and Internet/online use of older adults in the United States (N=6680).

Internet use patterns	%[a]
Technology equipment among all sample persons	
A working cell phone	80.19
A working computer at home and knew how to use	64.39
A computer at home but did not know how to use	4.11
No computer at home but used it elsewhere last month	2.20
Type of Internet use among all sample persons	
For any purpose (listed below and other tasks)	50.60
To send emails or text messages	43.35
To order or refill prescriptions	8.41
To contact any medical provider	7.45
To handle Medicare or other health insurance matters	5.64
To obtain information about health conditions for self or others	16.83
To pay bills or do banking	20.74
To shop for groceries or personal items	14.88
Type of Internet use among any Internet users (n=3380 [a])	
To send emails or text messages	85.68
To order or refill prescriptions	16.62
To contact any medical provider	14.72
To handle Medicare or other health insurance matters	11.15
To obtain information about health conditions for self or others	33.26
To pay bills or do banking	40.99
To shop for groceries or personal items	29.40
Summary of different types of Internet use among any Internet users (n=3380 [a])	
To send emails or text messages	85.68
For emails or texting purposes only (not any other use)	8.94
To conduct health-related tasks (order/refill prescriptions, contact medical provider, handle insurance matters, and/or obtain health information)	45.15
To pay bills, do banking, and/or shop for groceries or personal items	51.23
To conduct all of the above activities (emails/text messages, health-related tasks, and banking/shopping)	30.90
For other purposes than any of the above	8.76

[a] Weighted.

Table 2. Sample characteristics: weighted statistics.

Demographics/socioeconomic status	All (N=6680, 100%)	No Internet use (n=3300, 49.40%)	Any Internet use (n=3380, 50.60%)	*P* value[a]
Age group (years)				<.001
65-69	30.13	18.63	41.36	
70-74	26.17	22.70	29.56	
75-79	19.40	23.25	15.64	
80-84	14.16	19.16	9.28	
≥85	10.14	16.26	4.15	
Gender				<.001
Male	44.20	41.14	47.19	
Female	55.80	58.86	52.81	
Race/ethnicity				<.001
Non-Hispanic white	80.85	73.09	88.42	
Non-Hispanic black	7.97	11.51	4.53	
Hispanic	6.73	10.19	3.35	
All other/don’t know/refused	4.45	5.21	3.71	
Marital status				<.001
Married/cohabiting	59.64	49.87	69.18	
Widowed	24.86	12.50	12.11	
Divorced/separated	12.30	33.46	16.47	
Never married	3.19	4.18	2.24	
Live with spouse	58.69	48.61	68.52	<.001
Education				<.001
Less than high school/don’t know/refused	21.43	36.50	6.71	
High school diploma or GED	27.08	33.94	20.38	
Some college or associate degree	26.61	19.93	33.13	
Bachelor’s degree or higher	24.88	9.62	39.78	
Income ($), median	32,000	21,511	50,000	
Health conditions/needs				
Chronic medical conditions, mean (SE)	2.27 (0.03)	2.44 (0.03)	2.11 (0.03)	<.001
Dementia/Alzheimer’s disease, %	2.05	3.58	0.01	<.001
ADL/IADL impairments, mean (SE)	1.03 (0.06)	1.44 (0.06)	0.64 (0.07)	<.001
Psychological capital				
Depressive symptoms last month	16.28	21.89	10.80	<.001
Anxiety symptoms last month	13.19	18.30	8.19	<.001
Efficacy score, mean (SE)	10.71 (0.03)	10.44 (0.04)	10.97 (0.03)	<.001
Social capital				
Have at least 1 living child	88.21	86.06	90.31	<.001
Have at least 1 sibling	80.00	79.47	80.51	.30
Worked for pay last month	19.63	10.77	28.28	<.001
Did formal volunteering last month	26.33	17.37	35.07	<.001
Provided informal caregiving last month	20.00	16.78	23.14	<.001
Visited family/friend last month	88.24	83.44	92.92	<.001

Demographics/socioeconomic status	All (N=6680, 100%)	No Internet use (n=3300, 49.40%)	Any Internet use (n=3380, 50.60%)	P value[a]
Attended religious service last month	57.69	56.30	59.04	.02
Participated in clubs/classes/other organized activities last month	38.12	25.51	50.43	<.001
Went out for enjoyment last month	80.48	70.28	90.44	<.001

[a] *P* values denote difference between nonusers and users based on chi-square tests or independent samples *t* tests.

Association Between Internet Use and Health Needs, Psychological Capital, and Social Capital

As seen in Table 3, controlling for demographic and socioeconomic variables, a diagnosis of dementia or Alzheimer's disease was the only health status variable significantly associated with Internet use. Those individuals with these diagnoses were significantly less likely to use the Internet (odds ratio [OR] 0.37, 95% CI 0.20-0.65, *P*<.001). Depressive and anxiety symptoms were also negatively associated with the Internet use (depression: OR 0.83, 95% CI 0.70-0.98, *P*=.03; anxiety: OR 0.79, 95% CI 0.65-0.97, *P*=.03), but self-efficacy score was not. In terms of social capital resources, having a child (OR 1.47, 95% CI 1.18-1.84, *P*<.001), engagement in paid work (OR 1.65, 95% CI 1.34-2.03, *P*<.001) and formal volunteering (OR 1.33, 95% CI 1.09-1.62, *P*=.01), friend/family visits (OR 1.25, 95% CI 1.03-1.52, *P*=.02), attending organized activities (OR 1.73, 95% CI 1.46-2.05, *P*<.001), and participating in entertainment activities (OR 1.69, 95% CI 1.36-2.08, *P*<.001) were all positively associated with Internet use, whereas having a sibling (OR 0.81, 95% CI 0.68-0.97, *P*=.02) and attending religious services (OR 0.82, 95% CI 0.73-0.94, *P*=.01) were significantly negatively associated with use. Informal caregiving was not a significant correlate.

Age group, race/ethnicity, level of education, living arrangement, and total income were significantly associated with Internet use versus nonuse. Compared with the 65 to 69 age group, older age groups had significantly lower odds of Internet use (80-84 years: OR 0.21, 95% CI 0.18-0.26, *P*<.001; ≥85 years: OR 0.12, 95% CI 0.09-0.16, *P*<.001). Compared with non-Hispanic whites, non-Hispanic blacks and Hispanics had significantly lower odds of Internet use (non-Hispanic black: OR 0.41, 95% CI 0.33-0.51, *P*<.001; Hispanic: OR 0.55, 95% CI 0.39-0.78, *P*<.001). Compared to those with at least a bachelor's degree, those with less than a high school education or who refused to reveal their level of education had Internet use odds of 0.08 (95% CI 0.06-0.11, *P*<.001), those with high school diploma or General Education Development (GED) had odds of 0.18 (95% CI 0.14-0.24, *P*<.001), and those with some college education had odds of 0.46 (95% CI 0.37-0.57, *P*<.001). Compared to not living with a spouse, those living with a spouse had higher odds of Internet use (OR 1.38, 95% CI 1.19-1.59, *P*<.001). $F_{28,29}$ was 37.65 (*P*<.001).

Association Between Different Types of Internet Use and Health Needs, Psychological Capital, and Social Capital

As Table 4 shows, Internet use for health-related tasks among older adults was significantly associated with the number of chronic medical conditions. Having a greater number of chronic medical conditions was associated with a higher likelihood (OR 1.15, 95% CI 1.08-1.23, *P*<.001) of using the Internet for health-related tasks as opposed to other tasks. However, a diagnosis of dementia/Alzheimer's disease and the number of ADL/IADL impairments were not significant correlates. Anxiety symptoms was associated with a lower likelihood (OR 0.74, 95% CI 0.55-0.99, *P*=.05). Depressive symptoms and self-efficacy were not significant correlates. Among social capital variables, formal volunteering was significantly positively associated with Internet use for health-related tasks (OR 1.28, 95% CI 1.05-1.57, *P*=.02). Age group, race/ethnicity, level of education, living arrangement, but not total income, were significant correlates of Internet use for health-related tasks as opposed to other tasks. For example, non-Hispanic blacks, as opposed to non-Hispanic whites, had lower odds (0.70, 95% CI 0.53-0.92, *P*=.01) of Internet use for health-related tasks, whereas Hispanics and the "other" racial/ethnic group did not differ significantly from non-Hispanic whites. *F* tests for health-related tasks, shopping/banking, and email/texting only were $F_{28,29}$=7.62 (*P*<.001), $F_{28,29}$=6.60 (*P*<.001), $F_{28,29}$=4.56 (*P*<.001), respectively.

Table 3. Correlates of any Internet/online use among all sample persons: logistic regression analysis results (N=6680).

Variable		Internet/online use vs no Internet use	
		OR (SE)	95% CI
Age group (years)			
	65-69	1.00	
	70-74	0.62 (0.07)[a]	0.49-0.78
	75-79	0.31 (0.03)[a]	0.25-0.38
	80-84	0.22 (0.02)[a]	0.18-0.26
	≥85	0.12 (0.02)[a]	0.09-0.16
Gender			
	Male	1.00	
	Female	0.97 (0.07)	0.83-1.12
Race/ethnicity			
	Non-Hispanic white	1.00	
	Non-Hispanic black	0.41 (0.04)[a]	0.33-0.51
	Hispanic	0.55 (0.09)[a]	0.39-0.78
	All other/don’t know/refused	0.86 (0.18)	0.56-1.32
Education			
	BA/BS or higher	1.00	
	Less than high school/don’t know/refused	0.08 (0.01)[a]	0.06-0.10
	High school diploma or GED	0.18 (0.02)[a]	0.14-0.24
	Some college or associate degree	0.46 (0.05)[a]	0.37-0.57
Living arrangement			
	Not living with a spouse	1.00	
	Living with a spouse	1.38 (0.10)[a]	1.19-1.59
Total income (in $10,000)		1.01 (0.01)	1.00-1.02
Number of chronic illnesses		1.01 (0.02)	0.97-1.05
Dementia/Alzheimer’s disease			
	No	1.00	
	Yes	0.37 (0.11)[a]	0.20-0.66
Number of ADL/IADL impairments		1.01 (0.02)	0.97-1.04
Depression			
	No	1.00	
	Yes	0.83 (0.07)[c]	0.70-0.99
Anxiety			
	No	1.00	
	Yes	0.79 (0.08)[c]	0.65-0.97
Self-efficacy		1.05 (0.03)	0.99-1.11
Living child			
	No	1.00	
	Yes	1.47 (0.16)[a]	1.18-1.84

Variable	Internet/online use vs no Internet use	
	OR (SE)	95% CI
Living sibling		
No	1.00	
Yes	0.81(0.07)[c]	0.68-0.99
Worked for pay last month		
No	1.00	
Yes	1.65 (0.17)[a]	1.34-2.03
Did volunteering last month		
No	1.00	
Yes	1.33 (0.13)[b]	1.09-1.62
Informal caregiver last month		
No	1.00	
Yes	1.00 (0.09)	0.83-1.19
Visited family/friend last month		
No	1.00	
Yes	1.25 (0.12)[c]	1.03-1.52
Attended religious service last month		
No	1.00	
Yes	0.82 (0.05)[c]	0.73-0.94
Attended clubs/classes/organized activities last month		
No	1.00	
Yes	1.73 (0.15)[a]	1.46-2.05
Went out for enjoyment last month		
No	1.00	
Yes	1.69 (0.18)[a]	1.36-2.08

[a] *P*<.001

[b] *P*<.01

[c] *P*<.05

Table 4. Correlates of different types of Internet/online use among Internet/online users: logistic regression analysis results.

	Health-related tasks[a]		Shopping/banking[b]		Email/texting only[c]	
Variable	OR (SE)	95% CI	OR (SE)	95% CI	OR (SE)	95% CI
Age group (years)						
65-69	1.00		1.00		1.00	
70-74	0.76 (0.07)[e]	0.64-0.91	0.63 (0.07)[d]	0.50-0.79	1.25 (0.23)	0.87-1.82
75-79	0.71 (0.07)[e]	0.58-0.88	0.64 (0.08)[e]	0.50-0.82	1.27 (0.22)	0.90-1.79
80-84	0.63 (0.08)[d]	0.49-0.81	0.40 (0.06)[d]	0.30-0.55	2.60 (0.55)[d]	1.70-3.98
≥85	0.66 (0.11)[f]	0.48-0.92	0.32 (0.05)[d]	0.24-0.43	3.17 (0.77)[d]	1.95-5.17
Gender						
Male	1.00		1.00		1.00	
Female	1.09 (0.10)	0.91-1.32	1.21 (0.12)	0.99-1.48	0.76 (0.12)	0.56-1.03
Race/ethnicity						
Non-Hispanic white	1.00		1.00		1.00	
Non-Hispanic black	0.70 (0.09)[f]	0.53-0.92	0.90 (0.13)	0.67-1.21	1.60 (0.35)[f]	1.03-2.49
Hispanic	0.85 (0.20)	0.54-1.46	1.01 (0.25)	0.61-1.66	1.19 (0.45)	0.56-2.54
All other/don't know/refused	0.69 (0.16)	0.42-1.11	1.16 (0.23)	0.78-1.72	2.31 (0.63)[e]	1.33-3.99
Education						
BA/BS or higher	1.00		1.00		1.00	
Less than high school/don't know/refused	0.39 (0.07)[d]	0.27-0.56	0.34 (0.06)[d]	0.24-0.50	2.20 (0.60)[e]	1.35-3.39
High school diploma or GED	0.49 (0.06)[d]	0.38-0.63	0.45 (0.07)[d]	0.34-0.62	1.61 (0.31)[f]	1.09-2.38
Some college or associate degree	0.68 (0.06)[d]	0.56-0.82	0.79 (0.08)[f]	0.64-0.98	1.02 (0.20)	0.69-1.51
Living arrangement						
Not living with a spouse	1.00		1.00		1.00	
Living with a spouse	1.23 (0.12)[f]	1.03-1.51	0.85 (0.08)	0.70-1.02	1.21 (0.21)	0.85-1.73
Total income (in $10,000)	1.00 (0.01)	0.99-1.00	1.00 (0.01)	0.99-1.00	0.93 (0.02)[e]	0.89-0.98
Number of chronic illnesses	1.15 (0.04)[d]	1.08-1.23	1.00 (0.03)	0.94-1.07	0.99 (0.05)	0.89-1.10
Dementia/Alzheimer's disease						
No	1.00		1.00		1.00	
Yes	1.22 (0.71)	0.38-3.91	0.86 (0.50)	0.27-2.73	2.68 (1.98)	0.61-11.77
Number of ADL/IADL impairments	1.01 (0.02)	0.97-1.05	1.02 (0.02)	0.97-1.07	0.99 (0.03)	0.93-1.06
Depression						
No	1.00		1.00		1.00	
Yes	1.07 (0.20)	0.75-1.54	1.14 (0.17)	0.85-1.53	1.34 (0.33)	0.82-2.20
Anxiety						
No	1.00		1.00		1.00	
Yes	0.74 (0.11)[f]	0.55-0.99	0.78 (0.13)	0.56-1.09	1.75 (0.39)[f]	1.12-2.75
Self-efficacy	0.95 (0.04)	0.88-1.02	1.03 (0.04)	0.97-1.11	1.13 (0.07)	0.99-1.29
Living child						
No	1.00		1.00		1.00	
Yes	1.06 (0.17)	0.77-1.47	1.29 (0.20)	0.95-1.76	1.65 (0.42)	0.99-2.76

	Health-related tasks[a]		Shopping/banking[b]		Email/texting only[c]	
Variable	OR (SE)	95% CI	OR (SE)	95% CI	OR (SE)	95% CI
Living sibling						
No	1.00		1.00		1.00	
Yes	0.95(0.10)	0.77-1.18	0.97 (0.10)	0.79-1.20	0.97 (0.15)	0.72-1.32
Worked for pay						
No	1.00		1.00		1.00	
Yes	0.97 (0.09)	0.80-1.17	1.13 (0.10)	0.95-1.35	1.23 (0.24)	0.83-1.82
Did volunteering						
No	1.00		1.00		1.00	
Yes	1.28 (0.13)[f]	1.05-1.57	1.12 (0.12)	0.79-1.20	0.63 (0.12)[f]	0.43-0.92
Informal caregiver						
No	1.00		1.00		1.00	
Yes	1.07 (0.09)	0.91-1.27	1.10 (0.12)	0.89-1.35	0.74 (0.12)	0.53-1.02
Visited family/friend						
No	1.00		1.00		1.00	
Yes	1.26 (0.21)	0.91-1.74	1.10 (0.17)	0.80-1.51	1.04 (0.26)	0.63-1.72
Attended religious service						
No	1.00		1.00		1.00	
Yes	0.84 (0.07)	0.70-1.01	0.75 (0.7)[e]	0.62-0.91	1.35 (0.21)	0.99-1.84
Attended clubs/classes/ organized activities						
No	1.00		1.00		1.00	
Yes	1.15 (0.12)	0.93-1.42	1.08 (0.10)	0.89-1.31	0.75 (0.13)	0.53-1.06
Went out for enjoyment						
No	1.00		1.00		1.00	
Yes	1.10 (0.17)	0.81-1.50	1.10 (0.18)	0.79-1.53	0.71 (0.16)	0.45-1.10

[a] Coded as 1 for using Internet for any health-related task and 0 for not using the Internet for health-related task.

[b] Coded as 1 for using Internet for any shopping/banking task and 0 for not using the Internet for shopping/banking task.

[c] Coded as 1 for using Internet for email/texting purposes only and 0 for using the Internet for email/texting and other tasks (ie, health-related tasks and/or shopping/banking tasks).

[d] *P*<.001.

[e] *P*<.01.

[f] *P*<.05.

Internet use for shopping/banking activities among older adults was significantly negatively associated with religious service attendance only (OR 0.75, 95% CI 0.62-0.91, *P*=.01). None of the health needs and psychological and other social capital variables was correlated with this type of Internet use. Of the demographic and socioeconomic status variables, age group and education level were significant correlates, whereas gender, race/ethnicity, and income were not significant correlates.

Internet use solely for sending emails or text messages was significantly positively associated with anxiety symptoms (OR 1.75, 95% CI 1.12-2.75, *P*=.02), but it was significantly negatively associated with engagement in formal volunteering (OR 0.63, 95% CI 0.43-0.92, *P*=.02). Compared to those in the 60 to 65 age group, those in the 80 to 84 year and 85 year and older age groups had significantly higher odds (80-84 years: OR 2.60, 95% CI 1.70-3.98, *P*<.001; ≥85 years: OR 3.17, 95% CI 1.95-5.17, *P*<.001) of Internet use for emails/texting exclusively. Compared to non-Hispanic whites, non-Hispanic blacks and other racial/ethnic groups had higher odds (OR 1.60, 95% CI 1.03-2.49, *P*=.04 and OR 2.31, 95% CI 1.33-3.99, *P*=.01, respectively) of using the Internet for emails/texting only. Compared to Internet users with a 4- or 5-year college degree or higher-level education, users with less than a high school education or unknown (don’t know/refused) level of education or a high school education/GED, had higher odds (OR 2.20, 95% CI 1.28-3.79, *P*=.01 and OR 1.61, 95% CI 1.09-2.38, *P*=.02, respectively) of using the Internet for emails/texting only. Those with higher income (in $10,000) had lower odds (OR 0.93, 95% CI 0.89-0.98, *P*=.01) of using the Internet for emails/texting only.

Discussion

This study examined not only the relationships among Internet use and health needs, psychological capital, and social capital, but also the relationships among different types of Internet use and these variables among a nationally representative sample of community-dwelling older adults aged 65 and older in the United States. Although some previous studies have examined the characteristics of older health information technology users [8,14,16,17,25], this study is one of the first to examine the characteristics of older adults who engage in other types of Internet use activities. The 51% prevalence of Internet use among older adults in 2011 (compared to 58% in the 2012 Pew Internet use survey) lags far behind that of younger adults, including those in the 50 to 64 age group. Nevertheless, older Internet users engaged in diverse types of Internet activities: almost 86% of the users sent emails/text messages, 51% shopped, paid bills, and/or did banking, and 45% conducted health-related tasks on the Internet. Just 9% of the users used the Internet only for sending emails/text messages.

The findings show that demographic and socioeconomic status variables were significant predictors of Internet use versus nonuse. As previous studies demonstrated [14,16-18], black and Hispanic individuals are less likely to use the Internet, and one of the strongest determinants of older adults' Internet use is their education level. Compared to college graduates, high school graduates were 80% less likely to use the Internet, and those with less than a high school education were 90% less likely to use the Internet. As expected, having a diagnosis of dementia or Alzheimer's disease significantly lowered the odds of Internet use, but the number of chronic medical conditions (excluding dementia or Alzheimer's disease) and ADL/IADL impairments were not significant factors. With regard to psychological capital, H1 was supported because both depressive symptoms and anxiety symptoms were associated with a lower likelihood of Internet use, and H2 was not supported because self-efficacy was not related to Internet use. With regard to social capital, the findings support H3 because having both a living child and having a living sibling significantly increased the odds of Internet use. H4 was largely supported because all social integration/tie indicators, except the informal caregiving variable, were significantly associated with Internet use. However, unlike other social capital variables, religious service attendance decreased the odds of Internet use. In general, those who attended religious services were more likely to be women (whose Internet use did not differ from that of men) and non-Hispanic black, Hispanic, and those of other ethnic groups (who are less likely to use the Internet), but attenders also had characteristics associated with higher levels of Internet use, specifically higher levels of education and social capital (eg, more interactions with family and friends, more volunteering, and more participation in clubs, classes, and other organized activities).

The findings also show that different types of Internet users share some similar characteristics, but have different characteristics as well. Having a higher number of medical conditions (implying more health care needs) and engaging in formal volunteering increased the odds of Internet use for health-related tasks, thus supporting H5. Also, H6 and H7 regarding psychological and social capital factors associated with Internet use for various purposes were also partially supported. Anxiety symptoms decreased the odds of Internet use for health-related tasks and increased the odds of email/texting only. Engagement in volunteer work was associated with increased odds of Internet use for health-related tasks, but decreased odds of using the Internet for email/texting only. Religious service attendance was associated with decreased odds of Internet use for shopping/banking tasks. Sociodemographic correlates of using the Internet only for email/texting were the older age groups (80-84 and ≥85 years), a black or other racial/ethnic background, a high school education or less, and lower income. These findings show that older adults who used the Internet for email/texting purposes only were the most socially and economically disadvantaged group of the Internet users.

As discussed, Internet technology can offer multiple benefits and conveniences for older adults dealing with physical and functional decline and social isolation in later life. Owing to advances in Internet and other mobile technology, individuals now can access more information about their health than ever before [19]. The Internet also has the potential to help older adults with disabilities carry out health care-related and other activities with greater ease (eg, without having to rely on others for transportation). This study confirms the findings of previous studies that older adults who are older and socioeconomically disadvantaged are significantly less likely to use the Internet, including accessing health-related information. Given the pervasive Internet technology use among young and middle-aged people, Internet use among future generations of older adults will be common; however, the current generation of older adults who use the Internet, especially those in the older group (≥80 years), learned to use the Internet in late life [6,9]. A previous study found that nonusers were most likely to cite financial reasons for their lack of computer use, specifically the cost of computer equipment and Internet access [19]. The present study suggests that a large proportion of the oldest age group does not use computers/Internet for a variety of reasons, such as lack of financial resources or of social support to do so. Given the decreasing cost of computers/tablets, public or private not-for-profit programs are needed to provide inexpensive devices (eg, netbooks, Chromebooks) and Internet subscriptions for low-income older adults.

Along with sociodemographic variables, this study also found that most social capital variables were significantly correlated with Internet use, as hypothesized. This confirmation of the importance of social integration/ties and social support in facilitating older adults' learning and adoption of Internet technology also suggests a synergistic relationship: by teaching those with less social capital to use computers and the Internet, their social capital may increase because computer/Internet use can increase their ties to others (relatives, support groups, hobby groups, etc).

The study has a few limitations. First, the NHATS presently offers only a cross-sectional dataset (longitudinal data will be provided in the future); thus, only correlational, not causal, relationships could be deduced. Second, measures of psychological capital used in NHATS—depression, anxiety, and self-efficacy—were abbreviated, not full, scales. The shortened scales may not have adequately captured the complex nature of psychological capital. Moreover, the self-efficacy and anxiety scales were not specific to computer/Internet use. Third, although NHATS provides the most recent data on technology use among a nationally representative sample of US older adults, it did not include a full array of Internet activities in which these older adults may have engaged. Such data would have provided a more valuable description of older adults' Internet activity. Finally, NHATS did not distinguish email from texting. The distinction may have provided a clearer picture of either activity.

Despite these limitations, this study's results have significant implications for future research and computer/Internet technology training for older adults. First, research should reexamine the role of psychological capital, especially self-efficacy and anxiety symptoms, using scales that specifically measure psychological capital pertaining to computer/Internet use and using longitudinal data. Second, research should identify characteristics of religious service attenders that may be associated with lower odds of their Internet use, since church settings may provide venues for overcoming barriers to Internet use, teaching computer/Internet skills, and encouraging computer/Internet use. Third, computer/Internet training for older adults needs to consider the significant role other social support networks can play as well. Children, other family members, and friends may rally around older adults who have anxiety about learning Internet technology. A related benefit is that younger people may feel a sense of accomplishment from teaching older adults how to use the Internet or other technology. Intergenerational connections can be established by expanding or developing programs in which high school and college students volunteer at senior programs, assisted living facilities, or in the homes of homebound older adults to teach computer and Internet operational skills, including how to use the Internet for fun and relaxation as well as obtaining health information, making appointments, banking, and other tasks. Fourth, computer/Internet technology training for older adults needs to focus on the older age group of older adults, racial/ethnic minority older adults, older adults with low levels of education and low income, those not married and living alone, and those with low levels of social integration and social support. Older adults with these characteristics can potentially benefit the most from what Internet technology can offer.

Health care sectors are adopting increasing numbers of telehealth and telemental health interventions for older adults [39-41]. With accumulating evidence of their potential to improve access to health and mental health services among geographically and socially isolated older adults and other underserved groups, Internet- and mobile-based health and mental health care service delivery is expected to become a widespread reality in the near future [42,43]. Older adults must be prepared for the changing health care delivery and eHealth services by improving their access to and training for Internet technology. Previous studies have found that older adults with socioeconomic disadvantages were able to learn computer and Internet use to seek health information in collaborative training sessions, and that the participants in training sessions showed a reduction in computer anxiety and increase in computer self-efficacy in retrieving and evaluating online health information [6,44]. Unfortunately, the current study shows that the digital divide is still very real, and that poorly educated, socially isolated, racial/ethnic minority older adults are still not riding the Internet technology wave.

Conflicts of Interest

None declared.

References

1. Anderson G. Chronic care: making the case for ongoing care. Princeton, NJ: Robert Wood Johnson Foundation; 2009. URL: http://www.rwjf.org/content/dam/farm/reports/reports/2010/rwjf54583 [accessed 2013-05-01] [WebCite Cache ID 6GIEXYNDr]
2. Cornwell EY, Waite LJ. Measuring social isolation among older adults using multiple indicators from the NSHAP study. J Gerontol B Psychol Sci Soc Sci 2009 Nov;64 Suppl 1:i38-i46 [FREE Full text] [doi: 10.1093/geronb/gbp037] [Medline: 19508982]
3. Cornwell EY, Waite LJ. Social disconnectedness, perceived isolation, and health among older adults. J Health Soc Behav 2009 Mar;50(1):31-48 [FREE Full text] [Medline: 19413133]
4. Coyle CE, Dugan E. Social isolation, loneliness and health among older adults. J Aging Health 2012 Dec;24(8):1346-1363. [doi: 10.1177/0898264312460275] [Medline: 23006425]
5. Xie B. Using the Internet for offline relationship formation. Soc Sci Comput Rev 2007 Aug 2007;25(3):396-404. [doi: 10.1177/0894439307297622] [Medline: 22973420]
6. Xie B. Older adults, e-health literacy, and collaborative learning: An experimental study. J Am Soc Inf Sci 2011 Mar 2011;62(5):933-946. [doi: 10.1002/asi.21507]
7. AARP. 2009 Dec. Internet use among midlife and older adults: an AARP bulletin poll URL: http://assets.aarp.org/rgcenter/general/bulletin_internet_09.pdf [accessed 2013-05-01] [WebCite Cache ID 6GIEj9Cb6]
8. Crabb RM, Rafie S, Weingardt KR. Health-related internet use in older primary care patients. Gerontology 2012;58(2):164-170. [doi: 10.1159/000329340] [Medline: 21734360]

9. Czaja SJ, Lee CC. The impact of aging on access to technology. Univ Access Inf Soc 2006 Dec 2006;5(4):341-349. [doi: 10.1007/s10209-006-0060-x]
10. Gatto SL, Tak SH. Computer, Internet, and e-mail use among older adults: benefits and barriers. Educational Gerontology 2008 Aug 2008;34(9):800-811. [doi: 10.1080/03601270802243697]
11. Russell C, Campbell A, Hughes I. Ageing, social capital and the Internet: findings from an exploratory study of Australian 'silver surfers'. Australas J Ageing 2008 Jun;27(2):78-82. [doi: 10.1111/j.1741-6612.2008.00284.x] [Medline: 18713197]
12. Sum S, Mathews RM, Hughes I. Participation of older adults in cyberspace: how Australian older adults use the Internet. Australas J Ageing 2009 Dec;28(4):189-193. [doi: 10.1111/j.1741-6612.2009.00374.x] [Medline: 19951340]
13. Xie B. Effects of an eHealth literacy intervention for older adults. J Med Internet Res 2011 Nov;13(4):e90 [FREE Full text] [doi: 10.2196/jmir.1880] [Medline: 22052161]
14. Choi N. Relationship between health service use and health information technology use among older adults: analysis of the US National Health Interview Survey. J Med Internet Res 2011;13(2):e33 [FREE Full text] [doi: 10.2196/jmir.1753] [Medline: 21752784]
15. Demographics of internet users. Washington, DC: Pew Internet & American Life Project; 2012 Aug. URL: http://pewinternet.org/Static-Pages/Trend-Data-(Adults)/Whos-Online.aspx [accessed 2012-08-25] [WebCite Cache ID 6AOT1DrMH]
16. Jensen JD, King AJ, Davis LA, Guntzviller LM. Utilization of internet technology by low-income adults: the role of health literacy, health numeracy, and computer assistance. J Aging Health 2010 Sep;22(6):804-826. [doi: 10.1177/0898264310366161] [Medline: 20495159]
17. Neter E, Brainin E. eHealth literacy: extending the digital divide to the realm of health information. J Med Internet Res 2012 Jan;14(1):e19 [FREE Full text] [doi: 10.2196/jmir.1619] [Medline: 22357448]
18. Werner JM, Carlson M, Jordan-Marsh M, Clark F. Predictors of computer use in community-dwelling, ethnically diverse older adults. Hum Factors 2011 Oct;53(5):431-447 [FREE Full text] [Medline: 22046718]
19. Carpenter BD, Buday S. Computer use among older adults in a naturally occurring retirement community. Computers in Human Behavior 2007 Nov 2007;23(6):3012-3024. [doi: 10.1016/j.chb.2006.08.015] [Medline: 23402809]
20. Gracia E, Herrero J. Internet use and self-rated health among older people: a national survey. J Med Internet Res 2009 Dec;11(4):e49 [FREE Full text] [doi: 10.2196/jmir.1311] [Medline: 19955041]
21. Medeiros Fde L, Xavier AJ, Schneider IJ, Ramos LR, Sigulem D, d'Orsi E. Digital inclusion and functional capacity of older adults living in Florianópolis, Santa Catarina, Brazil (EpiFloripa 2009-2010). Rev Bras Epidemiol 2012 Mar;15(1):106-122 [FREE Full text] [Medline: 22450497]
22. Ilyas M. A study of web accessibility barriers for older adults, and heuristics evaluation of email websites based on web accessibility heuristics for older adults by AARP. J Emerging Trends in Computing and Information Sciences 2012;3(5):806-813 [FREE Full text]
23. Flynn KE, Smith MA, Freese J. When do older adults turn to the internet for health information? Findings from the Wisconsin Longitudinal Study. J Gen Intern Med 2006 Dec;21(12):1295-1301 [FREE Full text] [doi: 10.1111/j.1525-1497.2006.00622.x] [Medline: 16995892]
24. Mitzner TL, Boron JB, Fausset CB, Adams AE, Charness N, Czaja SJ, et al. Older adults talk technology: technology usage and attitudes. Comput Human Behav 2010 Nov 1;26(6):1710-1721 [FREE Full text] [doi: 10.1016/j.chb.2010.06.020] [Medline: 20967133]
25. Ybarra M, Suman M. Reasons, assessments and actions taken: sex and age differences in uses of Internet health information. Health Educ Res 2008 Jun;23(3):512-521 [FREE Full text] [doi: 10.1093/her/cyl062] [Medline: 16880222]
26. Charness N, Boot WR. Aging and information technology use. Curr Dir Psychol Sci 2009;18(5):253-258. [doi: 10.1111/j.1467-8721.2009.01647.x]
27. Marquié JC, Jourdan-Boddaert L, Huet N. Do older adults underestimate their actual computer knowledge? Behaviour & Information Technology 2002 Jan 2002;21(4):273-280. [doi: 10.1080/0144929021000020998]
28. Adams N, Stubbs D, Woods V. Psychological barriers to Internet usage among older adults in the UK. Med Inform Internet Med 2005 Mar;30(1):3-17. [doi: 10.1080/14639230500066876] [Medline: 16036626]
29. Dow B, Moore K, Scott P, Ratnayeke A, Wise K, Sims J, et al. Rural carers online: a feasibility study. Aust J Rural Health 2008 Jul;16(4):221-225. [doi: 10.1111/j.1440-1584.2008.00982.x] [Medline: 18652610]
30. Nyqvist F, Gustavsson J, Gustafson Y. Social capital and health in the oldest old: The Umeå 85+ Study. Int J Ageing Later Life 2006;1(1):91-114 [FREE Full text] [doi: 10.3384/IJAL.1652_8670.061191]
31. Cresci MK, Yarandi HN, Morrell RW. The Digital Divide and urban older adults. Comput Inform Nurs 2010 Apr;28(2):88-94. [doi: 10.1097/NCN.0b013e3181cd8184] [Medline: 20182159]
32. van Deursen AJ, van Dijk JA. Using the Internet: skill related problems in users' online behavior. Interacting with Computers 2009 Dec 2009;21(5-6):393-402 [FREE Full text] [doi: 10.1016/j.intcom.2009.06.005]
33. van Deursen AJ. Internet skill-related problems in accessing online health information. Int J Med Inform 2012 Jan;81(1):61-72. [doi: 10.1016/j.ijmedinf.2011.10.005] [Medline: 22079240]
34. Feufel MA, Stahl SF. What do web-use skill differences imply for online health information searches? J Med Internet Res 2012 Jun;14(3):e87 [FREE Full text] [doi: 10.2196/jmir.2051] [Medline: 22695686]

35. What internet users do online?. Washington, DC: Pew Internet & American Life Project; 2012 Mar. URL: http://pewinternet.org/Trend-Data-(Adults)/Online-Activites-Total.aspx [accessed 2012-08-25] [WebCite Cache ID 6AOTQe3nJ]
36. National Aging and Health Trends Study. 2012 May. Background and overview URL: http://www.nhats.org/scripts/background.htm [accessed 2012-07-21] [WebCite Cache ID 6AOToWh7P]
37. Montaquila J, Freedman VA, Edwards B, Kasper JD. NHATS Technical Paper #1: National Health and Aging Trends Study Round 1 Sample Design and Selection. Baltimore, MD: Johns Hopkins University School of Public Health; 2012 May 10. URL: http://www.nhats.org/scripts/sampling/NHATS%20Round%201%20Sample%20Design%2005_10_12.pdf [accessed 2013-05-01] [WebCite Cache ID 6GIFMbE6q]
38. Kasper JD, Freeman VA. National Health and Aging Trends Study Round 1 User Guide: Final Release. Baltimore, MD: Johns Hopkins University School of Public Health; 2012 Nov 29. URL: http://www.nhats.org/scripts/documents/NHATS_Round_1_User_Guide_Final_Release.pdf [accessed 2013-05-01] [WebCite Cache ID 6GIFCNCD5]
39. Grady B, Myers KM, Nelson EL, Belz N, Bennett L, Carnahan L, American Telemedicine Association Telemental Health Standards and Guidelines Working Group. Evidence-based practice for telemental health. Telemed J E Health 2011 Mar;17(2):131-148. [doi: 10.1089/tmj.2010.0158] [Medline: 21385026]
40. van den Berg N, Schumann M, Kraft K, Hoffmann W. Telemedicine and telecare for older patients--a systematic review. Maturitas 2012 Oct;73(2):94-114. [doi: 10.1016/j.maturitas.2012.06.010] [Medline: 22809497]
41. Wilcox ME, Adhikari NK. The effect of telemedicine in critically ill patients: systematic review and meta-analysis. Crit Care 2012 Jul 18;16(4):R127 [FREE Full text] [doi: 10.1186/cc11429] [Medline: 22809335]
42. Richards D, Richardson T. Computer-based psychological treatments for depression: a systematic review and meta-analysis. Clin Psychol Rev 2012 Jun;32(4):329-342. [doi: 10.1016/j.cpr.2012.02.004] [Medline: 22466510]
43. Wootton R. Twenty years of telemedicine in chronic disease management--an evidence synthesis. J Telemed Telecare 2012 Jun;18(4):211-220 [FREE Full text] [doi: 10.1258/jtt.2012.120219] [Medline: 22674020]
44. Chu A, Huber J, Mastel-Smith B, Cesario S. "Partnering with Seniors for Better Health": computer use and Internet health information retrieval among older adults in a low socioeconomic community. J Med Libr Assoc 2009 Jan;97(1):12-20 [FREE Full text] [doi: 10.3163/1536-5050.97.1.003] [Medline: 19159002]

Abbreviations

ADL: activities of daily living
IADL: instrumental activities of daily living
NHATS: National Aging and Health Trends Study

Edited by G Eysenbach; submitted 03.09.12; peer-reviewed by F Schneider, L Fernandez-Luque; comments to author 08.02.13; revised version received 14.02.13; accepted 24.04.13; published 16.05.13.

Please cite as:
Choi NG, DiNitto DM
Internet Use Among Older Adults: Association With Health Needs, Psychological Capital, and Social Capital
J Med Internet Res 2013;15(5):e97
URL: http://www.jmir.org/2013/5/e97/
doi:10.2196/jmir.2333
PMID:23681083

Original Paper

Perceptions of Family Physician Trainees and Trainers Regarding the Usefulness of a Virtual Community of Practice

Stephen Barnett[1], BMed, MRCGP, DCH(Lond), FRACGP; Sandra C Jones[2], BA, MBA, PostGradDipHlthProm, MPH; Sue Bennett[3], BSC, BSC(Hons), GCertHEd, PhD, MSc; Don Iverson[4], BSC, MSc, PhD; Andrew Bonney[1], MBBS(Hons), MFM(Clin), PhD, FRACGP

[1]General Practice Academic Unit, Graduate School of Medicine, University of Wollongong, Wollongong, Australia
[2]Centre for Health Initiatives, University of Wollongong, Wollongong, Australia
[3]Faculty of Education, University of Wollongong, Wollongong, Australia
[4]Health and Behavioural Sciences, University of Wollongong, Wollongong, Australia

Corresponding Author:
Stephen Barnett, BMed, MRCGP, DCH(Lond), FRACGP
General Practice Academic Unit
Graduate School of Medicine
University of Wollongong
Wollongong, 2522
Australia
Phone: 61 2 4221 ext 4613
Fax: 61 2 42214341
Email: sbarnett@uow.edu.au

Abstract

Background: Training for Australian general practice, or family medicine, can be isolating, with registrars (residents or trainees) moving between rural and urban environments, and between hospital and community clinic posts. Virtual communities of practice (VCoPs), groups of people sharing knowledge about their domain of practice online and face-to-face, may have a role in overcoming the isolation associated with general practice training.

Objective: This study explored whether Australian general practice registrars and their supervisors (trainers) would be able to use, and would be interested in using, a VCoP in the form of a private online network for work and training purposes. It also sought to understand the facilitators and barriers to intention to use such a community, and considers whether any of these factors may be modifiable.

Methods: A survey was developed assessing computer, Internet, and social media access and usage, confidence, perceived usefulness, and barriers, facilitators, and intentions to use a private online network for training purposes. The survey was sent by email link to all 139 registrars and 224 supervisors in one of Australia's 17 general practice training regions. Complete and usable responses were received from 131 participants (response rate=0.4).

Results: Most respondents had access to broadband at home (125/131, 95.4%) and at work (130/131, 99.2%). Registrars were more likely to spend more than 2 hours on the Internet (*P*=.03), and to use social media sites for nonwork purposes (*P*=.01). On a 5-point Likert scale, confidence was high (mean 3.93, SD 0.63) and was negatively associated with higher age (*P*=.04), but not associated with training stage. Social media confidence was lower, with registrars more confident than supervisors for almost all social media activities. On a 5-point Likert scale, overall usefulness was scored positively (n=123, mean 3.63, SD 0.74), and was not significantly associated with age or training level. The main concerns of respondents were worries about privacy (registrar: 61/81, 75.3%; supervisor: 30/50, 60.0%) and insufficient time (registrar: 41/81, 50.6%; supervisor: 36/50, 72.0%). Using a multivariate generalized linear regression model, training stage and perceived usefulness were positively predictive, and concerns about privacy and time were negatively predictive of intention to use a private online network.

Conclusions: General practice registrars and supervisors are interested in using a private online network, or VCoP, for work and training purposes. Important considerations are the extent to which concerns such as privacy and usefulness may be overcome by training and support to offset some other concerns, such as time barriers. Participants at an early stage in their training are more receptive to using an online network. More senior registrars and supervisors may benefit from more training and promotion of the online network to improve their receptiveness.

(J Med Internet Res 2013;15(5):e92) doi:10.2196/jmir.2555

KEYWORDS

community of practice; virtual community of practice; general practice; family physician; training; education; medical graduate; social media

Introduction

Training for general practice, or family medicine, in Australia is a postgraduate specialty program. After graduation from medical school, doctors spend a minimum of 1 year in the hospital system. To become a general practitioner, they must join a 3-year general practice training program run by one of 17 regional training providers across Australia. This program consists of 1 hospital year and 2 supervised general practice years. During these 3 years, trainees are required to work in a number of different rural and urban general practice locations, with at least 6 months located in a rural area. These locations are often small practices with a limited number of medical colleagues on-site, in contrast to the large hospitals with many colleagues that characterize early medical training.

As a result of these features, general practice training can be isolating [1], resulting in decreased knowledge sharing [2], and can affect career choices [3], including lowering intention to work in rural areas [1]. This has implications for the quality of training, standard of the primary care workforce, and retention of a rural general practice workforce.

The types of isolation experienced can be categorized as structural, personal, and professional [1]. Structural isolation refers to smaller practices with closed consulting rooms and occurs across urban and rural sites [1]. Social isolation, which can be described as a kind of loneliness [4], is more common in rural placements [1,5]. Professional isolation results from a lack of clinical support and is also potentially a greater problem in rural areas [1]. Professional isolation is linked to barriers to knowledge sharing, with reduced tacit knowledge exchange, and networking opportunities [2]. Problems with training, including all 3 types of isolation, are associated with a decreased intention to work in rural or regional areas [1].

The general practice workforce in Australia is under pressure [6], particularly in rural areas [7]. Given that isolation can lead to a lower intention to practice in rural and regional areas, it is important to try to overcome isolation to maintain a sustainable general practice workforce.

A recent literature review proposed a role for virtual communities of practice (VCoP) in overcoming isolation, particularly professional isolation, through improved knowledge sharing [8]. The literature review built on an accepted business VCoP framework [9], proposing a framework for VCoPs in health. Communities of practice (CoPs) are “groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly” [10]. These groups build shared resources that maintain ways of working, standards, and values within the community [11,12]. As technology has progressed, collaboration is being facilitated by social media tools [13-15] resulting in a blending of face-to-face and virtual communities of practice [16,17]. This differs from a simple virtual community that is fluid and without formal boundaries or membership [18] and, most importantly, may be purely based on a shared interest, such as movie trivia, rather than a shared practice. Probst and Borzillo [9] have developed a framework for CoPs implementation on the basis of 57 face-to-face and virtual CoPs in large companies such as IBM and Siemens. Barnett et al [8] have refined this for the health sector after a comprehensive review of the health literature and suggested a role for VCoPs, in the form of online private networks, in overcoming isolation through improved interaction with colleagues and knowledge sharing.

This study explored whether Australian general practice trainees and their supervisors would be able to use, and would be interested in using, a VCoP of this type for work and training purposes. It also sought to understand the facilitators and barriers to intention to use, such as community, and considered whether any of these factors could be modified.

Methods

Participants

The sampling frame for the current study included all general practice trainees and supervisors in a large regional training provider in Australia in May 2010. In ascending order, the training levels are basic registrar, advanced registrar, subsequent registrar, supervisor, and educator. The training provider, Coast City Country General Practice Training (CCCGPT), provides general practice training across a wide geographic area, including the urban centers of Canberra in the Australian Capital Territory and Wollongong in New South Wales, alongside large regional and small rural centers spread across approximately 160,000 square kilometers.

Surveys were sent to all trainers and trainees on the CCCGPT database via an email link to SurveyMonkey [19], a Web-based survey creation tool. A participant information sheet was provided. Surveys were sent to the total sampling frame of 363 people, which included 139 registrars and 224 supervisors. A total of 146 completed surveys were returned (40.2%); 15 participants were removed for reasons such as not completing at least half of the survey (n=10), not completing demographic data (n=3), and not ticking the consent box on the survey (n=2). This left 131 (36.1%) for analysis.

Ethics approval was obtained from the University Human Research Ethics Committee.

Questionnaire

There is a lack of literature on VCoPs in general practice training [8]; therefore, the survey was developed by the authors to assess computer, Internet, and social media access and usage, confidence, perceived usefulness, intentions to use, and barriers to use for training purposes.

The instrument was piloted among a group of general practitioners, general practice trainees, and health researchers. Afterwards, a group discussion among pilot participants led to the amendment of wording and several response options alterations, to improve clarity and better reflect GP work.

The final survey consisted of 26 questions, including categorical and Likert response items (see Table 1). Specifically, the questions covered demographics (questions 1-5), computer and Internet access and usage (questions 6-9), computer and social media confidence (questions 10 and 11), social networking usage (questions 12-21), social media usefulness (questions 22 and 27), barriers to use (questions 23 and 24), and intention to use social media for training purposes (questions 25 and 26).

Statistical Analysis

Data were analyzed using SPSS version 19 (IBM Corp, Armonk, NY, USA). Respondents were categorized as registrar or supervisor for comparisons between groups. The *t* test and chi-square test were used to determine differences between responses based on rurality, gender, age, and training level. Paired-samples *t* tests were used to compare means of scale data, such as intention to use a private social network for work purposes and intention to use an open social network for work purposes. Independent-sample *t* tests were used to compare categorical and scale data, such as computer confidence, and for the analysis involving all categories of training level. The chi-square test was used to compare differences between categorical data, such as rurality and training level. All statistical comparisons were 2-tailed and statistical significance was set at *P*<.05.

Factor analysis using varimax rotation was used to determine which Likert items grouped naturally in questions with multiple Likert items for constructs such as computer confidence (questions 10 and 11) and usefulness (question 22). Factors were included if their eigenvalues were >1.0. The Cronbach alpha test for reliability was used to determine the degree of agreement between the Likert items. Cronbach alpha was >.8 for both items, higher than the recommended threshold of .70.

A confidence scale was constructed using all items from questions 10 and 11; the summated data were used as an independent variable in further analysis. The Pearson product moment correlation (*r*) was used to determine agreement between variables, such as confidence and intention to use a private network for training purposes. The multivariate associations of independent variables, such as confidence and training level, with the dependent variable of intention to use a private network for training purposes were examined using multivariate general linear regression modeling.

Table 1. Survey content and question type.

Question content	Question type	Question number (categorical options or Likert items)
Demographic	Categorical	1 (2), 2 (2),3 (1), 4 (2), 5 (2)
Access and usage	Categorical	6 (2), 7 (2), 8 (6), 9 (7)
Confidence	Likert items	10 (4), 11 (7)
Social networking usage	Categorical	12 (2), 13 (9), 14 (11), 15 (2), 16 (9),17 (2), 18 (1), 19 (2), 20 (5), 21 (8)
Usefulness	Likert items	22 (14)
Usefulness	Categorical	27 (6)
Barriers	Categorical	23 (8), 24 (8)
Intention to use	Likert items	25 (2), 26 (2)

Results

Characteristics of the Survey Population

Of the 131 respondents, gender was evenly split (males: 66/131, 50.4%; females: 65/131, 49.6%). Registrars accounted for 61.8% (81/131) of respondents and the remainder were supervisors. The response rate among trainees was higher than supervisors (registrar: 81/139, 58%; supervisor: 50/224, 22%). The mean age of the sample was 41.5 years (range 23-66 years, SD 10.369), with a significant difference between ages of trainees and supervisors (trainees: mean 35.9, SD 7.21; supervisors mean 51.0, SD 7.21, *P*<.001).

Over half (75/131) of respondents were from rural settings, whereas the remainder worked in a general (nonrural) setting, with no significant differences between training stage and rurality or age and rurality.

Access and Usage

Almost all general practice trainees and supervisors had access to broadband Internet at home (125/131, 95.4%) and at work (130/131, 99.2%). However, usage was found to be significantly different between registrars and supervisors, with 20.0% (10/50) of supervisors compared to 33.3% (27/81) of registrars spending more than 2 hours per day on the Internet (*P*=.03). Internet usage of greater or less than 2 hours per day was not significantly associated with age (*P*=.17)

Registrars were significantly more likely to use social networking sites for nonwork purposes (registrars: 41/81, 50.6%; supervisors: 14/50, 28%, *P*=.01), and higher usage was associated with lower age (*P*<.001). Both registrars and supervisors were unlikely to use social networking sites for work purposes (registrars: 13/81, 16.0%; supervisors: 4/50, 8.0%) and there was no statistically significant difference between the groups.

Out of all online social media activities, registrars and supervisors were most likely to watch online videos (registrars: 63/81, 77.8%; supervisors: 27/50, 54.0%), followed by reading discussions (registrars: 53/81, 65.4%; supervisors: 25/50, 50.0%). They were least likely to construct a wiki (registrars: 3/81, 3.7%; supervisors: 0/50, 0.0%). Video watching was significantly correlated with age, with younger users watching more video (*P*=.001) and registrars watching more video than supervisors (*P*=.004). Reading online discussions was not significantly different between registrars and supervisors and was not associated with age.

Confidence

Factor analysis was performed on the 4 general computer confidence items, revealing only 1 factor, which was labeled *computer confidence*. The factor analysis was reliable (Cronbach alpha=.82) and valid (eigenvalue=2.66). Overall confidence was high (n=131, mean 3.93, SD 0.63) and confidence was negatively associated with age (*r*= –0.18, *P*=.04), but not significantly associated with being a registrar or a supervisor.

Confidence using discussion boards, wikis, blogs, online communities, chat, online video, and Twitter was assessed on a 5-point Likert scale for each of the 7 items. Confidence among supervisors was low to moderate, from a mean of 2.32 (SD 0.91) to a mean of 2.98 (SD 1.29), and was significantly lower than among registrars for all applications except Twitter, which was low for both groups (see Table 2).

Factor analysis was performed on the 7 social media confidence items, revealing only 1 factor which was labeled *social media confidence*. The factor analysis was reliable (Cronbach alpha=.93) and valid (eigenvalue=5.0). Social media tool confidence overall was moderate (n=131, mean 3.03, SD 0.99) and was negatively associated with age (*r*=–0.38, *P*<.001) and training level (*P*<.001), with younger respondents and registrars more likely to be confident with social media tools.

Cronbach alpha for the items in the confidence scale including all 11 items was .92. The inter-item correlations ranged between 0.21 and 0.78 indicating that there were no redundant items.

Usefulness

Using a 5-point Likert scale, 13 items were asked regarding perceived usefulness of social networks, regardless of whether the respondent currently used social networks, for aspects such as training purposes, keeping in touch with other trainees, job networking, and social support (Table 3).

The question "keeping in touch with other registrars" was the only item to show a significant difference between registrars and supervisors (*P*=.002). On review of the result, it was decided that the question was confusing because supervisors were being asked to value the usefulness of keeping in touch with other registrars, for which they have little need, as opposed to keeping in touch with other supervisors. Because of the confusing nature of the question, it was discarded from the subsequent factor analysis. Factor analysis of the remaining 12 items revealed a single factor (Cronbach alpha=.96; eigenvalue= 8.3) labeled *usefulness*. Overall usefulness was scored positively (n=123, mean 3.63, SD 0.74), and was not significantly associated with age or training level. Usefulness was not significantly correlated with computer confidence, but was significantly correlated with social media tool confidence (*r*=0.27, *P*=.02).

Barriers to Use

A number of barriers to using social networks for work were described. The main concerns were worries about privacy (registrar: 61/81, 75.3%; supervisor 30/50, 60.0%) and insufficient time (registrar: 41/81, 50.6%; supervisor: 36/50, 72.0%; see Table 4). Factor analysis was not performed as these barriers were categorical questions.

Intention to Use

An important aim of the survey was to assess whether doctors would use a social network for training purposes. Respondents were asked whether they would use a private network or an open network, such as Facebook, for work purposes or social purposes.

Respondents differed in their intentions to use private as compared with open networks. All respondents were significantly more likely to use a private network for work purposes compared to using an open network for work purposes (*P*<.001). On subgroup analysis, both registrars and supervisors were more likely to use a private network for work purposes than an open network (*P*<.001), but registrars were more likely to use a private network for work purposes than supervisors (*P*<.001). Both registrars and supervisors were equally likely to use an open or private network for social purposes (Table 5).

To investigate which factors had an independently predictive value for the outcome "I would use a private network for work and training purposes," a multivariate generalized linear regression model was developed using private work as the dependent variable. To inform this model, multiple correlations and *t* tests were performed to identify individual factors that correlated with the intention to use a private network for work and training purposes (Table 6). These factors were then entered into the regression model as independent factors.

In the initial model, age was not independently predictive, whereas training level was predictive. Given that training level is related to age, the subcategories of training status were analyzed in the model.

The final model was significant (R^2=.365). In the final model, controlling for other factors, training level was an independently significant predictor of intention to use a private network for work and training. The beta coefficient fell as training level rose, showing the most significant predictor was early training stage, declining as registrars progressed through training. Concerns about privacy and time were negatively predictive, whereas security concerns were nonsignificant. Usefulness was independently predictive of use of a private network for work and training purposes. Confidence was not statistically significant (*P*=.06; see Table 7).

Table 2. Means and standard deviations for confidence using Internet-based applications and services.

Item and group[a]	n	Mean	SD	t_{129}	*P*	95% CI	
						LL	UL
Discussion forums				2.05	.04	0.01	0.82
Registrars	81	3.40	1.02				
Supervisors	50	2.98	1.29				
Wikis				4.21	<.001	0.44	1.21
Registrars	81	3.22	1.07				
Supervisors	50	2.60	1.11				
Blogs				2.68	.008	0.14	0.91
Registrars	81	3.12	1.02				
Supervisors	50	2.60	1.20				
Online communities (eg, Facebook)				4.17	<.001	0.46	1.30
Registrars	81	3.48	1.22				
Supervisors	50	2.60	1.23				
Online chat/instant messaging				3.98	<.001	0.40	1.27
Registrars	81	3.46	1.22				
Supervisors	50	2.62	1.24				
Online video				3.60	<.001	0.34	1.13
Registrars	81	3.69	1.01				
Supervisors	50	2.96	1.26				
Twitter				1.32	.19	–0.12	0.59
Registrars	81	2.56	1.04				
Supervisors	50	2.32	0.91				

[a] Likert scale: 1=strongly disagree, 2=disagree, 3=neither agree nor disagree, 4=agree, 5=strongly agree.

Table 3. Responses of registrars and supervisors about the usefulness of social networks.

Item and group[a]		n	Mean	SD
Training purposes				
	Registrars	80	3.60	1.01
	Supervisors	49	3.43	0.82
Keeping in touch with other registrars				
	Registrars	80	4.11	0.83
	Supervisors	48	3.69	0.55
An extra way of interacting with current supervisors				
	Registrars	79	3.37	1.12
	Supervisors	49	3.61	0.76
A way of interacting with previous supervisors/other clinical mentors				
	Registrars	79	3.61	0.93
	Supervisors	49	3.63	0.57
Job networking				
	Registrars	80	3.61	0.95
	Supervisors	49	3.59	0.65
Staying in touch with people				
	Registrars	79	3.96	0.86
	Supervisors	49	3.78	0.65
Social support from peers				
	Registrars	80	3.60	0.99
	Supervisors	49	3.63	0.67
Professional support from peers				
	Registrars	80	3.60	0.99
	Supervisors	49	3.63	0.10
Professional support from supervisors				
	Registrars	80	3.40	1.06
	Supervisors	49	3.63	0.71
A knowledge resource for solving clinical problems with the help of other clinicians				
	Registrars	79	3.58	1.01
	Supervisors	49	3.47	0.82
A way of sharing useful resources with colleagues				
	Registrars	80	3.81	0.94
	Supervisors	49	3.63	0.67
A forum for expressing or hearing opinions on clinical and political topics				
	Registrars	80	3.64	0.98
	Supervisors	49	3.65	0.72
A resource of useful learning tools (eg, video tutorials)				
	Registrars	80	3.86	0.92
	Supervisors	48	3.65	0.76
Other				
	Registrars	24	3.13	0.68
	Supervisors	14	3.50	0.76

[a] Likert scale: 1=strongly disagree, 2=disagree, 3=neither agree nor disagree, 4=agree, 5=strongly disagree.

Table 4. Perceived difficulties in using online social networks for professional purposes.

Difficulty	Registrars, n (%) n=81	Supervisors, n (%) n=50
Worried about privacy	61 (75.3)	30 (60.0)
Insufficient time	41 (50.6)	36 (72.0)
Worried about security	39 (48.1)	19 (38.0)
Not sure how to use them	22 (27.2)	20 (40.0)
Not interested	12 (14.8)	17 (34.0)
Technical Issues	23 (28.4)	9 (18.0)
Lack of other colleagues known to use them	27 (33.3)	22 (44.0)
Other	4 (4.9)	4 (8.0)

Table 5. Private versus open network usage among registrars and supervisors.

Item and group		Open mean (SD)	Private mean (SD)	*P*
Work				
	All	2.09 (0.97)	3.57 (0.93)	<.001
	Registrars	2.2 (0.99)	3.85 (0.77)	<.001
	Supervisors	1.9 (0.90)	3.16 (0.97)	<.001
Social purposes				
	Registrars	3.21 (1.30)	3.19 (1.10)	.85
	Supervisors	2.40 (1.35)	2.62 (1.05)	.25

Table 6. Factors correlated with the intention to use a private network for work or training purposes.

Factor	Significance (*P*)
Training level: supervisor or registrar	<.001
Rural versus urban	.42
Age	.01
Confidence (computer + social)	.03
Usefulness	.03
Concern about privacy	.11
Concern about time	.004
Concern about security	.82
Not sure how to use	.61
Uses Facebook	.24
Gender	.07

Table 7. Intention to use a private network for work purposes.

Factor	Beta	SE	t_1	*P*	95% CI		Effect size[a]
					LL	UL	
Privacy	–0.382	0.166	–2.296	.02	–0.711	–0.052	0.046
Time	0.561	0.149	3.765	<.001	0.266	0.856	0.115
Confidence: social and computer	0.211	0.111	1.901	.06	–0.009	0.431	0.032
Age	0.008	0.010	0.763	.45	–0.012	0.028	0.005
Usefulness	0.318	0.095	3.327	.001	0.128	0.507	0.092
Basic registrar	1.371	0.346	3.963	<.001	0.685	2.056	0.126
Advanced registrar	0.998	0.390	2.558	.01	0.225	1.771	0.057
Subsequent registrar	0.884	0.346	2.550	.01	0.197	1.570	0.056
Supervisor	0.693	0.298	2.321	.02	0.101	1.284	0.047
Medical educator	0[a]						

[a] Measured by partial eta squared.

Discussion

Principal Findings

The purpose of this study was to assess whether general practice registrars and supervisors in Australia would use a VCoP in the form of a private online network for training purposes and what factors are important in this decision. The results demonstrate that doctors in this sample have the access and interest needed to use a VCoP. High levels of access to computers and the Internet were coupled with overall high computer confidence. Although computer confidence was high, confidence using social media tools was lower and varied significantly between registrars and supervisors, and between applications. Confidence was also found to be related to training stage and age, but given that training stage and age are related, it was interesting to see in the regression that training stage became significant but age did not. This is in-line with previous findings that age is not a significant predictor of physicians' use of social media [20]. Therefore, the most receptive group of doctors may be those at a more junior training stage, rather than those who are the youngest.

Confidence was found to correlate with intention to use an online community, but did not reach significance in the generalized linear regression. This may be because confidence overlaps with training stage and, thus, it is the training stage that is the greatest predictor with confidence of secondary importance. However, confidence may still be worth considering when in the implementation of a virtual community. A study from the United Kingdom showed high levels of interest in social media among British doctors, but low levels of usage, with the authors concluding training as a potential gap [21]. This suggests that a lack of training or exposure results in a lack of confidence.

In spite of good levels of access and confidence, overall use of social media for work purposes was low. This is in contrast to a recent study in the United States that showed a high uptake of social media tools, in particular physician-only communities, with 52% of respondents using online communities, such as Sermo or Ozmosis [20]. This contrast may reflect a more mature market in the United States with a longer history of online communities. In the United States, the largest online community launched in 2006 and now has more than 125,000 members, whereas in Australia serious online medical communities only began to appear in 2010.

Perceived usefulness is another important predictor of use of an online community in this study. Initially it was thought that respondents' levels of perceived usefulness and intention to use an online community could be covariate, but this was not the case and usefulness was an independent predictor of intention to use an online community. This is in keeping with findings of 2 studies of use and intention to use social media among health care professionals, and previous studies on technology acceptance [20,22,23]. The Technology Acceptance Model was developed to describe the most significant predictors of technology use in the general community. The most significant was perceived usefulness of the technology [23]. In a US study of physician social media usage, physicians with a higher perception of usefulness of technology overcame their barriers to use [20], and in Canada, participants in a stroke knowledge transfer planning study expressed high levels of perceived usefulness of social media tools for stroke knowledge exchange [22]. The authors of the Canadian stroke study perceived a higher level of usefulness for rural users, but respondents in their study did not support this, consistent with the finding in the current study that rurality was nonsignificant. It may be that rural users are seen as the beneficiaries of online knowledge sharing tools, and this has been the case in other studies, for example, knowledge sharing among emergency medicine workers in Canada [23]. One reason for the difference may be that general practice registrars can experience structural isolation as a result of working in small practices with less professional contact than hospital workers, in urban as well as rural environments [1]; conversely, as in the Canadian stroke study, respondents may already have strong established local networks [22]. Perceived usefulness is also important because it is potentially modifiable through training and promotion of the potential benefits of an online community to its users.

Finally, barriers are important to address. In this study, time and concerns about privacy were important negative predictors of use, but concerns about security were not significant. This may have been because of a lack of understanding of the difference between privacy and security, or a lack of concern about security, or a higher value being placed on personal or patient confidentiality than computer security. In contrast to these possible concerns, in the Canadian stroke study, participants did not express particular concern regarding patient confidentiality in online exchanges [22]. Once again, this may be due to a more evolved North American market with more experience in online exchanges, as the participants were said to be "fully aware that written communication within a Web platform must ensure confidentiality and respect ethics rules" [22]. Time as a barrier correlates with the findings of the recent Canadian stroke study [22], and a number of previous studies on health professional use of VCoPs [24,25]. It is a difficult factor to modify. However the US physician Web 2.0 study found that in spite of a high perception of barriers, if usefulness and ease of use are taken into account, usage is still high [20]. Thus, the barrier of time needs to be recognized and addressed with training and promotion on potential usefulness.

Ease of use of a network is another important consideration [23]. The preference among doctors for a private network compared with an open network for work and training purposes was significant and most likely related to privacy concerns. This is supported by their lack of preference for a private network when using an online network for social purposes in which patient confidentiality is not an issue. Importantly, previous work has expressed concern that private networks may have an effect on decreasing ease of use by introducing the need for passwords [22]. Given the importance among respondents of a private network, ease of use may be able to be addressed through technical and training avenues, such as the use of a current password (ie, integrating the network with a current training platform), the ability to "remember me," and easy retrieval of lost passwords.

The findings from this study can be looked at in terms of the proposed Health VCoP framework presented in the recent literature review of VCoPs in general practice training [8]. In that framework, elements of Probst and Borzillo's [9] recognized business VCoP framework were modified for the health sector based on the current literature. The framework consists of 7 factors (see Textbox 1), including facilitation, champion and support, objectives and goals, a broad church, a supportive environment, measurement benchmarking and feedback, technology, and community. In the current study, in the broad church category, it seems that not only does a network need to engage users with varying abilities (eg, registrars and supervisors), registrars may actually be more likely to engage than general practice supervisors. In the technology and community category, training is an important factor when implementing a VCoP. As well as focusing on technical training, training could include promoting usefulness and confidence in using the online network, as well as addressing the barriers of time and privacy. This is consistent with findings from a US physician study in which barriers were perceived, but they were overcome if usefulness was perceived to be high [20]. This promotion of usefulness may also be a role for the facilitator. Facilitators can make sure that users are engaged, are realizing the potential of the site, that feedback is responded to, and that necessary changes are made to the site in response to feedback and usage. A facilitator can also grow the community by monitoring and ensuring the usefulness of the site for both active and passive users, as the health framework proposes that both groups are valuable to the community. Finally, if a general practice training network were to be considered, concerns about privacy would need to be addressed through design (eg, password authentication). The resulting usage barrier would need to be offset by appropriate design to ensure ease of access on the password-protected site.

Textbox 1. Health virtual community of practice framework based on Barnett et al [8].

1. Facilitation

- Facilitators promote engagement and maintain community standards

2. Champion and support

- The network needs to have an initial stakeholder champion, with stakeholder support

3. Objectives and goals

- Clear objectives provide members with responsibilities and motivates them to contribute more actively

4. A broad church

- Consider involving different overlapping, but not competing, professional groups, different organizations, and external experts. However, make sure the church is not too broad

5. Supportive environment

- Health VCoPs should promote a supportive and positive culture that is both safe for members and encouraging of participation

6. Measurement, benchmarking, and feedback

- Health VCoPs should consider measurement as a factor in their design, including benchmarking and feedback

7. Technology and community

- Online CoPs should ensure ease of use and access, along with asynchronous communication. Other options including chat and meetings can also be considered, along with the need for training
- Communities are more likely to share knowledge when there is a mixture of online and face-to-face meetings, members self-select, and both passive and active users are encouraged

Limitations

There are a number of limitations in this study. One limitation is that users self-selected to answer a survey on computing and social media by clicking a link in an email to an online survey. The resulting self-selection bias may therefore overreport computer confidence across the whole general practice registrar and supervisor population in the chosen training region. However, it should be noted that the levels of user confidence reported in this study are in keeping with, if not lower, than that found in other recent research [20]. Another limitation is that the response rate was much higher among registrars than supervisors, which may make the results for supervisor responses potentially less representative. Further research on the attitudes of supervisors is needed.

Conclusions

General practice training can be isolating in Australia. Registrars move from a hospital environment with many colleagues, often in large urban centers, to small practices in urban and rural areas with fewer colleagues. The resulting structural, professional, and social isolation is one of the problems that can lead registrars to consider reducing working hours and moving away from rural work. The Australian general practice workforce is already under pressure, and if isolation can be addressed, this has positive implications for quality of primary care delivery and retention of a rural workforce.

Virtual communities of practice are an effective means of overcoming professional isolation in the business sector and show promise in the health sector. They can overcome isolation by providing a vehicle for knowledge sharing and social interaction. This study shows that general practice registrars and supervisors, in particular registrars, have the access, confidence, and interest to use a VCoP for work and training purposes. The main drivers for use appear to be perceived usefulness and a more junior training stage, with a suggestion that current computer and social media confidence is also beneficial. Barriers to use such networks include time and privacy.

These findings fit with some of the aspects of the Barnett et al [8] health VCoP framework (see Textbox 1). In particular, they provide some pointers for implementing a VCoP for general practice training. Given their high interest and confidence, general practice registrars may be the easiest group with which to pilot such a network. In doing so, consideration needs to be given to design, maximizing ease of use, while barriers around time and privacy are addressed through training and promotion. Lastly, despite some apparent barriers, if adequate consideration is given to promotion and training to demonstrate usefulness, these barriers may well be overcome.

Acknowledgments

The authors would like to thank Coast City Country General Practice Training for funding support for this study. The assistance of Laura Robinson and Lance Barrie is also much appreciated.

Conflicts of Interest

Stephen Barnett is the Medical Director and part owner of E-Healthspace, an online community for Australian doctors.

References

1. Larkins SL, Spillman M, Parison J, Hays RB, Vanlint J, Veitch C. Isolation, flexibility and change in vocational training for general practice: personal and educational problems experienced by general practice registrars in Australia. Fam Pract 2004 Oct;21(5):559-566 [FREE Full text] [doi: 10.1093/fampra/cmh513] [Medline: 15367479]
2. Cooper CD, Kurland NB. Telecommuting, professional isolation, and employee development in public and private organizations. J. Organiz. Behav 2002 Jun 2002;23(4):511-532. [doi: 10.1002/job.145]
3. Williams ES, Konrad TR, Scheckler WE, Pathman DE, Linzer M, McMurray JE, et al. Understanding physicians' intentions to withdraw from practice: the role of job satisfaction, job stress, mental and physical health. Health Care Manage Rev 2001;26(1):7-19. [Medline: 11233355]
4. Weiss RS. Loneliness: The Experience of Emotional and Social Isolation. Cambridge, MA: MIT Press; 1973.
5. Larkins SL, Spillman M, Vanlint JW, Hays RB. Stress, personal and educational problems in vocational training. A prospective cohort study. Aust Fam Physician 2003 Jun;32(6):473-5, 480. [Medline: 12833779]
6. Thomson JS, Anderson KJ, Mara PR, Stevenson AD. Supervision--growing and building a sustainable general practice supervisor system. Med J Aust 2011 Jun 6;194(11):S101-S104. [Medline: 21644851]
7. Campbell DG, Greacen JH, Giddings PH, Skinner LP. Regionalisation of general practice training--are we meeting the needs of rural Australia? Med J Aust 2011 Jun 6;194(11):S71-S74. [Medline: 21644857]
8. Barnett SR, Jones SJ. General practice training and virtual communities of practice - a review of the literature. BMC Family Practice 2012;13:87. [doi: 10.1186/1471-2296-13-87]
9. Probst G, Borzillo S. Why communities of practice succeed and why they fail. European Management Journal 2008 Oct 2008;26(5):335-347. [doi: 10.1016/j.emj.2008.05.003]
10. Wenger E. Communities of Practice: Learning Meaning and Identity. Cambridge, UK: Cambridge University Press; 1998.
11. Lave J, Wenger E. Situated Learning: Legitimate Peripheral Participation. Cambridge, UK: Cambridge University Press; 1991.
12. Wenger E. Communities of practice and social learning systems. Organization 2000 May 2000;7(2):225-246. [doi: 10.1177/135050840072002]
13. Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. J Med Internet Res 2008;10(3):e22 [FREE Full text] [doi: 10.2196/jmir.1030] [Medline: 18725354]
14. Boulos MN, Maramba I, Wheeler S. Wikis, blogs and podcasts: a new generation of Web-based tools for virtual collaborative clinical practice and education. BMC Med Educ 2006;6:41 [FREE Full text] [doi: 10.1186/1472-6920-6-41] [Medline: 16911779]
15. McLean R, Richards BH, Wardman JI. The effect of Web 2.0 on the future of medical practice and education: Darwikinian evolution or folksonomic revolution? Med J Aust 2007 Aug 6;187(3):174-177. [Medline: 17680746]
16. Poissant L, Ahmed S, Riopelle RJ, Rochette A, Lefebvre H, Radcliffe-Branch D. Synergizing expectation and execution for stroke communities of practice innovations. Implement Sci 2010;5:44 [FREE Full text] [doi: 10.1186/1748-5908-5-44] [Medline: 20529305]
17. Paton C, Bamidis PD, Eysenbach G, Hansen M, Cabrer M. Experience in the use of social media in medical and health education: contribution of the IMIA Social Media Working Group. Yearb Med Inform 2011;6(1):21-29. [Medline: 21938320]
18. Johnson CM. A survey of current research on online communities of practice. The Internet and Higher Education 2001 Jan 2001;4(1):45-60. [doi: 10.1016/S1096-7516(01)00047-1]
19. SurveyMonkey. URL: http://www.surveymonkey.com/ [accessed 2013-04-24] [WebCite Cache ID 6G7TFbsID]
20. McGowan BS, Wasko M, Vartabedian BS, Miller RS, Freiherr DD, Abdolrasulnia M. Understanding the factors that influence the adoption and meaningful use of social media by physicians to share medical information. J Med Internet Res 2012;14(5):e117 [FREE Full text] [doi: 10.2196/jmir.2138] [Medline: 23006336]
21. Sandars J, Schroter S. Web 2.0 technologies for undergraduate and postgraduate medical education: an online survey. Postgrad Med J 2007 Dec;83(986):759-762 [FREE Full text] [doi: 10.1136/pgmj.2007.063123] [Medline: 18057175]
22. David I, Poissant L, Rochette A. Clinicians' expectations of web 2.0 as a mechanism for knowledge transfer of stroke best practices. J Med Internet Res 2012;14(5):e121 [FREE Full text] [doi: 10.2196/jmir.2016] [Medline: 23195753]
23. Davis FD, Bagozzi RP, Warshaw PR. User acceptance of computer technology: a comparison of two theoretical models. Management Science 1989 Aug 1989;35(8):982-1003. [doi: 10.1287/mnsc.35.8.982]

24. Curran JA, Murphy AL, Abidi SS, Sinclair D, McGrath PJ. Bridging the gap: knowledge seeking and sharing in a virtual community of emergency practice. Eval Health Prof 2009 Sep;32(3):312-325. [doi: 10.1177/0163278709338570] [Medline: 19696084]
25. Nagy P, Kahn CE, Boonn W, Siddiqui K, Meenan C, Knight N, et al. Building virtual communities of practice. J Am Coll Radiol 2006 Sep;3(9):716-720. [doi: 10.1016/j.jacr.2006.06.005] [Medline: 17412156]

Abbreviations

CoP: community of practice
VCoP: virtual community of practice

Edited by G Eysenbach; submitted 29.01.13; peer-reviewed by C Paton, F Ikioda; comments to author 21.02.13; revised version received 13.03.13; accepted 26.03.13; published 10.05.13.

Please cite as:
Barnett S, Jones SC, Bennett S, Iverson D, Bonney A
Perceptions of Family Physician Trainees and Trainers Regarding the Usefulness of a Virtual Community of Practice
J Med Internet Res 2013;15(5):e92
URL: http://www.jmir.org/2013/5/e92/
doi:10.2196/jmir.2555
PMID:23666237

Original Paper

Prevalence of Behavior Changing Strategies in Fitness Video Games: Theory-Based Content Analysis

Elizabeth Jane Lyons[1], PhD, MPH; Claire Hatkevich[2]

[1]Institute for Translational Sciences, School of Medicine, University of Texas Medical Branch, Galveston, TX, United States

[2]Department of Psychology, University of Delaware, Newark, DE, United States

Corresponding Author:
Elizabeth Jane Lyons, PhD, MPH
Institute for Translational Sciences
School of Medicine
University of Texas Medical Branch
301 University Blvd.
Galveston, TX, 77555-0342
United States
Phone: 1 409 772 1917
Fax: 1 409 772 1968
Email: ellyons@utmb.edu

Abstract

Background: Fitness video games are popular, but little is known about their content. Because many contain interactive tools that mimic behavioral strategies from weight loss intervention programs, it is possible that differences in content could affect player physical activity and/or weight outcomes. There is a need for a better understanding of what behavioral strategies are currently available in fitness games and how they are implemented.

Objective: The purpose of this study was to investigate the prevalence of evidence-based behavioral strategies across fitness video games available for home use. Games available for consoles that used camera-based controllers were also contrasted with games available for a console that used handheld motion controllers.

Methods: Fitness games (N=18) available for three home consoles were systematically identified and play-tested by 2 trained coders for at least 3 hours each. In cases of multiple games from one series, only the most recently released game was included. The Sony PlayStation 3 and Microsoft Xbox360 were the two camera-based consoles, and the Nintendo Wii was the handheld motion controller console. A coding list based on a taxonomy of behavioral strategies was used to begin coding. Codes were refined in an iterative process based on data found during play-testing.

Results: The most prevalent behavioral strategies were modeling (17/18), specific performance feedback (17/18), reinforcement (16/18), caloric expenditure feedback (15/18), and guided practice (15/18). All games included some kind of feedback on performance accuracy, exercise frequency, and/or fitness progress. Action planning (scheduling future workouts) was the least prevalent of the included strategies (4/18). Twelve games included some kind of social integration, with nine of them providing options for real-time multiplayer sessions. Only two games did not feature any kind of reward. Games for the camera-based consoles (mean 12.89, SD 2.71) included a greater number of strategies than those for the handheld motion controller console (mean 10.00, SD 2.74, *P*=.04).

Conclusions: Behavioral strategies for increasing self-efficacy and self-regulation are common in home console fitness video games. Social support and reinforcement occurred in approximately half of the studied games. Strategy prevalence varies by console type, partially due to greater feedback afforded by camera-based controllers. Experimental studies are required to test the effects of these strategies when delivered as interactive tools, as this medium may represent an innovative platform for disseminating evidence-based behavioral weight loss intervention components.

(J Med Internet Res 2013;15(5):e81) doi:10.2196/jmir.2403

KEYWORDS

video game; theory; content analysis; fitness; physical activity; exergame

Introduction

Insufficient physical activity and poor dietary habits contribute to obesity [1-3], which in turn contributes to numerous negative health outcomes [4,5]. The current and persistent high prevalence of obesity in the United States [6] will require innovative solutions to this seemingly intractable problem.

A potential platform for those solutions is the video game console. Due to their popularity and potential for influencing health, fitness-themed video games have recently attracted substantial research attention [7-13]. Fitness games are a subset of motion-controlled or "active" games that specifically emphasize fitness/exercise content, extending the traditional format of workout videos by increasing their interactivity. For example, the games may allow players to adjust their difficulty level and choose preferred exercises. Because the games use motion-sensing controllers, they also allow for feedback on user performance. Studies of fitness games have found that they are capable of producing a range of energy expenditure values, from light to vigorous intensity physical activity [14-19]. Though these games mostly are targeted towards and appeal to middle-aged women [20], they appear to be acceptable across a range of ages and in both genders [11,13,17,21].

Little is known about their content and how differences in content may affect player behavior. Specifically, many fitness games include interactive behavioral tools. These tools typically use strategies that are hallmarks of successful weight loss interventions such as modeling and goal-setting [22-26]. There is evidence that increased use of behavioral strategies can improve the outcomes of weight loss trials [27,28], but programs that use these strategies are quite costly [29]. Using interactive technological tools to deliver behavioral weight loss interventions has been shown to be less costly and as or more efficacious [30]. Video-game based tools may offer an opportunity to deliver portions of clinical weight loss programs in settings previously unable to receive them due to cost.

Behavioral Strategies to Enhance Self-Efficacy

Standard behavioral weight loss interventions typically include a large number of strategies aimed at behavior change. Recent meta-analyses and meta-regressions have identified several strategies that appear to be particularly effective for promoting weight loss and physical activity [25,31]. Many of these strategies target increases in self-efficacy, or confidence in one's ability to perform a specific course of action, which is strongly related to beneficial weight loss intervention effects.

A strategy from face-to-face interventions used commonly in video games is modeling, also called observational learning or vicarious experience. In this strategy, an individual is observed while performing targeted activities; the player learns how to perform the activities by watching the model. Models can be computer-generated agents such as virtual trainers, or they can be representations of the player him/herself in video or computer-generated avatar form. Virtual self-modeling using video or avatars may be particularly powerful. Several studies have found that watching a virtual self eat or exercise (as compared to watching a virtual other) can affect later real-world eating and exercise [32,33].

Another very common strategy with proven effectiveness is provision of feedback on performance [25]. One of the benefits of technology-based intervention is that feedback on performance and progress can be provided automatically and immediately. Both general (calorie burn, number of sessions completed) and specific (accuracy of individual exercises) feedback may be provided by a fitness video game. Some camera-based games also provide players with visual feedback in the form of real-time video footage of their movements.

Both modeling and feedback can be integrated with guided practice, also known as guided mastery. Guided practice provides a chance for an individual to practice enacting a skill while receiving instruction. In fitness video games, guided practice may consist of players simultaneously receiving instruction, watching a model perform a set of exercises, enacting the movements themselves, and receiving feedback on the accuracy of their practice movements. Verbal persuasion as to the player's competence (ie, encouragement) may also be integrated with these strategies. Verbal persuasion can occur during exercise ("You can do it!") or afterward as part of evaluative feedback ("Good job, you really have a knack for this.").

Behavioral Strategies to Enhance Self-Regulation

Self-regulation is often used synonymously with self-control and encompasses self-corrective adjustments towards some purpose [34]. Self-regulation strategies are also central to behavior change interventions. In fact, self-regulation strategies such as self-monitoring of caloric intake, physical activity, and weight are among the strongest predictors of weight loss [22]. Strategies that influence self-regulation may include self-monitoring, goal-setting, action planning, and self/social comparison.

Many current fitness video games track physical activity frequency, duration, and caloric expenditure. Some also track weight (via use of a balance board controller) and fitness (via heart rate and/or number of repetitions during periodic fitness tests). This information is typically provided as graphs, progress bars, and leaderboards. Players may also earn achievements or trophies (ie, virtual badges) for reaching caloric expenditure or frequency cut-points. These tracking systems are more sophisticated than physical activity self-monitoring in typical weight loss interventions, which is often self-reported. Automated measurement and feedback from monitoring systems similar to these have been found to be very effective in weight loss trials [35-37].

Goal-setting provides a framework for self-monitoring and feedback, which are specific to a particular goal (eg, eating 1500 calories per day). Goals can also influence performance in multiple ways, including via motivating greater effort and by directing effort towards task-relevant activities [38]. Goals can be integrated with other strategies to enhance their effectiveness; for example, successful attainment of subgoals could be reinforced by a reward system. Action planning to reach the goals may include creating weekly schedules for play sessions, choosing from suggested content for each session, and following preset guidelines (eg, a 30-day challenge). Diagnostic pretests can be used in interactive media to determine an individual's current level of fitness, set proximal and distal goals, and set a time frame for accomplishing those goals. These pretests collect information for use in tailoring later content much like baseline assessments and initial individual sessions would in a face-to-face intervention.

Comparison is also an important component of feedback that affects self-monitoring. By viewing workout calendars and graphs of progress, individuals can compare their current performance to past performance. Inclusion of multiplayer graphs and leaderboards allow individuals to compare their performance to that of other individuals. Monitoring one's progress and comparing it to benchmarks allows individuals to quickly adapt their behavior (eg, exercising more on a day in which calorie intake goals were not met). Comparison is also very effective in increasing self-efficacy for exercise [25].

Other Social-Cognitive Behavioral Strategies: Reinforcement and Social Integration

Several additional behavioral strategies used in weight loss studies may be implemented in fitness video games, such as reinforcement and social integration. Reinforcement is a key feature of video games that is also used in fitness video games. These games may include in-game and/or console-based rewards. In-game rewards typically are virtual badges of some kind that are achieved by reaching preset goals. These badges may also be tied to unlocking new parts of the game, such as new environments, music, or exercises. Console-based rewards are also virtual badges, but these are tied to an individual's online account and are visible to others on online game services. In addition to serving as rewards and indicators of progress, these virtual badges (called achievements on Xbox Live and trophies on PlayStation Network) also indicate group affiliations and individual status by displaying to others what games individuals play and how they play them. It has been hypothesized that virtual badges may be more motivating when they serve these additional social purposes [39,40], and thus console-based rewards should be considered separately from in-game awards.

Other methods of integrating social support and influence may also affect physical activity and weight loss behaviors. Social support from family, friends, and other participants is often a feature of in-person and Internet-mediated programming. Social play is also one of the major uses and gratifications of video game play [41]. Generalized social integration may include leaderboards or asynchronous multiplayer play (eg, trying to beat a previous high score). Synchronous multiplayer features allow players to cooperatively or competitively play with one another at the same time either in-person or over the Internet. Because feelings of relatedness to others are central to intrinsic motivation (the desire to engage in a behavior for its own sake in the absence of external pressures/rewards) [42], more social play options may produce greater adherence to use of the game.

Behavioral Strategies and Active Video Games

Though we are unaware of any studies of behavioral strategies in commercially available video games, these strategies have been used in technology-enhanced interventions using activity monitors, PDAs, and mobile phones. Some activity monitoring systems provide detailed graphs and leaderboards to show progress over time and in comparison to others (eg, *BodyMedia*, *FitBit*). Several studies have found that technology-enhanced self-monitoring produces greater adherence and thus greater intervention effects when compared to traditional paper self-monitoring [43-45]. Thus, more than simply encouraging greater energy expenditure during screen time, fitness video games hold the potential for intervening on intermediate psychosocial variables that affect weight. There is a need for a better understanding of the prevalence of game tools incorporating these strategies.

The purpose of this study was to characterize currently available fitness games based on the prevalence of interactive tools using behavioral strategies from successful weight loss interventions. A secondary goal was to compare behavioral tools across two different types of consoles—those that use camera-based controllers and those that use handheld controllers. We hypothesized that games for the camera-based consoles would include more behavioral strategies than those available for a handheld controller-based console. Camera-based controls may allow for the use of more types of strategies because they can measure player movement more precisely and provide video feedback.

Methods

Console and Controller Descriptions

The three major home consoles for video game play (as of August, 2012) are the Microsoft Xbox 360, Nintendo Wii, and Sony PlayStation 3. Each console uses a different method of evaluating player movement during play of fitness video games.

The Xbox 360 uses its Kinect peripheral, which is a camera that analyzes body movement with no need for handheld controllers. Because the Kinect is camera-based, it allows for still pictures and videos to be used by game software. Real-time video of player movement can be shown on the screen and integrated into game scenes.

The Wii uses two handheld controllers (Wiimote and Nunchuk) and a balance board to evaluate player movement. Different games use different combinations and configurations of these three controllers to measure arm, leg, and body movement. The balance board can detect shifts in weight, allowing it to be used for weigh-ins as well.

The PlayStation 3 uses the PlayStation Eye and Move peripheral devices. The Eye is a camera, and the Move controllers are similar to Wiimotes. Thus, this system is a hybrid of the two mentioned above. Still pictures and videos can appear on screen, and the player also holds a tangible controller.

Game Inclusion

A systematic search was conducted to find available fitness games for home consoles. Two of the largest sellers of video games, Amazon.com and Gamestop.com, were searched using four search terms: “fit,” “fitness,” “active,” and “workout” (for Amazon, these searches were conducted specifically within the video game category). After eliminating duplicate entries, a total of 40 unique titles were found. To be included in the analysis, games must have been the most recent game available within a franchise (eg, *Jillian Michaels Fitness Adventure* is the 2012 entry into the Jillian Michaels Fitness franchise), and they must have primarily a fitness focus rather than a party game or minigame collection focus (excluded: games in the Active Life franchise, *Boot Camp*, *Family Party: Fitness Fun*, *Kid Fit Island Resort*, *Nickelodeon Fit*). After excluding multiple games in a franchise, 23 games remained; six were eliminated due to a primary focus as a party/minigame game. To this total of 17 games, an additional game was added. It was deemed that a downloadable fitness pack created sufficient fitness content that *The Fight: Lights Out* could be included. Thus, the final total of games was 18. The preliminary search was conducted in November 2011. A follow-up search was conducted in June 2012 to update franchises to their latest iterations (*Jillian Michaels Fitness Adventure* and *Zumba Fitness Rush* replaced earlier versions of both games). We chose to include *My Fitness Coach* despite the existence of *My Fitness Coach 2* because it was an updated re-release of the Xbox/PC game *Yourself Fitness*, whereas the US release of *My Fitness Coach 2* was a re-branded version of the *New U* series of games.

In cases in which a game was ported to multiple consoles, each version of the game was play-tested. The version that included the highest number of behavioral tools was included in this analysis (for *EA Sports Active 2* and *UFC Personal Trainer*, PlayStation 3 and Wii versions were excluded and the Xbox360 version used; for *Fit in Six* and *Get Fit With Mel B*, Wii versions were excluded and the PlayStation 3 version was used). These games were typically identical across consoles except for slight changes made possible by different controller systems, which allowed inclusion of several behavioral tools (ie, viewing real-time video of the self on the screen).

Included games played on an Xbox 360 console were: *The Biggest Loser: Ultimate Workout*, *EA Sports Active 2*, *Jillian Michaels Fitness Adventure*, *UFC Personal Trainer*, *Your Shape: Fitness Evolved 2012*, and *Zumba Fitness Rush*. Games played on a PlayStation 3 console were: *Fix in Six*, *Get Fit With Mel B*, and *The Fight: Lights Out* (with downloaded Fitness Pack content). Games played on a Nintendo Wii console were: *10 Minute Solution*, *Daisy Fuentes Pilates*, *Exerbeat*, *Gold’s Gym Cardio Workout*, *Gold’s Gym Dance Workout*, *My Fitness Coach*, *New U Fitness First Yoga and Pilates*, *Walk It Out!*, and *Wii Fit Plus*.

Coding List and Procedure

Coding procedures for this study followed both theory-based and grounded theory strategies. The 2 coders began with a coding list based on Abraham and Michie’s taxonomy of behavior change strategies [46] as well as strategies used to increase self-efficacy from Bandura and from the research literature [23,25,31]. Then, using grounded theory, codes were added and adapted throughout the playtesting process to reflect the content of the games [47]. This process was similar to that used in our previous content analyses [48].

A final list of 17 codes is displayed in Table 1. A screenshot from *Your Shape: Fitness Evolved 2012* in Figure 1 shows an example of modeling by a virtual trainer, virtual self-modeling (showing the individual performing the exercise), accuracy feedback (checkmarks in the top corner for each portion of the move performed correctly, green lines superimposed on the body to show how the limbs are bent/straight, glowing body to indicate a “combo” of correct movements in a row), and video of body movement. The body on the left in the screenshot is the virtual trainer, and the body on the right is a real-time video feed of the player. A screenshot from Wii Fit Plus in Figure 2 shows an example of a workout calendar. Additional descriptions of games and screenshots are available in Multimedia Appendix 1.

Each game was play-tested for at least 3 hours by each independent coder. Interrater agreement between the 2 coders was high (0.90). Cohen’s kappa was also calculated to compare coder agreement to chance (κ=.80). The 2 coders met to discuss all disagreements and decide upon appropriate final codes.

Simple descriptive statistics were calculated to investigate the prevalence of strategies in the games. To compare consoles, Student’s *t* tests were used.

Table 1. Code list with descriptions.

	Code	Description
Self-efficacy		
	Modeling by trainer	A virtual trainer performs the exercises to show proper form.
	Virtual self-modeling	An avatar or video of the player's face and body is shown, modeling the exercise behavior.
	Guided practice	A practice or tutorial session led by a trainer is included.
	Verbal persuasion	The virtual trainer verbally encourages greater exercise self-efficacy. ("You can do it!")
	Accuracy feedback	Specific feedback on the accuracy of individual exercises is provided.
	Performance feedback	Overall feedback on player performance during a workout session is provided.
	Calorie burn feedback	Numeric totals for estimated caloric burn are provided.
	Video of body movement	Real-time video is shown on screen (player representation may be a colored shape).
Self-regulation		
	Goal-setting	Players are prompted to set goals for themselves.
	Diagnostic pretest	A pretest is given to help in the selection of appropriate goals, programs, and difficulty.
	Scheduling	Players schedule workout days in advance, either manually or as part of a pre-made program.
	Workout calendar	A calendar is provided that shows a history of game play and, in some cases, upcoming scheduled workouts.
	Comparison to past	Player progress over time is shown in chart form.
Other		
	Social integration	Other players are incorporated into the game in some fashion (eg, leaderboards, asynchronous multiplayer).
	Multiplayer	Individuals can play together with another person at the same time either in person or via the Internet.
	In-game rewards	The game provides virtual rewards for progress.
	Console-based rewards	The game provides achievements or trophies that are shown on the console's online service to other users.

Figure 1. An example of self-efficacy behavioral strategies in Your Shape: Fitness Evolved 2012.

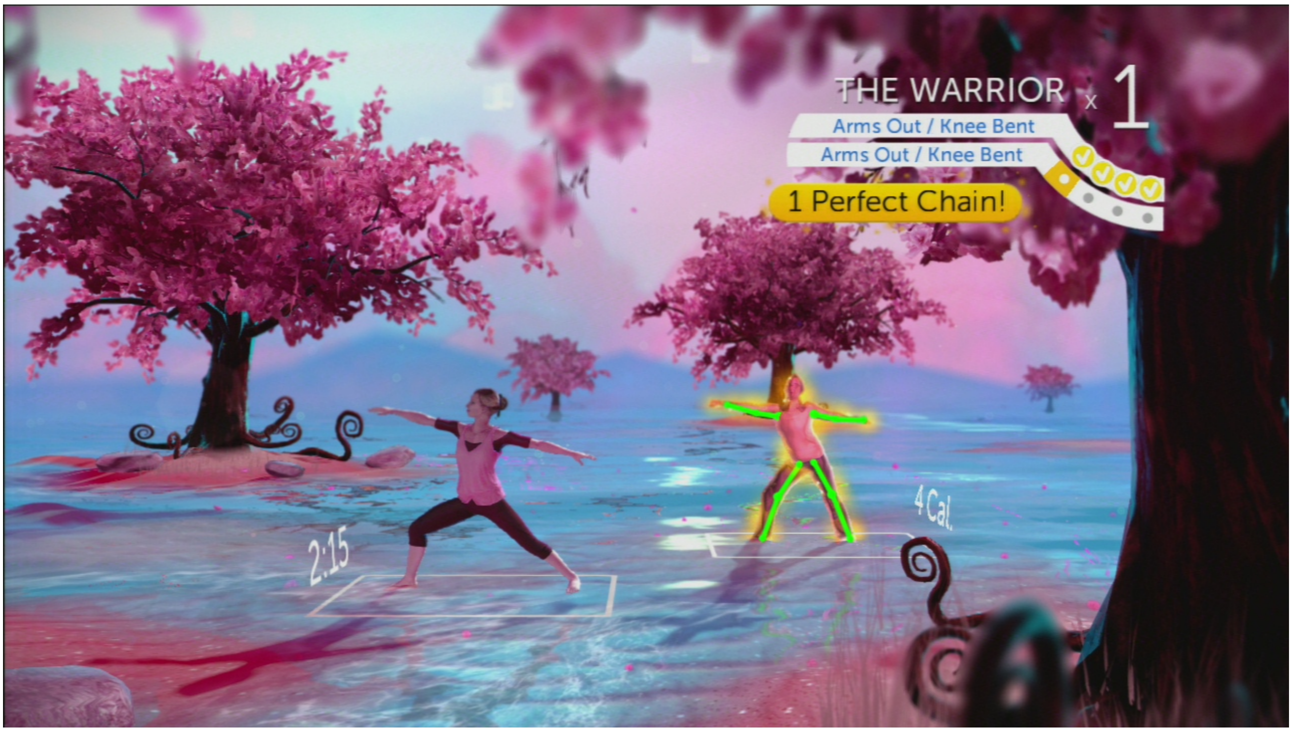


Figure 2. An example of a workout calendar from Wii Fit Plus.

Results

Behavioral strategies found in each game are shown in Multimedia Appendix 2 (camera-based games) and Multimedia Appendix 3 (controller-based games). Feedback comparing current to past behavior (either performance, attendance, or estimated calorie burn) was present in all of the studied games. Modeling (17/18 games), immediate performance feedback (17/18), caloric expenditure feedback (15/18), guided practice (15/18), and a workout calendar (14/18) were included in a majority of the games. All but two of the games (16/18) included some kind of reward system, either directly in the game itself or integrated into a console-wide online virtual badge system. Few games included a pretest (5/18) or the ability to schedule future workouts (4/18).

The number of strategies used in a game were higher in the camera-based games (mean 12.89, SD 2.71) than in controller-based games (mean 10.00, SD 2.74; *P*=.04).

Discussion

Principal Findings

This content analysis demonstrated that interactive behavioral tools for promoting physical activity and weight loss are common in fitness video games for home consoles. Feedback, modeling, rewards, practice, self-monitoring, and reinforcement were the most prevalent strategies. Games that used camera-based controllers (Xbox 360, PlayStation 3) contained more strategies than games that used non–camera-based controllers (Wii).

Reviews and secondary analyses of behavioral weight loss trials suggest that inclusion of self-monitoring [22,26], goal-setting [22,28], action planning [23], reinforcement [23], practice [26,49], and social support and comparison [23,26,49] likely contributes to intervention success. Many fitness video games include behavioral tools that closely mimic the implementation of these behavioral strategies in face-to-face and eHealth settings. Numerous studies have tested fitness video games, but we are unaware of any that have specifically investigated possible effects of their behavioral content. Because these interactive tools closely resemble behavioral strategies used successfully in clinical weight loss interventions, games containing them may hold potential as inexpensive, highly disseminable intervention media.

The public health impact of an intervention can be conceptualized by the RE-AIM framework (Reach, Effectiveness, Adoption, Implementation, Maintenance) [50]. Increasing the reach of clinical weight loss interventions, even if the effectiveness is slightly lowered, could greatly increase their ultimate public health impact. Internet-based studies have successfully translated behavioral weight loss interventions into a more disseminable format while retaining clinically meaningful effectiveness [51]. Additional studies using electronic monitors have shown that technology-assisted self-monitoring and automatic feedback can successfully translate self-regulatory portions of these interventions to nonclinical settings [36,37]. Fitness video games could potentially be a next step in the process of further translation, as they may also be able to use interactive strategies such as virtual self-modeling to increase self-efficacy [11].

Weight loss trials that adhere to theory have been found to be more effective than those that do not [52,53]. Thus, based on theoretical conceptualizations of self-efficacy, we would expect feedback that is immediate, specific, clear, based on goals, and that includes comparisons (both to past performance and to others) to produce greater self-efficacy and physical activity [31]. Fitness video games are capable of offering richer and more extensive feedback than noninteractive exercise instruction via audio or video cues. For example, *Your Shape: Fitness Evolved 2012* superimposes lines on video of the player's arms, trunk, and legs during yoga moves. As the player's body aligns properly for the move, the lines change color to indicate successful performance. Non–camera-based games can also provide in-depth feedback. They typically use the placement of the handheld controller to sense whether actions are being performed precisely and provide numerical (number of repetitions) or qualitative (eg, miss/good/perfect) feedback. By immediately evaluating the precision of the player's movements and encouraging correct form, these games may promote safe and effective home-based exercise.

Behavioral weight loss interventions often include assistive devices that help participants self-monitor progress towards their goals. These devices can include calorie books, diaries, activity monitors, scales, and online monitoring programs [38]. Many of the games studied here could be considered assistive devices, providing extensive feedback on objectively measured activity. Some upcoming games, such as *Wii Fit U*, will also be able to track lifestyle activity by incorporating pedometers.

The games studied here included a wide variety of evidence-based interactive tools. However, some effective strategies were underrepresented. Action planning, operationalized here as scheduling workouts, is associated with increased efficacy [23] but was rarely found in these games. Other, more involved forms of action planning (such as making specific action plans for different types of exercise and for overcoming barriers) were not found. Diagnostic pretests, which could serve as a method of gathering information for goal-setting, action planning, and tailoring programs to individual preferences were also rare.

Games for the camera-based Kinect and Move controllers (for the Microsoft Xbox 360 and Sony PlayStation 3) provided more tools for promoting self-efficacy, self-regulation, and weight loss than games for a console with no camera (Nintendo Wii). By its nature, a camera-based controller allows for more extensive feedback than a handheld controller that uses an accelerometer. These console differences may change with the upcoming next generation of the three major home consoles, however. The Nintendo Wii U will use a tablet-based controller that houses a camera in addition to a touch screen and motion control. Also, two of the game franchises that included the highest number of behavioral strategies, *Your Shape* and *Wii Fit*, will be available for this console. Follow-ups to the PlayStation 3 and/or Xbox 360 may have more technologically sophisticated camera controllers, which could impact the types of motions that can be interpreted by games. In addition, camera-based game apps for mobile devices have also begun to appear. For example, *Bit Breaker* for iOS uses a mobile device's camera to sense movement and map that movement onto a simple, Pong-like game. Many mobile devices include cameras, accelerometers, and GPS, making them an attractive option for future fitness game development. For example, the smartphone game *Zombies, Run!* provides extensive performance feedback on distance and speed for overall workouts and even during specific songs the player listened to during the workout. GPS capabilities of smartphones provide more accurate and sophisticated data than are possible from current consoles. Thus, mobile games may also be a fruitful area for future research into behavioral strategies, particularly feedback.

Limitations

This study represents a first step in identifying and measuring interactive tools in video games that may hold potential for weight loss, but its preliminary nature prevents the drawing of strong conclusions. Because this was a content analysis, we cannot determine from these data whether or not the existence of more behavioral tools in a game is associated with greater effectiveness in promoting weight loss or physical activity. The comparison across console types is also limited by our inclusion criteria, as we specifically included only the version of some games that had the most behavioral tools so as not to compare different console versions of the same game (ie, we did not include the Wii or PlayStation 3 versions of the UFC game, only the Xbox360 version).

Commercial (ie, not based in the home) exergames and mobile exergames were not included in this analysis, nor were active games that did not focus on fitness. Some motion-controlled games are now available for tablets, smartphones, and other consoles (eg, *XaviX*). Further, many nongame applications for smartphones and tablets have been "gamified" and thus, though they are not true video games, they include many game-like aspects (eg, virtual badges, leaderboards). Some nonfitness games also include some integration of fitness content, such as calorie tracking in dance simulation games. These other games and applications and their incorporation of behavioral strategies are worth research attention in the future.

Conclusions

A broad range of fitness video games are available for home use. All of the studied games incorporated at least five behavioral strategies similar to those used in clinical weight loss interventions. It is premature to draw conclusions as to whether games with more behavioral strategies may produce greater physical activity or weight loss; the potential of specific strategies or groups of strategies for increasing the effectiveness of active video games deserves study in both cross-sectional laboratory studies and in randomized controlled trials. There is a need for careful attention to game content prior to the implementation of active games in health promotion programs. Future studies should closely investigate how behavioral tools in fitness video games are used by participants and measure intermediate process and mediating variables to better understand the possible impacts of interactive behavioral tools.

Acknowledgments

Dr. Lyons is supported by a research career development award (K12HD052023: Building Interdisciplinary Research Careers in Women's Health Program – BIRCWH) from the National Institute of Allergy and Infectious Diseases (NIAID), the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), and the Office of the Director (OD), National Institutes of Health. This study was conducted with the support of the Institute for Translational Sciences at the University of Texas Medical Branch, supported in part by a Clinical and Translational Science Award (UL1TR000071) from the National Center for Advancing Translational Sciences, National Institutes of Health.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Brief descriptions and screenshots from all of the included games.

[PDF File (Adobe PDF File), 3MB - jmir_v15i5e81_app1.pdf]

Multimedia Appendix 2

Behavioral strategies in camera-based games.

[PDF File (Adobe PDF File), 42KB - jmir_v15i5e81_app2.pdf]

Multimedia Appendix 3

Behavioral strategies in controller-based games.

[PDF File (Adobe PDF File), 25KB - jmir_v15i5e81_app3.pdf]

References

1. Jakicic JM, Davis KK. Obesity and physical activity. Psychiatr Clin North Am 2011 Dec;34(4):829-840. [doi: 10.1016/j.psc.2011.08.009] [Medline: 22098807]
2. Catenacci VA, Wyatt HR. The role of physical activity in producing and maintaining weight loss. Nat Clin Pract Endocrinol Metab 2007 Jul;3(7):518-529. [doi: 10.1038/ncpendmet0554] [Medline: 17581621]
3. Wu T, Gao X, Chen M, van Dam RM. Long-term effectiveness of diet-plus-exercise interventions vs. diet-only interventions for weight loss: a meta-analysis. Obes Rev 2009 May;10(3):313-323. [doi: 10.1111/j.1467-789X.2008.00547.x] [Medline: 19175510]
4. Wolin KY, Carson K, Colditz GA. Obesity and cancer. Oncologist 2010;15(6):556-565 [FREE Full text] [doi: 10.1634/theoncologist.2009-0285] [Medline: 20507889]
5. Poirier P, Giles TD, Bray GA, Hong Y, Stern JS, Pi-Sunyer FX, et al. Obesity and cardiovascular disease: pathophysiology, evaluation, and effect of weight loss. Arterioscler Thromb Vasc Biol 2006 May;26(5):968-976 [FREE Full text] [doi: 10.1161/01.ATV.0000216787.85457.f3] [Medline: 16627822]
6. Ogden CL, Carroll MD, Kit BK, Flegal KM. Prevalence of obesity in the United States, 2009-2010. NCHS Data Brief 2012 Jan(82):1-8. [Medline: 22617494]
7. Agmon M, Perry CK, Phelan E, Demiris G, Nguyen HQ. A pilot study of Wii Fit exergames to improve balance in older adults. J Geriatr Phys Ther 2011;34(4):161-167. [doi: 10.1519/JPT.0b013e3182191d98] [Medline: 22124415]
8. Baranowski T, Abdelsamad D, Baranowski J, O'Connor TM, Thompson D, Barnett A, et al. Impact of an active video game on healthy children's physical activity. Pediatrics 2012 Mar;129(3):e636-e642 [FREE Full text] [doi: 10.1542/peds.2011-2050] [Medline: 22371457]
9. Yuen HK, Holthaus K, Kamen DL, Sword DO, Breland HL. Using Wii Fit to reduce fatigue among African American women with systemic lupus erythematosus: a pilot study. Lupus 2011 Oct;20(12):1293-1299 [FREE Full text] [doi: 10.1177/0961203311412098] [Medline: 21700656]
10. Owens SG, Garner JC, Loftin JM, van Blerk N, Ermin K. Changes in physical activity and fitness after 3 months of home Wii Fit™ use. J Strength Cond Res 2011 Nov;25(11):3191-3197. [doi: 10.1519/JSC.0b013e3182132d55] [Medline: 21993031]
11. Staiano AE, Abraham AA, Calvert SL. Adolescent Exergame Play for Weight Loss and Psychosocial Improvement: A Controlled Physical Activity Intervention. Obesity (Silver Spring) 2012 Jun 14. [doi: 10.1038/oby.2012.143] [Medline: 22790236]
12. Graves LE, Ridgers ND, Atkinson G, Stratton G. The effect of active video gaming on children's physical activity, behavior preferences and body composition. Pediatr Exerc Sci 2010 Nov;22(4):535-546. [Medline: 21242603]

13. Maddison R, Foley L, Ni Mhurchu C, Jiang Y, Jull A, Prapavessis H, et al. Effects of active video games on body composition: a randomized controlled trial. Am J Clin Nutr 2011 Jul;94(1):156-163 [FREE Full text] [doi: 10.3945/ajcn.110.009142] [Medline: 21562081]
14. Miyachi M, Yamamoto K, Ohkawara K, Tanaka S. METs in adults while playing active video games: a metabolic chamber study. Med Sci Sports Exerc 2010 Jun;42(6):1149-1153. [doi: 10.1249/MSS.0b013e3181c51c78] [Medline: 19997034]
15. Lyons EJ, Tate DF, Ward DS, Bowling JM, Ribisl KM, Kalyararaman S. Energy expenditure and enjoyment during video game play: differences by game type. Med Sci Sports Exerc 2011 Oct;43(10):1987-1993 [FREE Full text] [doi: 10.1249/MSS.0b013e318216ebf3] [Medline: 21364477]
16. Douris PC, McDonald B, Vespi F, Kelley NC, Herman L. Comparison between Nintendo Wii Fit aerobics and traditional aerobic exercise in sedentary young adults. J Strength Cond Res 2012 Apr;26(4):1052-1057. [doi: 10.1519/JSC.0b013e31822e5967] [Medline: 22446674]
17. Garn AC, Baker BL, Beasley EK, Solmon MA. What are the benefits of a commercial exergaming platform for college students? Examining physical activity, enjoyment, and future intentions. J Phys Act Health 2012 Feb;9(2):311-318. [Medline: 22368230]
18. Graves LE, Ridgers ND, Williams K, Stratton G, Atkinson G, Cable NT. The physiological cost and enjoyment of Wii Fit in adolescents, young adults, and older adults. J Phys Act Health 2010 May;7(3):393-401. [Medline: 20551497]
19. Guderian B, Borreson LA, Sletten LE, Cable K, Stecker TP, Probst MA, et al. The cardiovascular and metabolic responses to Wii Fit video game playing in middle-aged and older adults. J Sports Med Phys Fitness 2010 Dec;50(4):436-442. [Medline: 21178930]
20. Kim R. Women's fitness proving to be a new market for video games.: San Francisco Chronicle; 2009 May 22. URL: http://www.sfgate.com/business/article/Women-s-fitness-proving-to-be-a-new-market-for-3297518.php [accessed 2013-03-28] [WebCite Cache ID 6FSkfeKt6]
21. Rosenberg D, Depp CA, Vahia IV, Reichstadt J, Palmer BW, Kerr J, et al. Exergames for subsyndromal depression in older adults: a pilot study of a novel intervention. Am J Geriatr Psychiatry 2010 Mar;18(3):221-226 [FREE Full text] [doi: 10.1097/JGP.0b013e3181c534b5] [Medline: 20173423]
22. Michie S, Abraham C, Whittington C, McAteer J, Gupta S. Effective techniques in healthy eating and physical activity interventions: a meta-regression. Health Psychol 2009 Nov;28(6):690-701. [doi: 10.1037/a0016136] [Medline: 19916637]
23. Williams SL, French DP. What are the most effective intervention techniques for changing physical activity self-efficacy and physical activity behaviour--and are they the same? Health Educ Res 2011 Apr;26(2):308-322 [FREE Full text] [doi: 10.1093/her/cyr005] [Medline: 21321008]
24. Venditti EM, Kramer MK. Necessary components for lifestyle modification interventions to reduce diabetes risk. Curr Diab Rep 2012 Apr;12(2):138-146. [doi: 10.1007/s11892-012-0256-9] [Medline: 22350807]
25. Ashford S, Edmunds J, French DP. What is the best way to change self-efficacy to promote lifestyle and recreational physical activity? A systematic review with meta-analysis. Br J Health Psychol 2010 May;15(Pt 2):265-288. [doi: 10.1348/135910709X461752] [Medline: 19586583]
26. Greaves CJ, Sheppard KE, Abraham C, Hardeman W, Roden M, Evans PH, IMAGE Study Group. Systematic review of reviews of intervention components associated with increased effectiveness in dietary and physical activity interventions. BMC Public Health 2011;11:119 [FREE Full text] [doi: 10.1186/1471-2458-11-119] [Medline: 21333011]
27. Wing RR, Crane MM, Thomas JG, Kumar R, Weinberg B. Improving weight loss outcomes of community interventions by incorporating behavioral strategies. Am J Public Health 2010 Dec;100(12):2513-2519. [doi: 10.2105/AJPH.2009.183616] [Medline: 20966375]
28. Saelens BE, Gehrman CA, Sallis JF, Calfas KJ, Sarkin JA, Caparosa S. Use of self-management strategies in a 2-year cognitive-behavioral intervention to promote physical activity. Behavior Therapy 2000;31(2):365-379.
29. Hernan WH, Brandle M, Zhang P, Williamson DF, Matulik MJ, Ratner RE, Diabetes Prevention Program Research Group. Costs associated with the primary prevention of type 2 diabetes mellitus in the diabetes prevention program. Diabetes Care 2003 Jan;26(1):36-47 [FREE Full text] [Medline: 12502656]
30. Archer E, Groessl EJ, Sui X, McClain AC, Wilcox S, Hand GA, et al. An economic analysis of traditional and technology-based approaches to weight loss. Am J Prev Med 2012 Aug;43(2):176-182. [doi: 10.1016/j.amepre.2012.04.018] [Medline: 22813682]
31. Bandura A. Self-efficacy: the exercise of control. New York: WH Freeman; 1997.
32. Fox J, Bailenson JN. Virtual Self-Modeling: The Effects of Vicarious Reinforcement and Identification on Exercise Behaviors. Media Psychology 2009;12(1):1-25.
33. Fox J, Bailenson J, Binney J. Virtual Experiences, Physical Behaviors: The Effect of Presence on Imitation of an Eating Avatar. Presence-Teleoperators and Virtual Environments 2009;18(4):294-303.
34. Carver CS, Scheier MF. Self-regulation of action and affect. In: Vohs KD, Baumeister RF, editors. Handbook of Self-Regulation: Research, Theory, and Applications. New York: The Guilford Press; 2011:3-21.
35. Polzien KM, Jakicic JM, Tate DF, Otto AD. The efficacy of a technology-based system in a short-term behavioral weight loss intervention. Obesity (Silver Spring) 2007 Apr;15(4):825-830. [doi: 10.1038/oby.2007.584] [Medline: 17426316]

36. Pellegrini CA, Verba SD, Otto AD, Helsel DL, Davis KK, Jakicic JM. The comparison of a technology-based system and an in-person behavioral weight loss intervention. Obesity (Silver Spring) 2012 Feb;20(2):356-363. [doi: 10.1038/oby.2011.13] [Medline: 21311506]
37. Shuger SL, Barry VW, Sui X, McClain A, Hand GA, Wilcox S, et al. Electronic feedback in a diet- and physical activity-based lifestyle intervention for weight loss: a randomized controlled trial. Int J Behav Nutr Phys Act 2011;8:41 [FREE Full text] [doi: 10.1186/1479-5868-8-41] [Medline: 21592351]
38. Pearson ES. Goal setting as a health behavior change strategy in overweight and obese adults: a systematic literature review examining intervention components. Patient Educ Couns 2012 Apr;87(1):32-42. [doi: 10.1016/j.pec.2011.07.018] [Medline: 21852063]
39. Antin J, Churchill EF. Badges in Social Media: A Social Psychological Perspective. In: Proceedings of the CHI EA '11. 2011 Presented at: CHI EA'11; 2011; Vancouver, BC, Canada.
40. Laschke M, Hassenzahl M. Mayor or patron? The difference between a badge and a meaningful story. In: Proceedings of the CHI EA '11. 2011 Presented at: CHI EA '11; 2011; Vancouver, BC, Canada.
41. Sherry JL, Greenberg BS, Lucas K, Lachlan K. Video game uses and gratifications as predictors of use and game preference. In: Vorderer P, Bryant J, editors. Playing video games: motives, responses, and consequences. Mahwah, NJ: Lawrence Erlbaum Associates; 2006.
42. Deci EL, Ryan RM. The "what" and "why" of goal pursuits: Human needs and the self-determination of behavior. Psychological Inquiry 2000;11(4):227-268.
43. Burke LE, Conroy MB, Sereika SM, Elci OU, Styn MA, Acharya SD, et al. The effect of electronic self-monitoring on weight loss and dietary intake: a randomized behavioral weight loss trial. Obesity (Silver Spring) 2011 Feb;19(2):338-344 [FREE Full text] [doi: 10.1038/oby.2010.208] [Medline: 20847736]
44. Conroy MB, Yang K, Elci OU, Gabriel KP, Styn MA, Wang J, et al. Physical activity self-monitoring and weight loss: 6-month results of the SMART trial. Med Sci Sports Exerc 2011 Aug;43(8):1568-1574. [doi: 10.1249/MSS.0b013e31820b9395] [Medline: 21200337]
45. Kirwan M, Duncan MJ, Vandelanotte C, Mummery WK. Using smartphone technology to monitor physical activity in the 10,000 Steps program: a matched case-control trial. J Med Internet Res 2012;14(2):e55 [FREE Full text] [doi: 10.2196/jmir.1950] [Medline: 22522112]
46. Abraham C, Michie S. A taxonomy of behavior change techniques used in interventions. Health Psychol 2008 May;27(3):379-387. [doi: 10.1037/0278-6133.27.3.379] [Medline: 18624603]
47. Glaser B. Theoretical sensitivity: advances in the methodology of grounded theory. Mill Valley, CA: Sociology Press; 1978.
48. Meier A, Lyons EJ, Frydman G, Forlenza M, Rimer BK. How cancer survivors provide support on cancer-related Internet mailing lists. J Med Internet Res 2007;9(2):e12 [FREE Full text] [doi: 10.2196/jmir.9.2.e12] [Medline: 17513283]
49. Bélanger-Gravel A, Godin G, Vézina-Im LA, Amireault S, Poirier P. The effect of theory-based interventions on physical activity participation among overweight/obese individuals: a systematic review. Obes Rev 2011 Jun;12(6):430-439. [doi: 10.1111/j.1467-789X.2010.00729.x] [Medline: 20331511]
50. Glasgow RE, Vogt TM, Boles SM. Evaluating the public health impact of health promotion interventions: the RE-AIM framework. Am J Public Health 1999 Sep;89(9):1322-1327. [Medline: 10474547]
51. Manzoni GM, Pagnini F, Corti S, Molinari E, Castelnuovo G. Internet-based behavioral interventions for obesity: an updated systematic review. Clin Pract Epidemiol Ment Health 2011;7:19-28 [FREE Full text] [doi: 10.2174/1745017901107010019] [Medline: 21552423]
52. Rovniak LS, Hovell MF, Wojcik JR, Winett RA, Martinez-Donate AP. Enhancing theoretical fidelity: an e-mail-based walking program demonstration. Am J Health Promot 2005;20(2):85-95. [Medline: 16295700]
53. Turner-McGrievy GM, Campbell MK, Tate DF, Truesdale KP, Bowling JM, Crosby L. Pounds Off Digitally study: a randomized podcasting weight-loss intervention. Am J Prev Med 2009 Oct;37(4):263-269 [FREE Full text] [doi: 10.1016/j.amepre.2009.06.010] [Medline: 19765496]

Abbreviations

iOS: “i” Operating System (operating system used by iPhones and iPads)
PDA: Personal Digital Assistant
RE-AIM: Reach Effectiveness Adoption Implementation Maintenance
UFC: Ultimate Fighting Championship

Edited by G Eysenbach; submitted 17.10.12; peer-reviewed by M Simons, R Maddison; comments to author 11.02.13; revised version received 26.02.13; accepted 08.03.13; published 07.05.13.

Please cite as:
Lyons EJ, Hatkevich C
Prevalence of Behavior Changing Strategies in Fitness Video Games: Theory-Based Content Analysis
J Med Internet Res 2013;15(5):e81
URL: http://www.jmir.org/2013/5/e81/
doi:10.2196/jmir.2403
PMID:23651701

Original Paper

Evaluation of a Web-Based Social Network Electronic Game in Enhancing Mental Health Literacy for Young People

Tim MH Li[1,2], MSc; Michael Chau[3], PhD; Paul WC Wong[1], DPsych (Clinical); Eliza SY Lai[2], MSS; Paul SF Yip[1,2], PhD

[1]Department of Social Work and Social Administration, The University of Hong Kong, Hong Kong, China (Hong Kong)
[2]HKJC Centre for Suicide Research and Prevention, The University of Hong Kong, Hong Kong, China (Hong Kong)
[3]School of Business, The University of Hong Kong, Hong Kong, China (Hong Kong)

Corresponding Author:
Michael Chau, PhD
School of Business
The University of Hong Kong
8/F K K Leung Building
Pokfulam Road
Hong Kong,
China (Hong Kong)
Phone: 852 39171014
Fax: 852 28585614
Email: mchau@business.hku.hk

Abstract

Background: Internet-based learning programs provide people with massive health care information and self-help guidelines on improving their health. The advent of Web 2.0 and social networks renders significant flexibility to embedding highly interactive components, such as games, to foster learning processes. The effectiveness of game-based learning on social networks has not yet been fully evaluated.

Objectives: The aim of this study was to assess the effectiveness of a fully automated, Web-based, social network electronic game on enhancing mental health knowledge and problem-solving skills of young people. We investigated potential motivational constructs directly affecting the learning outcome. Gender differences in learning outcome and motivation were also examined.

Methods: A pre/posttest design was used to evaluate the fully automated Web-based intervention. Participants, recruited from a closed online user group, self-assessed their mental health literacy and motivational constructs before and after completing the game within a 3-week period. The electronic game was designed according to cognitive-behavioral approaches. Completers and intent-to-treat analyses, using multiple imputation for missing data, were performed. Regression analysis with backward selection was employed when examining the relationship between knowledge enhancement and motivational constructs.

Results: The sample included 73 undergraduates (42 females) for completers analysis. The gaming approach was effective in enhancing young people’s mental health literacy (d=0.65). The finding was also consistent with the intent-to-treat analysis, which included 127 undergraduates (75 females). No gender differences were found in learning outcome (P=.97). Intrinsic goal orientation was the primary factor in learning motivation, whereas test anxiety was successfully alleviated in the game setting. No gender differences were found on any learning motivation subscales (P>.10). We also found that participants’ self-efficacy for learning and performance, as well as test anxiety, significantly affected their learning outcomes, whereas other motivational subscales were statistically nonsignificant.

Conclusions: Electronic games implemented through social networking sites appear to effectively enhance users’ mental health literacy.

(J Med Internet Res 2013;15(5):e80) doi:10.2196/jmir.2316

KEYWORDS

digital game-based learning; mental health literacy; social networking sites; motivation

Introduction

The Internet plays an increasingly important role in our daily lives. With the shift of the World Wide Web from Web 1.0 to Web 2.0, the Web becomes an essential platform for information sharing, user-centered design, and collaboration. The Web 2.0 concept has led to the development and evolution of Web-based communities and applications, such as social networking sites (SNS), video-sharing sites, blogs, forums, wikis, and interactive games.

Apart from leisure use, some studies have indicated that the Internet has become an instrumental information-searching tool for people with health concerns [1,2], especially for adolescents [3,4]. Informative educational websites containing physical and mental health information, such as the National Institutes of Health, Beacon Health, and beyondblue [5-7] are examples of contemporary health education initiatives. The Internet has been proposed to be an efficient platform to engage, educate, and intervene in the younger generation's health concerns, especially for those who are not easily engaged by traditional methods [8,9]. Previous literature suggested that Internet-based intervention on health education for adolescents was more effective than for adults [9]. There are some interventions primarily focused on providing mental health education, such as Kindertelefoon, YooMagazine, and ReachOut [10-12]. Those interventions engage young people through interactive forums, games, and websites to enhance their mental health literacy.

Different kinds of multimedia techniques and interaction methods based on advanced technologies have been evaluated for their learning efficacy through preliminary evidence [13-15]. In particular, the potential benefits of using digital games for instructional purposes are worthy of investigation. Many studies have shown the benefits and educational effectiveness of digital game-based learning (DGBL) in both classroom and laboratory settings, and in various subjects like computer science, engineering, mathematics, and physics [16-20]. The literature identifies motivational characteristics of educational computer games and also establishes characteristics that consistently facilitate game design and development [21-24]. Those characteristics encompass the use of a fantasy environment, scenarios that engage curiosity, present challenges, and are dependent on the player's control. It is believed that the learning experience can be enriched by those characteristics. For example, adding gaming features like fantasy and mastery could make learning more interesting and enjoyable [25,26], and electronic games could enhance children's and adolescents' knowledge, attitudes, and health behaviors as effectively, or even more, than means of conventional instruction [19]. In addition, the game environment is not only goal-directed and rule-governed, but also contains interactive elements (eg, competition), whether it is intended for one or multiple players [21,27]. Furthermore, literature suggests that games can foster high interactivity and experiential learning, improving players' health-related self-efficacy and behaviors; engage young people who are difficult to influence through traditional health education interventions; provide supportive and informative feedback on health choices; support self-paced progress; offer opportunities for social interaction and health-related social support (both within the game and around it), increasing players' motivation towards improving health behaviors; and offer opportunities to rehearse self-care skills, which can be applied in real-life situations [19,28]. Nonetheless, the effectiveness of DGBL in mental health education has been underexplored. In merging the findings and benefits of DGBL in health education, it is worthwhile to examine the effects of DGBL on mental health education.

In Hong Kong, mental health education is not a regular school subject in the school curriculum. Rather, some concepts and skills may be taught in subjects like Life Education or Liberal Studies. Therefore, some school-based mental health promotion programs were developed. For instance, "The Little Prince is Depressed" project was a 12-week, school-based, universal program aimed at reducing depressive symptoms and enhancing protective factors of depression among secondary school students [29]. Its curriculum was developed based on the cognitive-behavioral model and included topics like stress and depression, and cognitive restructuring and problem-solving skills. Students showed positive development in help-seeking attitudes and self-esteem in general, and those with more depressive symptoms significantly improved their cognitive restructuring skills and support-seeking behaviors after participating. However, the number of beneficiaries of school-based programs is limited to the resources available, and competition for school teaching hours to carry out such a program is significant. Therefore, a new form of intervention to promote mental health among young people is necessary in Hong Kong.

In the past few years, online social networks, an important aspect of Web 2.0 applications, have emerged as a mainstream communication and interaction modality, especially among young people. SNS, such as Facebook, can be an excellent platform to reach a large spectrum of the population. People make use of these platforms to have fun and socialize with each other through games, chats, and status updates. Games on social networks are called "social games" and attract large numbers of players every day. For example, many people, especially adolescents, spend a lot of time growing crops on "Happy Farm" and feeding pets in "Pet Society" on Facebook. This new form of communication modality, however, has created both concerns and opportunities for health professionals and researchers. For instance, some reported that SNS might be related to problematic use of the Internet [30], whereas others found SNS to be a more useful tool for procuring social support [31] and improving participants' engagement and retention in Web-based interventions [32]. Nevertheless, Facebook has been regarded as a good platform to reach and educate young people, with its large number of members across the world. Studies concerning interventions with the help of Facebook have emerged recently [32,33].

Previous studies revealed gender differences in the use of Internet. For example, males have been shown to spend more time playing games and on other forms of entertainment, whereas females use the Internet more for communication and SNS [34,35]. Therefore, it is important to investigate whether gender plays a role in DGBL on Internet SNS.

The current study attempted to evaluate a novel approach of using DGBL through an SNS for mental health education. We designed a learner-centered, self-paced, electronic game, meaning that people could play and learn whenever they wanted to and could achieve as much as they preferred in terms of domain knowledge enhancement. The game developed for this study was placed on Facebook, and no facilitator was required. We hypothesized that mental health literacy would be enhanced through Web-based DGBL and three motivational constructs (ie, expectancy, value, and affect), would influence learning outcomes. Mental health literacy was first defined as "knowledge and beliefs about mental disorders which aid their recognition, management or prevention" (page 182, [36]). Here, the definition of mental health literacy not only included knowledge of a mental disorder (ie, depression), but also knowledge related to mental health problems, such as stress, its management, and important skills that might be helpful for one's mental health (eg, cognitive restructuring skills and problem-solving skills). Beliefs about mental disorders were beyond the scope of current study. Specifically, we sought to:

1. explore the effectiveness of using DGBL to enhance mental health literacy through an SNS;
2. explore learning motivation in DGBL;
3. examine whether gender plays a role in intervention effectiveness and learning motivation; and
4. explore the impact of motivational constructs on mental health literacy.

Methods

Participants

Participants were recruited at a major university in Asia. An invitation email was sent to all undergraduate and postgraduate students' (N=22,260) university email accounts inviting them to participate in the current study. Students who were between 17-25 years old, had adequate Internet literacy and a Facebook account, and were reachable via the local network were eligible to participate. The invitation email explained to participants that they would not only be required to complete a 3-week game on Facebook, but would also be asked to complete a set of Web-based, self-assessed questionnaires both before and after finishing the game. They were allowed to play the game anytime and anywhere with a computer connected to the Internet within the study period. Those who completed the game and the online questionnaires received cash compensation and were entered in a drawing for a tablet computer, supermarket coupons, and theme park tickets. Interested students replied to the invitation email and provided their Facebook ID for verification. The research team then confirmed their eligibility through email.

The Game: "Ching Ching Story"

Theoretical Background

The electronic game "Ching Ching Story" and its content were developed by the authors of the paper. The development process involved contextual and technical aspects. For the contextual aspect, the learning content was adopted and modified from a school-based, mental health enhancement program for adolescents by members of the research team. The school-based program effectively reduced depressive symptoms within those with highly depressed moods [29]. Its content was developed based on a cognitive-behavioral therapeutic approach, which is consistent with diathesis-stress models of depression. Such models emphasize the cognitive and behavioral characteristics of an individual, which not only affect the impact of adverse life events, but also have a direct influence upon the development of depression. Cognitive-behavioral therapy is an evidence-based treatment approach for various mental health problems, such as depression and anxiety [37,38].

"Ching Ching Story" consisted of 10 topics: (1) identifying stressors and how to handle stress, (2) understanding the relationship between stress and coping, and the consequence of depression, (3) understanding what goal-directed thinking is, (4) affirming existing strengths and acknowledging the concept of "self", (5) cognitive restructuring, (6) advanced cognitive restructuring, (7) understanding others' feelings, (8) communication skills, (9) conflict resolution based on a problem-solving approach, and (10) anger management [29].

Technology

Adobe Flash was used to produce interactive gaming elements and animated graphics on the client side of the system. Flash ActionScript 3.0 handled the logic of the game and sent requests to the backend in response to user actions. Moreover, we used Facebook API, where both Facebook iFrame and Javascript SDK facilitated the retrieval of a user's profile and social network data from the Facebook application. Javascript was used for backend programming. Questionnaire and game progress data were stored in a MySQL database. The system was hosted on a computer server on the authors' host institution network. The game was accessible by the public on Facebook [39]. Three screenshots of the game are shown in Figures 1-3.

Structure

"Ching Ching Story" is a role-playing game. It is thought that proper instructional design is capable of facilitating both mental health learning and intervention [40]. The game adopted a problem-based, narrative, adventure approach. Players assumed the role of the game character, Ching Ching, and moved around different areas of the game to complete all missions by talking to nonplayer characters, exploring different places and objects, and playing various minigames, which taught instrumental skills. The whole game consisted of ten missions to be fulfilled as shown in Figure 1 with a storyline. Each mission incorporated different mental health concepts. Some of the missions were expected to be either more challenging or required prior knowledge, which was learned in other missions. As shown in Figure 2, after participants successfully completed particular tasks in the "psychological gym room", some skills, such as ones within the communication domain, could become part of Ching Ching's abilities. Such abilities were required to complete other tasks, thereby encouraging participants to recall those important skills more often throughout the game. Ching Ching's "energy" was consumed after working on some tasks, and when Ching Ching consumed all possible energy, the player could not progress and advance the plot until energy was recovered. This aspect was incorporated in order to avoid players completing the whole game in a very short time, which might have deterred effective learning.

Despite the limitations on playtime, players still had great flexibility within the game, selecting the mission they preferred. In an effort to encourage active and self-paced learning, there was no predefined order of completion. Once players completed the ten missions, no advanced plots and/or tools were provided. Also, a level system was installed to record the level and skills learned for each player. The record was shared among friends who also joined the game to establish a leader board and create an atmosphere of competition to enhance the game's appeal. Moreover, the game facilitated social support by encouraging interaction between players. Examples included sending gifts and greetings among friends, shown in Figure 3, which served to increase player retention. Since some tasks required special tools to accomplish, players could help each other by sending the tools as gifts. Moreover, to encourage players to invite their friends to join the game, gifts were offered to players who sent more invitations to play the game. "Level-up" and "task completed" notifications were posted on players' Facebook walls to acknowledge their achievements. The players' friends therefore knew of, and could comment on, players' progress and achievements. The research team provided technical support in case participants encountered any technical problems while playing the game. Apart from this, no other intervention or support was provided. Finally, no prompts or reminders were used in the game to maintain gameplay frequency or duration.

Figure 1. Missions for players to choose.

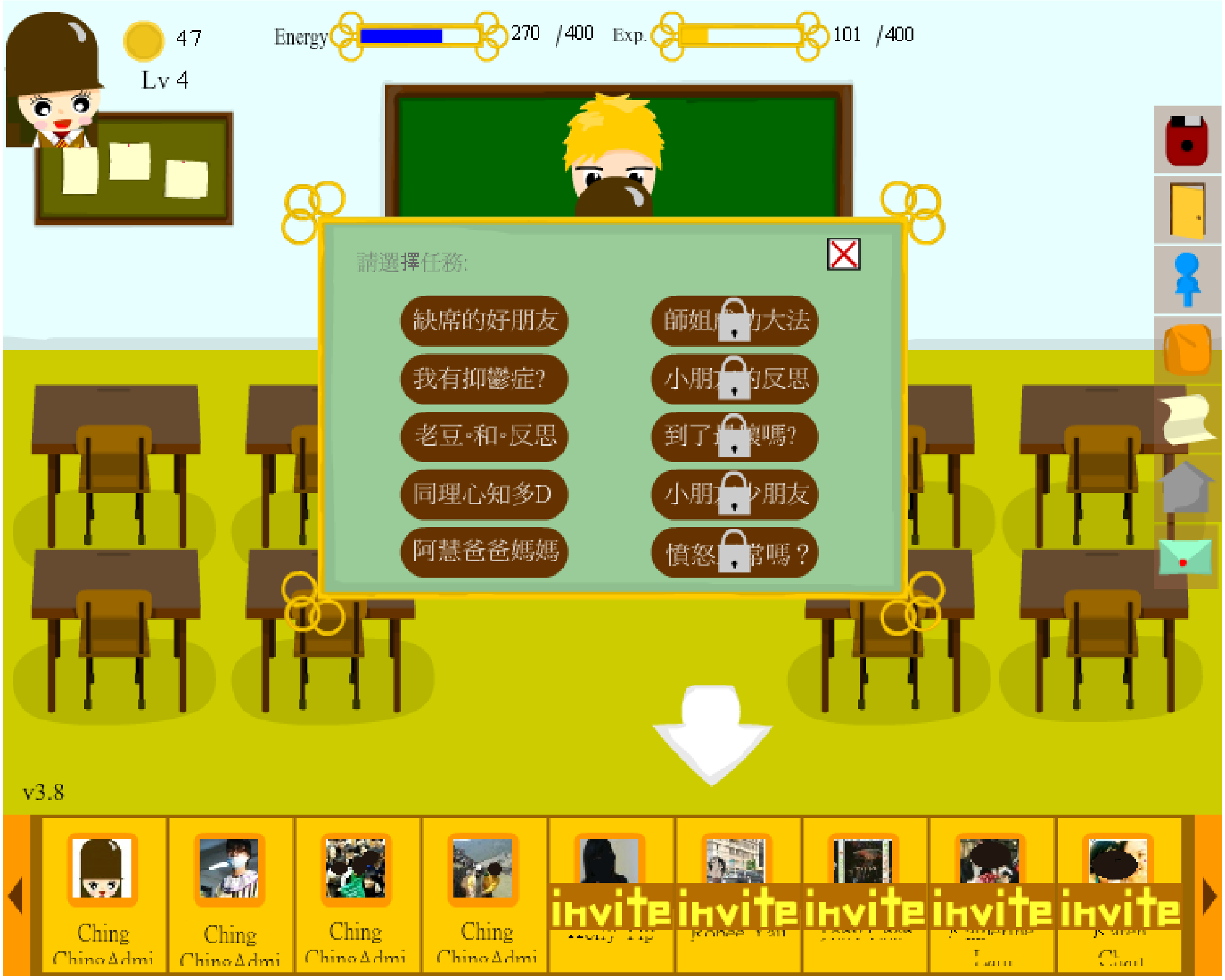
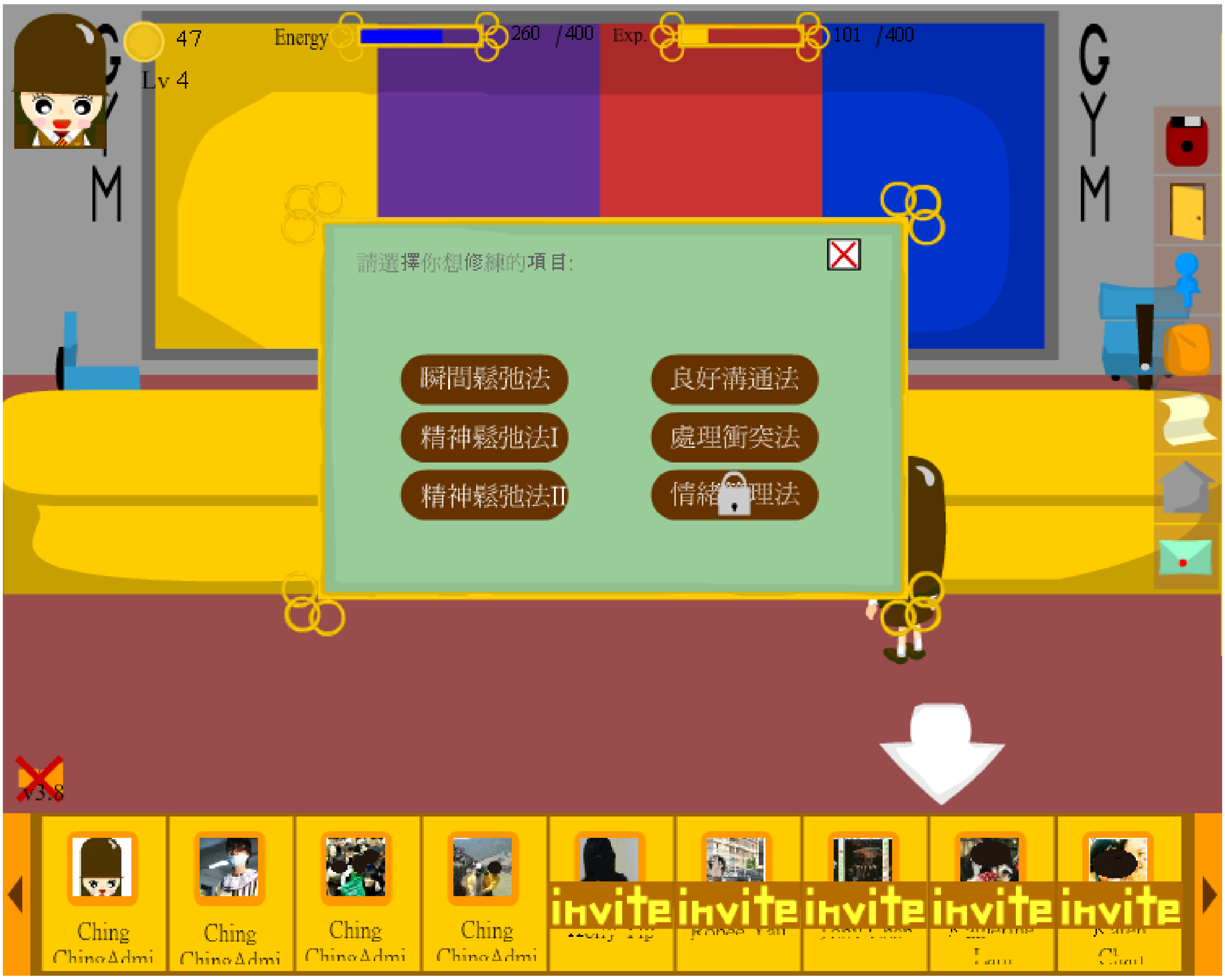


Figure 2. Psychological gym room.



請選擇你想修練的項目:

Figure 3. Visiting friends and sending gifts.

Outcome Measures

Overview

Two sets of Web-based, self-assessed questionnaires were developed for measuring participants' mental health literacy (primary outcome) and their learning motivation (secondary outcome). Facebook ID was used as a user identifier for verification and avoided duplicate entries. Pre- and posttests automatically popped up once the game started and ended, respectively. The pretest consisted of demographic information and self-developed questions on mental health literacy, whereas the posttest consisted of the same questions for mental health literacy plus modified questions for learning motivation from the Motivated Strategies for Learning Questionnaire (MSLQ) [41].

Mental Health Literacy

Mental health literacy was measured through 31 questions, which were constructed by the researchers to address the 10 topics of the game. They included true-or-false, sequencing, multiple-choice, and matching questions. The questions, designed to evaluate a broader understanding of learning through online DGBL, covered topics like understanding of mental health concepts and application of skills. Sample questions may be found in Multimedia Appendix 1.

Learning Motivation

Participants' learning motivation was measured in terms of (1) *value*: intrinsic goal orientation (4 items), extrinsic goal orientation (4 items), task value (6 items), (2) *expectancy*: control of learning beliefs (4 items), self-efficacy for learning and performance (8 items), and (3) *affect*: test anxiety (5 items). Reliability and predictive validity of the MSLQ were properly evaluated in previous studies [41]. All items were rated on a 7-point Likert scale (1 = *not at all true for me*; 7 = *very true of me*). The list of items used is shown in Multimedia Appendix 1.

Statistical Methods

Descriptive statistics were used to illustrate the general picture of the data for each measurement. Any participants with missing data or who dropped out were not included in the completers analysis. In addition to completers analysis, data were analyzed through an intent-to-treat (ITT) analysis, using multiple imputation (MI) to address loss of follow-up data. Dropout participants who completed questionnaires only at the pretest were handled by applying the technique of MI with 5 imputations for missing data [42]. We conducted missing values analysis to investigate whether data were missing completely at random (MCAR). A within-subject Student's *t*-test was used to analyze the statistical significance of changes in knowledge, and a Student's *t*-test for independent samples was employed to test for gender differences.

Linear regression was used to examine the relation between knowledge enhancement and motivational constructs. By fitting knowledge enhancement with motivational constructs, the coefficient and 95% confidence interval could be presented. The regression was further adjusted by adding pretest score, gender, and age as control variables. Backward selection was employed in the regression analysis. All data analyses were conducted using SPSS software.

Ethics and Informed Consent

Ethics approval, from the Human Research Ethics Committee for Non-Clinical Faculties at the authors' institution, was obtained before data collection. Participants provided informed online consent before they started the game. The informed consent form detailed information about the procedures of the study.

Results

Recruitment and Subjects

Participants were recruited from November to December 2011 at the authors' institution. A total of 221 undergraduates agreed to participate in the study. Out of those who started the game (n=136), a majority completed the pretest (n=127). The other 9 participants did not fully complete the pretest due to technical problems, such as early termination of the questionnaire. Out of these 127 participants, 73 completed both the pre- and posttest. All 127 participants were included in the ITT analysis, whereas only data from the 73 participants who completed both assessments were used for the completers and regression analyses. Figure 4 shows the participant flow. A total of 31 males and 42 females, ranging from 17-25 years old (M=20.82, SD 1.81), completed both assessments.

Mental Health Literacy

Table 1 shows the number of correct responses participants achieved on the mental health literacy assessment both before and after playing the game, as well as their overall improvement levels. Both male and female participants achieved over half correct at pretest, suggesting participants' possessed good background knowledge on mental health. The pretest scores of males and females were similar, indicating that their familiarity with mental health was comparable. The improvement of both genders was also statistically significant and consistent, revealing the effectiveness of the game play intervention for both males and females. In a *t*-test comparison between the results of the pre- and posttest, a statistically significant improvement was documented. On average, participants answered 2.21 more questions correctly after the intervention (total of 31 questions on the knowledge test). Participants demonstrated moderate improvements between pre- and posttests in terms of mental health literacy (*d*=0.65). Furthermore, there was not a statistically significant gender difference in knowledge improvement (*P*=.97). Apart from completers analysis, noncompleters were also included in the ITT analysis to provide more understanding about the effects of the intervention. Missing values analysis demonstrated that the hypothesis that the data were MCAR could not be rejected, χ^2_{Little}=3.75, (*P*=.15). ITT analysis showed that the improvement between pre- and posttest was statistically significant, with a moderate effect size (*d*=0.66). This result was consistent with the completers analysis (*d*=0.65).

Learning Motivation

Table 2 presents the descriptive statistics of the motivational subscales. *Value* focuses on the reasons why participants engaged in the educational game. Among the three subscales that made up the construct (intrinsic and extrinsic goal orientation and task value), both genders achieved the highest score on intrinsic goal orientation. On the other hand, extrinsic goal orientation was the lowest among the three value subscales. *Expectancy* refers to participants' beliefs that they could accomplish tasks in the game. Satisfactory scores on both subscales of the expectancy construct demonstrated participants' confidence in the acquisition of mental health knowledge. *Affect* concerns test anxiety associated with the knowledge test. It is reasonable that the anxiety scores were low in a gaming context since learning in a game should be enjoyable and relaxing. Moreover, since the test in this study was conducted online and without a time limit, test anxiety was likely alleviated. Indeed, participants' scores on the anxiety measure were the lowest among the 6 motivational subscales. *T*-tests revealed no statistically significant gender differences on any of the 6 motivational subscales (Table 2).

Influence of Motivational Constructs on Learning Outcomes

Nonsignificant motivational subscales were eliminated in the regression analysis with backward selection. Nonsignificance of the three subscales within the value construct indicated that reasons for participating in the game did not affect knowledge enhancement. The influence of control of learning beliefs in the expectancy construct was also not statistically significant. Control variables, namely pretest score, gender, and age, were retained in the model regardless of their level of statistical significance. As expected, gender and age did not affect learning outcomes, whereas pretest score did significantly affect knowledge enhancement (see Table 3). This result is reasonable given that pretest score restricted the maximum possible improvement on the posttest. In other words, participants attaining high scores on the pretest, when compared to those with lower scores on the pretest, could not improve as much on the posttest. Consequently, pretest score negatively influenced knowledge improvement. Furthermore, self-efficacy for learning and performance significantly affected knowledge improvement. Test anxiety, on the other hand, negatively affected knowledge enhancement.

Figure 4. Participant flowchart.

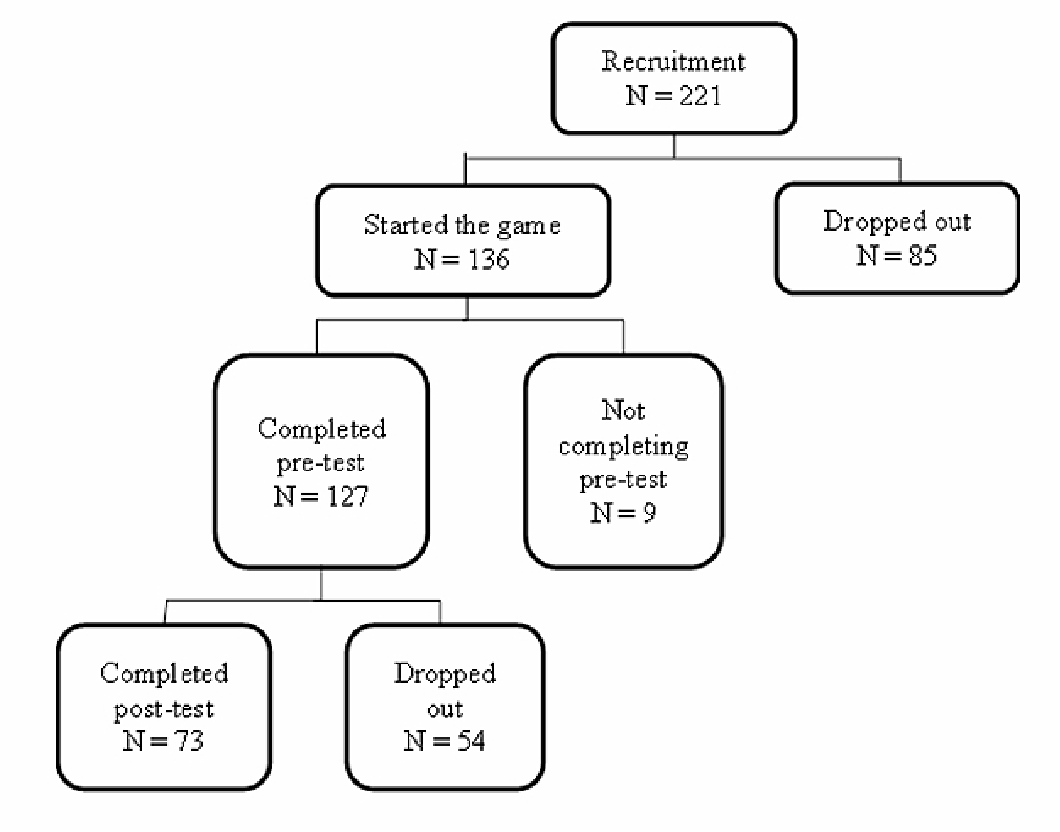


Table 1. Descriptive statistics of pretest, posttest, and evidenced improvement on the knowledge test.

	Male	Female	All
Pretest score, mean (SD)	19.61 (3.30)	18.55 (3.63)	19.00 (3.51)
Posttest score, mean (SD)	21.85 (3.53)	20.74 (3.12)	21.21 (3.33)
Improvement, mean (SD)	2.23 (4.39)	2.19 (3.07)	2.21 (3.66)
P value of *t*-test between pre- and posttest scores	.008	<.001	<.001

Table 2. Descriptive statistics of the six motivational subscales and gender comparisons.

Motivational subscales		Male, mean (SD)	Female, mean (SD)	All, mean (SD)	*P* value of *t* test between genders
Value					
	Intrinsic goal orientation	5.02 (0.78)	4.93 (1.01)	4.97 (0.91)	.68
	Extrinsic goal orientation	4.18 (1.22)	3.71 (1.34)	3.91 (1.30)	.13
	Task value	4.74 (0.73)	4.66 (1.17)	4.70 (1.00)	.72
Expectancy					
	Control of learning beliefs	4.82 (0.83)	4.70 (0.93)	4.75 (0.88)	.56
	Self-efficacy for learning and performance	4.92 (0.70)	4.71 (0.92)	4.80 (0.83)	.29
Affect					
	Test anxiety	3.59 (1.19)	3.16 (1.23)	3.34 (1.23)	.14

Table 3. Regression of knowledge enhancement on motivational constructs adjusted by pretest score, gender, and age after backward selection.

Variables	Coefficients	95% CI Lower	95% CI Upper	*P* value
Self-efficacy for learning and performance	.21	0.09	0.32	<.001
Test anxiety	-.19	-0.31	-0.06	.005
Gender	.81	-0.55	2.18	.24
Age	.18	-0.20	0.56	.34
Pretest score	-.63	-0.83	-0.44	<.001

Discussion

The fully automated Web-based intervention was effective in enhancing young people's mental health literacy. Intrinsic goal orientation was the primary factor in learning motivation, whereas test anxiety was successfully alleviated in the game setting. No gender differences were found on any outcome measures. Moreover, self-efficacy for learning and performance positively influenced learning outcomes, whereas test anxiety negatively affected them.

Mental Health Literacy

To our knowledge, this is one of the first studies to explore the use of DGBL through an SNS to enhance mental health literacy. Despite the limitations of this exploratory study, participants attained mental health knowledge in a continual and self-paced manner. With moderate improvements among participants, it seems players may be able to acquire knowledge in the game at their own learning pace and apply the skills to solve real-life problems. This finding provides supporting evidence that Web-based DGBL can effectively enhance mental health knowledge. The combination of gaming concepts and online education may also facilitate self-paced learning processes in higher-order thinking. It seems that this new type of learning initiative for mental health information is efficient for both male and female learners.

Thus, the current study reinforces Lieberman's suggestion [28] that games in health education are beneficial in various aspects, including the support of a self-paced learning process. Furthermore, although the learning content of the electronic game was modified from a school-based mental health enhancement program for adolescents [29], it demonstrated its effectiveness in enhancing the mental health literacy of young people aged 17-25. Therefore, we may extend the findings to a slightly older age group on Internet-based intervention on health education. Previous literature suggested that Internet-based intervention on health education was more effective on adolescents than on adults, as such intervention for adolescents demonstrated small-to-moderate effect size, whereas similar interventions for adults usually yielded small effect size only [9]. With moderate effect size found in the current study, it is suggested that social and gaming features may enhance the effectiveness of Internet-based intervention on health education for young adults.

Learning Motivation and Its Influence on Learning Outcomes

Participants' learning motivation was generally positive. They believed in their own abilities to learn in the game and tailored their learning processes in the absence of a facilitator. Although participants who were outstanding in the knowledge test were rewarded with an extra prize, intrinsic goal orientation was still stronger when compared to extrinsic orientation. High intrinsic motivation indicates that participants primarily perceived that they took part in the game for its challenges, out of curiosity, and in an effort to attain mastery. Therefore, participants enjoyed playing the game and learning about mental health knowledge throughout the intervention, instead of simply pursuing rewards. With high expectancy, participants also believed that their efforts to learn throughout the self-paced game would result in positive learning outcomes. Self-directed learning was possible in the game. The positive influence of self-efficacy for learning and performance on learning outcomes implies participants' expectations about their own performance and judgment generally reflected their learning outcomes. Participants were capable of enhancing their mental health knowledge and manage the learning process in the game. Moreover, the game-based environment provided an enjoyable learning environment for participants, evidenced by substantially reductions in their stress over the knowledge test. However, participants' worries and concerns about the test could have still resulted in performance decrements. Although the knowledge test was conducted in a casual way, relationships between test anxiety and test results still existed.

In addition, the feedback collected from participants on learning motivation and game design provided additional information about the high intrinsic goal orientation. The feedback from participants was generally positive and encouraging. Participants appreciated the combination of gaming concepts and mental health knowledge. The transformation of mental health knowledge into a game made mental health knowledge easy to understand and attractive (eg, "The game helped me understand more about stress management"; "Overall the game was quite interesting as it used animations to show what stress and emotional distress are and solutions to manage them"). They also found that the game was good to raise their awareness in mental health (eg, "Informative about mental disorder"; "A good way to promote awareness in mental health"), and the game itself was interesting and interactive (eg, "Interactive and easy to play"). This may explain why intrinsic goal orientation remained high in the learning process. Some participants, however, pointed out the game sometimes had too many words, which may decrease the enjoyment of the game (eg, "More informative than interesting”; “Sometimes want to skip information and conversations to advance plots”). We therefore may need to think of balancing information and entertainment to achieve better learning motivation in our future intervention development.

Limitations

There are some limitations of this exploratory study: lack of a control group, small sample size, high dropout rate, and a biased sample. Moreover, the social functions in the game might not have been fully utilized, as the total number of players was not large. Time limitations prevented the number of players in the game to grow to an adequate size. Since the number of players influences the interactivity of a social game, the game in this study might not have been as interactive as other social games for pure entertainment on the market. In addition, our DGBL study was domain-specific, a common issue in most previous studies.

Further Research

In sum, DGBL in combination with an online social communication platform in health education should be advocated as a way to promote mental health awareness and equip people with domain-specific knowledge education, and warrants further examination. Future studies should involve a larger sample, incorporate a control group, and recruit different age groups in order to have a more comprehensive understanding of the effects of this Web-based electronic game on mental health education. In addition to augmenting the sample size, another future research direction includes investigating the effectiveness of social game education based on this study. Social games on SNS facilitate social interaction and communication, making them different from traditional online games. SNS could provide tools to embed communication platforms (eg, blogs, forums) into games, which may, in turn, substantially enhance levels of sharing and knowledge exchange among players [43]. These social elements can motivate players to learn and potentially foster the learning process. DGBL should not be restricted to learning inside the game but should extend outside the realm of the game (eg, discussing learning material on blogs or forums). The effectiveness of social game education needs further evaluation. Also, the scope of this research should be extended to different health issues, such as mood and eating disorders. Through such future work, DGBL can be fully utilized and evaluated in different aspects of health education.

Acknowledgments

This research has been supported in part by the following grants: Health Care and Promotion Fund (#23090514) , Food and Health Bureau, Hong Kong Government; General Research Fund (#742012), Research Grants Council, Hong Kong Government; Azalea (1972) Endowment Fund, The University of Hong Kong; and Quality Education Fund, Education Bureau, Hong Kong Government. The authors thank Chris Wong, Broderick Koo, Alice Lee, and Wai-ki Sung of the University of Hong Kong for their assistance in the project.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Questionnaire items.

[PDF File (Adobe PDF File), 231KB - jmir_v15i5e80_app1.pdf]

Multimedia Appendix 2

CONSORT-EHEALTH checklist V1.6.2 [44].

[PDF File (Adobe PDF File), 986KB - jmir_v15i5e80_app2.pdf]

References

1. Fox S, Rainie L, Horrigan J. The online health care revolution: How the web helps Americans take better care of themselves. Washington, DC: Pew Internet & American Life Project; 2006. URL: http://www.pewinternet.org/~/media//Files/Reports/2000/PIP_Health_Report.pdf.pdf [accessed 2012-06-28] [WebCite Cache ID 68klKm9cj]
2. 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. [doi: 10.1001/jama.289.18.2400] [Medline: 12746364]
3. Rideout V. Generation Rx.com. What are young people really doing online? Mark Health Serv 2002;22(1):26-30. [Medline: 11881541]
4. Borzekowski DL, Rickert VI. Adolescent cybersurfing for health information: a new resource that crosses barriers. Arch Pediatr Adolesc Med 2001 Jul;155(7):813-817. [Medline: 11434849]
5. National Institutes of Health. URL: http://health.nih.gov/ [WebCite Cache ID 6Dvjlv9zd]
6. Beacon Health. URL: http://www.beacon.anu.edu.au/ [WebCite Cache ID 6Dvjootrm]

7. beyondblue. URL: http://www.beyondblue.org.au/ [WebCite Cache ID 6DvjrP227]
8. Barak A, Grohol JM. Current and Future Trends in Internet-Supported Mental Health Interventions. Journal of Technology in Human Services 2011;29(3):155-196. [doi: 10.1080/15228835.2011.616939]
9. Siemer CP, Fogel J, Van Voorhees BW. Telemental health and web-based applications in children and adolescents. Child Adolesc Psychiatr Clin N Am 2011 Jan;20(1):135-153 [FREE Full text] [doi: 10.1016/j.chc.2010.08.012] [Medline: 21092918]
10. Fukkink RG, Hermanns JM. Children's experiences with chat support and telephone support. J Child Psychol Psychiatry 2009 Jun;50(6):759-766. [doi: 10.1111/j.1469-7610.2008.02024.x] [Medline: 19207634]
11. Santor DA, Poulin C, LeBlanc JC, Kusumakar V. Online health promotion, early identification of difficulties, and help seeking in young people. J Am Acad Child Adolesc Psychiatry 2007 Jan;46(1):50-59. [doi: 10.1097/01.chi.0000242247.45915.ee] [Medline: 17195729]
12. Nicholas J. The role of internet technology and social branding in improving the mental health and wellbeing of young people. Perspect Public Health 2010 Mar;130(2):86-90. [Medline: 20455488]
13. Chau M, Huang Z, Chen H. Teaching key topics in computer science and information systems through a web search engine project. J Educ Resour Comput 2003 Sep 2003;3(3):1-14. [doi: 10.1145/1029994.1029996]
14. Chau M, Wong CH, Zhou Y, Qin J, Chen H. Evaluating the use of search engine development tools in IT education. J Am Soc Inf Sci 2010;61(2):288-299. [doi: 10.1002/asi.21223]
15. Chen H, Li X, Chau M, Ho Y, Tseng C. Using Open Web APIs in Teaching Web Mining. IEEE Trans Educ 2009;52(4):482-490. [doi: 10.1109/TE.2008.930509]
16. Ebner M, Holzinger A. Successful implementation of user-centered game based learning in higher education: An example from civil engineering. Compu Educ 2007;49(3):873-890.
17. Ke F, Grabowski B. Gameplaying for maths learning: cooperative or not? Br J Educ Technol 2007 Mar 2007;38(2):249-259. [doi: 10.1111/j.1467-8535.2006.00593.x]
18. Papastergiou M. Digital game-based learning in high school computer science education: Impact on educational effectiveness and student motivation. Compu Educ 2009;52(1):1-12. [doi: 10.1016/j.compedu.2008.06.004]
19. Papastergiou M. Exploring the potential of computer and video games for health and physical education: A literature review. Compu Educ 2009;53(3):603-622. [doi: 10.1016/j.compedu.2009.04.001]
20. Squire K, Barnett M, Grant JM, Higginbotham T. Learning physics with digital simulation games. In: Proceedings of the 6th International Conference on Learning Sciences. 2004 Presented at: 6th International Conference on Learning Sciences; June 22-26, 2004; Santa Monica, CA.
21. Malone T. Toward a theory of intrinsically motivating instruction. Cognitive Science 1981;4:333-370. [doi: 10.1207/s15516709cog0504_2]
22. Malone T. What makes computer games fun? BYTE. In: Proceedings: selected papers from the Conference on Easier and More Productive Use of Computer Systems. New York: Association for Computing Machinery; 1981.
23. Bowman RF. A "Pac-Man" theory of motivation: Tactical implications for classroom instruction. Educ Technol 1982;22(9):14-17.
24. Malone T, Lepper M. Making learning fun: A taxonomy of intrinsic motivations of learning. In: Snow RE, Farr MJ, editors. Aptitude, learning, and instruction. Hillsdale, NJ: Lawrence Erlbaum; 1987:223-253.
25. Garris R, Ahlers R, Driskell JE. Games, motivation, and learning: A research and practice model. Simulat Gaming 2002;33(4):441-467.
26. Wilson KA, Bedwell WL, Lazzara EH, Salas E, Burke CS, Estock JL, et al. Relationships between game attributes and learning outcomes: Review and research proposals. Simulat Gaming 2009;40(2):50. [doi: 10.1177/1046878108321866]
27. Dempsey JV, Rasmussen K, Lucassen B. The instructional gaming literature: Implications and 99 sources. Alabama: University South Alabama, College of Education; 1996. URL: http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.202.2287&rep=rep1&type=pdf [WebCite Cache ID 6DvgytE3K]
28. Lieberman DA. Management of chronic pediatric diseases with interactive health games: theory and research findings. J Ambul Care Manage 2001 Jan;24(1):26-38. [Medline: 11189794]
29. Wong PW, Fu KW, Chan KY, Chan WS, Liu PM, Law YW, et al. Effectiveness of a universal school-based programme for preventing depression in Chinese adolescents: a quasi-experimental pilot study. J Affect Disord 2012 Dec 15;142(1-3):106-114. [doi: 10.1016/j.jad.2012.03.050] [Medline: 22840612]
30. Kittinger R, Correia CJ, Irons JG. Relationship between Facebook use and problematic Internet use among college students. Cyberpsychol Behav Soc Netw 2012 Jun;15(6):324-327. [doi: 10.1089/cyber.2010.0410] [Medline: 22703039]
31. Manago AM, Taylor T, Greenfield PM. Me and my 400 friends: the anatomy of college students' Facebook networks, their communication patterns, and well-being. Dev Psychol 2012 Mar;48(2):369-380. [doi: 10.1037/a0026338] [Medline: 22288367]
32. Poirier J, Cobb NK. Social influence as a driver of engagement in a web-based health intervention. J Med Internet Res 2012;14(1):e36 [FREE Full text] [doi: 10.2196/jmir.1957] [Medline: 22356829]

33. Gold J, Pedrana AE, Stoove MA, Chang S, Howard S, Asselin J, et al. Developing health promotion interventions on social networking sites: recommendations from The FaceSpace Project. J Med Internet Res 2012;14(1):e30 [FREE Full text] [doi: 10.2196/jmir.1875] [Medline: 22374589]
34. Lim K, Meier EB. Different but similar: computer use patterns between young Korean males and females. Education Tech Research Dev 2011 Apr 2011;59(4):575-592. [doi: 10.1007/s11423-011-9206-5]
35. Joiner R, Gavin J, Brosnan M, Cromby J, Gregory H, Guiller J, et al. Gender, internet experience, Internet identification, and internet anxiety: a ten-year followup. Cyberpsychol Behav Soc Netw 2012 Jul;15(7):370-372. [doi: 10.1089/cyber.2012.0033] [Medline: 22690795]
36. Jorm AF, Korten AE, Jacomb PA, Christensen H, Rodgers B, Pollitt P. "Mental health literacy": a survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment. Med J Aust 1997 Feb 17;166(4):182-186. [Medline: 9066546]
37. Butler AC, Chapman JE, Forman EM, Beck AT. The empirical status of cognitive-behavioral therapy: a review of meta-analyses. Clin Psychol Rev 2006 Jan;26(1):17-31. [doi: 10.1016/j.cpr.2005.07.003] [Medline: 16199119]
38. Hofmann SG, Smits JA. Cognitive-behavioral therapy for adult anxiety disorders: a meta-analysis of randomized placebo-controlled trials. J Clin Psychiatry 2008 Apr;69(4):621-632 [FREE Full text] [Medline: 18363421]
39. Ching-Ching Story. URL: http://apps.facebook.com/mentalhealthgame/ [WebCite Cache ID 6FjFFbHvy]
40. Hilgart MM, Ritterband LM, Thorndike FP, Kinzie MB. Using instructional design process to improve design and development of Internet interventions. J Med Internet Res 2012;14(3):e89 [FREE Full text] [doi: 10.2196/jmir.1890] [Medline: 22743534]
41. Pintrich PR, Smith D, Garcia T, Mckeachie W. Reliability and predictive validity of the Motivated Strategies for Learning Questionnaire (MSLQ). Educ Psychol Meas 1993;53(3):801-813.
42. Schafer JL. Multiple imputation: a primer. Stat Methods Med Res 1999 Mar;8(1):3-15. [Medline: 10347857]
43. Chau M, Xu J. Business intelligence in blogs: Understanding consumer interactions and communities. MIS Quarterly 2012;36(4):1189-1216.
44. Eysenbach G, CONSORT-EHEALTH Group. CONSORT-EHEALTH: improving and standardizing evaluation reports of Web-based and mobile health interventions. J Med Internet Res 2011;13(4):e126 [FREE Full text] [doi: 10.2196/jmir.1923] [Medline: 22209829]

Abbreviations

DGBL: digital game-based learning
ITT: intent-to-treat
MCAR: missing completely at random
MI: multiple imputation
MSLQ: Motivated Strategies for Learning Questionnaire
SNS: social networking sites

Edited by G Eysenbach; submitted 17.08.12; peer-reviewed by E Black, E Lyons; comments to author 29.12.12; revised version received 08.02.13; accepted 08.03.13; published 15.05.13.

Please cite as:
Li TMH, Chau M, Wong PWC, Lai ESY, Yip PSF
Evaluation of a Web-Based Social Network Electronic Game in Enhancing Mental Health Literacy for Young People
J Med Internet Res 2013;15(5):e80
URL: http://www.jmir.org/2013/5/e80/
doi:10.2196/jmir.2316
PMID:23676714

Original Paper

Work and “Mass Personal” Communication as Means of Navigating Nutrition and Exercise Concerns in an Online Cancer Community

Brad Love[1], PhD; Charee M. Thompson[2], MA; Brittani Crook[3], MA; Erin Donovan-Kicken[3], PhD

[1]Belo Center for New Media, Department of Advertising and Public Relations, University of Texas, Austin, TX, United States

[2]School of Communication Studies, Ohio University, Athens, OH, United States

[3]College of Communication, Department of Communication Studies, University of Texas, Austin, TX, United States

Corresponding Author:
Brad Love, PhD
Belo Center for New Media
Department of Advertising and Public Relations
University of Texas
300 W Dean Keeton St
A1200
Austin, TX, 78712
United States
Phone: 1 5124713482
Fax: 1 5124717018
Email: lovebrad@utexas.edu

Abstract

Background: Health and psychosocial outcomes for young adults affected by cancer have improved only minimally in decades, partially due to a lack of relevant support and information. Given significant unmet needs involving nutrition and exercise, it is important to understand how this audience handles information about food and fitness in managing their cancer experiences.

Objective: Using the theory of illness trajectories as a framework, we explored how four lines of work associated with living with a chronic illness such as cancer (illness, everyday life, biographical, and the recently explicated construct of communication work) impacts and is impacted by nutrition and exercise concerns.

Methods: Following a search to extract all nutrition- and exercise-related content from the prior 3 years (January 2008 to February 2011), a sample of more than 1000 posts from an online support community for young adults affected by cancer were qualitatively analyzed employing iterative, constant comparison techniques. Sensitized by illness trajectory research and related concepts, 3 coders worked over 4 months to examine the English-language, de-identified text files of content.

Results: An analysis of discussion board threads in an online community for young adults dealing with cancer shows that nutrition and exercise needs affect the young adults’ illness trajectories, including their management of illness, everyday life, biographical, and communication work. Furthermore, this paper helps validate development of the “communication work” variable, explores the “mass personal” interplay of mediated and interpersonal communication channels, and expands illness trajectory work to a younger demographic than investigated in prior research.

Conclusions: Applying the valuable concepts of illness, everyday life, biographical, and communication work provides a more nuanced understanding of how young adults affected by cancer handle exercise and nutrition needs. This knowledge can help provide support and interventional guidance for the well-documented psychosocial challenges particular to this demographic as they manage the adversities inherent in a young adult cancer diagnosis. The research also helps explain how these young adults meet communication needs in a “mass personal” way that employs multiple communication channels to meet goals and thus might be more effectively reached in a digital world.

(J Med Internet Res 2013;15(5):e102) doi:10.2196/jmir.2594

KEYWORDS

technology; young adult; psychosocial factors; social support; cancer; communication; exercise; dietetics; Internet

Introduction

Despite advances in medical care and treatment, survival rates for many young adults affected by cancer have not improved in recent decades [1,2]. Posttreatment issues remain common [3], in part from reduced access to age-appropriate support resources, which can negatively affect psychological and social development [4-8]. Additionally, a lack of information about exercise and nutrition is acutely prominent during the young adult cancer journey [5,9], despite exercise and nutrition's role in managing symptoms and contributing to health outcomes.

As many as 52% of adolescent cancer survivors do not engage in enough physical activity, and 79% do not meet guidelines for fruit and vegetable consumption [10]. Poor diet and exercise behaviors contribute to comorbidities, including secondary cancers, cardiovascular disease, and diabetes (see Arroyave and colleagues [11], for a review). Furthermore, unmet physical and daily living needs are related to greater depression and anxiety [9].

An individual's illness trajectory encompasses more than the physiological course of the illness; it involves broader and more social factors such as work associated with the illness, the impact on relationships, and how these factors affect outcomes for the person diagnosed with the illness [12]. Serious illnesses such as cancer are experienced as trajectories, "the course of an illness over time, plus the action of clients, families, and healthcare professionals to manage the course" p. 257 [13], which involves negotiating types of work to manage the broader challenges associated with disease [13]. Identifying how the young adult cancer community handles nutrition- and exercise-related work during their cancer trajectory would contribute to understanding the development of a "new normal."

Additionally, exploring a topic such as nutrition and exercise that has relevance across cancers presents an opportunity to learn about the broader young adult cancer experience. Cancer as a disease consists of many different conditions. As such, cancer research tends to focus on specific diagnoses instead of examining the overall experience; thus, another benefit of research focusing on broadly useful topics such as food and exercise is the chance to better understand commonalities among cancer experiences.

The Work of Establishing a New Normal

A cancer diagnosis disrupts every facet of life and introduces chaos as a normal part of daily existence [14], both for those receiving the diagnosis and their supporters. As a result, cancer becomes more than a biological and physical state—it becomes a social experience [15], and for those affected, managing illness necessitates additional tasks including learning to access needed information, re-negotiating identities and relationships, and coping across the illness' effects [16,17]. These efforts help patients adjust to life after diagnosis and define a "new normal" as they move through the illness journey [18].

An informative way to understand this time of transition is Corbin and Strauss's [13] theory of illness trajectories with its central component of work. Their examination of couples dealing with chronic conditions specified three lines of work: illness, everyday life, and biographical. Illness work consists of managing tasks related to the health condition, ranging from regular responsibilities such as tracking blood sugar to crisis prevention. Everyday life work covers tasks related to maintaining a functioning household such as housekeeping, child-raising, marital obligations, and occupational responsibilities. Biographical work involves management of the biographical disruption that comes with chronic illness, including the reconstruction of identity and life planning [13].

Based on Corbin and Strauss's analysis, Donovan-Kicken and colleagues [15] summarized a number of dimensions that characterize cancer management behaviors as work, including completing tasks and assigning responsibility for completion; exerting effort, allocating resources, coordinating duties; and dividing up labor throughout the trajectory. Further, Donovan-Kicken and colleagues identified communication work as an important fourth line of work to consider in understanding illness trajectories. Communication work entails the coordinated management of creating, exchanging, and interpreting messages pertinent to the experience of illness and is embedded in the larger context of daily life and ongoing relationships [19]. Because it constitutes the most recent extension of the theory of illness trajectories, we provide an additional overview of the construct of communication work next.

As has been noted in a range of chronic-illness environments (eg, [20,21]), exchanging information about a disease may occur as demanding, challenging work beyond simply seeking and receiving information to meet a need [22]. Communication work reflects an updated way of thinking about communication in illness trajectory research [19]. Studying communication work "means shifting the focus from communication as a necessary behind-the-scenes duty that allows the other lines of work to exist and succeed, to a focus on communication in the foreground, wherein the processes of exchanging messages and achieving meaning are examined as essential elements of the illness experience" p. 648 [15]. Because the construct of communication work concerns the labor of interacting with information and with other people, it provides a means of conceptualizing the effort that people devote to locating, using, understanding, sharing, and managing information both intra- and interpersonally [15,21]. It enables scholars to account for the burden, effort, process, resources, and outcomes of communication in addition to how these aspects relate to illness, everyday life, and biographical work.

Articulation work refers to the coordination activities necessary to complete all four lines of work (illness, everyday, biographical, communication) and thus sits across the illness trajectory framework, playing a role in each aspect [19]. Articulation work "is work that gets things back 'on track' in the face of the unexpected," p. 275 [23], encompassing the organization necessary to make arrangements for other work to take place [20]. Such efforts play an essential role in the management of work flow, according to Strauss [24], as articulation is "the coordination of lines of work. This is accomplished by means of the interactional processes of working out and carrying through of work-related arrangements" p. 87 [25].

In explicating communication work, Donovan-Kicken analyzed the properties of two existing elements of the theory of illness trajectories: information work and articulation work [19]. The three related concepts intermingle in that information work, a functional activity about searching for information, fits inside the more comprehensive concept of communication work, which also entails the interpersonal communicative efforts not discussed either as part of or in service to the other three lines of work. While communication involves gathering information, it also entails effortfully employing that information to interact with other people and the work required to negotiate relationships, including expressing emotions and moods, which can be particularly demanding for people dealing with illnesses or disabilities [26].

Previous research on communication work in the cancer context has indicated that communication work is present in social and personal relationships as people engage in effortful tasks such as disclosing illness status, explaining medical details, defending treatment decisions, and communicating support [15]. Some of those interactions entail traditional information work in making sense of illness-related information like risks and success rates for treatment options. Other interactions go beyond that scope into what is labeled here as communication work and involve a broader array of interpersonal obligations and conversational demands demonstrated in prior research, such as maintaining social networks, managing private information, and comforting others [27-30]. Isolation and uncertainty serve to make these work tasks even more labor-intensive [31]. Further, patients and their support networks may engage in articulation work to coordinate communication efforts and to divide up the labor, for example by assigning information dissemination tasks [15].

Work in the Young Adult Cancer Context

Young adults with cancer are likely to experience the four types of work as uniquely challenging. Consistent with research on “emerging adulthood” [32], the transition from adolescence to adulthood (18 to 39-year-olds, per the official US Department of Health and Human Services definition) [33] is a unique time for young adults critical to future well-being [2,34]. The experience of cancer derails young adult identity development and in many cases makes achieving milestones (eg, attending college, getting married) more difficult [35-37].

The well-being of those affected by cancer depends in part on psychological and social development [38], and many young adult patients deal with serious psychosocial troubles [6,39-41]. Even those doing quite well still deal with quality-of-life concerns ranging from worries about how their health impacts family members to reduced marriage and fertility rates [42-44]. The mobile nature of young adult lives can worsen unmet support needs and further limit contact with health care providers [45] as they transition among cities, jobs, and medical options. Despite these issues, researchers lump young adults in with other demographics and fail to examine their age-specific needs [4,8].

In general, young adult cancer survivors experience significant stress around information needs [2]. While almost every respondent to one broad survey (N=879) expressed a need for further information about illness and treatment, two-thirds voiced a desire for content about exercise and nutrition specifically [2], findings supported by other projects [7,8,46]. This scholarship suggests that the young adult cancer community has needs that are different from the general cancer community, including needs related to information about exercise and nutrition. To better understand that trajectory, we posed the following research question:

RQ1: What is the nature of work around exercise and nutrition for young adults affected by cancer?

Mediated Communication and Work

Young adults live digital lives [47,48], and those affected by cancer are no exception [49,50]. Health professionals and patient advocates increasingly recognize digital media for spreading health information tailored to youth [51-56]. Thus, not only does studying mediated communication provide an opportunity to learn more about the exercise- and nutrition-related needs and behaviors of young adults with cancer, but the online context also presents an innovative approach to applying the concept of communication work and the theory of illness trajectories.

Corbin [57] acknowledges that theory of illness trajectories could and should be updated to consider modern developments. When Corbin and Strauss [13] developed illness trajectories, the impact of technology was yet to be realized for its informative and supportive utility in health contexts. Further, Donovan-Kicken and colleagues’ [15] definition of communication work also supports the utility of digital media for its ability to help individuals manage and process information [58] through interactions with others sharing similar health concerns and information needs [49,59]. We felt it important to recognize the influence of digital media as a primary source of information and support for young adults dealing with cancer [50], as understanding choices and tailoring to the needs of young adults can allow for effective and efficient digital support interventions [53]. Thus, we posed the second research question:

RQ2: What is the role of mediated communication in illness-trajectories work among young adults affected by cancer?

Methods

Sample

Data from an online young adult cancer forum were compiled from de-identified text-only files of full conversation threads, after Institutional Review Board approval and cooperation from community managers. Community membership registration states that content may be used for research purposes as well as a statement that content can be used for “well-behaved,” noncommercial efforts, subject to the definition and discretion of network administrators.

The forum is one of several online, English-language forums open to any young adult affected by cancer across the treatment spectrum. The online community that produced the text has several thousand users responsible for almost 20,000 monthly visits. Based upon required questions posed to all new members and the content of the community discussions, we can infer that community members are within an age range of 18-39, fitting the generally accepted AYA definition. Additionally, user data aggregated by the community indicates that users are slightly more likely to be female, have English as a mother tongue, and come primarily from the United States with single-digit percentages of members participating from Australia, the United Kingdom, and Canada.

Posters in the sample discussed cancer as a lived, first-person experience as opposed to writing about others' happenings. Care providers and supporters of individuals diagnosed with cancer do make up a small percentage of the community membership but did not come up in this sampling.

The first 3 authors (hereafter referred to as researchers) read through a subsection of the entire pool of threads to identify relevant nutrition- and exercise-related terms, including exercise, sport, work out, gym, nutrition, nutrients, diet, and weight management. Researchers compiled and agreed upon a list of terms and then extracted all other threads in which at least one of the terms was discussed. The original post did not have to be about nutrition or exercise to be included in the sample. Often, individuals would mention nutrition and/or exercise in response to the original comment that may have had nothing to do with nutrition or exercise; however, it was clear that nutrition and exercise were ways individuals understood and responded to others' questions and concerns. This way, we were able to see what nutrition and exercise mean to people affected by cancer in a naturalistic way that is more in line with how individuals experience illness trajectories.

The final text sample consisted of 1000 posts comprising 79 complete threads (initial post and corresponding comments) across 342 pages. Threads were initiated by users from January 2008 to February 2011 and ranged widely in length and duration. Some threads received little engagement, consisting of only an initial post. Other threads addressed engaging topics and continued for more than a hundred follow-up posts during the course of 2 full years.

Data Analysis

We employed an iterative approach over 4 months to analyze the text. We grounded our analysis in sensitizing concepts [60] from Corbin and Strauss's [13] scholarship on work and illness trajectories, along with Donovan-Kicken et al's [15] review and contribution, as well as Becker's [14] phenomenological research on chaos and sense-making during life crises. Chaos and uncertainty research presents important concepts in this context because they signal the work of creating a "new normal" for individuals dealing with difficult life experiences such as a cancer diagnosis. Engaging these texts allowed the research team to better understand the relationships among work, uncertainty, and daily life for those affected by illness. By examining the data initially and reviewing it following sensitization to key concepts, researchers operated per grounded theory expectations of continuous data collection and analysis [61].

Using constant comparison methods [62], we looked for themes in the text to better understand the role of exercise and nutrition in the young adult cancer experience. Researchers examined the text incrementally to allow for intermittent discussion of emergent themes so that ideas could be tested and improved during follow-up readings [63,64]. All researchers contributed to guiding the data analysis by analyzing text individually and then discussing and challenging findings as a group. The research team established coder agreement through discussions over 4 months and based findings on agreement that the themes and relationships were present [65].

The team maintained theoretical notes throughout the coding process and used peer debriefing to establish trustworthiness of findings [66]. Through regular debriefing, the fourth author served to verify the researchers' application of the key concepts to the data and provided a disinterested perspective during analytic sessions. The following section presents findings and exemplars. All proper nouns such as names of people and treatment facilities are pseudonyms, and potentially identifying details are edited for anonymity.

Results

Our analysis of the data suggests that managing cancer in the context of nutrition and exercise is effortful, demanding, and burdensome in ways consistent with Corbin and Strauss's [13] conceptualization of work. These lines of work—illness, everyday life, biographical, and communication—overlap and compete as young adults try to achieve some semblance of normality. Our findings suggest that not only do eating and exercising become more effortful, but they also make other types of work more onerous. Each line of work is elaborated next to address our first research question concerning the nature of work around exercise and nutrition for young adults affected by cancer.

Illness Work

Illness work refers to the scope of tasks connected to managing the health condition, including both daily responsibilities such as taking pills and irregular activity such as follow-up visits with an oncologist. Illness work is most prominent in our data concerning how nutrition and activity can be employed as a way for these young adults to maximize their health by fighting cancer itself or managing the side effects of cancer and treatment.

Young adults in our sample describe how modifications in diet and exercise can maximize health during treatment by serving as another means of combatting the disease. One member explains: "I was on a high-dose chemo regimen for CNS lymphoma (brain tumor), so for me it was good to have high protein and lots of fresh fruits and veggies, according to what my dietitian said. My docs said I couldn't have supplements because of my treatment."

In addition, young adults describe how nutrition and exercise become ways of managing side effects. They talk about being surprised and disheartened by the way cancer affected their bodies—through weight gain and loss, changes in body composition or mobility (eg, loss of a limb), and decreases in energy. As one member wrote:

> *While I was going through the chemo, I did not realize what I do now, that prednisone and like drugs mess with your body's sugar metabolism. So, now when I*

> *am on it for a month at a time, I find I can minimize the weight gain by watching my sugar intake. I still gain a bit (5-8 lbs) overnight it seems, and get the moon face and fat neck, but the overall number of pounds is much less that when I did not watch my sugars.*

Making diet modifications and exercising become ways of combating and alleviating negative effects while asserting some control. As one poster succinctly commented, “at least during treatment you feel like you’re actively doing something about the cancer.”

Exercise, in particular, is described by young adults as mandatory because of its role in weight management and importance in adjusting to physical changes from treatment. Posters document their activity regimens and successful outcomes as necessary illness-driven aspects of their trajectories. One member wrote about his daily gym routine:

> *With me it was pretty quick after I finished radiation treatments that I got back to it. I just started off easy and upped time/difficulty every day. I gave myself a week to rest before I got back to it. For me it wasn’t an option not to exercise because I’ll backslide at an amazing rate due to nerve damage. Fun stuff. I don’t know. For me, I just tried to mentally psych myself up for it. And told myself I HAVE to do it.*

Physical changes often take the form of working against such nerve damage or adjusting to amputations. A poster discussed the consistent work required to re-establish hand mobility following surgery:

> *I have had to have physical therapy in order to learn how to use my right hand again as I had a Ewing’s Sarcoma of the left middle finger. My finger was amputated and the forefinger pulled towards the other fingers in a procedure called a Ray Resection. I was determined and within 4 months of surgery had almost full use of that hand again. People don’t even notice I missing something until I show them.*

These exercise and nutrition efforts constitute illness work because fighting cancer and managing side effects are aspects of dealing with illness-related issues above and beyond basic tasks of normal life. In dealing with how cancer has affected their bodies, consistent activity and a focus on food become obligatory tasks for these young adults to deal with their illnesses and accompanying issues. Exercise and nutrition offer a way of grappling with the weight changes common to cancer treatment as well as learning to function with more extreme physical issues such as nerve damage or balance problems.

Everyday Life Work

According to Corbin and Strauss’s [13] original conceptualization, everyday life work involves activities done to maintain a household and life as an independent adult. While diet and exercise may not be as crucial to household functioning as paying bills, young adult comments suggest depleted energy and physical (in)capacity impact the feasibility of everyday tasks. As one contributor wrote, “Time is pushing down on me and it is going to run out. Every day I think, ‘I don’t have enough time!’ while I am simultaneously washing my dishes, having a phone conversation and cooking dinner!”

Our reading of the data suggests that nutrition and exercise activities make the everyday life work of household management more effortful and onerous. For example, preparing meals and exercising become “work”, and young adults talk about not fully appreciating food and fitness as leisure. Diet and exercise concerns move from being issues of “want to” to “have to”. Cancer takes away choices individuals have with respect to diet and exercise. As one young adult describes:

> *I’m tired of being virtuous. I’m tired of doing an hour of meditation. Of making perfect organic meals three times a day. Of making a pint of fresh carrot juice. Of drinking green tea instead of a nice cup of coffee. Of missing desserts. Of the possibility of getting drunk (since I know it will depress my immune system). Of exercising even when I feel bad. Of reading dozens of self-help books. Of feeling I should be doing something productive like guided imagery when I lay down to rest. Of acupuncture appointments. Of the uphill task of researching supplements and making intelligent decisions about dosages.*

For this community member, dealing with food and activity adds to the burden of the illness trajectory by creating demands to make life as an independent adult that much harder. Activities that may have been enjoyable pre-cancer (ie, preparing food, exercising) switch to effortful parts of life.

Required everyday nutrition management plays into difficult feelings, as food preparation creates burdensome demands per treatment or maintenance requirements, according to many young adults. The low-iodine diet recommended to thyroid cancer patients stands out as an example of nutrition management becoming everyday life work and driving strong emotions: “But that combo of deprivation and exhaustion and effort required to eat in an iodine-less way is a killer. It sucks. I made the mistake of going out to eat once…It was so hard not to cry into my lettuce with olive oil and vinegar (and to not grab fistfuls of French fries and oysters off the table)!! That was torture.”

Additional effort and time for nutritional needs adds to the burden of the young adult cancer experience, particularly intersecting with life stage issues such as being away from family or having extensive early career work burdens. As one member wrote when discussing her low-iodine diet:

> *I can’t believe I have to do this for another nine days. I cannot cook anymore! I spent an entire afternoon making my tortillas for this last week and I don’t have the time! I’m a single woman with a full time job and no friends nearby. It’s like the whole thing was created for people with the time to cook and/or the money to purchase organic meats so they won’t starve. It’s bullshit!...I’m so over this and so angry that I want to call my endocrinologist and bitch, just so I can blame someone and because it concerns me that I feel so physically bad. I don’t know what I can do to fix this. Take sick days so I can cook?? I am at*

> *the end of my rope. I'm tired, pissed off, really hungry, and out of patience.*

Exercise and nutrition impact everyday life work by forcing previously optional activities to become required ones. Physical activity and food management become necessary household responsibilities essential to well-being and ability to complete other work. Previously positive or interesting hobbies can even transition from blessings into burdens.

Biographical Work

Exercise and nutrition affect biographical work by influencing how individuals process temporal aspects of identity re-construction, particularly when viewed through pre-cancer experiences. Fitness and food affect how young adults view their pre-cancer selves, how they deal with the present, and how they prepare for the future. Biographical work is particularly colored by body image perceptions—and resulting self-esteem attitudes—in addition to concerns about making the most of life through improved nutrition and exercise; thus, the topic areas become ways of adding hope to their identity re-building.

Comparison to prior fitness achievements and pre-cancer selves presents a direct challenge to aspects of identity re-construction including making sense of ongoing effects. As one member wrote:

> *I am a choreographer and was in the studio dancing 5 or 6 days a week before I was diagnosed. I feel like cancer did a number on that part of my identity. For me it was not just a matter of having the physical energy to get back into it, there has been a huge mental block there too.*

Viewing the present through an activity-related past adds an identity-driven challenge inherent in any diagnosis and treatment regimen; many young adults no longer know how to label themselves in line with their exercise efforts nor how permanent those classifications are. As one post read: "I was an athlete before one of many surgeries. I hate using 'was'. I suppose it is now in dormancy…How do you guys deal with temporary or permanent loss of sports?" Young adults in such situations are then forced to re-evaluate key self-ascribed labels (eg, "athlete") that may have been foundational pre-diagnosis, and in many cases, finding new labels is a monumental challenge for which they are unprepared.

Comparisons to prior exercise routines also overlap with key moments in personal relationships and major events that helped individuals mark time in their pre-cancer lives. Changing fitness norms can impact regular routines as well as milestones that serve as personal highlights and create identity within families. One member commented regarding difficulties with re-establishing his exercise regimen and the impact on noteworthy fitness events related to his long-term identity as a cyclist:

> *Pre-cancer, I was at the gym three-four times a week, and was in a nice groove of getting up at 6 for a work-out before heading to the office. Needless to say, life's a bit different now, I really love and need my rest, and I am as stiff as hell when I wake up in the morning. At the end of the day, I am tired from working all day!!…I really feel like I want to start - slowly - getting back into an exercise groove. But I am having a devil of a time kick-starting this thing. I am also an avid cyclist and have pretty much missed the whole riding season. In a few weeks, the annual MS 150 Ride which my partner and I have been doing for years is coming up, and I feel a certain sadness that I just didn't have the strength or energy to train this year.*

Along with identity questions driven by pre-diagnosis activity-focused experiences, exercise and nutrition also affect ongoing biographical work by influencing feelings about body image and self-esteem. For some, fitness and food are a means of recognizing and expressing how life is different post diagnosis. As one person noted: "I finished my chemo a little over two years ago, and am only just coming to grips with the changes. I am NOT the same person I was BC (before cancer). Lots has changed: I get tired a lot easier, my diet has changed (can't eat fast food, gotta watch fat intake), my eyesight is different, and on and on." Young adults in such situations grapple with the challenge of creating a new identity more in line the current reality, including what cancer has done to dietary habits and body composition. Each meal time, for example, can force ongoing realizations that life has irrevocably changed.

Exercise and nutrition can be empowering for other young adults, however, as they use weight management to assert control over an area of life and self-perception. One poster discussed her weight management as something she could track and take comfort in while moving forward from the difficulties of illness: "I lose about half to a kilogram a week but if it's less (like this week 0.1) I'm not upset as I know it's 0.1 that won't be back again. The biggest thrill is—and I'm sure you'll agree—walking in to shops and grabbing heaps of things you can try on and they look good." This community member found empowerment through exercise- and nutrition-related changes and the ability to create progress in some area of her life.

A future focus is also a key theme of how exercise and nutrition influence young adult biographical work. Some members of the community discussed food choices, for example, as taking precautions and staying healthy. Food becomes a way of investing in their future selves, such as in this post: "My diet I have changed some things. I eat more veggies, asparagus especially, because I read/was told that it gets rid of bad cells, and dead cells. I have no idea if it does, but I figured can't hurt to eat fresh veggies." Food allows young adults such as this to take daily action with future well-being in mind and move beyond the extremely focused present required in treatment or the past-centered framework common to those struggling with identity re-creation [67].

Exercise activity can play a similar role, according to members, by creating situations allowing for personal growth and changed self-perceptions through programs such as First Descents, an outdoor adventure camp for young adults affected by cancer:

> *I have found more of myself with life after cancer by going to a young adult retreat by First Descents…You get to find life again by kayaking on the river…[k]ayaking made me realize if I can beat*

> *cancer, I can beat the rapids on the river. You see, one of my fears is drowning, and after flipping over after I hit my head on into a rock, I survived. I realized not to be so scared and to live my life. I will run those 5K's, join a gym class, socialize more by inviting family members over more often.*

Biographical work makes up a large portion of the exercise and nutrition discussions. Ongoing development of self-image intertwines with how young adults remain or regain activity as well as how they cook and eat, particularly in social situations. Factors including weight gain play a central role in how young adults view themselves and manage interactions, particularly when considered in light of their pre-cancer selves.

Communication Work

Communication work describes the coordinated management of creating, exchanging, and interpreting messages, which affects whether individuals choose to communicate with others, share information, and use communication technology as a means of managing all types of work related to exercise and nutrition. The interplay of how users employ the mediated online community to discuss and prepare for face-to-face interpersonal conversations offers examples of how this specific demographic employs a combined "mass personal" approach to their communication work needs [68,69]. These findings help respond to our second research question about the role of mediated communication in illness-trajectories work among young adults affected by cancer.

An aspect of communication work discussed online is the challenge young adults feel in choosing to relate their cancer experience to others, particularly regarding diet restrictions. Discussing food and eating requires message preparation and planning for responses. According to the digital discussions, online groups and resources play a constructive role in helping individuals do the work needed to prepare for these offline conversations; participants exchange advice about communicating with doctors, loved ones, and work colleagues about food, in particular, and note the online community's importance with comments such as, "Thanks for the response, sharing information does help us all."

Similar communication work appears regarding exercise and nutrition in posts regarding message preparation for everything from medical-office visits to explaining post-treatment life to family members. Sometimes, communication work in this environment also entails trying to understand or predict reactions to communicative efforts about exercise, for example, including different responses among community members themselves. One young adult wrote to ask about a fellow survivor's reaction to communicating about fitness issues, seeking help to understand his perspective as an initial step to effectively reach him:

> *He is mad that he lost his muscles, however is not really getting out to the gym to get them back. It's as if he can't see that it could be worse, he could be dead. I have tried talk to him and help him see that there are so many great things that he could learn from our experience with chemo and that he should appreciate the life that he does have but he just is not hearing me…can anyone help me to understand his point of view or how to help him because at this point I'm at a loss for words and it hurts my heart to see him wasting the life he has been given a second chance at away sitting inside all the time feeling sorry for himself and like his life is ruined. HELP!*

For this community member, her digital peers were her preferred source for trying to understand past interpersonal conversations and also how to design messages most likely to be effective in future face-to-face interactions. The digital space became her testing ground for real-life discussion.

Community members in this case responded by offering thoughts on how to address the friend's likely ongoing biographical work related to fitness and personal identity, including what kinds of messages would be likely to get him to open up about his illness trajectory. For example, "Guys tend to take a loss of strength and stamina a lot more seriously. Though I can say from personal experience that the whole loss of strength and stamina has been extremely difficult for me. I think guys take it as a blow to their manhood though."

Pressure to effectively communicate one's needs also means that some young adults decide to avoid social situations related to activity or food. For example, the necessary communication work involved in explaining requirements to others can mean avoiding public eating experiences, as one young adult stated, "I also find being forced changed [sic] to my eating really stressful. I don't even like eating out because I feel out of control." Not being in a food-based situation eliminates the need for difficult communication.

Digital technologies and the involved communication work also impact other types of work related to exercise and nutrition, in line with Corbin and Strauss's [13] observation that various lines can simultaneously occur and influence each other. Illness work can be facilitated as users of online support groups share links to preferred exercise and nutrition resources such as calorie counters and offer tips for managing illness issues. For example, one community member offers ideas for activities and connects those tips to a larger resource:

> *Swimming is a great exercise and can help you lose weight. :-) In fact, there are lots of small things you do everyday (walking for instance) that help burn calories and thus weight…You can do it though, just don't give up! If you are interested, The American Cancer Society just made this wellness type program for women, and you can choose a weight goal and people can follow you. Like I said, don't know if you are interested, but thought I would share. :-D*

Everyday life work coincides with communication work when digital communication tools aid management of food-related concerns, such as recipe-planning. Using digital tools to share information sources about weight and exercise also overlaps with biographical work by impacting self-perceptions of identity. A member discusses how a communication technology—a phone application, in this case—helped with the everyday effort of food planning and eventually aided biographical development as this individual experienced success with weight management:

> *I've got a great app on my phone called Lose It, which I use to track my calories. I've told it that I want to lose two lbs a week, and it gives me a calorie limit per day. I track everything I eat and when you go over your daily limit, the chart turns red. The program has a huge database of food (calorie counts for many restaurants). It can be difficult to get into the habit, but now I'm addicted to tracking calories for everything.*

Communication work, biographical work, and everyday life work co-mingle for this individual to drive better outcomes for weight management and body composition goals. Communication tools help manage the actual everyday task of food preparation toward the end goal of a different leaner physical self-presentation.

Communication work stands out as a varied but essential element of young adults' illness trajectories, including how they design messages, manage information, and employ technology. Communication work also intersects with other kinds of work related to exercise and nutrition, including illness work through tips on symptom management, everyday life work involving recipe-sharing or meal-planning, and biographical work in helping plan messages to discuss sensitive issues, to name some examples.

Discussion

Principal Results

The findings of this article, in response to our first research question, describe how young adults affected by cancer experience significant exercise and nutrition needs and the notion of work helps to define their efforts, as these individuals manage the illness, everyday life, biographical, and communication aspects of cancer [13,15]. The four lines of work overlap and compete for limited resources during the time when young adults report significant unmet needs related to exercise and nutrition and strive to create a "new normal" for themselves [2].

A more nuanced grasp of how young adults deal with exercise and nutrition can help develop support efforts and approach the well-documented psychosocial challenges particular to cancer diagnoses during their life stage [2,8,70]. Nurses, dietitians, social workers, and health communication practitioners, for example, could use these findings to tailor support efforts, focusing on the ways young adults affected by cancer balance competing work demands across varying illness trajectories.

This study also expands the demographic focus of illness trajectory research by examining the young adult experience, whereas other illness trajectories research has tended to involve middle-aged or older participants. Such expansion helps better document the understanding of illness trajectories and allows for comparison among age cohorts.

Additionally, driven by our second research question, this article extends the concept of communication work into the realm of digital media and online support. The study expands the application of research into the interplay among communication channels to examine the mix of interpersonal and mediated communication, building upon information-flow and limited-effects streams of research [71,72]; individuals undertake communication work by moving back and forth between online and offline contexts. Young adults in this sample participate in person-to-person conversations through posts in the online group about exercise and nutrition and then use those interactions to shape face-to-face conversations with friends and family. Young adults can also use older posts in the support group as an archive to gather needed content for face-to-face connections with loved ones and care providers—occasionally re-starting long-dormant online conversation threads out of a need for further information, support, or interaction. The result is an understudied "mass personal" mix of communication channels bringing the digital and the physical together into an essential resource for young adults laboring to complete work.

Understanding this interplay of communication channels offers opportunity to create focused interventions based upon the way individuals prefer to use media as well as their information needs [73]. Previously tested health interventions tailored to cultural norms, health literacy, and media-use preferences have demonstrated the impact and importance of fully considering audience factors [74,75]. Taking advantage of channel preferences or sharing across channels can be equally important. If the desired audience prefers to receive new information through short Facebook posts so that the knowledge can be discussed at more length face-to-face among friends and then further spread through crystalized 140-character Twitter messages, this is the scenario for which health promotions professionals should prepare. In other health contexts, patients have reported appreciating when health care professionals express openness to patients pursuing and discussing outside information [76].

Food- and activity-related tasks become required, demanding, and effortful while needing coordination and management over time for the expectation of longer-term benefits. Our findings indicate that illness, everyday life, biographical, and communication work concerning exercise and nutrition are relevant to this population in different but overlapping ways. Illness work is expressed mostly around modifying activity and diet to fight cancer itself as well as making changes to manage side effects. Young adults discuss illness work related to exercise and nutrition as a means of maximizing health during difficult and stressful times.

Exercise and nutrition's role in everyday life work for young adults comes out as onerous and particularly demanding because of physical and emotional limitations from treatment as well as the barrier of the biographical-work comparison to their pre-cancer selves. Young adults discuss the need to re-start exercise regimens as a source of significant frustration, and the same applies to nutritional changes. Community members discuss feeling forced to simultaneously manage the work of deliberately shifting food-consumption patterns while grappling with body-image issues related to weight gain. Such feelings indicate an area for nursing or social work support to overcome challenges common to young adult nutrition and exercise concerns [77]. Support services focused on helping young adults affected by cancer manage needed nutrition changes can help routinize and ease the burden of practical barriers such as learning to cook.

Biographical work stands out as the most discussed area of work within our data, as it is both prominent on its own and frequently woven into other lines of work while young adults struggle to manage body-image and self-esteem questions. Key identity re-construction takes place here in a time-related manner [34]. Many individuals frame identities through past exercise and nutrition experiences while ongoing movement and food challenges strongly affect current self-perceptions. Looking to the future, young adults use exercise and nutrition as a tool to actively build hope into their expectations by employing activity and diet to fight off future problems and maintain wellness. Knowledge of the food and exercise behaviors that help young adults feel empowered relating to their futures could play a useful role in supportive educational interventions, where the need for nutritionally focused efforts is particularly acute. Little research has examined nutritional/dietary interventions for cancer survivors in general [78], and almost none looks into young adults specifically [77]. This line of research into nutritionally influenced health and identity outcomes presents significant potential for impact on young adults' cancer trajectories.

Communication work plays an involved and nuanced role in how young adults express, share, and manage exercise and nutrition across illness trajectories. Users of the online community studied here employ a "mass personal" approach where they work seamlessly between their face-to-face conversations and online interactions to gather information, discuss thoughts and feelings, and prepare for interpersonal conversations of all kinds, including elsewhere online, with medical professionals, and with colleagues. Such communication patterns open opportunities for the digitally focused support interventions shown to be effective for mental and physical well-being of individuals dealing with chronic illness such as cancer [79].

Young adults often complete communication work in a range of ways to relate exercise and nutrition experiences to others, and these efforts intersect with other lines of work, as expected from prior research. Communication work on- and offline helps individuals manage preparations for message-design activities needed to complete illness work related, for example, to explaining diagnoses to others and biographical work about expressing and understanding the cancer experience. Everyday life work involves communication work when young adults employ communication tools such as online social network and phone applications to manage knowledge about exercise plans or to track nutrition planning. Health professionals would be well served to consider the interplay and range of work demands and communication channels when interacting with patients. By understanding how and why young adults employ sources and content, care providers can proactively address questions and offer accurate, useful content in the ways their patients prefer and are more likely to use.

Limitations

In line with the contributions of this research, it is also essential to note some limitations. Our dataset, being de-identified text from years of online conversations, was already established, eliminating the ability to directly probe at specific items. Reported behaviors and examples of work were thus not verifiable. Further, certain economic and cultural groups are less likely to use such resources [80], and it is also likely that certain treatment centers encourage online support more than others. As our sample consisted of de-identified text, demographic information could not be collected. The online community studied here includes individuals from a broad, English-speaking geographic range spanning ages 18-39 and dealing with a number of cancer diagnoses; thus, the data are useful for young adults affected by cancer but cannot effectively be applied to specific conditions, places along the cancer trajectory, or subgroups. Also, supporters of those diagnosed with cancer were not present in the data and could offer further depth and perspective on the young adult cancer experience related to illness trajectory work and "mass personal" communication. More research through different methodologies and topic areas beyond exercise and nutrition is needed to examine the role of work among young adults.

Comparison With Prior Work

Examining exercise and nutrition within the experience of young adult cancer makes several theoretical contributions when compared to prior research. First, this research brings the theory of illness trajectories into a new demographic and validates key concepts in a different sample. The demographic expansion adds nuance to our understanding of work, particularly biographical work, by studying its impact among individuals in a different life stage than older populations previously studied. As discussed earlier, young adults are more likely to use technology, be in a transitive life stage, have particular information needs, and actively deal with age-specific psychosocial needs. All of these factors help design tailored intervention messages to reach young adults with relevant information.

Second, the contents of this article help validate the recent communication work addition to theory of illness trajectories research [13,15] while extending the communication work addition to a mediated context. Our analysis demonstrated that communication work was present throughout the data. The fact that the conversations we analyzed were natural and unprompted, yet full of examples of communication work, lends credibility to the premise that communication work is a part of living with cancer. Understanding the presence of communication work can help support personnel better prepare those affected by cancer for the effort required.

Additionally, we examine the interplay of interpersonal and mediated communication in a "mass personal" environment where individuals complete communication work by co-mingling online and offline worlds. Community members in this sample create person-to-person interactions by exchanging posts in the online group about exercise and nutrition and then complete face-to-face conversations based on the experience of the online interaction. Older conversations serve an archival purpose useful for message preparation activities, resulting in a mix of communication channels that brings the online and offline together.

More practically, this article also adds to understanding of how food and activity affect the young adult cancer experience and also how young adults complete work to manage exercise and nutrition needs. Using young adults' own words allows for a more thorough understanding about how they discuss this top-level concern, which in turn sets up opportunities for more effective interventions. Furthermore, a better grasp of how young adults affected by cancer use different types of media to complete lines of work aids in planning for how to best help them finish those tasks. With knowledge about how they approach work, it becomes possible to train and coach young adults to more effectively balance the requirements of illness and biographical work, for example.

Conclusions

This article adds to our understanding of how young adults affected by cancer deal with one of their primary unmet needs, exercise and nutrition information. By applying the valuable heuristic concepts of illness, everyday life, biographical, and communication work, we have improved understanding of the young adult cancer experience and described processes by which they manage a series of challenges inherent in a cancer diagnosis to create a "new normal" [2]. A more nuanced understanding of how young adults handle exercise and nutrition can help provide support and make progress with the well-documented psychosocial challenges particular to this demographic [2,8,34], including re-developing a personal identity, maintaining a positive outlook on the future, maximizing health outcomes, and managing communication demands.

The "mass personal" way in which the young adults in this support community move between communication channels allows them to complete work in a number of ways, particularly relating to learning about exercise and nutrition needs as well as expressing their dietary limits. Members in the community gather information from mass media and interpersonal conversations with health care providers before turning to online groups to make sense of that content. Active and archived online group discussions additionally help users complete the work involved with processing their experiences and preparing for upcoming face-to-face and social media interactions. Traditional mass media blur with typically interpersonal outlets in a number of ways that allow for these young adults to create more personalized communication messages that can be delivered to one person or many and receive feedback on that content from the same, potentially long after the initial interaction.

Further investigation of communication patterns and lines of work in the illness trajectories of young adults affected by cancer could lead to interventions that improve on their comparatively poor health and psychosocial outcomes [1,2], including acute need for exercise and nutrition information [5,7].

Acknowledgments

The authors extend their sincere thanks to Drs. Sarah Arvey & Ruth Rechis at the LIVESTRONG Foundation for their support.

The authors also wish to acknowledge the financial support of Seattle Children's Hospital. This publication was supported by an award from Seattle Children's Hospital d/b/a Seattle Children's Research Institute, Seattle, Washington, under funding provided by the Teen Cancer Program. Any opinions, findings, and conclusions or recommendations expressed in this publication are those of the author and do not necessarily reflect the views of Seattle Children's. Seattle Children's neither reviewed nor approved the manuscript for publication.

Conflicts of Interest

None declared.

References

1. Bleyer A. Latest Estimates of Survival Rates of the 24 Most Common Cancers in Adolescent and Young Adult Americans. Journal of Adolescent and Young Adult Oncology 2011 Mar 2011;1(1):37-42. [doi: 10.1089/jayao.2010.0005]
2. Zebrack B. Information and service needs for young adult cancer survivors. Support Care Cancer 2009 Apr;17(4):349-357. [doi: 10.1007/s00520-008-0469-2] [Medline: 18543006]
3. Tai E, Buchanan N, Townsend J, Fairley T, Moore A, Richardson LC. Health status of adolescent and young adult cancer survivors. Cancer 2012 Oct 1;118(19):4884-4891. [doi: 10.1002/cncr.27445] [Medline: 22688896]
4. Haase JE, Phillips CR. The adolescent/young adult experience. J Pediatr Oncol Nurs 2004;21:145-149. [doi: 10.1177/1043454204264385]
5. Hall AE, Boyes AW, Bowman J, Walsh RA, James EL, Girgis A. Young adult cancer survivors' psychosocial well-being: a cross-sectional study assessing quality of life, unmet needs, and health behaviors. Support Care Cancer 2012 Jun;20(6):1333-1341. [doi: 10.1007/s00520-011-1221-x] [Medline: 21720746]
6. Kazak AE, Derosa BW, Schwartz LA, Hobbie W, Carlson C, Ittenbach RF, et al. Psychological outcomes and health beliefs in adolescent and young adult survivors of childhood cancer and controls. J Clin Oncol 2010 Apr 20;28(12):2002-2007 [FREE Full text] [doi: 10.1200/JCO.2009.25.9564] [Medline: 20231679]
7. Keegan TH, Lichtensztajn DY, Kato I, Kent EE, Wu XC, West MM, AYA HOPE Study Collaborative Group. Unmet adolescent and young adult cancer survivors information and service needs: a population-based cancer registry study. J Cancer Surviv 2012 Sep;6(3):239-250. [doi: 10.1007/s11764-012-0219-9] [Medline: 22457219]

8. Zebrack B, Bleyer A, Albritton K, Medearis S, Tang J. Assessing the health care needs of adolescent and young adult cancer patients and survivors. Cancer 2006 Dec 15;107(12):2915-2923 [FREE Full text] [doi: 10.1002/cncr.22338] [Medline: 17103383]
9. Dyson GJ, Thompson K, Palmer S, Thomas DM, Schofield P. The relationship between unmet needs and distress amongst young people with cancer. Support Care Cancer 2012 Jan;20(1):75-85. [doi: 10.1007/s00520-010-1059-7] [Medline: 21311915]
10. Demark-Wahnefried W, Werner C, Clipp EC, Guill AB, Bonner M, Jones LW, et al. Survivors of childhood cancer and their guardians. Cancer 2005 May 15;103(10):2171-2180 [FREE Full text] [doi: 10.1002/cncr.21009] [Medline: 15812823]
11. Arroyave WD, Clipp EC, Miller PE, Jones LW, Ward DS, Bonner MJ, et al. Childhood cancer survivors' perceived barriers to improving exercise and dietary behaviors. Oncol Nurs Forum 2008 Jan;35(1):121-130. [doi: 10.1188/08.ONF.121-130] [Medline: 18192161]
12. Schneider JW, Conrad P. Having Epilepsy: The Experience and Control of Illness. Philadelphia, PA: Temple University Press; 1983.
13. Corbin J, Strauss A. Managing chronic illness at home: Three lines of work. Qual Sociol 1985 1985;8(3):224-247. [doi: 10.1007/BF00989485]
14. Becker G. Disrupted lives: how people create meaning in a chaotic world. Berkeley: University of California Press; 1997.
15. Donovan-Kicken E, Tollison AC, Goins ES. The nature of communication work during cancer: advancing the theory of illness trajectories. Health Commun 2012 Oct;27(7):641-652. [doi: 10.1080/10410236.2011.629405] [Medline: 22168391]
16. Charmaz K. From the "sick role" to stories of the self: Understanding the self in illness. In: Self, social identity, and physical health: interdisciplinary explorations. New York: Oxford University Press; 1999:209-239.
17. Goldsmith DJ. Communicating Social Support (Advances in Personal Relationships). New York: Cambridge University Press; 2008.
18. Denford S, Harcourt D, Rubin L, Pusic A. Understanding normality: a qualitative analysis of breast cancer patients concepts of normality after mastectomy and reconstructive surgery. Psychooncology 2011 May;20(5):553-558. [doi: 10.1002/pon.1762] [Medline: 20878855]
19. Donovan-Kicken E. The unending work of communicating while coping with illness: An extension of Corbin & Strauss's theory of illness trajectories. In: Proceedings of the Kentucky Conference on Health Communication. 2010 Presented at: Kentucky Conference on Health Communication; Apr. 22-24, 2010; Lexington, Kentucky.
20. Corbin JM, Strauss A. Unending Work and Care: Managing Chronic Illness at Home. San Francisco: Jossey-Bass; 1988.
21. Hogan TP, Palmer CL. Information preferences and practices among people living with HIV/AIDS: results from a nationwide survey. J Med Libr Assoc 2005 Oct;93(4):431-439 [FREE Full text] [Medline: 16239938]
22. Barbour JB, Rintamaki LS, Ramsey JA, Brashers DE. Avoiding health information. J Health Commun 2012 Feb;17(2):212-229. [doi: 10.1080/10810730.2011.585691] [Medline: 22004015]
23. Star SL. The sociology of the invisible: the primacy of work in the writings of Anselm Strauss. In: Social organization and social process: essays in honor of Anselm Strauss. New York: A. de Gruyter; 1991:265-283.
24. Strauss A. The Articulation of Project Work: An Organizational Process. Sociological Quarterly 1988 Jun;29(2):163-178. [doi: 10.1111/j.1533-8525.1988.tb01249.x]
25. Strauss A. Continual Permutations of Action. New York: Aldine Transaction; 1993.
26. Dolce MC. The Internet as a source of health information: experiences of cancer survivors and caregivers with healthcare providers. Oncol Nurs Forum 2011 May;38(3):353-359. [doi: 10.1188/11.ONF.353-359] [Medline: 21531685]
27. Bawden D, Robinson L. The dark side of information: overload, anxiety, and other paradoxes and pathologies. Journal of Information Science 2009;35:180-191. [doi: 10.1177/0165551508095781]
28. Brashers DE, Neidig JL, Haas SM, Dobbs LK, Cardillo LW, Russell JA. Communication in the management of uncertainty: The case of persons living with HIV or AIDS. Communication Monographs 2000 Mar 2000;67(1):63-84. [doi: 10.1080/03637750009376495]
29. Case DO, Andrews JE, Johnson JD, Allard SL. Avoiding versus seeking: the relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts. J Med Libr Assoc 2005 Jul;93(3):353-362 [FREE Full text] [Medline: 16059425]
30. Love B, Crook B, Thompson CM, Zaitchik S, Knapp J, Lefebvre L, et al. Exploring psychosocial support online: a content analysis of messages in an adolescent and young adult cancer community. Cyberpsychol Behav Soc Netw 2012 Oct;15(10):555-559. [doi: 10.1089/cyber.2012.0138] [Medline: 22970826]
31. Brashers DE, Neidig JL, Cardillo LW, Dobbs LK, Russell JA, Haas SM. 'In an important way, I did die': uncertainty and revival in persons living with HIV or AIDS. AIDS Care 1999 Apr;11(2):201-219. [doi: 10.1080/09540129948090] [Medline: 10474623]
32. Arnett JJ. Emerging adulthood. A theory of development from the late teens through the twenties. Am Psychol 2000 May;55(5):469-480. [Medline: 10842426]
33. U.S. Department of Health and Human Services, National Cancer Institute, LIVESTRONG Young Adult Alliance. Closing the gap: research and care imperatives for adolescents and young adults with cancer. NIH Publication no. 06. 2006. URL:

https://docs.google.com/viewer?url=http%3A%2F%2Fplanning.cancer.gov%2Flibrary%2FAYAO_PRG_Report_2006_FINAL.pdf [accessed 2013-03-02] [WebCite Cache ID 6EpdrbGMu]
34. Jones BL, Parker-Raley J, Barczyk A. Adolescent cancer survivors: identity paradox and the need to belong. Qual Health Res 2011 Aug;21(8):1033-1040. [doi: 10.1177/1049732311404029] [Medline: 21447805]
35. Alfano CM, Rowland JH. Recovery issues in cancer survivorship: a new challenge for supportive care. Cancer J 2006;12(5):432-443. [Medline: 17034679]
36. Mykletun A, Dahl AA, Haaland CF, Bremnes R, Dahl O, Klepp O, et al. Side effects and cancer-related stress determine quality of life in long-term survivors of testicular cancer. J Clin Oncol 2005 May 1;23(13):3061-3068. [doi: 10.1200/JCO.2005.08.048] [Medline: 15860864]
37. Rudberg L, Carlsson M, Nilsson S, Wikblad K. Self-perceived physical, psychologic, and general symptoms in survivors of testicular cancer 3 to 13 years after treatment. Cancer Nurs 2002 Jun;25(3):187-195. [Medline: 12040227]
38. Chen E, Zeltzer LK, Bentler PM, Byrne J, Nicholson HS, Meadows AT, et al. Pathways Linking Treatment Intensity and Psychosocial Outcomes among Adult Survivors of Childhood Leukemia. J Health Psychol 1998 Jan;3(1):23-38. [doi: 10.1177/135910539800300102] [Medline: 22021340]
39. Hobbie WL, Stuber M, Meeske K, Wissler K, Rourke MT, Ruccione K, et al. Symptoms of posttraumatic stress in young adult survivors of childhood cancer. J Clin Oncol 2000 Dec 15;18(24):4060-4066. [Medline: 11118467]
40. Recklitis CJ, Diller LR, Li X, Najita J, Robison LL, Zeltzer L. Suicide ideation in adult survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. J Clin Oncol 2010 Feb 1;28(4):655-661 [FREE Full text] [doi: 10.1200/JCO.2009.22.8635] [Medline: 19841325]
41. Stuber ML, Christakis DA, Houskamp B, Kazak AE. Posttrauma symptoms in childhood leukemia survivors and their parents. Psychosomatics 1996;37(3):254-261. [doi: 10.1016/S0033-3182(96)71564-5] [Medline: 8849502]
42. Dama E, Maule MM, Mosso ML, Alessi D, Ghisleni M, Pivetta E, et al. Life after childhood cancer: marriage and offspring in adult long-term survivors--a population-based study in the Piedmont region, Italy. Eur J Cancer Prev 2009 Nov;18(6):425-430. [doi: 10.1097/CEJ.0b013e3283307770] [Medline: 19734794]
43. Gurney JG, Krull KR, Kadan-Lottick N, Nicholson HS, Nathan PC, Zebrack B, et al. Social outcomes in the Childhood Cancer Survivor Study cohort. J Clin Oncol 2009 May 10;27(14):2390-2395 [FREE Full text] [doi: 10.1200/JCO.2008.21.1458] [Medline: 19224833]
44. Zebrack BJ, Chesler MA. Quality of life in childhood cancer survivors. Psychooncology 2002 Mar;11(2):132-141. [Medline: 11921329]
45. Zebrack BJ, Chesler M. Health-related worries, self-image, and life outlooks of long-term survivors of childhood cancer. Health Soc Work 2001 Nov;26(4):245-256. [Medline: 11758866]
46. Lim JW, Zebrack B. Social networks and quality of life for long-term survivors of leukemia and lymphoma. Support Care Cancer 2006 Feb;14(2):185-192. [doi: 10.1007/s00520-005-0856-x] [Medline: 16007454]
47. Kohut A, Parker K, Keeter S, Doherty C, Dimock M. How young people view their lives, futures, and politics: A portrait of “generation next".: Pew Research Center for the People and Press; 2007. URL: http://www.people-press.org/2007/01/09/a-portrait-of-generation-next/ [accessed 2013-03-02] [WebCite Cache ID 6EpeOtBzv]
48. Vance K, Howe W, Dellavalle RP. Social internet sites as a source of public health information. Dermatol Clin 2009 Apr;27(2):133-6, vi. [doi: 10.1016/j.det.2008.11.010] [Medline: 19254656]
49. Fox S, Brenner J. The social life of health information.: Pew Internet & American Life Project; 2012. URL: http://pewinternet.org/Reports/2012/Caregivers-online/Main-Report/The-social-life-of-health-information.aspx [accessed 2013-03-02] [WebCite Cache ID 6EpeTob9l]
50. Schiffman JD, Csongradi E, Suzuki LK. Internet use among adolescent and young adults (AYA) with cancer. Pediatr Blood Cancer 2008 Sep;51(3):410-415. [doi: 10.1002/pbc.21616] [Medline: 18506753]
51. Adams H. Planet Cancer: A community of young adults with cancer. J Oncol Pract 2008;4:189. [doi: 10.1200/JOP.0845002]
52. Crespo R. Virtual community health promotion. 2007. URL: http://www.cdc.gov/pcd/issues/2007/jul/pdf/07_0043.pdf [accessed 2013-03-02] [WebCite Cache ID 6EphslaMU]
53. Im EO. Online support of patients and survivors of cancer. Semin Oncol Nurs 2011 Aug;27(3):229-236. [doi: 10.1016/j.soncn.2011.04.008] [Medline: 21783014]
54. Murray S, Giustini D, Loubani T, Choi S, Palepu A. Medical research and social media: Can wikis be used as a publishing platform in medicine? Open Med 2009;3(3):e121-e122 [FREE Full text] [Medline: 21603044]
55. Shaw B, Gustafson DH, Hawkins R, McTavish F, McDowell H, Pingree S, et al. How underserved breast cancer patients use and benefit from eHealth programs: implications for closing the digital divide. Am Behav Sci 2006;49:823-834. [doi: 10.1177/0002764205283803]
56. Whitten P, Mackert M, Love B, Winn B. Internet generation by disparities: ensuring low-literate adult access to online health information. In: Proceedings of the Annual Conference of the Association of Internet Researchers. 2005 Presented at: Annual Conference of the Association of Internet Researchers; Oct. 21-23, 2005; Gothenburg, Sweden.
57. Corbin JM. The Corbin and Strauss Chronic Illness Trajectory model: an update. Sch Inq Nurs Pract 1998;12(1):33-41. [Medline: 9805470]

58. Hogan TP, Brashers DE. The theory of communicationuncertainty management: implications from the wider realm of information behavior. In: Uncertainty, information management, and disclosure decisions: theories and applications. New York: Routledge; 2009:45-66.
59. Fox S. The social life of health information. Washington, DC: Pew Internet and American Life Project; 2011. URL: http://www.pewinternet.org/Reports/2011/Social-Life-of-Health-Info.aspx [accessed 2013-03-02] [WebCite Cache ID 6Epecjx8K]
60. Bowen GA. Grounded theory and sensitizing concepts. Intl J Qual Methods 2006;5:1-9 [FREE Full text]
61. Charmaz K. Qualitative interviewing and grounded theory analysis. In: Inside interviewing: new lenses, new concerns. Thousand Oaks, CA: Sage Publications; 2003:311-220.
62. Strauss A, Corbin JM. Basics of qualitative research: grounded theory procedures and techniques. In: Basics of qualitative research: grounded theory procedures and techniques. Newbury Park, CA: Sage Publications; 1990.
63. Morse JM, Barrett M, Mayan M, Olson K, Spiers J. Verification strategies for establishing reliability and validity in qualitative research. Intl J Qual Methods 2002;1:1-19 [FREE Full text]
64. Pyett PM. Validation of qualitative research in the "real world". Qual Health Res 2003 Oct;13(8):1170-1179. [Medline: 14556426]
65. Charmaz K. Constructing grounded theory: a practical guide through qualitative analysis. London: SAGE; 2006.
66. Lindlof TR, Taylor BC. Qualitative communication research methods. In: Qualitative Communication Research Methods. Thousand Oaks, CA: Sage Publications, Inc; 2002.
67. D'Agostino NM, Penney A, Zebrack B. Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. Cancer 2011 May 15;117(10 Suppl):2329-2334 [FREE Full text] [doi: 10.1002/cncr.26043] [Medline: 21523754]
68. O'Sullivan PB. Bridging the Mass-Interpersonal Divide Synthesis Scholarship in HCR. Human Comm Res 1999 Jun 1999;25(4):569-588. [doi: 10.1111/j.1468-2958.1999.tb00462.x]
69. Rogers EM. Anatomy of the Two Subdisciplines of Communication Study. Human Comm Res 1999 Jun 1999;25(4):618-631. [doi: 10.1111/j.1468-2958.1999.tb00465.x]
70. Jones BL. Promoting healthy development among survivors of adolescent cancer. Fam Community Health 2008;31 Suppl 1:S61-S70. [doi: 10.1097/01.FCH.0000304019.98007.ae] [Medline: 18091144]
71. Katz E, Lazarsfeld P. Personal Influence: The Part Played by People in the Flow of Mass Communications. New Jersey: The Free Press; 1955.
72. Park C. Does Twitter motivate involvement in politics? Tweeting, opinion leadership, and political engagement. Computers in Human Behavior 2013;29:1641-1648. [doi: 10.1016/j.chb.2013.01.044]
73. Cotten SR, Gupta SS. Characteristics of online and offline health information seekers and factors that discriminate between them. Soc Sci Med 2004 Nov;59(9):1795-1806. [doi: 10.1016/j.socscimed.2004.02.020] [Medline: 15312915]
74. Mackert M, Love B, Whitten P. Patient education on mobile devices: an e-health intervention for low health literate audiences. Journal of Information Science 2009;35(1):82. [doi: 10.1177/0165551508092258]
75. Kreuter MW, Alcaraz KI, Pfeiffer D, Christopher K. Using dissemination research to identify optimal community settings for tailored breast cancer information kiosks. J Public Health Manag Pract 2008;14(2):160-169. [doi: 10.1097/01.PHH.0000311895.57831.02] [Medline: 18287923]
76. Kahlor L, Mackert M. Perceptions of infertility information and support sources among female patients who access the Internet. Fertil Steril 2009 Jan;91(1):83-90. [doi: 10.1016/j.fertnstert.2007.11.005] [Medline: 18243181]
77. Love B, Moskowitz MC, Crook B, Thompson CM, Donovan-Kicken E, Stegenga K, et al. Defining adolescent and young adult (AYA) exercise and nutrition needs: Concerns communicated in an online cancer support community. Patient Educ Couns 2013 Mar 9:---. [doi: 10.1016/j.pec.2013.02.011] [Medline: 23490173]
78. Hartmuller VW, Milner JA. Nutrition: what do cancer survivors need? Nutr Cancer 2012 Jan;64(1):1-3. [doi: 10.1080/01635581.2012.630553] [Medline: 22172285]
79. Kuijpers W, Groen WG, Aaronson NK, van Harten WH. A systematic review of web-based interventions for patient empowerment and physical activity in chronic diseases: relevance for cancer survivors. J Med Internet Res 2013 Feb;15(2):e37 [FREE Full text] [doi: 10.2196/jmir.2281] [Medline: 23425685]
80. Zickuhr K, Smith A. Digital differences. Washington, DC: The Pew Research Center for the People and the Press; 2012. URL: http://pewinternet.org/Reports/2012/Digital-differences.aspx [accessed 2013-03-02] [WebCite Cache ID 6EpekOyXl]

Edited by G Eysenbach; submitted 03.03.13; peer-reviewed by T Hogan, M Souden; comments to author 26.03.13; revised version received 12.04.13; accepted 04.05.13; published 31.05.13.

Please cite as:
Love B, M. Thompson C, Crook B, Donovan-Kicken E
Work and "Mass Personal" Communication as Means of Navigating Nutrition and Exercise Concerns in an Online Cancer Community
J Med Internet Res 2013;15(5):e102
URL: http://www.jmir.org/2013/5/e102/
doi:10.2196/jmir.2594
PMID:23728365

Original Paper

Web-Based Newborn Screening System for Metabolic Diseases: Machine Learning Versus Clinicians

Wei-Hsin Chen[1], MS; Sheau-Ling Hsieh[2], PhD; Kai-Ping Hsu[3], PhD; Han-Ping Chen[4], BS; Xing-Yu Su[1], BS; Yi-Ju Tseng[1], BS; Yin-Hsiu Chien[5], MD, PhD; Wuh-Liang Hwu[5], MD, PhD; Feipei Lai[1,4,6], PhD

[1]National Taiwan University, Graduate Institute of Biomedical Electronics and Bioinformatics, Taipei, Taiwan
[2]National Chiao Tung University, Hsinchu, Taiwan
[3]National Taiwan University, Computer and Information Networking Center, Taipei, Taiwan
[4]National Taiwan University, Department of Computer Science and Information Engineering, Taipei, Taiwan
[5]National Taiwan University Hospital, Department of Medical Genetics, Taipei, Taiwan
[6]National Taiwan University, Department of Electrical Engineering, Taipei, Taiwan

Corresponding Author:
Sheau-Ling Hsieh, PhD
National Chiao Tung University
1001, University Road, Hsinchu, Taiwan
Hsinchu, 30010
Taiwan
Phone: 886 3 513 1351
Fax: 886 3 571 4031
Email: sl_hsieh@cc.nctu.edu.tw

Abstract

Background: A hospital information system (HIS) that integrates screening data and interpretation of the data is routinely requested by hospitals and parents. However, the accuracy of disease classification may be low because of the disease characteristics and the analytes used for classification.

Objective: The objective of this study is to describe a system that enhanced the neonatal screening system of the Newborn Screening Center at the National Taiwan University Hospital. The system was designed and deployed according to a service-oriented architecture (SOA) framework under the Web services .NET environment. The system consists of sample collection, testing, diagnosis, evaluation, treatment, and follow-up services among collaborating hospitals. To improve the accuracy of newborn screening, machine learning and optimal feature selection mechanisms were investigated for screening newborns for inborn errors of metabolism.

Methods: The framework of the Newborn Screening Hospital Information System (NSHIS) used the embedded Health Level Seven (HL7) standards for data exchanges among heterogeneous platforms integrated by Web services in the C# language. In this study, machine learning classification was used to predict phenylketonuria (PKU), hypermethioninemia, and 3-methylcrotonyl-CoA-carboxylase (3-MCC) deficiency. The classification methods used 347,312 newborn dried blood samples collected at the Center between 2006 and 2011. Of these, 220 newborns had values over the diagnostic cutoffs (positive cases) and 1557 had values that were over the screening cutoffs but did not meet the diagnostic cutoffs (suspected cases). The original 35 analytes and the manifested features were ranked based on *F* score, then combinations of the top 20 ranked features were selected as input features to support vector machine (SVM) classifiers to obtain optimal feature sets. These feature sets were tested using 5-fold cross-validation and optimal models were generated. The datasets collected in year 2011 were used as predicting cases.

Results: The feature selection strategies were implemented and the optimal markers for PKU, hypermethioninemia, and 3-MCC deficiency were obtained. The results of the machine learning approach were compared with the cutoff scheme. The number of the false positive cases were reduced from 21 to 2 for PKU, from 30 to 10 for hypermethioninemia, and 209 to 46 for 3-MCC deficiency.

Conclusions: This SOA Web service–based newborn screening system can accelerate screening procedures effectively and efficiently. An SVM learning methodology for PKU, hypermethioninemia, and 3-MCC deficiency metabolic diseases classification, including optimal feature selection strategies, is presented. By adopting the results of this study, the number of suspected cases could be reduced dramatically.

(J Med Internet Res 2013;15(5):e98) doi:10.2196/jmir.2495

KEYWORDS

Web-based services; neonatal screening; tandem mass spectrometry; information systems; metabolism; inborn errors

Introduction

Newborn screening (NBS) using biochemical markers to detect presymptomatic infants with certain congenital conditions has been performed for almost 50 years. The aim of NBS is to provide early treatment to prevent or ameliorate the long-term consequences of the detected condition [1-3]. Since the pioneering work by Guthrie [4], who discovered that phenylketonuria (PKU) could be detected from dried blood spots collected on filter paper and transported to a testing laboratory, dozens of congenital diseases, including metabolic and infectious diseases, can now be detected in NBS programs [5]. The advent of tandem mass spectrometry (MS/MS) has resulted in a substantial increase in the number of inborn errors of metabolism (IEMs) included in the NBS panel [6], including amino acid disorders, fatty acid oxidation disorders, and organic acid disorders [7].

Although MS/MS can detect many metabolic species and many IEMs, the diseases included in the NBS panels vary from country to country. For example, the American College of Clinical Genetics has proposed that 29 core and 25 secondary conditions be screened [8], whereas only 12 metabolic disorders are included in the German panel [9]. In Taiwan, the Newborn Screening Center of the National Taiwan University Hospital (NTUH) introduced MS/MS-based screening in 2001 [6]. Among the diseases that we can screen, PKU (screened by phenylalanine [Phe] level) and homocystinuria (screened by methionine [Met] level) have been included in the official recommended list [10]. Nevertheless, 3-methylcrotonyl-CoA carboxylase (3-MCC) deficiency, screened by 3-hydroxyisovalerylcarnitine (C5OH) level, has been the most common condition detected in the MS/MS panel [6].

The sensitivity of MS/MS screening for the 20 to 30 diseases included in the American College of Clinical Genetics screening panel varies among the individual diseases [11]. For example, PKU can be detected by the elevation of Phe levels and low or normal tyrosine (Tyr) levels. A timely and highly discriminating method, such as MS/MS, provides better performance than the previously used bacterial inhibitory method [6]. In contrast, Met is a less reliable marker for homocystinuria. Elevation of Met (hypermethioninemia) can occur in various conditions, such as methionine adenosyltransferase deficiency, glycine N-methyltransferase deficiency, S-adenosylhomocysteine hydrolase deficiency, and cystathionine beta-synthase deficiency (classical homocystinuria) [12], and transient elevation sometimes occurs with liver disease. Some conditions may be benign, with no treatment currently recommended. However, there is an estimated 20% false negative rate in homocystinuria neonatal screening [13], and the contributing factors include early discharge from hospital, low protein intake from breast-feeding, and pyridoxine responsiveness. Elevation of C5OH indicates 3-MCC deficiency and several related disorders; in addition, some newborns born to a 3-MCC-deficient mother can also test positive. The majority of patients with 3-MCC deficiency will not develop any signs or symptoms of disease. Therefore, a suitable interpretation and prediction method to decrease false positives and avoid false negatives is crucial for a newborn screening program.

To improve the specificity of screening, there are several approaches. The cutoff scheme has been a popular screening method [14-16]. Two-tier testing and the use of multiple markers can improve sensitivity and specificity [17]. For example, more specific markers, such as total homocysteine, methylmalonic acid, and isovalerylglycine, can be detected in dried blood spots (DBSs) and have reduced the false-positive rate and improved the positive predictive value of NBS for different diseases [18,19]. We also tested the possibility of applying molecular second-tier testing for citrin deficiency and carnitine uptake defects [20]. However, a different testing format is required that is expensive and time consuming. The interpretive tool developed by the Region 4 Genetics Collaborative may help us to enhance the predictive value and minimize the false-positive rate while retaining sensitivity [21]. Machine learning techniques offer another obvious and promising approach for the examination of high dimensional data. Thus, the goal of this paper is to describe feature selection strategies and use support vector machine (SVM) learning techniques to establish the classification models for metabolic disorder screening and diagnoses.

Methods

The NTUH initiated newborn screening research in 1981 and has performed the nation's newborn screening of metabolic diseases since July 1985. The NTUH simultaneously holds the responsibilities for national NBS, a phlebotomy hospital, and a referral hospital. The entire screening process workflow and the corresponding functions, relationships, and roles of participants are illustrated in Multimedia Appendix 1. At present, the NTUH Newborn Screening Center provides these services for approximately one-third of the nation's newborns. Currently, the coverage rate for NBS has improved to 99.9% in the past few years [22], and the NTUH Newborn Screening Center tests more than 70,000 babies every year.

System Architecture

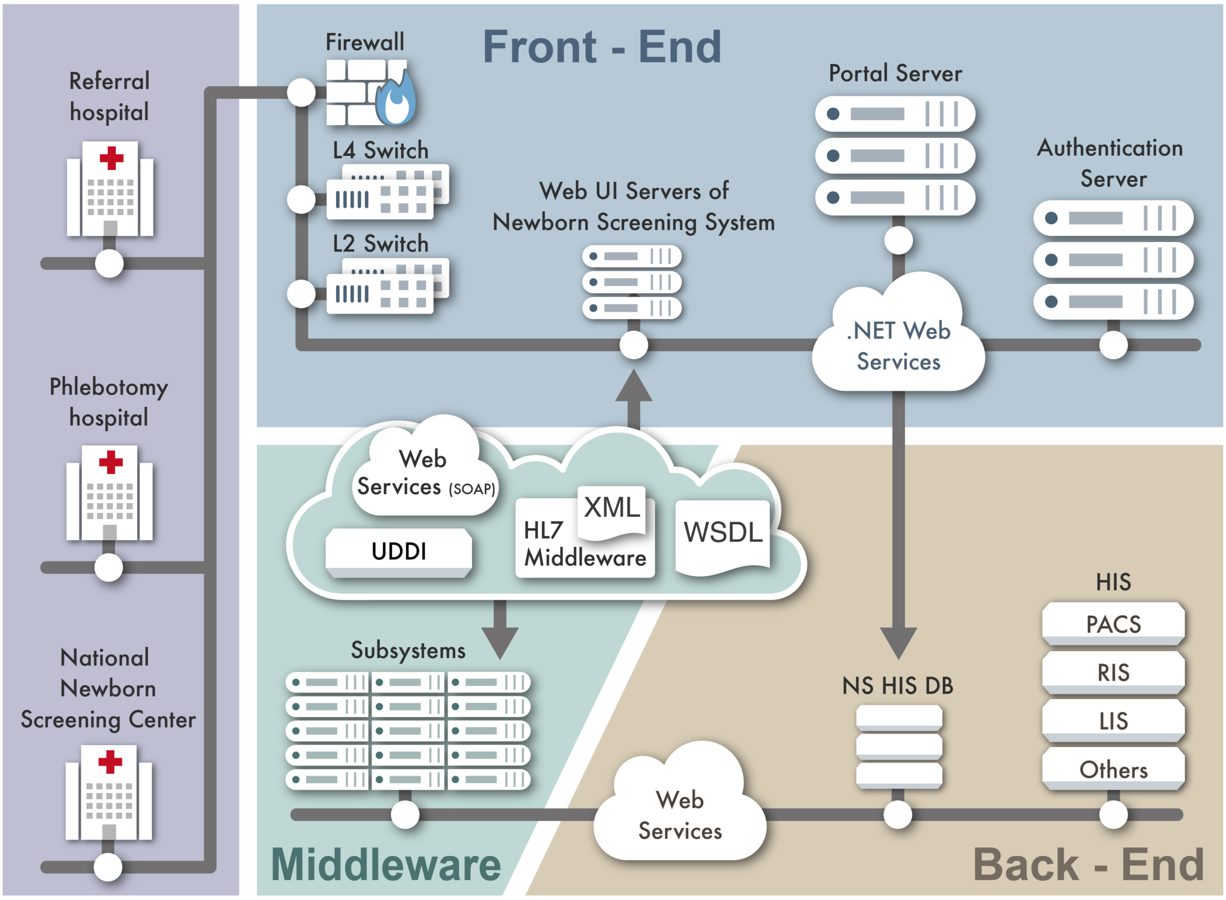
The overall architecture of the NTUH Newborn Screening Hospital Information System (NSHIS) is depicted in Figure 1. In this diagram, 3 major components, ie, the front-end module, the middleware module, and the back-end services including the database servers are shown. The front-end module handles user interfaces via Web browsers [23] and establishes the users' sessions with the authentication server. The server validates users' authentications and authorizations. The middleware module, ie, the Health Level Seven (HL7) middleware framework [24] indicated in the diagram, connects the front-end applications and the back-end facilities. It provides communication and connectivity via a service-oriented architecture (SOA; Web Services) mechanism in the .NET environment. The HL7-embedded Extensible Markup Language (XML)-formatted data are used in the framework for data exchanges among the modules over the simple object access protocol (SOAP) [25,26] and are described in Universal Description, Discovery, and Integration (UDDI) specification with the Web Service Description Language (WSDL). The back-end facilities support services and database storage. The portal server supports the login process with single sign-on service (SSOS) features [27]. The Web user interface server in the architecture generates Web-based pages for users' interactive activities, including the newborn screening system user interfaces.

In addition, the HL7 middleware framework performs data synchronization between the NSHIS and the NTUH hospital information system (HIS). The NTUH HIS integrates (1) patient demographic data, (2) patient radiology orders in the radiology information system (RIS) database involving the picture archiving and communication system (PACS), and (3) laboratory orders in a laboratory information system (LIS) to ensure data consistency and integrity across the NSHIS and HIS architecture as indicated in the back-end facilities [28-30].

To increase the performance of the NTUH HIS, a cluster of identical servers are deployed and dispatched dynamically by introducing layer 4 (L4) and layer 2 (L2) switches. All the servers are configured to run using load balancing, including failover modes to secure the system's availability and concurrency. Firewalls are also installed to enhance the security of the architecture.

The NSHIS system is accessible to all authorized screening program professionals and hospitals by enabling the unique identification of babies via screening samples and displaying the results. Authorized users can be doctors, medical staff, administrative personnel, and neonatal parents. The screening hospitals include the Newborn Screening Center, referral hospitals, and phlebotomy clinics as shown on the left in Figure 1. In other words, these members can access the subsystems of NSHIS for services related to their duties, following the newborn screening procedures and after authentication and authorization by the authentication server.

Figure 1. The system architecture of the Web-based newborn screening system.



Data Preparation

The data used in this paper were gathered from the Newborn Screening Center of NTUH between 2006 and 2011 (N=347,312). Dried blood samples from 3-day-old newborns were analyzed by MS/MS in a high-throughput process. The measured metabolic properties (35 measured metabolites including amino acids and acylcarnitines) were archived in the NTUH database. In this study, 3 metabolic diseases (PKU, hypermethioninemia, and 3-MCC deficiency) were reanalyzed. Both screening cutoffs and diagnostic cutoffs were applied in this study. Newborns with an initial screening value that exceeded the diagnostic cutoffs were classified as positive cases and were requested to participate in a confirmation test at our hospital. Newborns with an initial screening value not exceeding the diagnostic cutoff, but equal to or exceeding the screening cutoff, were classified as suspected cases and were asked to undergo another DBS screening. The cutoff values for each disease, the numbers of suspected cases and positive cases observed during this period are summarized in Table 1. During this period, we did not have any reports of false negatives for these 3 diseases.

Table 1. Summary of the disease data collected from neonates between 2006 and 2011 (N=347,312).

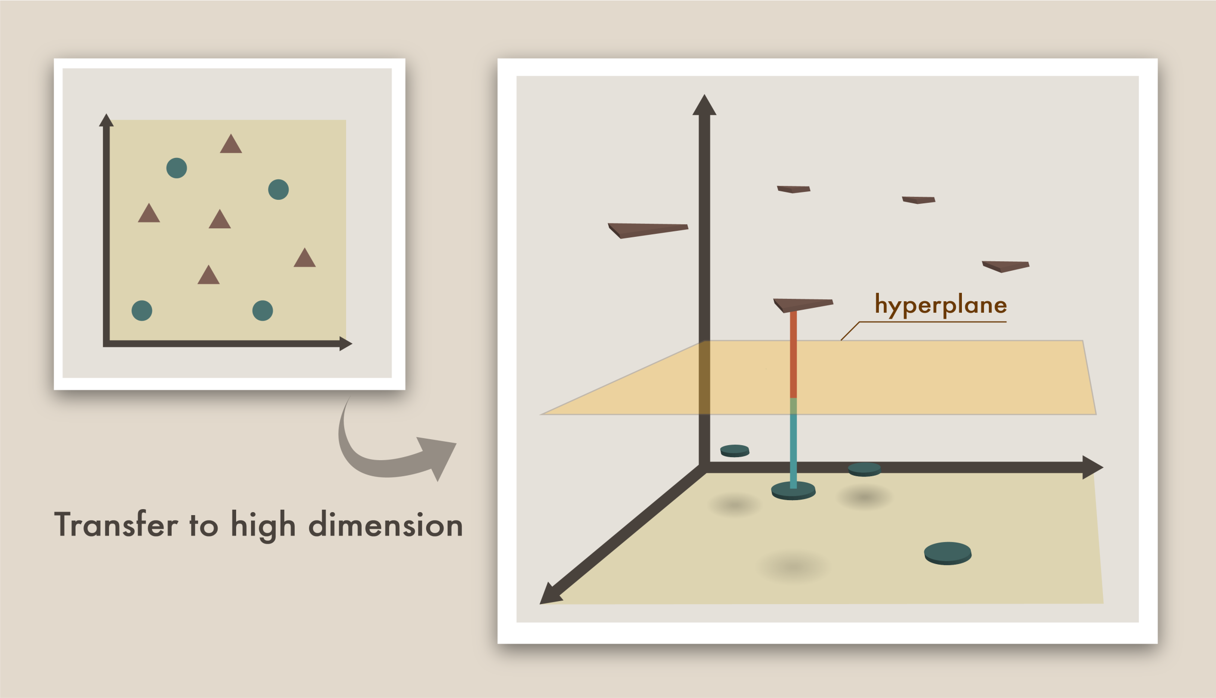
Disease	Screen markers	Suspected cases	Positive cases	Screening cutoff	Diagnostic cutoff
PKU	Phe	203	38	> 85.02 µM	> 220 µM
Hypermethioninemia	Met	261	40	> 54.12 µM	> 110 µM
3-MCC deficiency	C5OH	1093	142	> 0.56 µM	> 2.2 µM

Feature Selection Strategies

Support Vector Machines

An SVM [31,32] performs classification by constructing an N-dimensional hyperplane that optimally separates the data into 2 categories, as shown in Figure 2. In the parlance of the SVM literature, an *attribute* is a predictor variable, and a *feature* is a transformed attribute that is used to define the hyperplane. The task of choosing the most suitable representation is known as *feature selection*. A set of features that describes 1 case (ie, a row of predictor values) is called a *vector*. Therefore, the goal of SVM modeling is to find the optimal hyperplane that separates clusters of vectors. Several different kernel functions can be used, such as linear, polynomial, radial basis function (RBF), and sigmoid. The detailed descriptions of the SVM methodology are presented in Multimedia Appendix 2 [33]. In this study, the machine learning approach only used the SVM RBF kernel. There are 2 input parameters to an SVM: the slack variable (C) is set as default value 100, and the gamma value is set by default to the reciprocal of the number of input features.

Figure 2. The concept of support vector machine (SVM) methodology is transferring the vectors (ie, cases) to a higher dimension. The optimal linear hyperplane could be obtained from the largest distances between the 2 categories.



Data Training and Prediction

In this study, a properly supervised classification dataflow is proposed to enhance the accuracy and sensitivity of the NBS process, as depicted in Figure 3. In the diagram, the training data are used to produce the SVM prediction model. Next, the testing data uses the same methods to obtain the prediction result according to the trained model. Before training or predicting, the dataset is preprocessed by the MS/MS machine and digitization procedures. Feature selection generates the most relevant features.

For classifications, the data are divided into the training, testing, and prediction datasets. In the diagram, the strategies are illustrated step-by-step as follows:

Step 1

The MS/MS data from positive cases and from suspect cases were used as training (step 3) and testing (step 4) datasets. For each analyte, the difference of the median values between the positive cases and the suspect cases is represented as *D*, as in Figure 4. The primary weight for each analyte was calculated according to the formula defined in Figure 5.

Step 2

The highest 3 positive primary weights of the individual diseases among the 35 analytes were (1) PKU: Phe, stearoylcarnitine (C18), and octadecenoylcarnitine (C18:1); (2) 3-MCC deficiency: C5OH, ornithine (Orn), and arginine (Arg); and (3) hypermethioninemia: octenoylcarnitine (C8:1) and Met. In hypermethioninemia, only 2 analytes showed positive primary weights. The highest 3 negative primary weights of the individual diseases among the 35 analytes were (1) PKU: Arg, leucine (Leu), and Tyr; (2) 3-MCC deficiency: C16, C4, and C16:1; and (3) hypermethioninemia: C16, C16:1, and C12.

The manifested features are generated by combinations of the highest 3 positives and the highest 3 negatives as listed in Figure 6. The ratios of the highest 3 positives/negatives are also listed in Figure 6. Figure 6 presents the feature selection strategies used to construct the manifested features via the relevant features of the 3 diseases.

Step 3

The original 35 analytes and the manifested features were ranked according to the *F* score indicator. The values of the *F* score represent the importance of the features. The top 20 ranked features with the highest *F* scores were selected as the input features. Different combinations of the features, ie, C(20, 1), C(20, 2), C(20, 3),..., C(20, 20), were inputted into the SVM RBF classifier and used to generate the classification model for each combination. Each combination of the features was used as input for the classification models to calculate the sensitivity and specificity. The optimal feature set was defined as the combination with the highest specificity and 100% sensitivity.

Step 4

The optimal feature set is then fed into the SVM RBF classifier with 5-fold cross-validation and the optimal model is obtained from the 5 different models of each disease with the highest specificity and 100% sensitivity.

Step 5

Based on the optimal model with the optimal feature set, we provided the NBS data collected in 2011 to be used for prediction. The results were classified as either true positive, true negative, false positive, or false negative. The definition of cases was based on the current method and the confirmation results; therefore, we assumed no false negatives were revealed by the current method.

Figure 3. Training and prediction strategies.

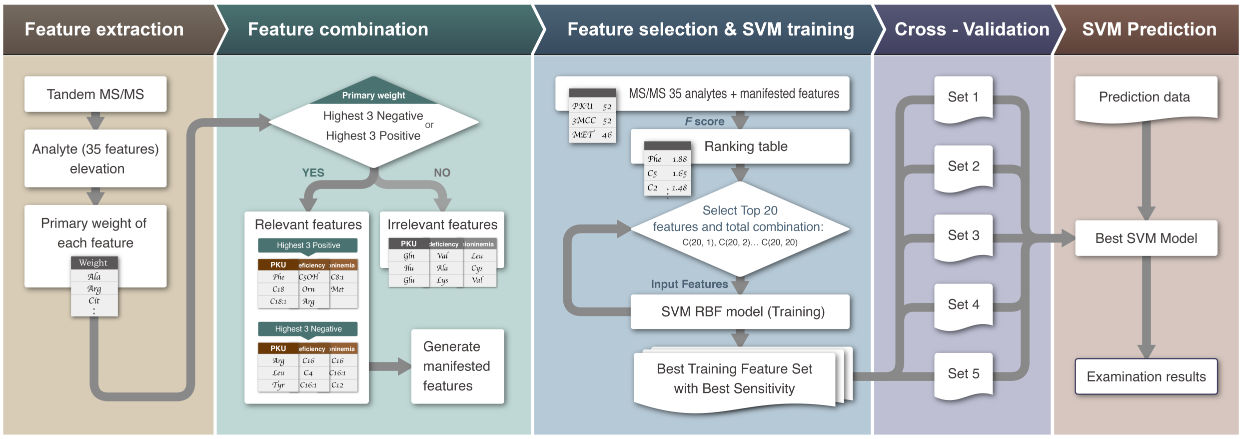


Figure 4. Boxplot of phenylalanine (Phe) showing the difference (D) between positive and suspected cases of the training data.

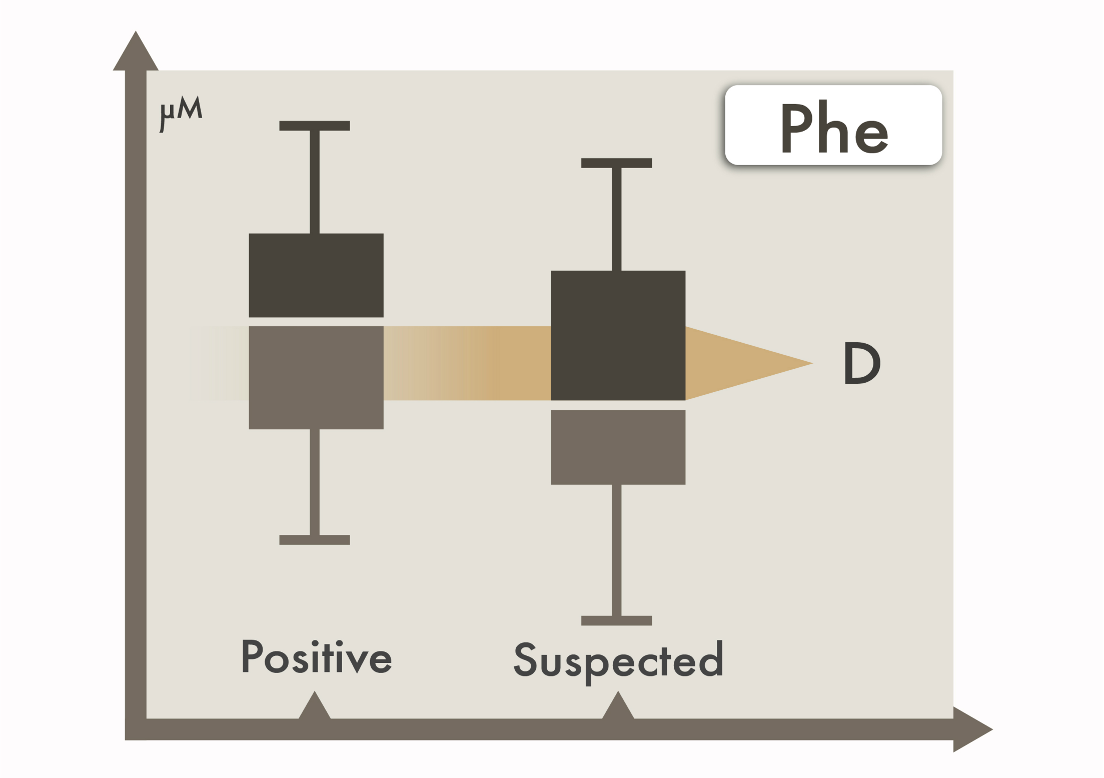
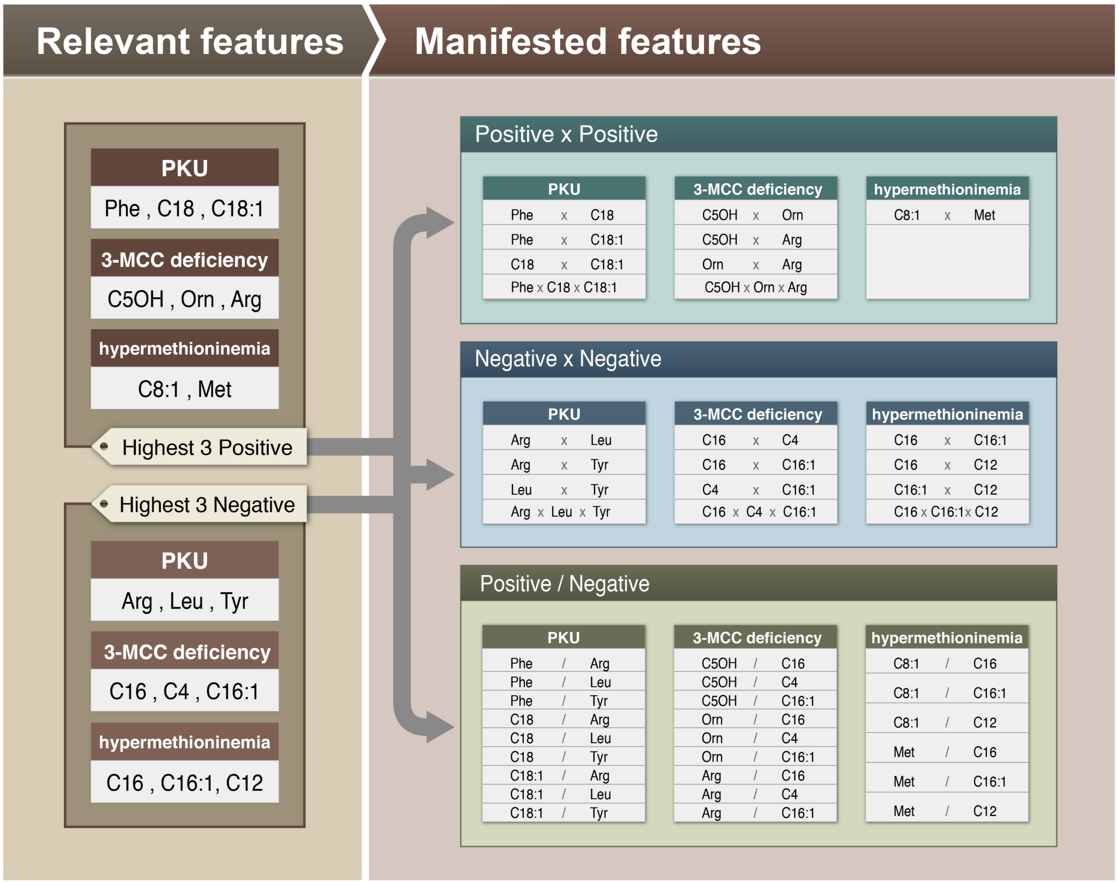


Figure 5. Primary weight formula.

$$D = Median(positive\ cases) - Median(suspected\ cases)$$

$$primary\ weight = \frac{D}{Median_{suspected}}$$

Figure 6. Feature selection strategies by relevant features.



Results

Newborn Screening Hospital Information System

A new generation of the NSHIS at the Newborn Screening Center of the NTUH was designed and deployed under a SOA Web services middleware framework. The framework applied embedded HL7 standards in SOAP messages to share data among heterogeneous platforms. The NSHIS successfully provides secure, Web-based, real-time, newborn screening applications in Taiwan.

Training Results

Optimal Feature Sets

According to the described feature selection strategies, the optimal selected markers, ie, optimal feature sets, of the 3 diseases are summarized in Table 2. After following step 4 as described previously, the optimal model for each disease is generated.

Prediction Results

Of the 347,312 newborn samples collected through the Newborn Screening Center of NTUH from 2006 to 2011, 220 were positive cases and 1557 were suspected cases for the 3 conditions. Because it was a retrospective analysis study, we can only compare the proposed method to the current method to determine if the proposed method has better discriminatory power. After obtaining the optimal model for individual disease from 2006 to 2010, we attempted to predict the disease state for the newborn samples collected in year 2011; the prediction results are listed in Table 3.

In Table 3, the proposed method receives the same sensitivity as that of the cutoff scheme, ie, 100%, for the 3 diseases. Similarly, for specificity and the accuracy, the proposed approach and the cutoff scheme achieve a sensitivity greater than 99% for the 3 diseases in the current experiments.

The effectiveness of the classifier is shown in Table 4. No false positive cases were generated using the proposed approach. Using the proposed approach can significantly decrease the false positive cases for PKU, hypermethioninemia, and especially 3-MCC deficiency.

Table 2. Selected markers of the three diseases.

Diseases	Selected markers[a]
PKU	Ala; Met; Phe; C4; C16:1; Leu×Tyr
Hypermethioninemia	Arg; Met; Phe; Val; C4; C8; C10; C10:1; C14; C14:1
3-MCC deficiency	C3; C5OH; C6; C8; C10:1; C14; C14:1; C16×C4; C4×C16:1; Orn/C16

[a] Ala: alanine; Met: methionine; Phe: phenylalanine; Leu: leucine; Tyr: tyrosine; Val: valine; Orn: ornithine; Arg: Arginine;C3: propionylcarnitine; C4: isobutyrylcarnitine; C5OH: 3-hydroxyisovalerylcarnitine; C6: hexanoylcarnitine; C8: octanoylcarnitine; C10: decanoylcarnitine; C10:1: decenoylcarnitine; C14: tetradecanoylcarnitine; C14:1: tetradecenoylcarnitine; C16: palmitoylcarnitine; C16:1: palmitoleylcarnitine.

Table 3. Comparison of the current versus the proposed method. The sensitivity, specificity and accuracy are calculated from predicting the neonatal samples of 2011.

Diseases	Methods	Sensitivity (%)	Specificity (%)	Accuracy (%)
PKU	Current	—	99.971	99.971
	Proposed	100	99.997	99.997
Hypermethionemia	Current	—	99.958	99.958
	Proposed	100	99.986	99.986
3-MCC deficiency	Current	—	99.711	99.711
	Proposed	100	99.936	99.936

Table 4. Comparison of the current method versus the proposed method. The numbers are obtained from predicting the neonatal samples.

Diseases	Methods	True positives (n)	True negatives (n)	False positives (n)	False negatives (n)
PKU	Current	3	—	21	—
	Proposed	3	72,111	2	0
Hypermethionemia	Current	3	—	30	—
	Proposed	3	72,112	10	0
3-MCC deficiency	Current	6	—	209	—
	Proposed	6	72,255	46	0

Discussion

The Newborn Screening Hospital Information System

The NSHIS is a newborn screening information management system providing services and applications to Newborn Screening Center referral hospitals, phlebotomy clinics, and neonatal parents. The system was designed, developed, and deployed based upon middleware, using SOA Web services loosely coupled to technologies in a .NET environment in C# programming language. The HL7 embedded XML formatted data are used in the system for data exchange among the modules over a SOAP request/response mechanism. This system can integrate diverse platforms and databases (eg, NSHIS and the NTUH HIS), and merge, extend, and enhance the accuracy and the reliability of the proposed screening applications. The functionalities include specimen receiving, specimen tracking, uploading of the testing results, screening data management, quality control analyses, classifications, and Web integration. Undoubtedly, the system can provide timely delivery of complete and accurate information for newborn screening. Therefore, the system is able to comprehensively improve the quality of care and well-being of newborns. A scenario for the NSHIS functionalities is presented in Multimedia Appendix 3.

Proposed Approach

The purpose of this research is to separate apparently healthy individuals who have a disease from those who most likely do not. In addition to the original 35 analytes, we also used different mathematical combinations of the analytes for the manifested features. The use of SVM methods contributes to the credibility of the examination and screening results. During the screening process, the false positive cases will be requested to repeat DBS screening or have a confirmation test. Therefore, these cases will consume additional medical resources and increase parents' anxiety. By adapting this approach, the number of suspected cases can be reduced substantially; additionally, medical resources will be used effectively and efficiently.

The Mayo Clinic College of Medicine cooperated and collaborated globally to establish a database of unprecedented size containing true positive cases [11]. Based on this database and multivariate pattern-recognition software and through the use of postanalytical and interpretive tools, multiple clinically significant results were compiled into a single score [21]. We also tested these tools and confirmed that they can significantly reduce the false positive cases and eliminate at least half of the cost resulting from unnecessary tests. Although we used only regional data to train our model, after combining our feature selection strategies and the ranked manifested markers, we can estimate the covariance among analytes and decrease the false positive cases. Therefore, we provide another approach to enhance NBS results, although further comparisons using the approach and revisions will be necessary.

Limitations

The feature selection strategies are initially designed based on mathematical expressions containing the highest 3 positive and negative ranked features to generate the manifested features. The manifested features and the original 35 analytes constitute the total features, for example, PKU has 52 features, whereas hypermethioninemia has 46 features and 3-MCC deficiency has 52 features. Among the total features, the top 20 *F* score–ranked features are selected for the total combinations as input features for training in order to create optimal feature sets for the 3 diseases. Apparently, the feature selection strategies did not include the total features for establishing either the manifested features or total combinations. To consider all of the features, additional human and computational resources are required to enhance the current automated programming methods.

Presently, PKU, hypermethioninemia, and 3-MCC deficiency are the emphasized metabolic diseases. Other diseases were considered; however, several diseases present problems: (1) carnitine transporter defect and citrullinemia cannot be fully detected using blood samples at birth [20], and (2) other diseases, such as medium-chain acyl-CoA dehydrogenase deficiency, cannot be evaluated using the proposed approach because of the low number of training cases.

Future Work

The NSHIS plans to promote comprehensive care by establishing additional applications for home follow-ups and working with the children with the rare inherited disorders and their families [34]. The exact applications are under evaluation and investigation. Recently, the system has been improved and enhanced to include online billing and charging facilities at phlebotomy clinics and referral hospitals. In addition, the newborn screening test for severe combined immunodeficiency (SCID) has been added to the system. Therefore, the development and deployment of the NTUH NSHIS is evolving as needed.

To assist the research group in exploring further feature selection strategies and machine learning algorithms and in improving classification accuracy, the Computer Center of National Taiwan University offers high-performance computing services. The group members can apply for accounts and use the facilities for both programming and computing resources.

Conclusion

A new generation of the NSHIS of the Newborn Screening Center at NTUH has been designed and deployed using a SOA middleware framework. The framework applies embedded HL7 standards in SOAP request/response for data exchanges among heterogeneous platforms integrated by Web Services. We have established SVM RBF classifiers using the experimental datasets of 35 original MS/MS analytes and the manifested features. The system supports a set of new methods to refine the screening statistics. The methodology we demonstrated here can effectively enhance screening accuracy and the quality controls without changing the current screening method. The methodology can be easily adapted for routine MS/MS newborn screening. Although we will need other true positive cases to train and define the features for other diseases, we demonstrate the superiority of SVM in this study.

Acknowledgments

The authors would like to acknowledge partial funding support from Microsoft Research Asia and assistance from their staff. In addition, the authors thank Professor Chih-Jen Lin and his research team members for kindly providing the LIBSVM tool. F Lai received grants from National Science Council, Taiwan (NSC101-2219-E-002-024) and Ministry of Education, Taiwan (102R7608-3). The funding organizations were not involved in designing or conducting the study, data collection, management, analysis, or interpretation, nor the preparation, review, and approval of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Newborn screening data workflow process.

[PDF File (Adobe PDF File), 658KB - jmir_v15i5e98_app1.pdf]

Multimedia Appendix 2

Newborn screening for phenylketonuria: machine learning vs clinicians.

[PDF File (Adobe PDF File), 397KB - jmir_v15i5e98_app2.pdf]

Multimedia Appendix 3

NSHIS implementation and a scenario.

[PDF File (Adobe PDF File), 218KB - jmir_v15i5e98_app3.pdf]

References

1. Newborn Screening Tests. URL: http://kidshealth.org/parent/system/medical/newborn_screening_tests.html [accessed 2012-11-26] [WebCite Cache ID 6CSJYu9CY]
2. The Children's Hospital at Westmead. The NSW Newborn Screening Programme. 2012. URL: http://www.chw.edu.au/prof/services/newborn/ [accessed 2012-11-26] [WebCite Cache ID 6CSKC26Tn]
3. Bodamer OA, Hoffmann GF, Lindner M. Expanded newborn screening in Europe 2007. J Inherit Metab Dis 2007 Aug;30(4):439-444. [doi: 10.1007/s10545-007-0666-z] [Medline: 17643197]
4. Guthrie R. Blood screening for phenylketonuria. JAMA 1961 Nov 1961;178(8):863. [doi: 10.1001/jama.1961.03040470079019]
5. Therrell BL. U.S. newborn screening policy dilemmas for the twenty-first century. Mol Genet Metab 2001;74(1-2):64-74. [doi: 10.1006/mgme.2001.3238] [Medline: 11592804]
6. Huang HP, Chu KL, Chien YH, Wei ML, Wu ST, Wang SF, et al. Tandem mass neonatal screening in Taiwan--report from one center. J Formos Med Assoc 2006 Nov;105(11):882-886. [doi: 10.1016/S0929-6646(09)60173-X] [Medline: 17098689]
7. Millington DS, Stevens RD. Acylcarnitines: analysis in plasma and whole blood using tandem mass spectrometry. Methods Mol Biol 2011;708:55-72. [doi: 10.1007/978-1-61737-985-7_3] [Medline: 21207283]
8. American College of Medical Genetics Newborn Screening Expert Group. Newborn screening: toward a uniform screening panel and system--executive summary. Pediatrics 2006 May;117(5 Pt 2):S296-S307 [FREE Full text] [doi: 10.1542/peds.2005-2633I] [Medline: 16735256]
9. Lindner M, Gramer G, Haege G, Fang-Hoffmann J, Schwab KO, Tacke U, et al. Efficacy and outcome of expanded newborn screening for metabolic diseases--report of 10 years from South-West Germany. Orphanet J Rare Dis 2011;6:44 [FREE Full text] [doi: 10.1186/1750-1172-6-44] [Medline: 21689452]
10. Niu DM, Chien YH, Chiang CC, Ho HC, Hwu WL, Kao SM, et al. Nationwide survey of extended newborn screening by tandem mass spectrometry in Taiwan. J Inherit Metab Dis 2010 Oct;33(Suppl 2):S295-S305. [doi: 10.1007/s10545-010-9129-z] [Medline: 20567911]
11. McHugh D, Cameron CA, Abdenur JE, Abdulrahman M, Adair O, Al Nuaimi SA, et al. Clinical validation of cutoff target ranges in newborn screening of metabolic disorders by tandem mass spectrometry: a worldwide collaborative project. Genet Med 2011 Mar;13(3):230-254. [doi: 10.1097/GIM.0b013e31820d5e67] [Medline: 21325949]
12. Bjursell MK, Blom HJ, Cayuela JA, Engvall ML, Lesko N, Balasubramaniam S, et al. Adenosine kinase deficiency disrupts the methionine cycle and causes hypermethioninemia, encephalopathy, and abnormal liver function. Am J Hum Genet 2011 Oct 7;89(4):507-515 [FREE Full text] [doi: 10.1016/j.ajhg.2011.09.004] [Medline: 21963049]
13. Naughten ER, Yap S, Mayne PD. Newborn screening for homocystinuria: Irish and world experience. Eur J Pediatr 1998 Apr;157 Suppl 2:S84-S87. [Medline: 9587032]
14. Ohkubo S, Shimozawa K, Matsumoto M, Kitagawa T. Analysis of blood spot 17 alpha-hydroxyprogesterone concentration in premature infants--proposal for cut-off limits in screening for congenital adrenal hyperplasia. Acta Paediatr Jpn 1992 Apr;34(2):126-133. [Medline: 1621517]
15. Lott JA, Sardovia-Iyer M, Speakman KS, Lee KK. Age-dependent cutoff values in screening newborns for hypothyroidism. Clin Biochem 2004 Sep;37(9):791-797. [doi: 10.1016/j.clinbiochem.2004.05.019] [Medline: 15329318]
16. Lindner M, Ho S, Fang-Hoffmann J, Hoffmann GF, Kölker S. Neonatal screening for glutaric aciduria type I: strategies to proceed. J Inherit Metab Dis 2006;29(2-3):378-382. [doi: 10.1007/s10545-006-0284-1] [Medline: 16763905]
17. Matern D, Tortorelli S, Oglesbee D, Gavrilov D, Rinaldo P. Reduction of the false-positive rate in newborn screening by implementation of MS/MS-based second-tier tests: the Mayo Clinic experience (2004-2007). J Inherit Metab Dis 2007 Aug;30(4):585-592. [doi: 10.1007/s10545-007-0691-y] [Medline: 17643193]
18. Turgeon CT, Magera MJ, Cuthbert CD, Loken PR, Gavrilov DK, Tortorelli S, et al. Determination of total homocysteine, methylmalonic acid, and 2-methylcitric acid in dried blood spots by tandem mass spectrometry. Clin Chem 2010 Nov;56(11):1686-1695 [FREE Full text] [doi: 10.1373/clinchem.2010.148957] [Medline: 20807894]
19. Shigematsu Y, Hata I, Tajima G. Useful second-tier tests in expanded newborn screening of isovaleric acidemia and methylmalonic aciduria. J Inherit Metab Dis 2010 Oct;33(Suppl 2):S283-S288. [doi: 10.1007/s10545-010-9111-9] [Medline: 20440648]
20. Wang LY, Chen NI, Chen PW, Chiang SC, Hwu WL, Lee NC, et al. Newborn screening for citrin deficiency and carnitine uptake defect using second-tier molecular tests. BMC Med Genet 2013;14:24 [FREE Full text] [doi: 10.1186/1471-2350-14-24] [Medline: 23394329]
21. Marquardt G, Currier R, McHugh DM, Gavrilov D, Magera MJ, Matern D, et al. Enhanced interpretation of newborn screening results without analyte cutoff values. Genet Med 2012 Jul;14(7):648-655. [doi: 10.1038/gim.2012.2] [Medline: 22766634]
22. NTUH Newborn Screening Center. Newborn Screening Items. 2012. URL: http://www.ntuh.gov.tw/gene/nbsc/screen/item.html [accessed 2012-12-02] [WebCite Cache ID 6Cbb70VUe]

23. Teodoro D, Pasche E, Gobeill J, Emonet S, Ruch P, Lovis C. Building a transnational biosurveillance network using semantic web technologies: requirements, design, and preliminary evaluation. J Med Internet Res 2012;14(3):e73 [FREE Full text] [doi: 10.2196/jmir.2043] [Medline: 22642960]
24. Ko LF, Lin JC, Chen CH, Chang JS, Lai F, Hsu KP, et al. HL7 middleware framework for healthcare information system. 2006 Presented at: 8th International Conference on e-Health Networking, Applications and Services (HEALTHCOM), 2006; Aug 17-19, 2006; New Delhi, India p. 17-19.
25. Yang TH, Cheng PH, Yang CH, Lai F, Chen CL, Lee HH, et al. A Scalable Multi-tier Architecture for the National Taiwan University Hospital Information System based on HL7 Standard. 2006 Presented at: 19th IEEE International Symposium on Computer-Based Medical Systems (CBMS), 2006; Jun 22-23, 2006; Salt Lake City, UT p. 99-104.
26. Phan C. Service Oriented Architecture (SOA) - Security Challenges and Mitigation Strategies. 2007 Presented at: Military Communications Conference, 2007; Oct 29-31, 2007; Orlando, FL p. 1-7.
27. Cheng PH, Yang TH, Chen HS, Hsu KP, Chen SJ, Lai JS. Codesign of a healthcare enterprise information portal and hospital information systems. 2005 Presented at: Proceedings of 7th International Workshop on Enterprise networking and Computing in Healthcare Industry, 2005; Jun 23-25, 2005; Busan, South Korea p. 446-449.
28. Hsieh SL, Feipei L, Cheng PH, Chen JL, Lee HH, Tsai WN, et al. An Integrated Healthcare Enterprise Information Portal and Healthcare Information System Framework. 2006 Presented at: 28th Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBS), 2006; Aug 30-Sep 3, 2006; New York City, NY p. 4731-4734.
29. Hsieh SH, Hsieh SL, Weng YC, Yang TH, Feipei L, Cheng PH, et al. Middleware based Inpatient Healthcare Information System. 2007 Presented at: Proceedings of the 7th IEEE International Conference on Bioinformatics and Bioengineering (BIBE), 2007; Oct 14-17, 2007; Boston, MA p. 1230-1234.
30. Weng YC, Hsieh SL, Hsieh SH, Lai F. Design and Enhance a Dynamic Healthcare Portal Site. 2007 Presented at: IEEE/WIC/ACM International Conferences on Web Intelligence and Intelligent Agent Technology Workshops, 2007; Nov 5-12, 2007; Silicon Valley, CA p. 173-176.
31. Chen YW, Lin CJ. Combining SVMs with various feature selection strategies. In: Guyon I, editor. Feature Extraction: Foundations and Applications (Studies in Fuzziness and Soft Computing). The Netherlands: Springer Berlin Heidelberg; 2006:315-324.
32. Akay MF. Support vector machines combined with feature selection for breast cancer diagnosis. Expert Systems with Applications 2009 Mar;36(2):3240-3247. [doi: 10.1016/j.eswa.2008.01.009]
33. Chen WH, Chen HP, Tseng YJ, Hsu KP, Hsieh SL, Chien YH, et al. Newborn Screening for Phenylketonuria: Machine Learning vs Clinicians. 2012 Presented at: The 2012 IEEE/ACM International Conference on Advances in Social Networks Analysis and Mining; Aug 26-29, 2012; Istanbul, Turkey.
34. American Academy of Pediatrics. Newborn Screening Overview. 2010. URL: http://www.medicalhomeinfo.org/how/clinical_care/newborn_screening.aspx [accessed 2012-12-07] [WebCite Cache ID 6Cj1n80vl]

Abbreviations

3-MCC deficiency: 3-methylcrotonyl-CoA-carboxylase deficiency
Ala: alanine
Arg: arginine
C5OH: 3-hydroxyisovalerylcarnitine
DBS: dried blood spot
HIS: hospital information system
HL7: Health Level Seven
IEM: inborn error of metabolism
Leu: leucine
LIS: laboratory information system
Met: methionine
MS/MS: tandem mass spectrometry
NBS: newborn screening
NSHIS: Newborn Screening Hospital Information System
NTUH: National Taiwan University Hospital
Orn: ornithine
PACS: picture archiving and communication system
Phe: phenylalanine
PKU: phenylketonuria
RBF: radial basis function
RIS: radiology information system
SCID: severe combined immunodeficiency
SOA: service-oriented architecture

SOAP: simple object access protocol
SSOS: single sign-on service
SVM: support vector machine
Tyr: tyrosine
UDDI: Universal Description, Discovery, and Integration
Val: valine
WSDL: Web Service Description Language
XML: Extensible Markup Language

Edited by G Eysenbach; submitted 15.12.12; peer-reviewed by O Bodamer, A Tirado-Ramos; comments to author 22.01.13; revised version received 04.03.13; accepted 07.04.13; published 23.05.13.

Please cite as:
Chen WH, Hsieh SL, Hsu KP, Chen HP, Su XY, Tseng YJ, Chien YH, Hwu WL, Lai F
Web-Based Newborn Screening System for Metabolic Diseases: Machine Learning Versus Clinicians
J Med Internet Res 2013;15(5):e98
URL: http://www.jmir.org/2013/5/e98/
doi:10.2196/jmir.2495
PMID:23702487

Original Paper

Online Health-Searching Behavior Among HIV-Seropositive and HIV-Seronegative Men Who Have Sex With Men in the Baltimore and Washington, DC Area

Ying Li[1], PhD, MS; J Polk[1], MA; Michael Plankey[1], PhD

Division of Infectious Diseases, Department of Medicine, Georgetown University Medical Center, Washington, DC, United States

Corresponding Author:
Michael Plankey, PhD
Division of Infectious Diseases
Department of Medicine
Georgetown University Medical Center
Suite 130
2115 Wisconsin Avenue, NW
Washington, DC, 20007
United States
Phone: 1 202 784 2607
Fax: 1 202 784 0791
Email: mwp23@georgetown.edu

Abstract

Background: Searching online for health information is common among American adults. However, there have been few studies to investigate the online health-searching behaviors among men who have sex with men (MSM) with human immunodeficiency virus (HIV).

Objective: To estimate the prevalence of Internet use among HIV-seropositive MSM and compare their online behaviors with HIV-seronegative men with chronic disease(s).

Methods: This study was performed at the Baltimore/Washington, DC site of the Multicenter AIDS Cohort Study (MACS). A total of 200 MACS participants were asked to answer a self-administered questionnaire on a first-come basis during a semiannual study visit (from July to November 2011); 195 (97.5%) participants completed the survey. Multiple logistic regression models were used to investigate the factors influencing their online health-searching behaviors.

Results: The median age of the 195 MSM participants was 57 years, 64.6% were white, 59.0% were employed, and 88.2% had Internet access at home and/or other locations. Of the 95 HIV-seropositive participants, 89.5% currently used highly active antiretroviral therapy (HAART) and 82.1% had Internet access. After adjusting for age and race/ethnicity, the HIV-seropositive participants were less likely to perform online searches for general disease-related information compared to the HIV-seronegative men with chronic disease(s) (OR 0.20, 95% CI 0.06-0.68, *P*=.01). There were no statistically significant associations with HIV status and searching for new medications/treatments (OR 0.55, 95% CI 0.19-1.55, *P*=.26) or support/advice from other patients (OR 0.52, 95% CI 0.18-1.53, *P*=.24). Increasing age by 5 years led to a decrease by 29% in the odds of online health-related searches for general information (OR 0.71, 95% CI 0.52-0.98, *P*=.03) and 26% for support/advice from other patients (OR 0.74, 95% CI 0.56-0.98, *P*=.03). A decrease of 25% for new medications/treatments was also seen, but was not statistically significant (OR 0.75, 95% CI 0.57-1.01, *P*=.06).

Conclusions: This study shows that HIV-seropositive MSM have similar online health-searching behaviors as HIV-seronegative men with chronic disease(s). Independent of HIV status, older MSM are less likely to perform online health-related searches.

(J Med Internet Res 2013;15(5):e78) doi:10.2196/jmir.2479

KEYWORDS

Internet; information seeking behavior; HIV infections; chronic disease; patient care

Introduction

Approximately 80% of American adults used the Internet in 2010 [1]. For Internet users, searching online for health information has become highly prevalent. A national survey in 2005 found 59% of Internet users did online searching for health information for themselves [2]. A Pew Internet & American Life Project survey showed that 83% of Internet users searched for health information in 2010 [1]. Some studies have shown a high prevalence of health-related Internet use among people with human immunodeficiency virus (HIV) and suggested such Internet use to be beneficial in coping, support, and self-control in health behaviors [3-17]. Studies have also demonstrated that Internet use among people living with chronic diseases (such as diabetes and cancer) provides a sense of support and self-management [18-28].

A large number of studies [25,29-32], including a recent World Health Organization report [33], have suggested that HIV has shifted from a rapidly debilitating and fatal illness to a manageable chronic disease. However, few studies have compared the online health-searching behaviors of HIV-seropositive people with those of HIV-seronegative people with chronic disease(s).

We conducted a study of the online health-searching behaviors among the HIV-seropositive and HIV-seronegative men who have sex with men (MSM) currently enrolled in the Baltimore/Washington, DC site of the Multicenter AIDS Cohort Study (MACS). The aims of this study were to estimate the prevalence of Internet use and online heath-searching behaviors among the HIV-seropositive MSM compared to the HIV-seronegative men with chronic disease(s), and to identify the factors influencing these behaviors.

Methods

Recruitment

The MACS is an ongoing prospective study of the natural and treated histories of HIV infection among MSM in the United States. A total of 6972 men were recruited (4954 in 1984-1985, 668 in 1987-1991, and 1350 in 2001-2003) at 4 centers located in Baltimore/Washington, DC; Chicago; Los Angeles; and Pittsburgh. The study design of the MACS has been described in detail previously [34,35] and only methods relevant to the present study are presented here. All MACS questionnaires are available on the MACS website. MACS study protocols were approved by the institutional review boards of each of the participating centers, their community partners, and community advisory boards, and informed consent was obtained from all participants. MACS participants return every 6 months for detailed interviews, physical examinations, and collection of blood for laboratory testing and storage in a central repository. The interview includes a battery of questions related to medical conditions, medical treatments, sexual behavior, illicit drug use, and alcohol consumption since the previous visit. For this study, 200 participants (150 from Baltimore and 50 from Washington, DC) answered a self-administered questionnaire (see Multimedia Appendix 1 for details) on a first-come basis during their routine semiannual study visits from July to November 2011.

Questionnaire

Participants were asked about HIV or chronic disease(s) (including cancer, diabetes, depression, kidney disease, erectile dysfunction, etc); about their Internet access and where they accessed the Internet (no access, only at home, only at other locations including workplace and library, or both at home and other locations); the number of hours per week they used the Internet for personal purposes (1-2, 3-4, 5-9, ≥10 hours/week); and about whether they have used online disease-related searches for general information, new medications/treatments, and support/advice from other patients.

The outcomes of interest were the hours of Internet use and online disease-related searching. Participants' HIV status, age, and race/ethnicity (obtained from the centralized MACS database) were included as covariates.

Statistical Analysis

Descriptive statistics were generated by HIV status. The prevalence of Internet access was calculated. Univariate associations of Internet access with participant's employment status, race/ethnicity, age, and HIV status were examined using chi-square tests or Fisher exact tests for categorical variables, or Mann-Whitney tests for continuous variables. The associations between online behaviors and HIV status were investigated by using multiple logistic regression models. Age and race/ethnicity were included in the model. Statistical significance was evaluated at the .05 level. All analyses were performed using SAS version 9.2 (SAS Institute, Inc, Cary, NC, USA).

Results

Demographics, health conditions, and Internet access of the participants in this study are shown in Table 1. The median age was 57 years (IQR 51-63). Most were white (64.6%) and employed (59.0%), including full-time, part-time, and self-employment. Of the 195 participants completing the questionnaire, 172 (88.2%) used the Internet, 149 (76.4%) had Internet access at home, and 24 (12.3%) used a smartphone to access the Internet for general health. Of the 95 HIV-seropositive participants, 85 (89.5%) currently used highly active antiretroviral therapy (HAART) and 78 (82.1%) had Internet access. Of the 100 HIV-seronegative participants, 34 (34.0%) had cancer or other chronic disease(s). Having Internet access was statistically significantly associated with participant's employment status (*P*=.046), race/ethnicity (*P*<.001), and HIV status (*P*=.004), but was not associated with participant's age (*P*=.30). Internet access was higher among the employed participants compared to the unemployed (93.8% vs 84.9%), the white participants compared to the nonwhite participants (96.8% vs 76.5%), and the HIV-seronegative compared to the HIV-seropositive (95.9% vs 83.0%) (data not shown).

Table 1. Demographics, health condition, and Internet access of the participants in the study.

Variable		HIV serostatus		All participants N=195
		HIV– n=100	HIV+ n=95	
Age (years), median (IQR)		60 (53-65)	54 (49-60)	57 (51-63)
Race, n (%)				
	White	80 (80.0)	46 (48.4)	126 (64.6)
	Nonwhite	20 (20.0)	49 (51.6)	69 (35.4)
Employment, n (%)				
	Employed[a]	69 (69.0)	46 (48.4)	115 (59.0)
	Unemployed	30 (30.0)	43 (45.3)	73 (37.4)
	No response	1 (1.0)	6 (6.3)	7 (3.6)
Current therapy use, n (%)				
	No therapy use	—	6 (6.3)	—
	HAART	—	85 (89.5)	—
	Combination therapy	—	4 (4.2)	—
Chronic disease (except HIV), n (%)				
	None	45 (45.0)	—	—
	Cancer only	5 (5.0)	—	—
	Other chronic condition[b]	26 (26.0)	—	—
	Both cancer and other(s)	3 (3.0)	—	—
	No response	21 (21.0)	—	—
Self-reported HIV, n (%)		—	62 (65.3)	—
Internet access, n (%)				
	No	4 (4.0)	16 (16.8)	20 (10.3)
	Only at home	42 (42.0)	38 (40.0)	80 (41.0)
	Only at other locations[c]	10 (10.0)	13 (13.7)	23 (11.8)
	Both home and others	42 (42.0)	27 (28.4)	69 (35.4)
	No response	2 (2.0)	1 (1.1)	3 (1.5)
Smartphone, n (%)				
	Internet for general health	11 (11.0)	13 (13.7)	24 (12.3)

[a] including full-time, part-time, and self-employment

[b] Other chronic conditions included depression, kidney disease, erectile dysfunction, diabetes, arthritis, high blood pressure, heart disease, etc.

[c] Other locations included workplace and library.

The online behaviors of the HIV-seropositive participants were compared to the HIV-seronegative men with chronic disease(s) (see Table 2), of which 23 participants without Internet access (or no response), 61 HIV-seronegative participants without chronic disease(s) (or no response), and 17 HIV-seropositive participants who did not report their HIV infection in the survey were excluded. Of 61 HIV-seropositive participants and 33 HIV-seronegative participants with chronic disease(s), 21 (34.4%) and 12 (36.4%) spent ≥10 hours per week on the Internet for personal searching, respectively. There were no statistically significant differences between these 2 groups (OR 1.03, 95% CI 0.38-2.74, *P*=.96).

Table 2. Online behaviors of the HIV-seropositive participants compared to the HIV-seronegative participants with chronic disease.

Online behavior		HIV serostatus, n (%)	
		HIV– with chronic disease n=33	HIV+ n=61
Personal Internet use (hours/week)			
	1-2	5 (15.2)	14 (22.9)
	3-4	11 (33.2)	12 (19.7)
	5-9	5 (15.2)	14 (23.0)
	≥10	12 (36.4)	21 (34.4)
	No response	0	
Online disease-related[a] search for general information			
	No	6 (18.2)	23 (37.7)
	Yes	25 (75.7)	37 (60.7)
	No response	2 (6.1)	1 (1.6)
Online disease-related search for new medications or treatments			
	No	10 (30.3)	22 (36.1)
	Yes	21 (63.6)	38 (62.3)
	No response	2 (6.1)	1 (1.6)
Online disease-related search for support or advice from other patients			
	No	18 (54.5)	33 (54.1)
	Yes	12 (36.4)	25 (41.0)
	No response	3 (9.1)	3 (4.9)

[a] HIV-related information for the HIV-seropositive participants and specific disease-related information for the HIV-seronegative men with chronic disease(s).

After adjusting for age and race/ethnicity, the HIV-seropositive participants were less likely to search online for general disease-related information compared to the HIV-seronegative men with chronic disease(s) (OR 0.20, 95% CI 0.06-0.68, *P*=.01). There were no statistically significant differences in searching for new medications/treatments (OR 0.55, 95% CI 0.19-1.55, *P*=.26) or for support/advice from other patients (OR 0.52, 95% CI 0.18-1.53, *P*=.24) between these 2 groups.

Increasing age by 5 years led to a decrease by 29% in the odds of online health-related searches for general information (OR 0.71, 95% CI 0.52-0.98, *P*=.03) and 26% for support/advice from other patients (OR 0.74, 95% CI 0.56-0.98, *P*=.03). A decrease of 25% for new medications/treatments was also seen, but was not statistically significant (OR 0.75, 95% CI 0.57-1.01, *P*=.06).

Table 3. Analysis results of multiple logistic regressions.

Covariates	Internet use ≥10 hours/week		Online disease-related search					
			General information		New medications/ treatments		Support/advice	
	OR (95% CI)	*P*	OR (95% CI)	*P*	OR (95% CI)	*P*	OR (95% CI)	*P*
Age (5-yr increase)	0.99 (0.77, 1.27)	.95	0.71 (0.52, 0.98)	.03	0.75 (0.57, 1.01)	.06	0.74 (0.56, 0.98)	.03
Nonwhite vs white	0.70 (0.26, 1.92)	.49	1.30 (0.44, 3.83)	.64	1.07 (0.38, 3.01)	.90	2.66 (0.95, 7.39)	.06
HIV+ vs HIV with chronic disease	1.03 (0.38, 2.74)	.96	0.20 (0.06, 0.68)	.01	0.55 (0.19, 1.55)	.26	0.52 (0.18, 1.53)	.24

Discussion

To the best of our knowledge, this study is the first to compare the online behaviors among HIV-seropositive and HIV-seronegative MSM with chronic disease(s). We found that the HIV-seropositive participants showed similar online health-searching behaviors compared to the HIV-seronegative with chronic disease(s) participants. Independent of HIV status, older participants were less likely to do online health-related research.

In this study, 88% of the surveyed participants had Internet access, close to the prevalence (79%) among American adults in a 2010 report from the Pew Research Center [1]. In our study, 82% of the HIV-seropositive participants had access to Internet, more than the reported 56% from earlier studies of people living with HIV and/or acquired immune deficiency syndrome (AIDS) [9,13]. Among our HIV-seropositive participants, 68% had Internet access at home, more than twice than the number (33%) reported by Kalichman et al in 2002 [13].

It has been known that HIV disease meets several chronic disease criteria, including an uncertain course, a prescribed treatment regimen, requirements of self-care and management, changes in roles and relationships, shifts in identity, and psychological distress [25,32]. Because the health care goal is to control symptoms and prevent disability rather than cure them [25], both HIV infection and chronic diseases require considerable patient self-care or self-monitoring of symptoms [32]. As such, it was not unexpected that our results showed no statistical differences in the online health-searching behaviors of HIV-seropositive participants and HIV-seronegative participants with chronic disease(s). Coursaris and Liu [6] found that support-related information, including advice, referral, situation appraisal, and teaching, was exchanged most frequently in online HIV/AIDS self-help groups, which is in agreement with our observations. Of the HIV-seropositive participants with Internet access, 41% searched online for support/advice from other patients and 61% searched online for HIV-related information, more than the finding of a study of people living with HIV/AIDS that reported 45% for Internet health information-seeking behavior [36].

This study also showed that the odds of online health-related searching decreased with increasing age, in agreement with a recent report from the Pew Research Center that showed American adults older than 65 years were less likely than other age groups to use the Internet [37].

Certain limitations of this study deserve attention. We surveyed a convenience sample of MACS participants. Self-administration of the questionnaire did not provide an opportunity for participants to ask questions about the survey, so we could not verify the accuracy of the participants' interpretation of the survey questions and, thus, their responses. In addition, our sample was limited to participants enrolled in the Baltimore/Washington, DC site; therefore, our results may not be generalizable to all MACS participants or all HIV-infected men. Recall bias may have been present.

Although the sample size in this study is small, our results provide valuable insight into the expanding Internet use of health self-management of HIV-seropositive MSM and HIV-seronegative MSM with chronic disease(s). Further study is needed to substantiate these findings. The high prevalence of online health searching observed among the MSM participants in the Baltimore/Washington, DC site will encourage MACS to expand the online health-searching behavior study to all sites.

Acknowledgments

Support of the Baltimore-Washington, DC MACS site was provided by the National Institute of Allergy and Infectious Diseases, with additional supplemental funding from the National Cancer Institute (U01-AI-035042, UL1-RR025005 (GCRC). This study was funded by the Notice of Availability of Recovery Act Funds for Administrative Supplements, NOT-DD-99-056.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Questionnaire.

[PDF File (Adobe PDF File), 57KB - jmir_v15i5e78_app1.pdf]

References

1. Zickuhr K. Generations 2010. Washington, DC: Pew Internet & American Life Project; 2010 Dec 16. URL: http://www.pewinternet.org/~/media//Files/Reports/2010/PIP_Generations_and_Tech10.pdf [accessed 2012-11-13] [WebCite Cache ID 6C9I15Ynk]
2. Atkinson NL, Saperstein SL, Pleis J. Using the internet for health-related activities: findings from a national probability sample. J Med Internet Res 2009;11(1):e4 [FREE Full text] [doi: 10.2196/jmir.1035] [Medline: 19275980]
3. Brashers DE, Haas SM, Neidig JL, Rintamaki LS. Social Activism, self-advocacy, and coping with HIV illness. Journal of Social and Personal Relationships 2002;19:113-133. [doi: 10.1177/0265407502191006]

4. Brashers DE, Neidig JL, Goldsmith DJ. Social support and the management of uncertainty for people living with HIV or AIDS. Health Commun 2004;16(3):305-331. [doi: 10.1207/S15327027HC1603_3] [Medline: 15265753]
5. Chou FY, Holzemer WL, Portillo CJ, Slaughter R. Self-care strategies and sources of information for HIV/AIDS symptom management. Nurs Res 2004;53(5):332-339. [Medline: 15385870]
6. Coursaris CK, Liu M. An analysis of social support exchanges in online HIV/AIDS self-help groups. Computers in Human Behavior 2009;25:911-918. [doi: 10.1016/j.chb.2009.03.006]
7. Friedland J, Renwick R, McColl M. Coping and social support as determinants of quality of life in HIV/AIDS. AIDS Care 1996 Feb;8(1):15-31. [doi: 10.1080/09540129650125966] [Medline: 8664366]
8. Gómez EJ, Cáceres C, López D, Del Pozo F. A web-based self-monitoring system for people living with HIV/AIDS. Comput Methods Programs Biomed 2002 Jul;69(1):75-86. [Medline: 12088595]
9. Kalichman SC, Benotsch EG, Weinhardt L, Austin J, Luke W, Cherry C. Health-related Internet use, coping, social support, and health indicators in people living with HIV/AIDS: preliminary results from a community survey. Health Psychol 2003 Jan;22(1):111-116. [Medline: 12558209]
10. Kalichman SC, Benotsch EG, Weinhardt LS, Austin J, Luke W. Internet use among people living with HIV/AIDS: association of health information, health behaviors, and health status. AIDS Educ Prev 2002 Feb;14(1):51-61. [Medline: 11900110]
11. Kalichman SC, Cain D, Cherry C, Pope H, Eaton L, Kalichman MO. Internet use among people living with HIV/AIDS: coping and health-related correlates. AIDS Patient Care STDS 2005 Jul;19(7):439-448. [doi: 10.1089/apc.2005.19.439] [Medline: 16053401]
12. Kalichman SC, Cherry C, Cain D, Pope H, Kalichman M, Eaton L, et al. Internet-based health information consumer skills intervention for people living with HIV/AIDS. J Consult Clin Psychol 2006 Jun;74(3):545-554. [doi: 10.1037/0022-006X.74.3.545] [Medline: 16822111]
13. Kalichman SC, Weinhardt L, Benotsch E, DiFonzo K, Luke W, Austin J. Internet access and Internet use for health information among people living with HIV-AIDS. Patient Educ Couns 2002 Feb;46(2):109-116. [Medline: 11867240]
14. Lovejoy NC, Morgenroth BN, Paul S, Freeman E, Christianson B. Potential predictors of information-seeking behavior by homosexual/bisexual (gay) men with a human immunodeficiency virus seropositive health status. Cancer Nurs 1992 Apr;15(2):116-124. [Medline: 1617617]
15. Reeves PM. Coping in cyberspace: the impact of Internet use on the ability of HIV-positive individuals to deal with their illness. J Health Commun 2000;5 Suppl:47-59. [doi: 10.1080/10810730050019555] [Medline: 11010356]
16. Thomas S, Shuter J. Internet access and usage in a sample of inner-city HIV-infected patients. J Assoc Nurses AIDS Care 2010;21(5):444-448. [doi: 10.1016/j.jana.2010.01.006] [Medline: 20347343]
17. Horvath KJ, Danilenko GP, Williams ML, Simoni J, Amico KR, Oakes JM, et al. Technology use and reasons to participate in social networking health websites among people living with HIV in the US. AIDS Behav 2012 May;16(4):900-910. [doi: 10.1007/s10461-012-0164-7] [Medline: 22350832]
18. Fox S, Purcell K. Chronic Disease and the Internet. Washington, DC: Pew Internet & American Life Project; 2010 Mar 24. URL: http://pewinternet.org/~/media//Files/Reports/2010/PIP_Chronic_Disease_with_topline.pdf [accessed 2012-11-13] [WebCite Cache ID 6C9IJhXc7]
19. Glasgow RE, Kurz D, King D, Dickman JM, Faber AJ, Halterman E, et al. Twelve-month outcomes of an Internet-based diabetes self-management support program. Patient Educ Couns 2012 Apr;87(1):81-92. [doi: 10.1016/j.pec.2011.07.024] [Medline: 21924576]
20. Kaufman N. Internet and information technology use in treatment of diabetes. Int J Clin Pract Suppl 2010 Feb(166):41-46. [doi: 10.1111/j.1742-1241.2009.02277.x] [Medline: 20377663]
21. Kroenke CH, Kubzansky LD, Schernhammer ES, Holmes MD, Kawachi I. Social networks, social support, and survival after breast cancer diagnosis. J Clin Oncol 2006 Mar 1;24(7):1105-1111. [doi: 10.1200/JCO.2005.04.2846] [Medline: 16505430]
22. Longo DR, Schubert SL, Wright BA, LeMaster J, Williams CD, Clore JN. Health information seeking, receipt, and use in diabetes self-management. Ann Fam Med 2010;8(4):334-340 [FREE Full text] [doi: 10.1370/afm.1115] [Medline: 20644188]
23. McKay HG, Glasgow RE, Feil EG, Boles SM, Barrera MJ. Internet-based diabetes self-management and support: Initial outcomes from the Diabetes Network project. Rehabilitation Psychology 2002 2002;47(1):31-48. [doi: 10.1037/0090-5550.47.1.31]
24. 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]
25. Swendeman D, Ingram BL, Rotheram-Borus MJ. Common elements in self-management of HIV and other chronic illnesses: an integrative framework. AIDS Care 2009 Oct;21(10):1321-1334 [FREE Full text] [doi: 10.1080/09540120902803158] [Medline: 20024709]
26. Glasgow RE, Christiansen SM, Kurz D, King DK, Woolley T, Faber AJ, et al. Engagement in a diabetes self-management website: usage patterns and generalizability of program use. J Med Internet Res 2011;13(1):e9 [FREE Full text] [doi: 10.2196/jmir.1391] [Medline: 21371992]

27. Kuijpers W, Groen WG, Aaronson NK, van Harten WH. A systematic review of web-based interventions for patient empowerment and physical activity in chronic diseases: relevance for cancer survivors. J Med Internet Res 2013;15:e37. [Medline: 23425685]
28. Stellefson M, Chaney B, Barry AE, Chavarria E, Tennant B, Walsh-Childers K, et al. Web 2.0 chronic disease self-management for older adults: a systematic review. J Med Internet Res 2013;15(2):e35 [FREE Full text] [doi: 10.2196/jmir.2439] [Medline: 23410671]
29. Aberg JA. The changing face of HIV care: common things really are common. Ann Intern Med 2006 Sep 19;145(6):463-465. [Medline: 16983135]
30. Gifford AL, Groessl EJ. Chronic disease self-management and adherence to HIV medications. J Acquir Immune Defic Syndr 2002 Dec 15;31 Suppl 3:S163-S166. [Medline: 12562043]
31. Palella FJ, Delaney KM, Moorman AC, Loveless MO, Fuhrer J, Satten GA, et al. Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. HIV Outpatient Study Investigators. N Engl J Med 1998 Mar 26;338(13):853-860. [doi: 10.1056/NEJM199803263381301] [Medline: 9516219]
32. Siegel K, Lekas HM. AIDS as a chronic illness: psychosocial implications. AIDS 2002;16 Suppl 4:S69-S76. [Medline: 12699002]
33. World Health Organization (WHO). HIV/AIDS is becoming a manageable chronic disease: WHO. 2011 Nov 30. URL: http://www.searo.who.int/LinkFiles/Press_Releases_PR-1535.pdf [accessed 2012-11-13] [WebCite Cache ID 6C9LGUtwB]
34. Kaslow RA, Ostrow DG, Detels R, Phair JP, Polk BF, Rinaldo CR. The Multicenter AIDS Cohort Study: rationale, organization, and selected characteristics of the participants. Am J Epidemiol 1987 Aug;126(2):310-318. [Medline: 3300281]
35. Dudley J, Jin S, Hoover D, Metz S, Thackeray R, Chmiel J. The Multicenter AIDS Cohort Study: retention after 9 1/2 years. Am J Epidemiol 1995 Aug 1;142(3):323-330. [Medline: 7631636]
36. Samal L, Saha S, Chander G, Korthuis PT, Sharma RK, Sharp V, et al. Internet health information seeking behavior and antiretroviral adherence in persons living with HIV/AIDS. AIDS Patient Care STDS 2011 Jul;25(7):445-449 [FREE Full text] [doi: 10.1089/apc.2011.0027] [Medline: 21682586]
37. Zickuhr K, Madden M. Older adults and internet use: for the first time, half of adults ages 65 and older are online. Washington, DC: Pew Internet & American Life Project; 2012 Jun 06. URL: http://pewinternet.org/~/media/Files/Reports/2012/PIP_Older_adults_and_internet_use.pdf [accessed 2012-12-04] [WebCite Cache ID 6CfHqhYyk]

Abbreviations

AIDS: acquired immune deficiency syndrome
HAART: highly active antiretroviral therapy
HIV: human immunodeficiency virus
MACS: Multicenter AIDS Cohort Study
MSM: men who have sex with men

Edited by G Eysenbach; submitted 12.12.12; peer-reviewed by J Gillett, P Reeves, M Ybarra; comments to author 17.02.13; revised version received 20.02.13; accepted 25.02.13; published 03.05.13.

Please cite as:
Li Y, Polk J, Plankey M
Online Health-Searching Behavior Among HIV-Seropositive and HIV-Seronegative Men Who Have Sex With Men in the Baltimore and Washington, DC Area
J Med Internet Res 2013;15(5):e78
URL: http://www.jmir.org/2013/5/e78/
doi:10.2196/jmir.2479
PMID:23644412

Original Paper

Which Bundles of Features in a Web-Based Personally Controlled Health Management System Are Associated With Consumer Help-Seeking Behaviors for Physical and Emotional Well-Being?

Annie YS Lau[1], PhD; Judith Proudfoot[2], PhD; Annie Andrews[3]; Siaw-Teng Liaw[4], MBBS, PhD; Jacinta Crimmins[5], MBBS; Amaël Arguel[1], PhD; Enrico Coiera[1], MBBS, PhD

[1]Centre for Health Informatics, Australian Institute of Health Innovation, University of New South Wales, Sydney, Australia

[2]School of Psychiatry, University of New South Wales and Black Dog Institute, Sydney, Australia

[3]UNSW Counselling and Psychological Services, University of New South Wales, Sydney, Australia

[4]School of Public Health & Community Medicine, UNSW Centre for Primary Health Care and Equity, University of New South Wales, Sydney, Australia

[5]University Health Service, University of New South Wales, Sydney, Australia

Corresponding Author:
Annie YS Lau, PhD
Centre for Health Informatics, Australian Institute of Health Innovation, University of New South Wales
Level 1, AGSM Building (G27) UNSW
Sydney, 2052
Australia
Phone: 61 431 599 890
Fax: 61 2 9385 8692
Email: a.lau@unsw.edu.au

Abstract

Background: Personally controlled health management systems (PCHMS), which include a personal health record (PHR), health management tools, and consumer resources, represent the next stage in consumer eHealth systems. It is still unclear, however, what features contribute to an engaging and efficacious PCHMS.

Objective: To identify features in a Web-based PCHMS that are associated with consumer utilization of primary care and counselling services, and help-seeking rates for physical and emotional well-being concerns.

Methods: A one-group pre/posttest online prospective study was conducted on a university campus to measure use of a PCHMS for physical and emotional well-being needs during a university academic semester (July to November 2011). The PCHMS integrated an untethered personal health record (PHR) with well-being journeys, social forums, polls, diaries, and online messaging links with a health service provider, where journeys provide information for consumer participants to engage with clinicians and health services in an actionable way. 1985 students and staff aged 18 and above with access to the Internet were recruited online. Logistic regression, the Pearson product-moment correlation coefficient, and chi-square analyses were used to associate participants' help-seeking behaviors and health service utilization with PCHMS usage among the 709 participants eligible for analysis.

Results: A dose-response association was detected between the number of times a user logged into the PCHMS and the number of visits to a health care professional (*P*=.01), to the university counselling service (*P*=.03), and help-seeking rates (formal or informal) for emotional well-being matters (*P*=.03). No significant association was detected between participant pre-study characteristics or well-being ratings at different PCHMS login frequencies. Health service utilization was strongly correlated with use of a bundle of features including: online appointment booking (primary care: OR 1.74, 95% CI 1.01-3.00; counselling: OR 6.04, 95% CI 2.30-15.85), personal health record (health care professional: OR 2.82, 95% CI 1.63-4.89), the poll (health care professional: OR 1.47, 95% CI 1.02-2.12), and diary (counselling: OR 4.92, 95% CI 1.40-17.35). Help-seeking for physical well-being matters was only correlated with use of the personal health record (OR 1.73, 95% CI 1.18-2.53). Help-seeking for emotional well-being concerns (including visits to the university counselling service) was correlated with a bundle comprising the poll (formal or informal help-seeking: OR 1.03, 95% CI 1.00-1.05), diary (counselling: OR 4.92, 95% CI 1.40-17.35), and online appointment booking (counselling: OR 6.04, 95% CI 2.30-15.85).

Conclusions: Frequent usage of a PCHMS was significantly associated with increased consumer health service utilization and help-seeking rates for emotional health matters in a university sample. Different bundles of PCHMS features were associated with physical and emotional well-being matters. PCHMS appears to be a promising mechanism to engage consumers in help-seeking or health service utilization for physical and emotional well-being matters.

(J Med Internet Res 2013;15(5):e79) doi:10.2196/jmir.2414

KEYWORDS

personal health record; Web-based intervention; health service; help-seeking; emotional well-being; physical well-being; preventative health; eHealth; consumer; university

Introduction

Worldwide, governments have made multibillion dollar investments in eHealth to modernize health services delivery, with many questions still unanswered about the uptake, benefits, and cost-effectiveness of these investments [1,2]. In particular, personal health records (PHRs) now form a crucial component in many large-scale national eHealth reform strategies. However, uptake and utilization of PHRs is not as widespread as anticipated [1,2], and there are often gaps between proposed and actual benefits [3]. Finding approaches that effectively engage consumers in the use of PHRs, with the intention to improve health outcomes and reduce attrition rates, remains a high priority in consumer eHealth research [4-6].

PHRs have been advocated as the next generation tool that significantly improves consumers' health behaviors and health outcomes [7]. In a key discussion on personal health records (PHRs) presented by Tang and colleagues, a PHR is an electronic application through which individuals can access, manage, and share their health information [8]. A tethered PHR allows patients to view their own health information that is stored in their health care provider's electronic health record, whereas an untethered PHR is a stand-alone application that does not connect with any other system [8]. A personally controlled health management system (PCHMS) in this instance is a health management system that allows consumers and patients to connect and engage with their health services online to access tools and resources to manage their health. In this paper, our PCHMS integrated an untethered PHR with well-being journeys, social forums, polls, diaries, and online messaging links with a health service provider.

However, a PCHMS often consists of multiple features, which refer to the functionalities available on the system. What are the features in a PCHMS that encourage consumers and patients to seek help or engage with health services for their well-being concerns? To date, it is still unclear what features contribute to an engaging and efficacious PCHMS.

Past studies have resulted in guidelines for the development of Internet interventions for consumer health [9-12]. Other studies have found features such as personalization, tailoring, and behavior feedback associated with significant consumer health behaviors when applied in the right context [13,14]. Researchers have also advocated for the use of behavioral theories, such as the health belief model (HBM) [15], social cognitive theory (SCT) [16], transtheoretical model (TTM) [17], and the theory of reasoned action / planned behavior [18], in the development of eHealth applications to increase their acceptability and efficacy. Yet, there is currently little literature to guide the features of PCHMS.

In parallel, the idea of creating a "bundle" of actions has recently been advocated as a way to address system inertia to change [19]. While its clinical applications have been shown to improve the quality and safety in managing ventilation-assisted pneumonia [20] and sepsis in intensive care [21], its applicability in eHealth has not been examined previously. A care bundle is a grouping of care elements for a particular symptom, procedure, or treatment [22]. It follows the holistic principle where a bundle, as a grouping of several evidence-based practices, when used in combination or as a cluster, should have a greater effect on the positive outcome of patients [22]. In eHealth, while evidence is emerging on which "individual" features are associated with significant consumer health behaviors, the concept of identifying a "bundle" of effective features in eHealth interventions has not been addressed previously.

For this reason, identifying features (or "bundles of features") in a PCHMS that are associated with changes in consumers' health behaviors remains a crucial area for research. In response, we designed an online prospective study to examine how a group of participants in a university setting used a PCHMS to manage their physical and emotional well-being. University students are known to experience elevated distress levels over an academic semester [3,23-30]. Yet, they are infrequent users of health services and hardly engage with services for assistance [31-33]. The aim of this study is to (1) examine whether use of a PCHMS is associated with increased rates of health service utilization and help-seeking behaviors for physical and/or emotional well-being, and (2) identify whether use of any specific PCHMS feature (ie, journey, personal health record, forum, poll, diary, or online appointment service), or bundles of features, is associated with help-seeking behaviors and health service utilization for well-being matters.

Methods

Trial Design and Participants

A one-group pre/posttest online prospective study was conducted over a university academic semester (July to November 2011). Inclusion criteria were (1) aged 18 or above, and (2) with access to the Internet and email at least on a monthly basis.

Study Protocol

Students and staff were approached via email lists and advertisements in online print publications, which described the study and invited interested parties to use a PCHMS called *Healthy.me* developed at the University of New South Wales (UNSW) to manage their physical and emotional well-being for an academic semester. Written informed consent was sought online from each participant. Participants then completed a 15-minute online pre-study survey, followed by a 5-minute mandatory online tutorial about *Healthy.me* prior to using the site. At study completion (end of semester), participants received an email asking them to complete a 15-minute online post-study survey. Two follow-up emails 5 days apart were sent as reminders to noncompleters. Those who completed all surveys were entered into a draw for an AU$500 gift voucher. A researcher was available via a dedicated telephone line and email to answer participants' questions and concerns during the study. Ethics approval was obtained from the UNSW ethics committee.

Measures

At baseline, demographic information (such as age and gender) was collected, as well as information about their use of social networking websites, use of the Internet to find health-related information, and visits to a health professional (including whether they visited prior to the study a health care professional, University Health Service, and the University Counselling and Psychological Services).

In the pre- and post-study questionnaires, measures 1-3 were administered and additional measures (4-5) were administered in the postintervention questionnaire: (more details on each measure are available in Multimedia Appendix 1):

1. *COOP/WONCA charts* were used to evaluate participants' functional status, defined as physical, emotional, and social status. These scales, which have been demonstrated to be a valid and feasible one-time screening assessment for mental disorders in primary care [34], measure six domains, namely physical fitness, feelings, daily activities, social activities, change in health, and overall health. Responses are via a 1-5 Likert-scale where higher scores indicate a poorer functional status.
2. *Well-being self-ratings and lifestyle intention*: adapted from the last question in the standardized instrument EUROQOL (EQ-5D) [35], which measures health status, participants were asked to rate their physical and emotional well-being on a scale from 0 to 100. They were also asked to select one of four statements that best describes their intention to practice a lifestyle that benefits their well-being according to the transtheoretical model of behavior change [17].
3. *Health advice-seeking and health advice-providing networks*: adapted from the Norbeck Social Support Questionnaire [36], participants were asked to nominate up to 5 people they have sought advice from, or provided advice to, before and during the study.
4. *Help-seeking behaviors and health service utilization*: Help-seeking is defined as the behavior of actively seeking assistance [37], regardless of whether the source is informal or formal. A new scale was developed by the authors, adapted from the Actual Help-seeking Questionnaire (AHSQ) [37]. The scale covers help-seeking behaviors for physical and emotional well-being, informal and formal sources, as well as for self or others.
5. *Feedback on Healthy.me*: participants were asked to provide feedback on their overall experience of using *Healthy.me*, as well as their feedback on specific features on the website, using a range of scale items such as Likert scale, free-text comments, and checkbox answer options.

This paper focuses on usage of PCHMS features with consumers' health behaviors and thus only reports participants' help-seeking behaviors and health service utilization rates collected at post-study.

PCHMS Usage Metrics

A recent review by Danaher and Seeley [38] concluded there is no single, universally accepted measure for website usage, and researchers are still debating the best methods for defining and measuring website engagement [38].

In this study, we used simple website engagement measures to track participants' activity on the website (ie, PCHMS login frequency and whether participants accessed, or did not access, each website feature). These measures were used to assess whether (1) there was a dose-response effect, that is, was the frequency of PCHMS login associated with rates of health service utilization and help-seeking behaviors, and whether (2) access to PCHMS feature(s) (ie, journey, personal health record, forum, poll, diary, and/or online appointment service) was associated with participants' health service utilization and help-seeking behaviors for physical and/or emotional well-being.

PCHMS Web logs were analyzed to determine whether participants accessed (or did not access) any of the features at any time during the study. Some of these website engagement measures have previously been used to measure user engagement of PHR systems [39].

Intervention

Theoretical Construct

The dose-response phenomenon tested in this study is related to the *familiarity principle*, *reinforcement effect*, and the *mere exposure effect* described by Zajonc [40], where the level of repeated exposure to an intervention is associated with participants developing a familiarity and preference for the intervention and thus increasing the likelihood to use it at times of need. Features such as length of exposure, the spread of experiences, the partitioning of episodes, the peak-and-end events in an incident, and the degradation or improvement in experience over time have been reported to influence a person's overall impression of an experience [41]. While exposure to a website can be described using different measures, such as number of logins, repeated visits, and duration of visits, we used number of logins as our primary measure since it is one of the most common measures to describe participants' engagement with a website.

Healthy.me

Healthy.me was iteratively developed, and its first version was tested in other settings such as in vitro fertilization and influenza vaccination [42,43]. The first version contained features such as journey, the personal health record, and online appointment booking with the university primary care service. The version of *Healthy.me* (version 2.0) that was used in this study contained the above-mentioned features as well as online appointment booking with the university primary care and counselling services, a diary, forum, and poll. Details of each feature are described below:

1. Personal Health Record (PHR) for self-recording of medical test results, medications, scheduled appointments, and personnel looking after one's health (see Figure 1).
2. Online appointment booking with the University Health Service (primary care) and the UNSW Counselling and Psychological Services (sent via email using the "Book now" button in the PCHMS).
3. Diary for participants to write down their thoughts about their health. By default, the diary is private. However, participants can select to share their diary with all participants enrolled in the PCHMS.
4. Social communication spaces, which support interaction across the continuum of care between fellow participants and clinicians. Features include the poll system and forums moderated by clinicians. Poll system in which participants answer simple health questions (eg, how much sleep did you get last night?), where they can view and compare their response with other participants' aggregated answers in graph format (Figure 2). Forums moderated by clinicians (a primary care physician and a psychologist), where participants can either post their entries on the forum or send one-on-one email messages to other participants in the PCHMS (including clinicians). Guidelines on forum use and the protocol for responding to concerns reported in the forum were approved from the UNSW ethics committee. Posts sent by participants to the "Report concern" feature on the forum were emailed to clinical and research personnel during the study, who investigated any reported concerns. A Uniform Resource Locator (URL) available in the email to the dedicated staff allowed them to withdraw the forum post. The primary care physician and the psychologist not only moderated the forum but were also available to answer questions posted on the forums. No harm from the use of the forum or the PCHMS was reported by participants during the study.
5. Journeys that provide information for consumer participants to engage with clinicians and health services in an actionable way. Participants in this study had access to four well-being journeys for physical and emotional well-being: "Stay Healthy", "Stressed out?", "Feeling Anxious about the Exams?", and "My Emotional Well-being Program".

The four well-being journeys for physical and emotional well-being were designed and developed in consultation with University Counselling and Psychological Services psychologists and University Health Service primary care physicians, utilizing evidence-based consumer education material routinely used at UNSW to promote physical and emotional well-being. Written in youth-friendly language, using evidence-based mental health, psychoeducational, and psychosocial material, the journeys consisted of skills-focused content delivered online, as well as well-being workshops that participants could attend in-person at the University Counselling and Psychological Services. Participants could learn about mindfulness meditation, anxiety management, time management, and stress management at these workshops.

Journeys were delivered via the PCHMS at four pivotal time-points during a university academic semester (ie, beginning of semester, 4 weeks into semester, after mid-semester break, and before exams) to address physical and emotional well-being concerns likely to be concerning participants at each time-point. Participants were alerted with an email when a new journey became available on the PCHMS. These journeys provided task specific knowledge in an actionable way. For example, as participants read the journey for advice on physical or emotional well-being, they could immediately:

- book an appointment with a university primary care physician or a psychologist from the journey page,
- register to attend a well-being workshop,
- post a question on a forum to seek advice from fellow participants or a clinician (primary care physician or a psychologist), or
- send themselves an email reminder to do so later.

A pilot study was conducted in a controlled setting with 15 university staff and students of different ages, gender, and familiarity with computers to test the intervention, the measures, and the research design. Substantive usability issues were resolved before recruiting participants in their real-life setting.

Data Analysis

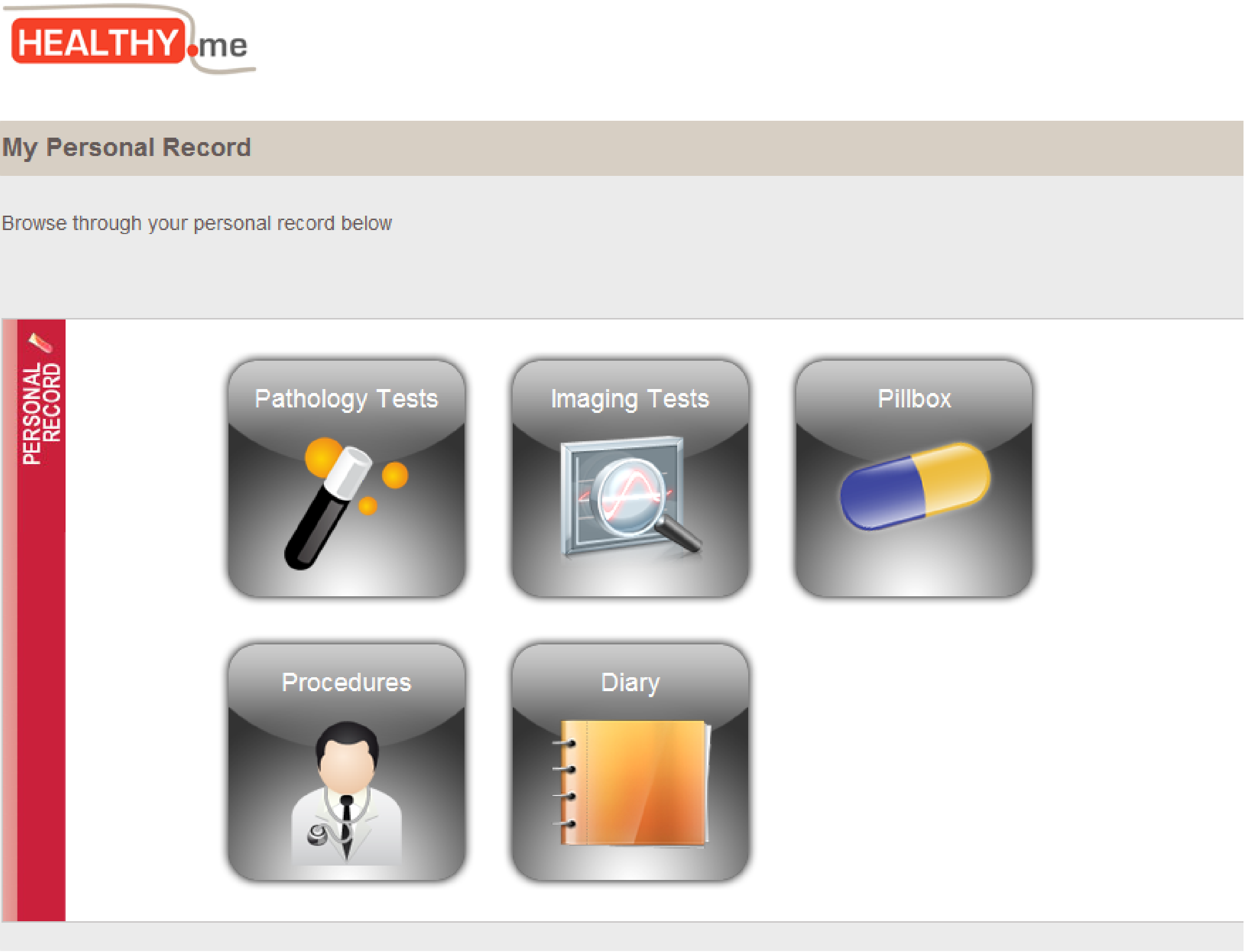
Analysis was conducted on an intention-to-treat basis. Sequential logistic regression analyses were undertaken to prospectively examine the crude and adjusted odds ratios (ORs) for participants' health service utilization and help-seeking behaviors for physical and emotional well-being matters [44]. Independent variables assessed included whether participants accessed (or did not access) each specific PCHMS feature (journey, personal health record, forum, poll, diary, and online appointment service), controlling for participant's gender, age, and potential confounders (eg, whether the participant was a university service patient/client prior to the study) to provide a stratified estimate of intervention effect. The Pearson product-moment correlation coefficient was used to examine correlations among usage of features that were associated with consumers' behaviors.

Participants' health service utilization rates (ie, visits to a health professional, University Health Service, or the University Counselling and Psychological Services), and their help-seeking behaviors for physical or emotional well-being matters were compared at different PCHMS login frequency thresholds (zero logins, once only, two to five times, six to 10 times, more than 10 times). The rationale for selecting these login frequency cutoffs is based on using heuristics to ensure important login frequency thresholds are covered (ie, zero, once only, and ≥ a high login frequency threshold) and that there are sufficient data points in each frequency threshold to conduct analyses.

Between group analyses were conducted using chi-square analysis. Participants' pre-study characteristics (namely use of the Internet to find health information, use of social networking websites, visits to a health care professional in the past 6 months, and their self-rated well-being ratings classified as over or below 50 at pre-study) were compared between different PCHMS login frequencies using chi-square to assess whether these characteristics were associated with PCHMS usage levels. Descriptive analyses were conducted on participants’ reasons for *not* seeking help during study.

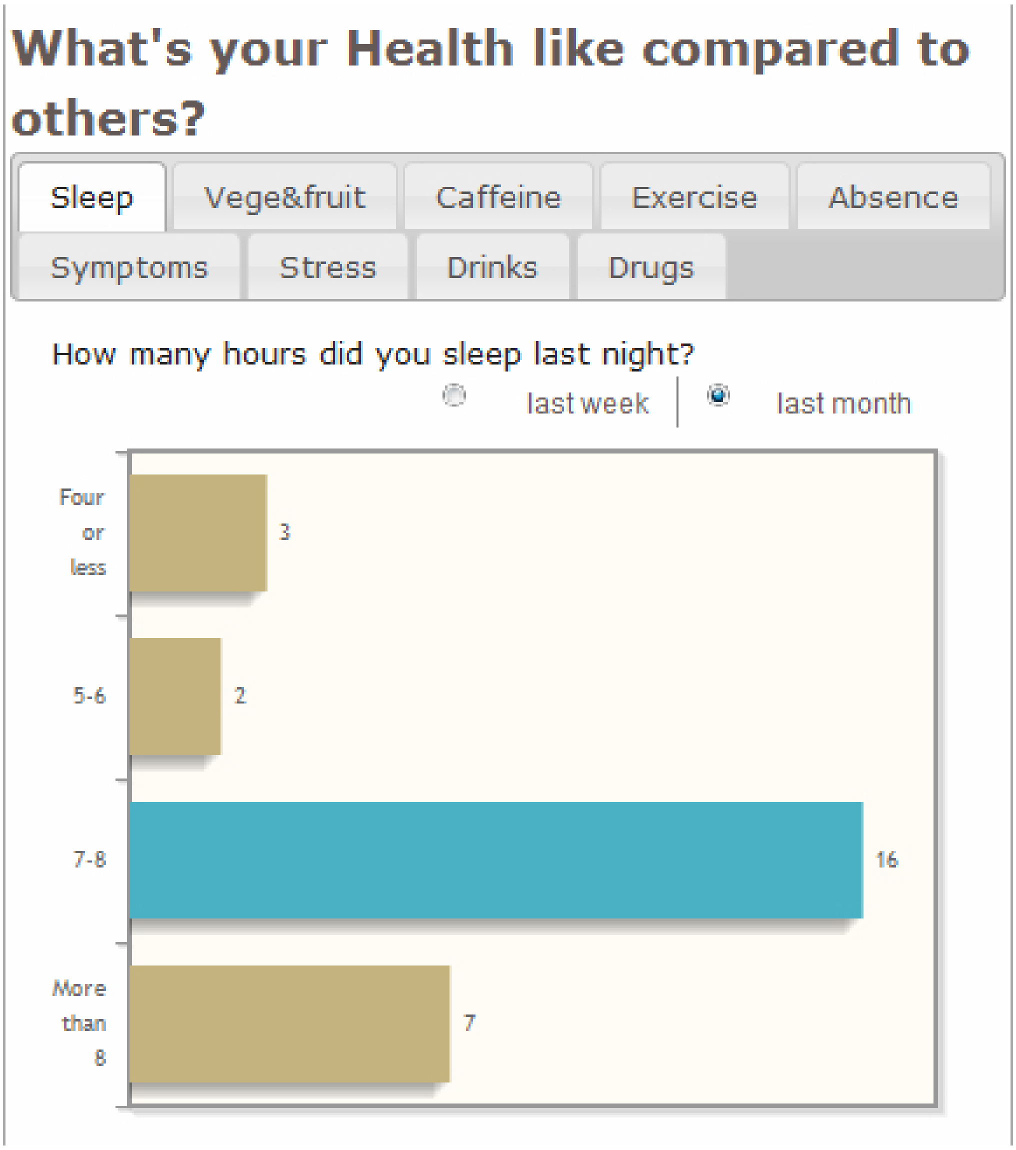
Data analysis was performed using IBM SPSS Statistics 20 [45]. Tests performed were two-tailed and assumed a cutoff of *P*<.05 for statistical significance.

Figure 1. Personal Health Record on Healthy.me (University of New South Wales, 2009-2013).



Browse through your personal record below

Figure 2. Poll on Healthy.me (University of New South Wales, 2009-2013).



What's your Health like compared to others?

How many hours did you sleep last night?

○ last week ● last month

Results

Participants

A total of 1985 participants met inclusion criteria and were recruited into the study. All completed the pre-study questionnaire. Of those, 709 completed the post-study questionnaire (Figure 3). Analyses were conducted on 709 eligible participants who completed both the pre-study and post-study questionnaires. Of these, 81% (572/709) participants logged into the PCHMS at least once. No significant differences were found between questionnaires completers and noncompleters in their pre-study characteristics or the number of PCHMS login sessions (*P*>.05). Among questionnaire completers, no significant differences were found between different PCHMS login frequencies (*P*>.05).

Baseline characteristics of eligible participants are presented in Table 1. Participants' well-being concerns during the study, their help-seeking behaviors, and their purpose for visiting a health care professional are outlined in Table 2.

Health Service Utilization

Overall, 50% (358/709) of participants visited a health care professional (for themselves or others) for a physical well-being concern and 13% (95/709) for emotional well-being during the study (Table 2). Health service utilization rates (ie, visits to a health professional, University Health Service, and University Counselling and Psychological Services) during the study are outlined in Table 3 and Figure 4 according to PCHMS login frequency.

Table 1. Baseline characteristics of study participants who completed both pre-study and post-study questionnaires.

Characteristics		Total n=709 (%)
Mean age, years (SD)		25.2 (9.41)
Female gender (%)		427 (60.2%)
University student		625 (88.1%)
Non-medicine faculty [a]		570 (80.4%)
Patient at University Health Service (prior to study)		148 (20.9%)
Visited UNSW Counselling and Psychological Service (prior to study)		83 (11.7%)
Use of social networking websites		
	Several times a day	434 (61.2%)
	Several times a week	183 (25.8%)
	Several times a month	29 (4.1%)
	Less often	39 (5.5%)
	I do not use social networking websites	24 (3.4%)
Use of Internet to find health-related information		
	Several times a week	79 (11.1%)
	Few times a month	161 (22.7%)
	Less often	93 (13.1%)
	Never	38 (5.4%)
Visited health care professional(s) in past 6 months		
	None	188 (26.5%)
	Once only	173 (24.4%)
	Two to three times	238 (33.6%)
	More often	110 (15.5%)

[a] Faculty refers to the School or the Faculty that a participant is from, regardless of whether he/she is a student or a staff member.

Table 2. Participants' health service utilization, help-seeking behaviors, and experiences of physical and emotional well-being concerns during the study.

		Number n=709 (%)
Self-experience well-being concern		
	I experienced a physical well-being concern during study	479 (67.6%)
	I experienced an emotional well-being concern during study	422 (59.5%)
Encountered someone with well-being concerns		
	I encountered someone with physical well-being concerns during study	400 (56.4%)
	I encountered someone with well-being concerns during study	365 (51.5%)
Health service utilization		
	I visited a health care professional for only physical well-being concerns (for self or others)	276 (38.9%)
	I visited a health care professional for only emotional well-being concerns (for self or others)	13 (1.8%)
	I visited a health care professional for both physical and emotional well-being concerns (for self or others)	82 (11.6%)
Help seeking (formal or informal sources)		
	I sought advice on physical well-being (for myself)	370 (52.2%)
	I sought advice on physical well-being (for others)	88 (12.4%)
	I sought advice on emotional well-being (for myself)	201 (28.3%)
	I sought advice on emotional well-being (for others)	75 (10.6%)
Not seeking or providing help		
	There was a need for physical well-being assistance (for self or others), but I did not seek help	109 (15.4%)
	There was a need for emotional well-being assistance (for self or others), but I did not seek help	221 (31.2%)
Confidence in providing help to others on, mean (SD) [a]		
	Physical well-being	2.2 (0.87)
	Emotional well-being	2.2 (0.82)

[a] Confidence: 1=not confident, 2=quite confident, 3=confident, 4=very confident

Table 3. Health service utilization and help-seeking behaviors according to different usage levels of PCHMS.

	% (95% CI)				
No. of PCHMS logins [a]	Visited health professional [b]	Visited University Health Service [c]	Visited University Counselling and Psychological Services [d]	Sought help for physical well-being [e]	Sought help for emotional well-being [f]
0 (n=136)	44 (36 to 53)	16 (11 to 23)	7 (4 to 13)	47 (39 to 55)	31 (24 to 39)
1 (n=287)	57 (51 to 62)	16 (13 to 21)	4 (2 to 6)	53 (47 to 58)	29 (24 to 34)
2 to 5 (n=165)	61 (53 to 68)	19 (14 to 26)	6 (3 to 10)	62 (54 to 69)	33 (27 to 41)
6 to 10 (n=61)	54 (42 to 66)	21 (13 to 33)	5 (2 to 13)	51 (39 to 63)	26 (17 to 38)
≥ 10 (n=59)	67 (53 to 77)	24 (15 to 36)	14 (7 to 25)	63 (50 to 74)	49 (37 to 62)

[a] 1 participant was excluded as his/her no. of logins is recorded as >4000. Among the 708 participants included in this analysis, the mean of login frequency is 4.3, standard deviation is 19.05, and the maximum number of logins is 456.

[b] Visited health professional during study: χ^2_4=11.80, *P*=.019, n=708.

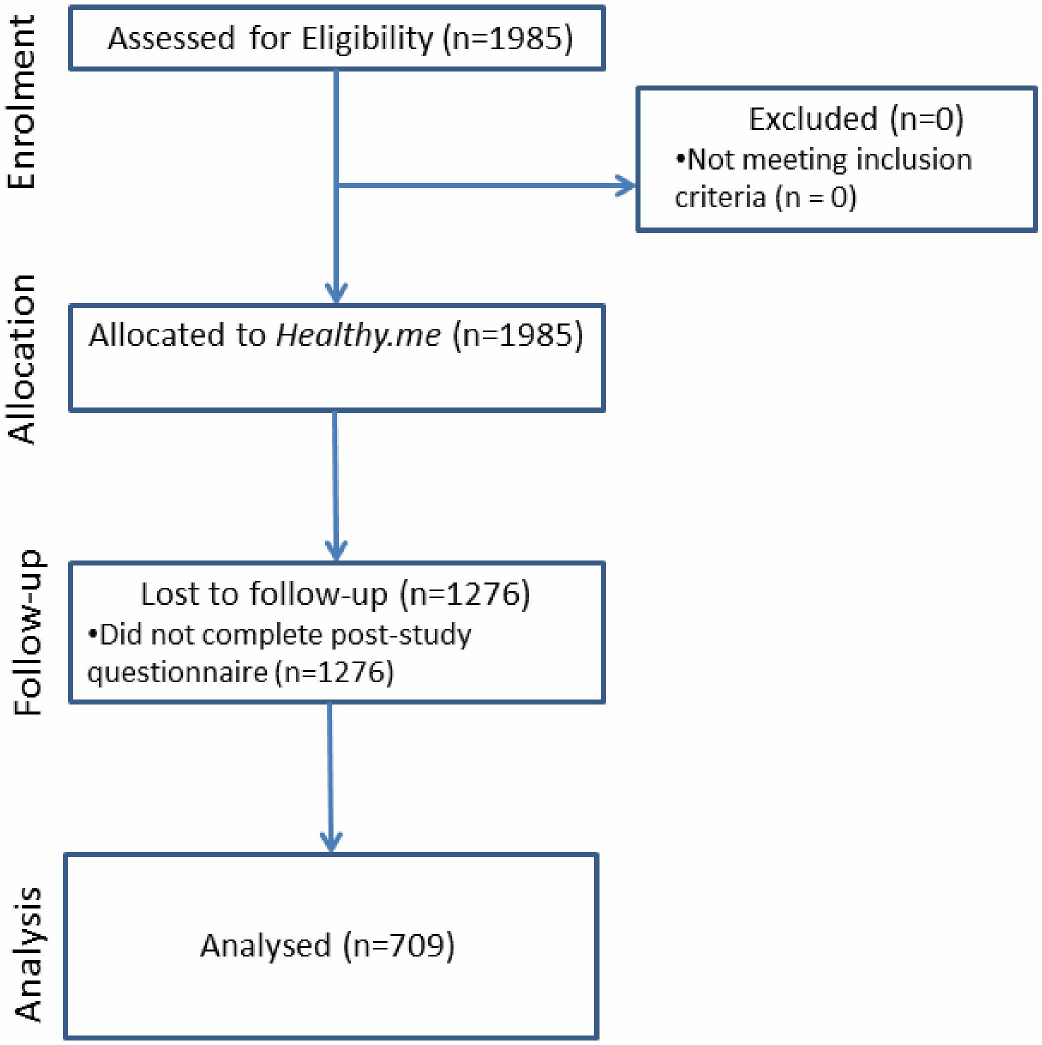
[c] Visited University Health Service during study: χ^2_4=2.79, *P*=.59, n=708.

[d] Visited UNSW Counselling and Psychological Service during study: χ^2_4=10.26, *P*=.036, n=708.

[e] Sought help for physical well-being during study: χ^2_4=8.94, *P*=.063, n=708.

[f] Sought help for emotional well-being during study: χ^2_4=10.70, *P*=.03, n=708.

Figure 3. Participant flowchart in the study.



In absolute terms, participants who logged into the PCHMS more than 10 times were 22 percentage points more than those who never logged in to visit a health care professional during the study: χ^2_4=11.80, P=.01, n=708; zero logins: 44% (60/136, 95% CI 36-53) vs ≥10 logins: 66% (39/59, 95% CI 53-77). Relative to participants who never logged in to the PCHMS, the proportion of participants visiting a health care professional during study was 50% higher for those who logged into the PCHMS more than 10 times: RR is 1.50 (95% CI 1.15-1.95).

Visits to the University Health Service did not differ significantly between different PCHMS login frequency thresholds: χ^2_4=2.79, P=.59, n=708. However, participants who logged into the PCHMS more than 10 times were 10 percentage points more than less-engaged PCHMS users to visit the University Counselling and Psychological Services during the study: χ^2_4=10.26, P=.03, n=708; once only was 4% (10/287, 95% CI 2-6) vs ≥ 10 logins at 14% (8/59, 95% CI 7-25). Relative to participants who logged into the PCHMS only once, the proportion of participants visiting the University Counselling and Psychological Services during the study was 289% higher for those who logged into the PCHMS more than 10 times: RR is 3.85 (95% CI 1.60-9.44).

Help-Seeking Behaviors

Overall, 54% (386/709) of participants sought formal or informal help (for themselves or others) for physical well-being and 32% (225/709) for emotional well-being during the study (Table 2). Participants' help-seeking behaviors during the study between different PCHMS login frequency thresholds are described in Table 3 and Figure 4.

Help-seeking behaviors for physical well-being matters did not differ significantly between different PCHMS login frequencies: χ^2_4=8.94, P=.06, n=708. However, participants who logged into the PCHMS 10 times or more were 20 percentage points more likely to seek help for an emotional well-being matter than less-engaged users, ie, χ^2_4=10.70, P=.03, n=708; once only: 29% (82/287, 95% CI 24-34) vs > 10 logins: 49% (29/59, 95% CI 37-62). Relative to participants who logged into the PCHMS only once, the proportion of participants seeking assistance for an emotional well-being matter during the study was 72% higher for those who logged into the PCHMS more than 10 times, ie, RR is 1.72 (95% CI 1.25-2.36).

Reasons for Not Seeking Help

Reasons for *not* seeking help during the study are outlined in Tables 4 and 5. The most frequent reason for not seeking help for a physical or emotional well-being matter was "no time / inconvenience", that is, physical: 51.4% (56/109); and emotional: 42.5% (94/221). Among those who did not seek help for their *emotional* well-being concern (n=221), the next frequently cited reason was "fear of confrontation and learning about the health issue" (40.0%), followed by "I didn't think anyone (or anything) could help" (36.2%). Among those who did not seek help for their *physical* well-being concern (n=109), the second most frequently cited reason was "I didn't know (or still don't know) what seems to be the problem" (31.2%), followed by "cost" (29.4%).

Feature Bundles Associated With Health Service Utilization and Help-Seeking Behaviors

Different groups of system features were correlated with different consumer behaviors:

- *Health service utilization* was strongly correlated with use of a bundle of features involving *online appointment booking* (primary care: OR 1.74, 95% CI 1.01-3.00; counselling: OR 6.04, 95% CI 2.30-15.85), *personal health record* (health care professional: OR 2.82, 95% CI 1.63-4.89), the *poll* (health care professional: OR 1.47, 95% CI 1.02-2.12), and *diary* (counselling: OR 4.92, 95% CI 1.40-17.35). For participants who utilized a health service, there was a strong positive correlation in usage frequency between the diary and poll (r=0.726, n=424, P<.001), a moderate positive correlation between the personal health record and poll (r=0.321, n=424, P<.001), and a small positive correlation between the personal health record and online appointment booking (r=0.234, n=424, P<.001).
- Formal or informal help-seeking behaviors for *physical* well-being matters was only correlated with use of the *personal health record* (OR 1.73, 95% CI 1.18-2.53).
- Help-seeking for *emotional* well-being concerns (including visits to the university counselling service) was correlated with a bundle comprising the *poll* (formal or informal help-seeking: OR 1.03, 95% CI 1.00-1.05), *diary* (counselling: OR 4.92, 95% CI 1.40-17.35), and *online appointment booking* (counselling: OR 6.04, 95% CI 2.30-15.85). For participants who sought help for emotional well-being concerns and/or visited the university counselling service, there was a strong positive correlation in usage frequency between the diary and poll (r=0.787, n=230, P<.001), and a small positive correlation between the poll and online appointment booking (r=0.145, n=230, P=.028).

Full details of the logistic regression models are summarized in Figure 5 and Multimedia Appendix 2.

Figure 4. Health service utilization rates and help-seeking behaviors between different PCHMS login frequency thresholds.

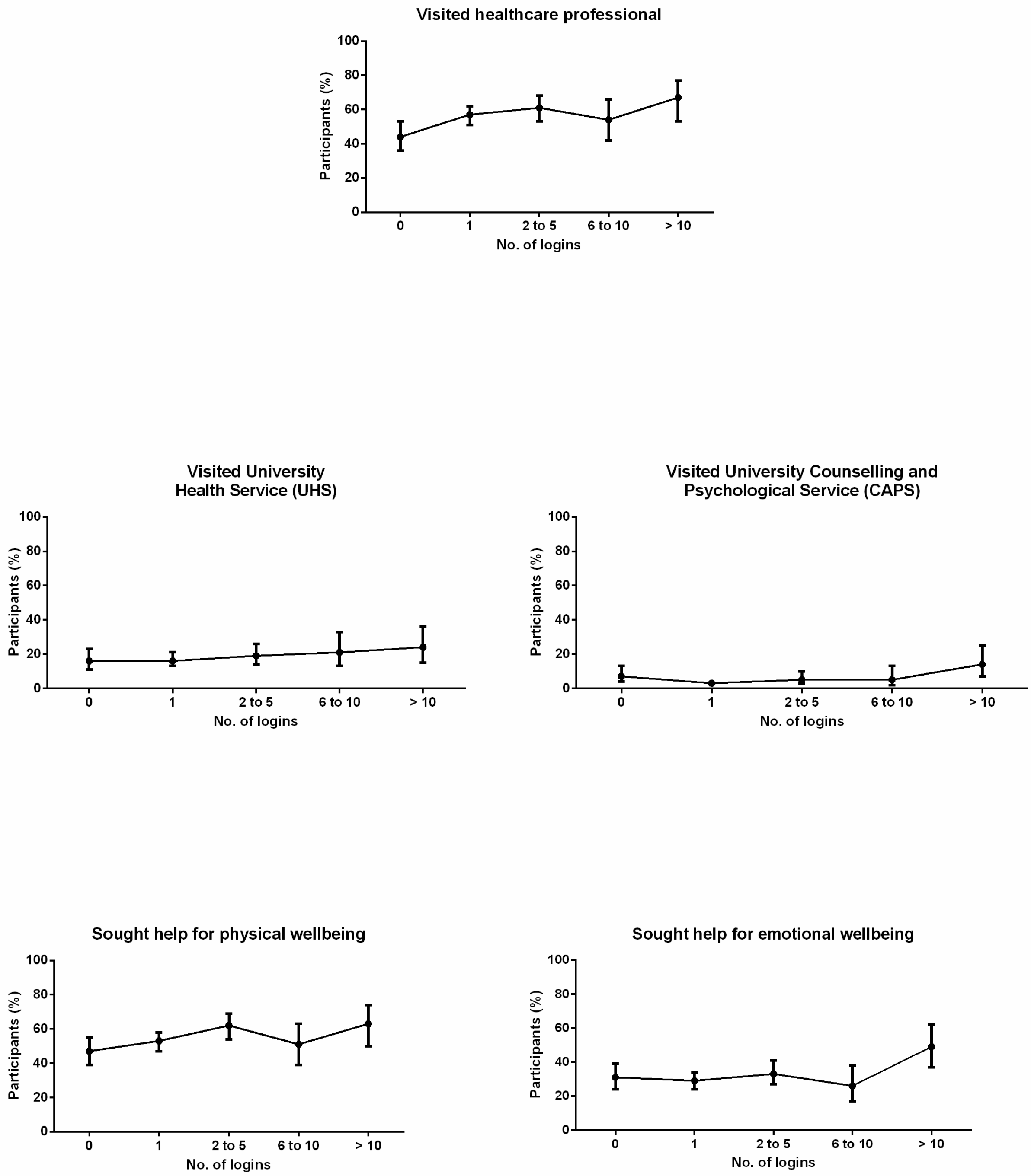


Table 4. Reasons for *not* seeking help for physical well-being concerns during study (n=109).

Reason	Number [a] n=109 (%)
No time / inconvenience	56 (51.4%)
I didn’t know (or still don’t know) what seems to be the problem	34 (31.2%)
Cost	32 (29.4%)
Not well enough (or motivated) to seek help	27 (24.8%)
I didn’t think anyone (or anything) can help	22 (20.2%)
I didn’t know how to seek help	16 (14.7%)
Fear of what others may think	14 (12.8%)
Fear of confrontation and learning about the health issue	14 (12.8%)
Previous unsatisfactory contacts with health care professionals	9 (8.3%)
Stigma or cultural attitudes	8 (7.3%)
Other	7 (6.4%)

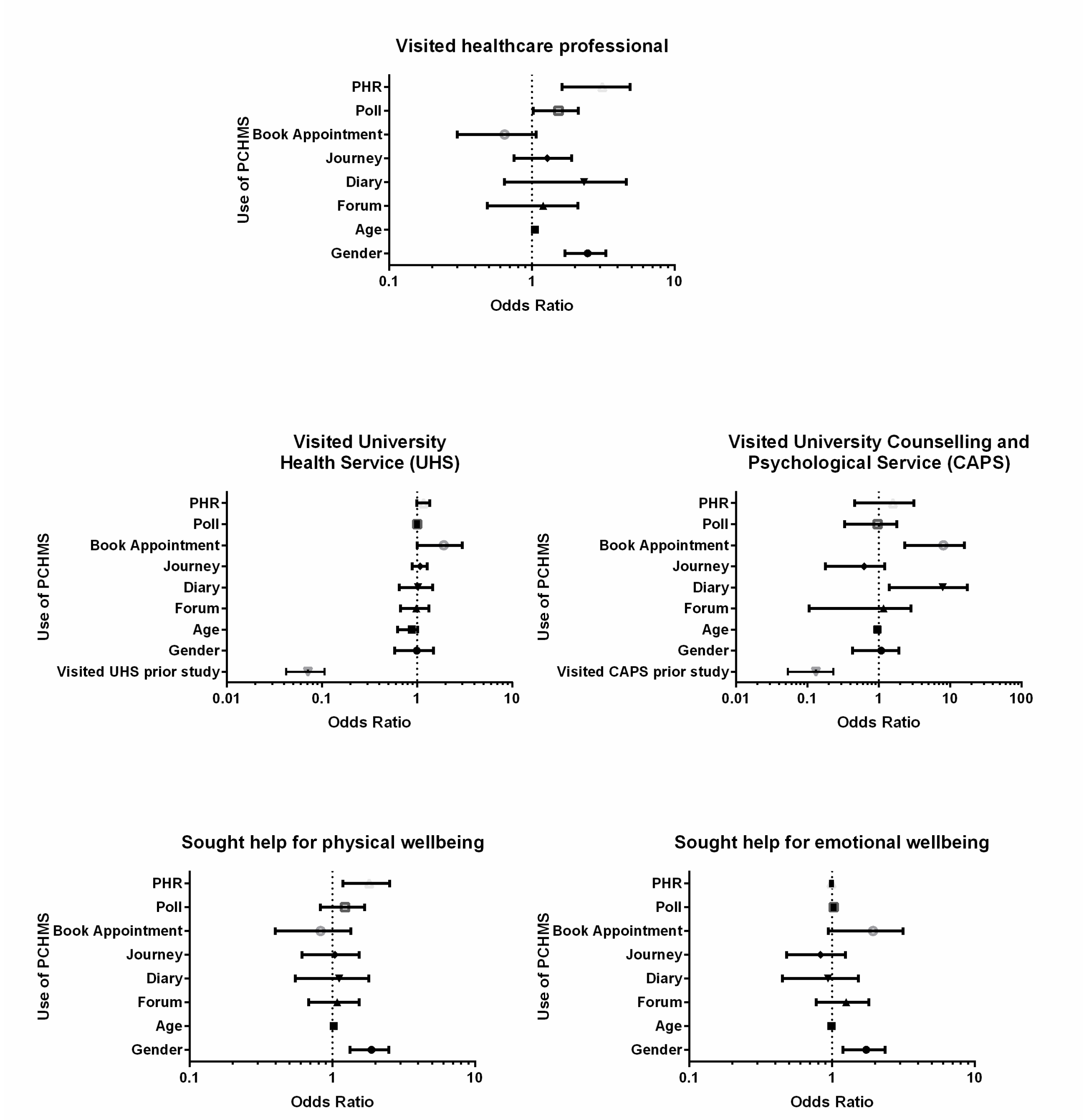
[a] Participants who experienced a physical well-being concern during study but did not seek help. Participants can select more than one reason.

Table 5. Reasons for *not* seeking help for emotional well-being concerns during study (n=221).

Reason	Number [a] n=221 (%)
No time / inconvenience	94 (42.5%)
Fear of confrontation and learning about the health issue	31 (40.0%)
I didn’t think anyone (or anything) can help	80 (36.2%)
I didn’t know (or still don’t know) what seems to be the problem	59 (26.7%)
Not well enough (or motivated) to seek help	54 (24.4%)
Cost	46 (20.8%)
Fear of what others may think	46 (20.8%)
I didn’t know how to seek help	39 (17.6%)
Stigma or cultural attitudes	33 (14.9%)
Other	27 (12.2%)
Previous unsatisfactory contacts with health care professionals	19 (8.6%)

[a] Participants who experienced an emotional well-being concern during study but did not seek help. Participants can select more than one reason.

Figure 5. PCHMS features associated with health service utilization and help-seeking behaviors.



Discussion

Dose-Response Effect

This is the first study that shows a dose-response effect of using a PCHMS on consumers' health service utilization (primary care and counselling) and help-seeking behaviors for emotional well-being. To our knowledge, this is also the first study that contributes an understanding of which bundles of PCHMS features are associated with consumer help-seeking and health service utilization behaviors.

The nature of this study only allows associational inferences to be drawn and specifically, we cannot say that it was the usage of these features that drove user behaviors. An alternate reading of our results is that those individuals who are most likely to use health services are also the population most likely to be drawn to use a PCHMS. Both causal readings are of interest, and it is also likely that both probably are to some extent in operation in the results reported here. As the pre-study characteristics and well-being ratings of users were uniformly distributed across different PCHMS login frequency thresholds, we could not in this study detect differences in users to explain differences in their behaviors, suggesting the dose-response reading of our results is more likely the explanation. Untangling these two alternate readings will undoubtedly be resolved with further research.

The dose-response effect observed in this study may be explained by the availability heuristic, which describes the "situation in which people assess the frequency of a class or the probability of an event by the ease with which instances or occurrences can be brought to mind." [46]. At times when participants experienced emotional and/or physical well-being matters, they may have utilized the availability heuristic to recall mechanisms they have been exposed to (in this case possibly the PCHMS), and accessed it to seek help and/or engage with health services. In addition, by providing informational cues in the PCHMS that are directly linked to an action (such as a "Book now" button embedded within consumer specific content) [15,43], we may have helped participants overcome their perceived barriers to visiting a health service (such as no time, inconvenience, or having to explain one's emotional concern over the phone), which may have hindered the step in making an appointment. Moreover, the PCHMS may have provided a supplementary tool for participants who are already patients at participating health services to manage their health care concerns in conjunction with the services.

Feature Bundles

A PCHMS in practice offers a "bundle" of eHealth services and features including but not limited to a PHR. However, no studies to date have examined which bundles of features might motivate consumers' health behaviors. Past studies that examined user engagement investigated the whole website [47-49], but not individual or bundles of features and not on associating PCHMS engagement with health behaviors.

While help-seeking for physical well-being was only correlated with use of the personal health record, a bundle of PCHMS features were correlated with emotional well-being help-seeking. Providing an environment that allows self-reflection (diary), social feedback (poll), and reducing the barriers to engage with health services (online appointment booking) appeared to work in combination for emotional well-being help-seeking. As suggested by Coiera, one reason such bundles might work is that they are programmatic, bringing together components that reinforce each other's value and use [19]. Unpacking the use and impact of complex eHealth interventions from a "bundle" perspective should help us understand the right type, number, and complexity of features needed for consumers' health behaviors. Identifying effective feature bundles thus appears to be a logical principle to follow in designing the next generation of PCHMS and PHR-related systems.

Feature Rationale

There are strong theoretical reasons why the features tested in this study could drive behavioral change:

- *The online appointment booking service*, embedded within health service information descriptions (ie, journeys), allows consumers to turn information into action. Use of the feature was significantly associated with visits to university primary care and counselling services, in keeping with the "cue to action" elements of the HBM [15].
- *Personal health records*, which encouraged participants to keep track of their personal health details (such as medication, test results, scheduled appointments, or health care team members), were significantly associated with visits to a health care professional and help-seeking for physical well-being matters. This is related to increasing one's self-efficacy by being aware of past and upcoming tasks and results [50].
- *A diary*, which encouraged self-reflection and self-awareness was also significantly associated with visits to the university counselling service, in accord with the principle of self-monitoring—one of the most common behavioral change techniques [51].
- *The poll*, which provided social feedback and social connectivity was also significantly associated with visits to a health care professional and help-seeking for emotional well-being matters. This is congruent with SCT [16] and the "subjective norms" aspect in the Theory of Planned Behavior / Reasoned Action [18], where an individual's perception of social normative pressures affects whether one will conduct such behavior. Social networking features that provide social norm information or allow participants to "discover" and connect with similar individuals may lead to greater engagement with the PCHMS.

Comparison With Prior Work

Our findings are in line with the emerging body of literature that associates eHealth interventions with consumers' health behaviors (such as personalization, tailoring, and behavioral feedback [13,14,51,52]). Previously, we have demonstrated that these PCHMS features have broad utility in a number of health areas including in vitro fertilization and influenza vaccination [42,43]. The current study extends those applications to help-seeking behaviors for physical and emotional well-being.

Our findings also extend previous studies that describe models, guidelines, and definitions on Internet interventions for consumers' health behaviors [9-12], especially PHR-related systems. For PCHMS to be valued by consumers, clinicians, and health service providers, they need to (1) address pressing needs faced by patients and consumers, (2) enable patients and consumers to accomplish tasks without further complicating their lives, and (3) avoid unnecessarily disrupting clinicians' workload or increasing pressure on health service providers [13].

Attrition is a significant concern in consumer eHealth research [5,53]. The Internet has the capacity to reach many individuals who may never seek formal treatment at physical or mental health services. Stumbling across an eHealth application, even for a short period of time, may trigger the much-needed opportunity for those in need to reflect and seek appropriate help. As suggested by Christensen and Mackinnon, the primary role of the Internet in disease prevention and early intervention could possibly be in the delivery of short positive health messages [53]. This study has identified bundles of features in a PCHMS that are associated with consumers' help-seeking and health service utilization rates. Encouraging participants to engage in "relevant" features, rather than the whole intervention, at times of need may lead to the desired health behaviors and outcomes. In fact, website adherence or "stickiness" may cease to be an issue when "sufficient" engagement with the "right" bundle of features are demonstrated to lead to similar health outcomes and help-seeking behaviors [53].

Strengths and Limitations

Key strengths include the large number of participants, a multifaceted PCHMS with connectivity to health service providers that model many of the generic PHR systems and the use of PCHMS usage metrics to associate with consumers' health behaviors. Some limitations include:

1. University setting: Participants in a university setting may have been more motivated and willing to try new technologies to manage their health than the general population [38,49]. An additional limitation is the short duration of the study (5 months). High attrition rates are common in eHealth intervention studies, with a recent systematic review revealing that completion of protocol rates for depression sites ranged from 43% to 99% [54]. One of the possible reasons for the attrition rate of 64% in this study is that participants were asked by email to complete their post-study questionnaire during the long university summer break, where students and staff were not as likely to check their university email. However, the number of participants eligible for analysis is still relatively large in this study (ie, 709), with 81% logging into the PCHMS at least once, providing a sufficient sample size to analyze whether participants' usage of the PCHMS is associated with their health service and help-seeking utilization rates. Overall, future studies conducted in the university setting should avoid commencing or completing the study during university breaks.
2. Self-reports and self-entry functionality: The study relied on self-reports by participants, which have been shown to be acceptable in studies of help-seeking, health service utilization, and mental health-related studies among students [30,55-57]. The PCHMS currently relies on self-entry functionality, which may have caused lower usage of the tool and reduced follow-up data collection. While it is possible that some patients could have used the PCHMS after visiting the university health services, we validated health service utilization rates by matching self-report from a subset of study participants with their health records at the University Counselling and Psychological Services, where system usage log files indicated that usage of the PCHMS preceded clinic visits or that the "Book now" button was used. Although this study focuses only on eligible participants who completed both the pre- and post-study questionnaires, this approach is appropriate as our aim is to identify whether help-seeking and health service utilization behaviors (collected only at post-study) are associated with participants' usage of the PCHMS. In fact, this study was conducted using intention-to-treat analysis as all eligible participants who used or did not use the PCHMS were included in the analysis.
3. Causality vs association: Although findings in this study are limited by its cross-sectional nature and we could attribute no causal relationships, our findings concur with Couper and colleagues' study, which found that website engagement was significantly associated with consumers' health behaviors [47]. In addition, our analyses showed that participants' pre-study characteristics and well-being ratings were uniformly distributed between different PCHMS login frequency thresholds.
4. PCHMS engagement measures: studies have reported numerous metrics for measuring user engagement with a website, such as number of website visits, time spent on a site, and number of features used [38,58]. This study used simple website engagement measures. Future studies could consider in-depth analyses of whether participants accessed a bundle of features in the same login session, or whether the features were accessed in a particular sequence over the duration of the study. In addition, future studies should consider incorporating a qualitative component to elicit participants' context and reasons (eg, why and how) for engaging with the website.

Conclusions

Our online prospective study provides evidence that PCHMS usage is associated with consumers' utilization of health services and help-seeking behaviors for emotional well-being concerns. The features in this PCHMS are sufficiently general to be applicable to a variety of help-seeking and preventative health tasks.

While there is evidence that Web interventions can trigger significant consumer health behaviors, the empirical and theoretical basis for developing PCHMS features in general is still weak. Abandoning an eHealth application is a common and significant phenomenon. Asking participants to engage in *all* features of an eHealth application may not be an effective strategy to reduce attrition or influence health behaviors. Strategies that alert participants to bundles of features that are of immediate relevance or benefit to them could possibly result in higher engagement with the intervention and achieve the desired health actions. Future studies should investigate whether participants' engagement with "tailored" bundles of PCHMS features are effective in achieving the desired health behaviors and outcomes, and that more correlation studies are needed to show which bundles of features are best for which kinds of consumers' health tasks, conditions, and help-seeking stages.

Acknowledgments

The authors thank Farshid Anvari, Jingbo Liu, Vitaliy Kim, and Jay Liu for their contributions to software development, and the staff and students at UNSW who assisted or participated in the study.

This research is supported in part by grants received from the National Health and Medical Research Council (NHMRC) Centre of Research Excellence in Informatics and E-Health (1032664), and the HCF Health and Medical Research Foundation. The funding bodies did not have a role in the design and conduct of the study; the collection, management, analysis, and interpretation of the data; or the preparation, review, or approval of the manuscript.

Authors' Contributions

Study design: AL, JP, AA1, JC, STL, EC. Journey design: AA1, JC, AL. Data collection: AL, AA1, JC. Data analyses: AL, AA2, EC. First draft: AL. Draft revision: AL, EC, JP, STL, AA1, AA2, JC.

Conflicts of Interest

The University of New South Wales and some of the researchers (EC, AL) at the Centre for Health Informatics involved in this project could benefit from commercialization of the PCHMS.

Multimedia Appendix 1

Details on questionnaire measures.

[PDF File (Adobe PDF File), 127KB - jmir_v15i5e79_app1.pdf]

Multimedia Appendix 2

Details of logistic regression results for each outcome measure.

[PDF File (Adobe PDF File), 193KB - jmir_v15i5e79_app2.pdf]

References

1. Greenhalgh T, Stramer K, Bratan T, Byrne E, Russell J, Potts HW. Adoption and non-adoption of a shared electronic summary record in England: a mixed-method case study. BMJ 2010;340:c3111 [FREE Full text] [Medline: 20554687]
2. Greenhalgh T, Hinder S, Stramer K, Bratan T, Russell J. Adoption, non-adoption, and abandonment of a personal electronic health record: case study of HealthSpace. BMJ 2010;341:c5814 [FREE Full text] [Medline: 21081595]
3. Black AD, Car J, Pagliari C, Anandan C, Cresswell K, Bokun T, et al. The impact of eHealth on the quality and safety of health care: a systematic overview. PLoS Med 2011;8(1):e1000387 [FREE Full text] [doi: 10.1371/journal.pmed.1000387] [Medline: 21267058]
4. Khadjesari Z, Murray E, Kalaitzaki E, White IR, McCambridge J, Thompson SG, et al. Impact and costs of incentives to reduce attrition in online trials: two randomized controlled trials. J Med Internet Res 2011;13(1):e26 [FREE Full text] [doi: 10.2196/jmir.1523] [Medline: 21371988]
5. Eysenbach G. The law of attrition. J Med Internet Res 2005;7(1):e11 [FREE Full text] [doi: 10.2196/jmir.7.1.e11] [Medline: 15829473]
6. Poirier J, Cobb NK. Social influence as a driver of engagement in a web-based health intervention. J Med Internet Res 2012;14(1):e36 [FREE Full text] [doi: 10.2196/jmir.1957] [Medline: 22356829]
7. Institute of Medicine. Health IT and Patient Safety: Building Safer Systems for Better Care. Washington, DC: The National Academies Press; 2011.
8. Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. J Am Med Inform Assoc 2006 Apr;13(2):121-126 [FREE Full text] [doi: 10.1197/jamia.M2025] [Medline: 16357345]
9. Ritterband LM, Thorndike FP, Cox DJ, Kovatchev BP, Gonder-Frederick LA. A behavior change model for internet interventions. Ann Behav Med 2009 Aug;38(1):18-27 [FREE Full text] [doi: 10.1007/s12160-009-9133-4] [Medline: 19802647]
10. Proudfoot J, Klein B, Barak A, Carlbring P, Cuijpers P, Lange A, et al. Establishing Guidelines for Executing and Reporting Internet Intervention Research. Cognitive Behaviour Therapy 2011 Jun 2011;40(2):82-97. [doi: 10.1080/16506073.2011.573807]
11. Barak A, Klein B, Proudfoot JG. Defining internet-supported therapeutic interventions. Ann Behav Med 2009 Aug;38(1):4-17. [doi: 10.1007/s12160-009-9130-7] [Medline: 19787305]
12. Krukowski RA, Harvey-Berino J, Ashikaga T, Thomas CS, Micco N. Internet-based weight control: the relationship between web features and weight loss. Telemed J E Health 2008 Oct;14(8):775-782 [FREE Full text] [doi: 10.1089/tmj.2007.0132] [Medline: 18954247]
13. Gibbons C, Wilson RF, Samal L, Lehmann CU, Dickersin K, Lehmann HP. The John Hopkins University Evidence-based Practice Centre. 2009. Impact of Consumer Health Informatics Applications URL: http://www.ahrq.gov/downloads/pub/evidence/pdf/chiapp/impactchia.pdf [accessed 2013-03-17] [WebCite Cache ID 6FBpCX6Ej]
14. Noar SM, Benac CN, Harris MS. Does tailoring matter? Meta-analytic review of tailored print health behavior change interventions. Psychol Bull 2007 Jul;133(4):673-693. [doi: 10.1037/0033-2909.133.4.673] [Medline: 17592961]
15. Janz NK, Becker MH. The Health Belief Model: a decade later. Health Educ Q 1984;11(1):1-47. [Medline: 6392204]
16. Bandura A. Human agency in social cognitive theory. Am Psychol 1989 Sep;44(9):1175-1184. [Medline: 2782727]
17. Prochaska J, DiClemente C. The Transtheoretical Approach: Crossing the Traditional Boundaries of Therapy. Homewood, IL: Dow Jones-Irwin; 1984.

18. Ajzen I. The Theory of Planned Behavior. Organ Behav Hum Decis Process 1991 Dec;50(2):79-211.
19. Coiera E. Why system inertia makes health reform so difficult. BMJ 2011;342:d3693. [Medline: 21700652]
20. Albertos R, Caralt B, Rello J. Ventilator-associated pneumonia management in critical illness. Curr Opin Gastroenterol 2011 Mar;27(2):160-166. [doi: 10.1097/MOG.0b013e32834373b1] [Medline: 21248638]
21. Barochia AV, Cui X, Vitberg D, Suffredini AF, O'Grady NP, Banks SM, et al. Bundled care for septic shock: an analysis of clinical trials. Crit Care Med 2010 Feb;38(2):668-678 [FREE Full text] [doi: 10.1097/CCM.0b013e3181cb0ddf] [Medline: 20029343]
22. Fulbrook P, Mooney S. Care bundles in critical care: a practical approach to evidence-based practice. Nurs Crit Care 2003 Dec;8(6):249-255. [Medline: 14725390]
23. Stallman HM. Prevalence of psychological distress in university students--implications for service delivery. Aust Fam Physician 2008 Aug;37(8):673-677. [Medline: 18704221]
24. Stallman HM, Shochet I. Prevalence of mental health problems in Australian university health services. Australian Psychologist 2009;44(2):122-127.
25. Leahy CM, Peterson RF, Wilson IG, Newbury JW, Tonkin AL, Turnbull D. Distress levels and self-reported treatment rates for medicine, law, psychology and mechanical engineering tertiary students: cross-sectional study. Aust N Z J Psychiatry 2010 Jul;44(7):608-615. [doi: 10.3109/00048671003649052] [Medline: 20560848]
26. Stallman HM. Psychological distress in university students: A comparison with general population data. Australian Psychologist 2010;45(4):249-257. [doi: 10.1080/00050067.2010.482109]
27. Song Y, Huang Y, Liu D, Kwan JS, Zhang F, Sham PC, et al. Depression in college: depressive symptoms and personality factors in Beijing and Hong Kong college freshmen. Compr Psychiatry 2008 Oct;49(5):496-502. [doi: 10.1016/j.comppsych.2008.02.005] [Medline: 18702936]
28. Gallagher R. National survey of counselling center directors. 2008. URL: http://www.iacsinc.org/2008%20National%20Survey%20of%20Counseling%20 [accessed 2013-03-17] [WebCite Cache ID 6FBpheFOq]
29. Bayram N, Bilgel N. The prevalence and socio-demographic correlations of depression, anxiety and stress among a group of university students. Soc Psychiatry Psychiatr Epidemiol 2008 Aug;43(8):667-672. [doi: 10.1007/s00127-008-0345-x] [Medline: 18398558]
30. Eisenberg D, Golberstein E, Hunt J. Mental Health and Academic Success in College. BE Journal of Economic Analysis & Policy 2009;9(1).
31. Ciarrochi J, Deane FP, Wilson CJ, Rickwood D. Adolescents who need help the most are the least likely to seek it: the relationship between low emotional competence and low intention to seek help. British Journal of Guidance and Counselling 2002;30:173-188.
32. Yap MB, Reavley NJ, Jorm AF. Australian youth still have limited awareness of headspace: results from a national survey. Aust N Z J Psychiatry 2012 Jan;46(1):28-34. [doi: 10.1177/0004867411427808] [Medline: 22247090]
33. Britt HMG, Charles J, Henderson J, Bayram C, Valenti L, Pan Y, et al. General practice activity in Australia 2000-01 to 2009-10. URL: http://www.aihw.gov.au/publication-detail/?id=6442472440%3E [accessed 2013-03-17] [WebCite Cache ID 6FBpvLKWg]
34. de Azevedo-Marques JM, Zuardi AW. COOP/WONCA charts as a screen for mental disorders in primary care. Ann Fam Med 2011 Aug;9(4):359-365 [FREE Full text] [doi: 10.1370/afm.1267] [Medline: 21747108]
35. Rabin R, de Charro F. EQ-5D: a measure of health status from the EuroQol Group. Ann Med 2001 Jul;33(5):337-343. [Medline: 11491192]
36. Norbeck JS. The Norbeck Social Support Questionnaire. Birth Defects Orig Artic Ser 1984;20(5):45-57. [Medline: 6536338]
37. Rickwood D, Deane FP, Wilson CJ, Ciarrochi J. Young people's help-seeking for mental health problems. Advances in Mental Health 2005;4(3):218-251.
38. Danaher BG, Seeley JR. Methodological issues in research on web-based behavioral interventions. Ann Behav Med 2009 Aug;38(1):28-39. [doi: 10.1007/s12160-009-9129-0] [Medline: 19806416]
39. Wicks P, Massagli M, Frost J, Brownstein C, Okun S, Vaughan T, et al. Sharing health data for better outcomes on PatientsLikeMe. J Med Internet Res 2010;12(2):e19 [FREE Full text] [doi: 10.2196/jmir.1549] [Medline: 20542858]
40. Zajonc RB. The Attitudinal Effects of Mere Exposure. Journal of Personality and Social Psychology 1968;9:1-27.
41. Varey CA, Kahneman D. Experiences extended across time: Evaluation of moments and episodes. J. Behav. Decis. Making 1992 Jul 1992;5(3):169-185. [doi: 10.1002/bdm.3960050303]
42. Lau AYS, Parker A, Early J, Sacks G, Anvari F, Coiera E. Comparative usage of a web-based personally controlled health management systemnormal support: a case study in IVF. electronic Journal of Health Informatics (eJHI) 2012;7(2):e12.
43. Lau AY, Sintchenko V, Crimmins J, Magrabi F, Gallego B, Coiera E. Impact of a web-based personally controlled health management system on influenza vaccination and health services utilization rates: a randomized controlled trial. J Am Med Inform Assoc 2012;19(5):719-727. [doi: 10.1136/amiajnl-2011-000433] [Medline: 22582203]
44. Tabachnick B, Fidell L. Using Multivariate Statistics. 5th edn. ed. Boston, MA: Allyn & Bacon; 2006.
45. IBM. 2012 Sep 19. SPSS Statistics 2012 URL: http://www-01.ibm.com/software/analytics/spss/products/statistics/ [accessed 2013-03-17] [WebCite Cache ID 6FBq7ZCOZ]

46. Kahneman D, Slovic P, Tversky A. Judgment under uncertainty: Heuristics and biases. New York: Cambridge University Press; 1982.
47. Couper MP, Alexander GL, Zhang N, Little RJ, Maddy N, Nowak MA, et al. Engagement and retention: measuring breadth and depth of participant use of an online intervention. J Med Internet Res 2010;12(4):e52 [FREE Full text] [doi: 10.2196/jmir.1430] [Medline: 21087922]
48. Glasgow ER, Christiansen MS, Kurz D, King KD, Woolley T, Faber JA, et al. Engagement in a diabetes self-management website: usage patterns and generalizability of program use. J Med Internet Res 2011;13(1):e9 [FREE Full text] [doi: 10.2196/jmir.1391] [Medline: 21371992]
49. 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] [doi: 10.2196/jmir.9.2.e11] [Medline: 17513282]
50. Bandura A. Self-efficacy: toward a unifying theory of behavioral change. Psychol Rev 1977 Mar;84(2):191-215. [Medline: 847061]
51. Webb TL, Joseph J, Yardley L, Michie S. Using the internet to promote health behavior change: a systematic review and meta-analysis of the impact of theoretical basis, use of behavior change techniques, and mode of delivery on efficacy. J Med Internet Res 2010;12(1):e4 [FREE Full text] [doi: 10.2196/jmir.1376] [Medline: 20164043]
52. Kelders SM, Kok RN, Ossebaard HC, Van Gemert-Pijnen JE. Persuasive system design does matter: a systematic review of adherence to web-based interventions. J Med Internet Res 2012;14(6):e152 [FREE Full text] [doi: 10.2196/jmir.2104] [Medline: 23151820]
53. Christensen H, Mackinnon A. The law of attrition revisited. J Med Internet Res 2006;8(3):e20; author reply e21 [FREE Full text] [doi: 10.2196/jmir.8.3.e20] [Medline: 17032636]
54. Christensen H, Griffiths MK, Farrer L. Adherence in internet interventions for anxiety and depression. J Med Internet Res 2009;11(2):e13 [FREE Full text] [doi: 10.2196/jmir.1194] [Medline: 19403466]
55. Eisenberg D, Downs MF, Golberstein E, Zivin K. Stigma and help seeking for mental health among college students. Med Care Res Rev 2009 Oct;66(5):522-541. [doi: 10.1177/1077558709335173] [Medline: 19454625]
56. Eisenberg D, Golberstein E, Gollust SE. Help-seeking and access to mental health care in a university student population. Med Care 2007 Jul;45(7):594-601. [doi: 10.1097/MLR.0b013e31803bb4c1] [Medline: 17571007]
57. Eisenberg D, Gollust SE, Golberstein E, Hefner JL. Prevalence and correlates of depression, anxiety, and suicidality among university students. Am J Orthopsychiatry 2007 Oct;77(4):534-542. [doi: 10.1037/0002-9432.77.4.534] [Medline: 18194033]
58. 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 May;34(5):373-381 [FREE Full text] [doi: 10.1016/j.amepre.2007.12.024] [Medline: 18407003]

Abbreviations

HBM: health belief model
OR: odds ratio
PCHMS: personally controlled health management system
PHR: personal health record
RCT: randomized controlled trial
RR: relative risk
SCT: social cognitive theory
TTM: transtheoretical model
UNSW: University of New South Wales

Edited by G Eysenbach; submitted 23.10.12; peer-reviewed by S Woods, J Jones; comments to author 14.11.12; revised version received 18.11.12; accepted 09.02.13; published 06.05.13.

Please cite as:
Lau AYS, Proudfoot J, Andrews A, Liaw ST, Crimmins J, Arguel A, Coiera E
Which Bundles of Features in a Web-Based Personally Controlled Health Management System Are Associated With Consumer Help-Seeking Behaviors for Physical and Emotional Well-Being?
J Med Internet Res 2013;15(5):e79
URL: http://www.jmir.org/2013/5/e79/
doi:10.2196/jmir.2414
PMID:23649790

Original Paper

Expectations of iPad Use in an Internal Medicine Residency Program: Is It Worth the “Hype”?

Nancy Luo[1], MD; Christopher G Chapman[1], MD; Bhakti K Patel[1], MD; James N Woodruff[2], MD; Vineet M Arora[2], MD, MAPP

[1]Department of Medicine, University of Chicago, Chicago, IL, United States

[2]Associate Program Director, Internal Medicine Residency, Department of Medicine, University of Chicago, Chicago, IL, United States

Corresponding Author:
Vineet M Arora, MD, MAPP
Associate Program Director, Internal Medicine Residency
Department of Medicine
University of Chicago
5841 S Maryland Ave
MC 2007, AMB W216
Chicago, IL, 60637
United States
Phone: 1 773 702 8157
Fax: 1 773 834 2238
Email: varora@medicine.bsd.uchicago.edu

Abstract

Background: While early reports highlight the benefits of tablet computing in hospitals, introducing any new technology can result in inflated expectations.

Objective: The aim of the study is to compare anticipated expectations of Apple iPad use and perceptions after deployment among residents.

Methods: 115 internal medicine residents received Apple iPads in October 2010. Residents completed matched surveys on anticipated usage and perceptions after distribution 1 month prior and 4 months after deployment.

Results: In total, 99% (114/115) of residents responded. Prior to deployment, most residents believed that the iPad would improve patient care and efficiency on the wards; however, fewer residents “strongly agreed” after deployment (34% vs 15% for patient care, $P<.001$; 41% vs 24% for efficiency, $P=.005$). Residents with higher expectations were more likely to report using the iPad for placing orders post call and during admission (71% vs 44% post call, $P=.01$, and 16% vs 0% admission, $P=.04$). Previous Apple iOS product owners were also more likely to use the iPad in key areas. Overall, 84% of residents thought the iPad was a good investment for the residency program, and over half of residents (58%) reported that patients commented on the iPad in a positive way.

Conclusions: While the use of tablets such as the iPad by residents is generally well received, high initial expectations highlight the danger of implementing new technologies. Education on the realistic expectations of iPad benefits may be warranted.

(J Med Internet Res 2013;15(5):e88) doi:10.2196/jmir.2524

KEYWORDS

iPad; mobile tablet computing; technology; expectation dynamics; hype

Introduction

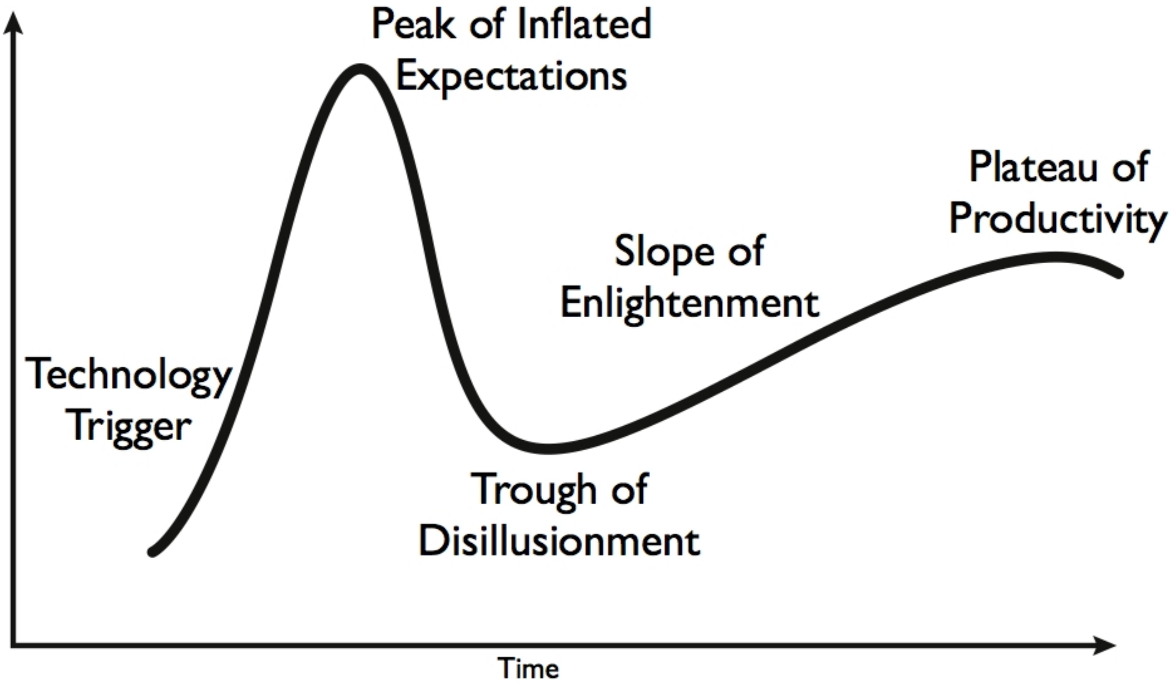
The use of mobile technology in hospitals is not a new development. Despite many iterations of PDAs and tablet computers, medical professionals have traditionally been stymied by poor user interfaces, inadequate information density, and insufficient interoperability [1]. The introduction of the Apple iPad sparked tremendous excitement. Reports quickly surfaced about the iPad being used in operating rooms and emergency rooms [2-4]. The Stanford and Yale medical schools adopted iPads for use as an adjunct to their medical curriculum [5,6]. Residency programs, including one at the University of Chicago, adopted the iPad. Systematic analyses of physician order entry from the electronic medical record demonstrated that the iPad affords significant improvements in both perceived and actual efficiency [7]. Other reviews confirm utilization with regard to communication and information management among providers in a health care setting [8].

While the release of the iPad was associated with tremendous excitement, any new technology can be plagued by inflated expectations, leading inevitably to disappointment. The Gartner Hype Cycle model describes the change in maturity and adoption rate for emerging technology over time and suggests any burgeoning technology is subject to the effects of hype [9]. As buzz grows after the release of a new technology, early adopters surface with anecdotal stories of tremendous success. Soon thereafter, as early expectations are not fully realized, popular sentiment swings the other direction, creating a “trough of disappointment”. Figure 1 shows a graphical representation of the excitement, adoption, and mature application of new technologies plotted over time.

Technology adoption will only become well embedded if new uses are realized, tested, and implemented, thereby permitting mainstream users to adopt the technology and reach the “plateau of productivity”. The Gartner Hype Cycle is facilitated by “early adopters,” or individuals who enter the cycle early, near the technology trigger. Early adopters are often instrumental in spreading the use of the technology to mainstream users. Mainstream users adopt the technology only once it has proven that its benefits outweigh the costs of learning a new interaction [10]. This model highlights the importance of characterizing early adopters who can become champions of new technology to help realize its full adoption.

In the hospital setting, it is critical to accurately assess whether the introduction of the iPad is associated with hype or inflated expectations, and how this hype affects adoption of the device. Furthermore, it is also important to understand characteristics of early adopters who can spread the innovation to facilitate large-scale adoption. Therefore, the objective of our study is to (1) characterize the hype associated with iPads by comparing anticipated use of an iPad with actual use among residents, and (2) characterize whether personal adoption of iPads is associated with various factors including prior Apple usage, year in training, and gender.

Figure 1. Gartner hype cycle.



Methods

iPad Deployment

In October 2010, all 115 internal medicine residents at the University of Chicago Medical Center were given Apple iPads. An initial task force of Internal Medicine faculty, residents, and department administrative staff, which had convened to assess and manage iPad distribution, had already determined through a small 2-month pilot study of 5 residents that iPads had the potential to improve house staff workflow on the wards. The pilot established the benefits of a carrying strap while using the iPad during daily rounds as well as the need to improve wireless network reception and coverage. Before being issued to a resident, each iPad was set up with access to the following software: (1) MobileIron, an institutionally controlled device management application that personalized and managed the permissions and user restrictions on the device, (2) Epic electronic health record and computer provider order entry systems via Citrix client, (3) short links to both the electronic paging directory and the institutional subscription to UpToDate, and (4) Epocrates, a mobile application drug database. Upon receiving the device, all residents attended a 1-hour orientation session covering its appropriate clinical use.

Study Design

This was a matched pre/post cohort survey study, using combined paper and online surveys (Perseus) to ensure a high response rate. To match responses, all respondents created their own unique identifier that enabled pairing of pre- and post-use responses but rendered the data anonymous. Residents were surveyed in the month prior to receiving their iPads with completion of the survey required prior to receiving an iPad. After 4 months of use in the hospital, residents were given the post-use survey. We felt a 3-month learning curve would sufficiently encompass most people's ability to learn and incorporate the iPad into their workflow. This study was deemed exempt from review by University of Chicago Medicine Institutional Review Board.

Data Collection

The authors developed the survey items to assess demographics, hype, and usage of the iPad. In addition to the standard demographic questions, such as age, gender, and training year, the pre-use survey included questions about current barriers to efficiency, attitudes toward the iPad, and expectations on its utility in the workplace. The post-use survey measured iPad effects on workflow and efficiency as well as self-reported estimates of device usage in various clinical scenarios such as rounding, inpatient and outpatient use, teaching, and use in front of patients through a 5-point Likert scale (with 5 being "strongly agree" and 1 being "strongly disagree").

Hype or anticipated excitement regarding the iPad was assessed on the pre-survey through the resident's selection of one of four statements with which they most agreed: (1) "I perceive little or no value in adding the iPad to our workflow", (2) "I would be interested in seeing how the iPad works, but I don't have a lot of extra time to learn a new system", (3) "I think the iPad will be great and am excited to use it on the wards", or (4) "It's all I need in my white coat! I already have one or... [am] seriously considering buying my own." The language used was developed by 2 resident champions (NL, CC) to reflect the feeling of the anecdotal emotions that other residents had expressed to them and was reviewed by the rest of the investigator team. A resident who exhibited hype was defined as whether he or she agreed with the latter two statements expressing positive expectation or excitement. Residents also identified various work-related tasks they performed with the iPad such as entering orders, typing notes, or reviewing labs and imaging.

Data Analysis

Descriptive statistics were performed to summarize the percentage of residents that reported demographic characteristics (gender, postgraduate year [PGY]), prior Apple iOS operating system use, perception of hype, and perceived and actual usage of the iPad for various tasks. Usage items were dichotomized to reflect those residents that reported frequent use of the iPad to perform a task. Two-sample tests of proportion were used to test for differences before and after iPad deployment between perceived and actual usage. To test the association between reporting hype (pre-use survey) and actual usage of the iPad (post-use survey), pre- and post-data were merged using the participant's unique identifier, which enabled a chi-square test. This merged dataset also enabled analysis of the association between demographic characteristics (pre-use survey) and adoption of the iPad (post-use survey) using chi-square tests. All statistical tests were performed in Stata 11.0, with statistical significance defined as $P<.05$.

Results

All of the residents except one completed both surveys (115/115 responses in the pre-use survey and 114/115 responses in the post-use survey). One resident returned his iPad to the program after 1 month of use. Of the 114 respondents in the post-use survey, 45 (39.5%) were PGY-1, 32 (28%) were PGY-2, and 37 (32%) were PGY 3-4. Of the residents, 55 (48%) were female, and 45 (39.5%) already owned a personal Apple product with a similar operating system to the iPad, like iPhone, iPod Touch, or a personal iPad. Hype was generally high, with 79% (90/114) of residents reporting excitement for the iPad. Interns had statistically higher excitement about the iPads than their peers: 91% (41/45) PGY-1, 78% (25/32) PGY-2, 65% (24/37) PGY-3, $P=.02$ (Table 1).

Table 1. Percentage of residents displaying hype.

Characteristics		Percentage
Apple user		
	Yes	83% (39/47)
	No	76% (51/67)
PGY		
	PGY-1	91% (41/45)[a]
	PGY-2	78% (25/32)[a]
	PGY-3	65% (24/37)[a]
Gender		
	Male	78% (46/59)
	Female	80% (44/55)
All residents		
		79% (90/114)

[a] Difference between PGY is statistically significant using chi-square test (*P*=.02).

Prior to using the iPad, residents expected that the iPad would have positive benefits on their daily practice, with several at the extremes. For example, several residents reported “strong” agreement with the potential impact of the iPad on future attendance at conference (44% or 50/114), benefits to patient care (34% or 39/114), and increased efficiency on wards (41% or 47/114). However, 4 months after deployment, significantly fewer residents felt that the iPad benefited attendance at conference, patient care, and efficiency on the wards with strong agreement: 17% or 19/114, *P*<.001; 15% or 17/114, *P*<.001; 24% or 27/114, *P*=.005, respectively using 2-sample tests of proportion. Figure 2 shows a decrease in percentage of respondents choosing “I strongly agree that the iPad will improve…” in 3 areas before and after using the iPad (n=114).

After merging the pre- and post-use data, we excluded 5 individuals whose pre- and post-identifiers did not match, leaving 109 for this analysis. Usage of the iPad was high for many tasks, such as reviewing labs (87% or 95/109), paging (76% or 83/109), and answering clinical questions (73% or 80/109). For these tasks, there was no association between reported hype prior to receipt of the iPad and usage of the iPad after distribution (see Figure 3 for a comparison of use between residents exhibiting hype vs those without hype, n=109). In contrast, residents who reported higher hype before iPad distribution were significantly more likely to report using the iPad for tasks related to placing orders, particularly entering orders post call and during admission: 71% or 61 of 86 hype-residents vs 44% or 10 of 23 nonhype-residents, post call, *P*=.01; and 16% or 14/86 vs 0% or 0/23, admission, *P*=.04, using chi-square tests (Figure 2). Interestingly, after iPad deployment, more residents reported they preferred pen and paper to organize their thoughts than before: 67% (76/114) post vs 39% (44/114) pre, *P*<.001 using chi-square test.

One of the strongest predictors of long-term iPad adoption was whether the resident was a private owner of an Apple iOS product such as iPhone, iPad, or iPod touch. Apple users were significantly more likely than non–Apple users to use the iPad to answer clinical questions (84% or 38 of 45 Apple users vs 65% or 45 of 69 non–Apple users, *P*=.02 using chi-square test) and enter orders post call (78% or 35/45 vs 57% or 39/69, *P*=.02 using chi-square test). Despite interns’ higher initial expectations, they were not more likely to use the iPad than senior residents, with the exception of using the iPad to input orders during rounds (86% or 38/44 vs 64% or 45/70, *P*=.01 using chi-square test). No significant difference was seen in iPad usage by gender.

After the deployment of the iPad, residents did report positive benefits of the iPad, such as less time searching for an available desktop computer and efficiency gains. Most (84% or 96/114) residents thought the iPad was a good investment for the residency program. Moreover, 58% (66/114) reported that a patient had commented on the iPad in a positive way.

Figure 2. Expectations of iPad use. **P*=.005, 2-sample tests of proportion. ***P*<.001, 2-sample tests of proportion.

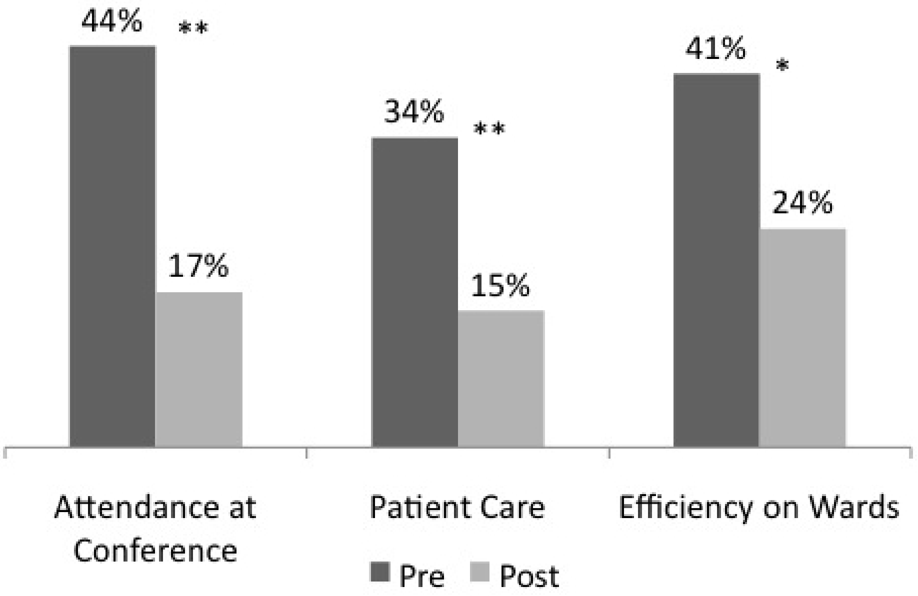
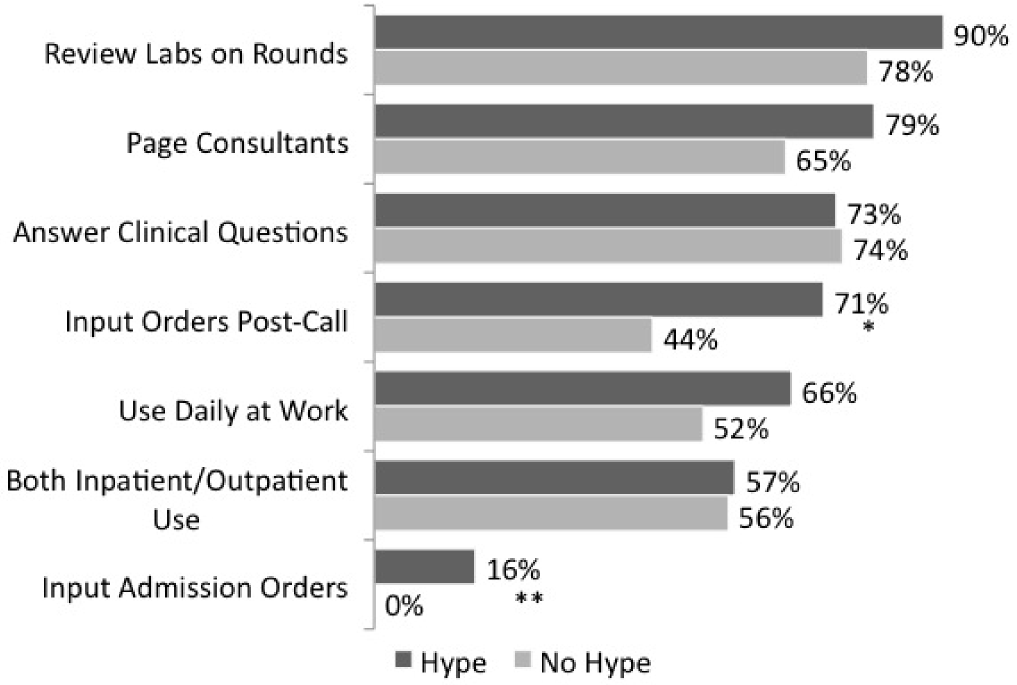


Figure 3. iPad usage by task: Hype versus non-hyped residents. **P*=.01, chi-square tests. ***P*=.04, chi-square tests.



Discussion

Principle Results

Our study confirms that distribution of the iPad in an internal medicine residency program is associated with high perceived expectations or hype. In fact, 4 months after iPad deployment, actual use of the device for certain tasks fell short of these initial high expectations. Residents who reported more hype prior to iPad deployment were more likely to use the iPad to enter orders. Lastly, those residents who used Apple products prior to iPad deployment were more likely to report higher usage of the iPad.

It is worth exploring why only certain tasks were associated with initial hype. One potential explanation is that many simple tasks (ie, reviewing labs, paging, and answering clinical questions) are inherently easier to learn. In contrast, entering orders post call and placing admission orders through the iPad are difficult, time-consuming tasks. Because these tasks are inherently more complex, it may be that residents who showed more excitement were more willing to expend the effort necessary to use their iPads in situations that required more time investment and effort. On the other hand, residents who did not report hype may have been more likely to revert to traditional methods when faced with technically complex tasks. In developing and encouraging continued use of the iPad and other tablets in the health care environment, it will become important to recognize which tasks are inherently easier to complete on a tablet compared to a desktop computer and which are not. Highlighting the simpler tasks will increase overall use, while efforts should be undertaken with developers to simplify the more difficult tasks.

It is not surprising that interns and Apple users were more likely to demonstrate hype. Interns, because of their age and comfort with technology, and Apple users, because of their existing familiarity with the interface, are more likely to be classified as “early adopters” in technology use [10]. Further characterizing what differentiates interns and Apple users from other groups may lead to methods of encouraging other residents to increase their hype, and accordingly, increase efficiency. Cultivating champions among these groups with high hype may be a helpful strategy to increase use and provide assistance to those residents who are more skeptical or are struggling with their device.

Comparison With Prior Work

These findings suggest several intriguing implications for other hospital-based physicians. Previously, we demonstrated that iPad deployment led to a higher proportion of orders being placed both earlier in the hospitalization and before the primary team left the hospital, leading to increased efficiency [7]. This effect was demonstrated through EMR order entry data. Here, we observed that when residents experienced greater hype for the iPad, they also placed significantly more orders post call, an area where previous efficiency gains were achieved. It is conceivable that continuing to encourage excitement and set high expectations will create greater gains in efficiency. Indeed, previous research in education has suggested that creating an engaged and excited student population leads to better performance [11]. Conversely, it is also important to understand how and why the iPad may fall short of expectations. Residents’ expressing a stronger preference for pen and paper even after using the tablet for 4 months highlights that mobile computing still lacks certain critical characteristics unique to the analog domain.

Limitations

There are several limitations to this study. First, this study was conducted in a single institution, with only Apple iPad and no other tablet devices, so results may not be transferable. Results may be skewed towards more inflated expectations because baseline surveys were completed as part of an initiative to receive an iPad. In addition, to measure hype, we created our survey tool since we lacked a validated one. Furthermore, data on how iPads were used were collected via self-report, which could be affected by recall bias.

Conclusions

In conclusion, this study shows that the deployment of Apple iPads in a residency program was associated with high expectations, consistent with prior models of technology innovation. Careful management of these expectations while promoting champions of use will be necessary to create an environment of successful adoption for mobile technology in the hospital setting.

Conflicts of Interest

None declared.

References

1. McAlearney AS, Schweikhart SB, Medow MA. Doctors' experience with handheld computers in clinical practice: qualitative study. BMJ 2004 May 15;328(7449):1162 [FREE Full text] [doi: 10.1136/bmj.328.7449.1162] [Medline: 15142920]
2. Wodajo FM. Column: The iPad in the Hospital and Operating Room. J Surg Rad 2010;2:1-2 [FREE Full text] [Medline: 15440335]
3. Nathanson L. The iPad goes live at BIDMC. 2010. URL: http://geekdoctor.blogspot.com/2010/04/ipad-goes-live-at-bidmc.html [accessed 2013-01-07] [WebCite Cache ID 6DVGzdK0o]
4. Dasari KB, White SM, Pateman J. Survey of iPhone usage among anaesthetists in England. Anaesthesia 2011 Jul;66(7):630-631. [doi: 10.1111/j.1365-2044.2011.06747.x] [Medline: 21682718]

5. Woodford A. Yale Daily News. 2011 Aug 16. Med school gives students iPads URL: http://yaledailynews.com/blog/2011/08/26/med-school-gives-students-ipads/ [accessed 2013-01-07] [WebCite Cache ID 6DVHgmVha]
6. White T. Will iPad transform med school? Inside Stanford Medicine. 2010 Sep 13. URL: http://med.stanford.edu/ism/2010/september/ipads-0913.html [accessed 2013-01-07] [WebCite Cache ID 6DVHxOpdS]
7. Patel BK, Chapman CG, Luo N, Woodruff JN, Arora VM. Impact of mobile tablet computers on internal medicine resident efficiency. Arch Intern Med 2012 Mar 12;172(5):436-438. [doi: 10.1001/archinternmed.2012.45] [Medline: 22412110]
8. Wallace S, Clark M, White J. 'It's on my iPhone': attitudes to the use of mobile computing devices in medical education, a mixed-methods study. BMJ Open 2012;2(4):--- [FREE Full text] [doi: 10.1136/bmjopen-2012-001099] [Medline: 22923627]
9. Fenn J, Raskino M. Mastering the Hype Cycle: How to Choose the Right Innovation at the Right Time (Gartner). Boston: Harvard Business School Press; 2008.
10. Rogers EM. Diffusion of innovations. New York: Free Press; 1995.
11. George D. Kuh, Ty M. Cruce, Rick Shoup, Jillian Kinzie, Robert M. Gonyea. Unmasking the Effects of Student Engagement on First-Year College Grades and Persistence. The Journal of Higher Education 2008 2008;79(5):540-563. [doi: 10.1353/jhe.0.0019]

Abbreviations

EMR: electronic medical record
iOS: iPhone operating system
PGY: postgraduate year

Edited by G Eysenbach; submitted 14.01.13; peer-reviewed by A Djuricich, M Laurent; comments to author 23.02.13; revised version received 19.03.13; accepted 26.03.13; published 08.05.13.

Please cite as:
Luo N, Chapman CG, Patel BK, Woodruff JN, Arora VM
Expectations of iPad Use in an Internal Medicine Residency Program: Is It Worth the “Hype”?
J Med Internet Res 2013;15(5):e88
URL: http://www.jmir.org/2013/5/e88/
doi:10.2196/jmir.2524
PMID:23656727

Review

Mapping mHealth Research: A Decade of Evolution

Maddalena Fiordelli[1], PhD; Nicola Diviani[1], PhD; Peter J Schulz[1], PhD

[1] Institute of Communication and Health, Faculty of Communication Sciences, University of Lugano, Lugano, Switzerland

Corresponding Author:
Maddalena Fiordelli, PhD
Institute of Communication and Health
Faculty of Communication Sciences
University of Lugano
Via G. Buffi, 13
Lugano, 6900
Switzerland
Phone: 41 586664757
Fax: 41 586664647
Email: maddalena.fiordelli@usi.ch

Abstract

Background: For the last decade, mHealth has constantly expanded as a part of eHealth. Mobile applications for health have the potential to target heterogeneous audiences and address specific needs in different situations, with diverse outcomes, and to complement highly developed health care technologies. The market is rapidly evolving, making countless new mobile technologies potentially available to the health care system; however, systematic research on the impact of these technologies on health outcomes remains scarce.

Objective: To provide a comprehensive view of the field of mHealth research to date and to understand whether and how the new generation of smartphones has triggered research, since their introduction 5 years ago. Specifically, we focused on studies aiming to evaluate the impact of mobile phones on health, and we sought to identify the main areas of health care delivery where mobile technologies can have an impact.

Methods: A systematic literature review was conducted on the impact of mobile phones and smartphones in health care. Abstracts and articles were categorized using typologies that were partly adapted from existing literature and partly created inductively from publications included in the review.

Results: The final sample consisted of 117 articles published between 2002 and 2012. The majority of them were published in the second half of our observation period, with a clear upsurge between 2007 and 2008, when the number of articles almost doubled. The articles were published in 77 different journals, mostly from the field of medicine or technology and medicine. Although the range of health conditions addressed was very wide, a clear focus on chronic conditions was noted. The research methodology of these studies was mostly clinical trials and pilot studies, but new designs were introduced in the second half of our observation period. The size of the samples drawn to test mobile health applications also increased over time. The majority of the studies tested basic mobile phone features (eg, text messaging), while only a few assessed the impact of smartphone apps. Regarding the investigated outcomes, we observed a shift from assessment of the technology itself to assessment of its impact. The outcome measures used in the studies were mostly clinical, including both self-reported and objective measures.

Conclusions: Research interest in mHealth is growing, together with an increasing complexity in research designs and aim specifications, as well as a diversification of the impact areas. However, new opportunities offered by new mobile technologies do not seem to have been explored thus far. Mapping the evolution of the field allows a better understanding of its strengths and weaknesses and can inform future developments.

(J Med Internet Res 2013;15(5):e95) doi:10.2196/jmir.2430

KEYWORDS

mHealth; systematic review; health outcomes

Introduction

In the last decade, mobile health (mHealth), the branch of eHealth broadly defined as “the use of mobile computing and communication technologies in health care and public health” [1], has been constantly expanding. Mobile applications for health can target heterogeneous audiences such as doctors, nurses, patients, or even healthy people [1]. Different features of mobile phones may address specific needs in different situations. Available literature suggests that the use of mobile phones serves a wide variety of purposes [2], such as smoking cessation, weight loss, diet and physical activity, treatment adherence, and disease management. The biggest advantages of using mobile devices, and in particular mobile phones, for health are that these devices are personal, intelligent, connected, and always with people [3,4]. Therefore, they can serve patients both in everyday life and during hospitalization or rehabilitation, as well as health care providers during emergency or routine visits. Current evidence suggests that the use of mobile technology can improve diagnosis and compliance with treatment guidelines, as well as patient information, and can increase administrative efficiency [5]. In particular, short message service (SMS) text messaging reminders have been shown to be a simple and efficient option for health services to use in order to improve service delivery, resulting in health benefits for the patients who receive them [6]. Mobile phone technologies have also been shown to be effective in smoking cessation, weight loss, physical activity, diabetes management, STD prevention and treatment, and hypertension [7].

The mobile phone market is constantly evolving. The first digital mobile phones appeared in the early 1990s, and since then, mobile technology has continued to be refined thanks to the development of new features and better networks. Current smartphones have been defined as “mobile telephones with computer features that may enable them to interact with computerized systems, send e-mails, and access the web” [8]. Over a third of US mobile phone users own a smartphone [3,9], and it is estimated that 67.6% of adults worldwide own a mobile phone [2,10], making it the most equitable communication technology [1]. It has been argued that mobile phones could be a solution to overcome the traditional digital divide derived from the introduction of the Internet because they provide new opportunities to reach underserved and previously unreachable parts of the population worldwide, especially in developing countries [2].

Mobile technology, with its diffusion and characteristics, holds a great potential for health care applications. However the use of mobile phones in health care delivery has not been fully explored, and the diverse outcomes of mHealth have barely been documented. Although some literature reviews cover one part or the other of the field [6,11,12], an overall picture is still missing, possibly due to the field’s constant evolution. A recent methodological review sought to map the domain of mobile phone health interventions [13], but it relied on describing the design of the interventions, with a clear focus on technology, rather than the outcomes. As the authors stated, their motivation lay in the fact that “effectiveness reviews can be best done at the level of a particular pathology”, while they wanted to draw a more comprehensive taxonomy of the field.

The main objective of this paper, as stated in the title, is to map the field, but without omitting the outcome measures. This means that our intention is to investigate how the impact of mobile phones on health has been assessed in peer-reviewed scientific literature. In particular, we are interested in understanding the evolution over the past decade, how the interventions have been developed, the main health care delivery areas where the impact of mobile technologies has been assessed, the methodology and features used, and finally, the type of outcome measures and general impact of the intervention.

The second objective of this review is to understand, after the 5 years since the introduction of the new generation of smartphones (eg, the iPhone in 2007), whether and how these devices have triggered research. The appeal of these new devices resides in the fact that they include several computer-like built-in features (eg, the GPS or the accelerometer) allowing the monitoring of a whole series of behaviors. Additionally, new mobile operating systems allow users to customize their devices according to their needs, by downloading apps available for free or for a low price from a central store. Klasnja and Pratt named this kind of feature “native application” [13], which is a typical complex and sophisticated application that can be implemented on major smartphone platforms (iOS, Android, Symbian, BlackBerry, webOS, and Windows Phone). In 2012, smartphone users spent US $8 billion for paid apps in the top 5 app platforms, and the European mobile app market size reached €1.68 billion [14]. Therefore, iPhones and similar devices are potentially very interesting for application in health care—they already integrate most of the features that researchers previously had to add to traditional mobile phones in order to use them for health-related purposes and monitoring [15,16].

Methods

The objective of this study was to provide a comprehensive picture of how the impact of mHealth was assessed in the scientific literature in its first decade of existence. For this purpose, a systematic literature review was conducted in which relevant studies were categorized in a two-step process. The first step included the review of the titles and abstracts of all publications that were identified as potentially relevant, with the goal of assessing whether they might meet the inclusion criteria for the systematic review. Selected abstracts were categorized at this stage using general typologies partly adapted from existing literature [1,2,12] and partly created inductively from a subsample of the publications. Categories referred to the type of methodology used, the impact area (ie, remote monitoring, data gathering, communication, self-management, training/education, improve adherence, health promotion), and the type of study. In a second step, all the publications not excluded during the abstract and title review stage underwent a full-text review. All publications that met all eligibility criteria (see below) made up the final sample.

Search Strategy

In February 2012, five electronic databases (CINAHL, Communication and Mass Media Complete, PubMed, PsycINFO, and Web of Science) were systematically searched. The choice of databases was deemed to reflect the multidisciplinary nature of the field. Among the most used medical databases, we decided to include PubMed only, since it comprises MEDLINE, while Embase was excluded because it has a stronger drug coverage, which was not relevant for the purposes of our research. A list of keywords was created around the two domains of "health" and "mobile technology". A search string was constructed using both the conjunction "AND" and the disjunction "OR" logical operators ([health OR medicine OR medical OR telemedicine OR health care OR "mHealth" OR "mobile health" OR "m - health" OR "mobile - health"] AND ["mobile phone" OR "cell phone" OR "cellphone" OR "cell - phone" OR "smartphone" OR "iPhone" OR "blackberry" OR "android"]). The search was based on metadata, ie, title, abstract, and keywords. Reference lists of selected studies were also checked for other potentially relevant studies.

Selection Criteria

Eligibility criteria for inclusion were as follows: records had to be written in English and discuss/acknowledge the role of mobile technology as a tool for promoting, managing, or monitoring health. This could include interventions, cross - sectional studies, literature reviews, conceptual papers, etc. All articles dealing with health effects of mobile phones (eg, effects of non-ionizing radiation on health or effect of mobile phone use on adolescents) were excluded. Records had to be officially published, either online or in print in a peer-reviewed publication (ie, journal articles, book chapters, and published proceedings papers). This means that poster presentations, (extended) abstracts, and encyclopedia entries were excluded. No time restriction was given; all publication dates were eligible for inclusion. Also, there was no restriction on the field of studies, ie, records that could be classified as social sciences, humanities, medicine, and others were all included.

The exclusion criteria that accounted for the biggest number of excluded articles included the following: the study provided descriptive summaries of mHealth programs but failed to provide an evaluation of the program; study provided a short description of multiple mHealth programs without providing specific details on an mHealth intervention; and the study focused on mHealth application design. The title and abstract review allowed us to exclude system design articles and to better identify all the studies that involved people in the testing of the intervention. A full-text article review was therefore conducted only on studies evaluating and assessing mHealth applications. The categories for full-text review were the following: continent where the study took place, condition addressed, type of technology, features used, basis for the intervention development, study design, sample size, aim of the evaluation, outcome measures, and overall impact assessed.

Results

The flowchart in Figure 1 summarizes the different steps of the literature search and review process. A first search identified 4039 articles. After checking for duplicates, 747 articles met the predefined inclusion criteria. Initially, articles were categorized by type of study: quantitative, qualitative, mixed methods, review, and system design. Since articles in the last typology described the development of a mobile technology but did not include any actual testing, they were excluded from further analysis together with reviews, reducing the final sample to 352 articles. More than half of the 352 studies (56%) included at least some testing of a mobile phone application via proper interventions or in small samples. Most of the studies analyzed (86%) applied a quantitative methodology and were designed to address simultaneously one or more impact areas. An upsurge was noted, starting from 2008, when the articles doubled in comparison with the previous year, and this upward trend reached its maximum in 2011 (36% of the total in a 10-year time period). The search of scientific databases without a time limit yielded an article distribution on the topic over 10 years, from 2002 to 2012.

The final sample for the full-text review included 117 [17-133] articles out of the 352 described above. After title and abstract review, an additional 157 articles were excluded because of no actual testing, while another 78 were excluded during full-text revision for different reasons (eg, no patients involved, mobile device other than phone, study duplicates). Looking at this past decade (Figure 2), we again observed an upsurge in the field: from 1 article in 2002 to 30 articles in 2011. The largest upsurge again came between 2007 and 2008, when the articles almost doubled, similar to what was already noted during the abstract review phase.

In order to better reflect the objectives of our review and to mirror the development over time, all the results are presented by splitting our observation period in two halves (2002-2007 and 2008-2012). The first period includes 23 articles, while the second period includes 94. The 117 articles in the final sample were published in 77 different journals, which can be grouped in four disciplinary fields: technology, medicine, social sciences, and the intersection between technology and medicine. During the first half of the observed decade, most of the articles on mHealth were published in medical journals (52%) and in journals focused on medicine and technology (44%).The remaining 4% of articles were published in journals focused only on technology. In the second half, the share of articles published in medical journals grew from 52% to 60%, while coverage of the topic by technology journals did not change (4%). At the same time, a decrease in the share of articles published by journals dealing with medicine and technology was observed (from 44% to 35%). In the second period, we found one article from a new disciplinary field, the social sciences.

The geographical areas focusing on this type of research were mainly Europe (34%) and North America (33%). However, if we look at results split by time periods, Europe's interest seems to decrease from the first period (52%) to the second (30%), and the same happens in Asia (from 17% to 10%). A different picture can be found on all the other continents, where the number of studies in the field increased. This is the case in North America (from 17% to 37%), Australia (from 13% to 15%), and especially Africa (from 0% to 6%) and South America (from 0% to 2%).

Specific health conditions addressed in the studies ranged from diabetes to mental health, from obesity to well-being and postoperative care. Figure 3 shows the number of articles for every health condition for which mHealth applications were studied. As shown in the graph, diabetes has received a great deal of attention. Moreover, after grouping the conditions into larger classes, it becomes clear that the focus of mHealth research is chronic conditions (74 studies), followed by prevention/well-being (22 studies), and acute conditions (21 studies).

In reviewing the background of the studies, we found that a description of the development of the intervention, and especially of how this was grounded, occurred more often in the second period (84%) than in the first (65%). During the last 5 years, only 1 study was uniquely theory-based (1%), while the majority was evidence-based (73%) or based both on theory and evidence (10%); 15 studies (16%) provided a more general description that was based on neither theory nor previous evidence.

From a methodological point of view, the majority of articles were clinical trials (50%), followed by pilot studies (44%). However, both of these study designs diminished over the last years of our observation period as new types of research designs were introduced, namely observational studies (2% of all articles in the second part of the observation period), case studies (2%), case series (2%), and cross-sectional studies (2%). The samples used to test mobile health applications were mostly small (less than 50 people) in both the first (61%) and the second half (49%) of our observation. Interestingly in the second half, the number of medium-sized samples increased (from 17% to 33%). Larger samples were used in 21 (19%) articles; however, they were more frequent in the first half of the observation (22%) than in the second half (18%).

Moving from research methodology to the actual target of investigation, ie, mobile phones, our classification highlighted a more rigorous and diversified description of the technology used in interventions. In recent years, new kinds of mobile phones have been used, such as smartphones (8%) and ad hoc phones (3%), which are devices developed specifically by the researchers to manage a specific condition. Unfortunately, the kind of mobile phone used was not even specified most of the time (71% of the overall sample).

We identified seven main categories of mobile features used in the studies, and an article could fall in one or more of these (ie, the categories were not mutually exclusive). Half of the studies (49%) applied text messaging, and 32% applied some features developed ad hoc for a specific condition. Add-ons (eg, a glucometer to measure blood sugar or a pedometer for physical activity) were used in 12% of the cases together with ad hoc features. Other features such as voice (10%), video (6%), and multimedia messaging service (MMS) (3%) were used less frequently. Native applications for smartphones were applied in 7 studies (6%) out of the 8 using smartphones. However, none of them applied already existing and publicly available apps.

The impact areas to which interventions were directed were coded into seven categories, again not mutually exclusive. The majority of articles addressed health promotion (38%) and self-management (33%), but also communication (22%), remote monitoring (21%), data gathering (21%), improvement of adherence (20%), and training/education (13%). The focus on most of these areas increased over time, eg, on self-management (from 30% to 33%) and communication (from 17% to 23%). Only health promotion (from 29% to 27%) and training/education (from 13% to 10%) had a slight decrease.

Regarding the aims of the interventions, both the evaluation of the technology itself (35%) and of its impact on health outcomes (43%) dominated in the first 5 years. In the second half, however, interest clearly moved toward evaluating the impact of mobile technology on health outcomes (73%). While the majority of the studies investigated only the impact of the mobile application on health outcomes (51%), some also assessed both the technology and its impact on health outcomes (22%).

Another point of interest was the outcome measure used to assess the impact of mobile phones. In the majority of cases, the outcome measures were a combination of both self-reported and objective data (44% of the overall sample). If we look at the evolution over time, self-reported measures increased (from 9% to 20%), whereas objective measures decreased slightly (from 39% to 36%), and this was also the case for the combination of self-reported and objective measures (from 52% to 43%).

Our examination of the type of data collected showed that clinical measures were often the only outcomes observed (30%), and this phenomenon increased over time (from 22% to 31%). 14% of the articles were focused only on user assessment of the technology, even if this decreased during the observation period (from 17% to 13%). Psychosocial measures were the outcome in 9% of the studies, and this increased slightly over time (from 9% to 10%). The remaining articles (53%) considered outcomes deriving from all possible combinations of these main three. The most frequent combination was clinical measures together with user assessment of technology (17%).

An overall positive impact of the intervention was described by a total of 69 studies (60%). In the first period, the impact of the interventions was mainly either mixed (43%) or positive (57%). In the second part of the observation, the number of interventions with a positive impact slightly increased (60%), while the number of those with mixed impact decreased (33%). In this second period, interventions with negative (6%) or no impact (1%) were reported as well.

Figure 1. Summary of literature search and review process.

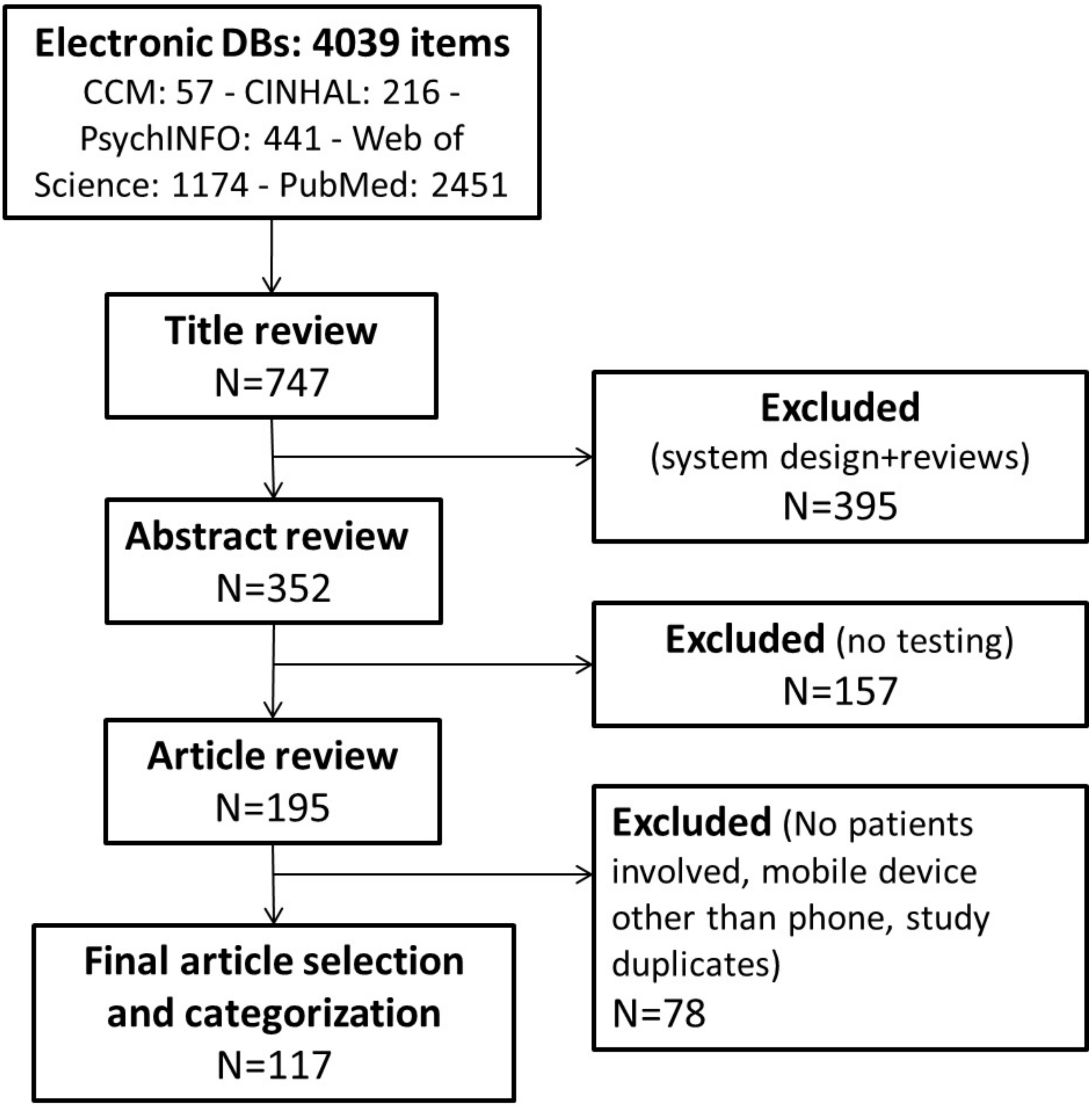


Figure 2. Distribution of articles over time.

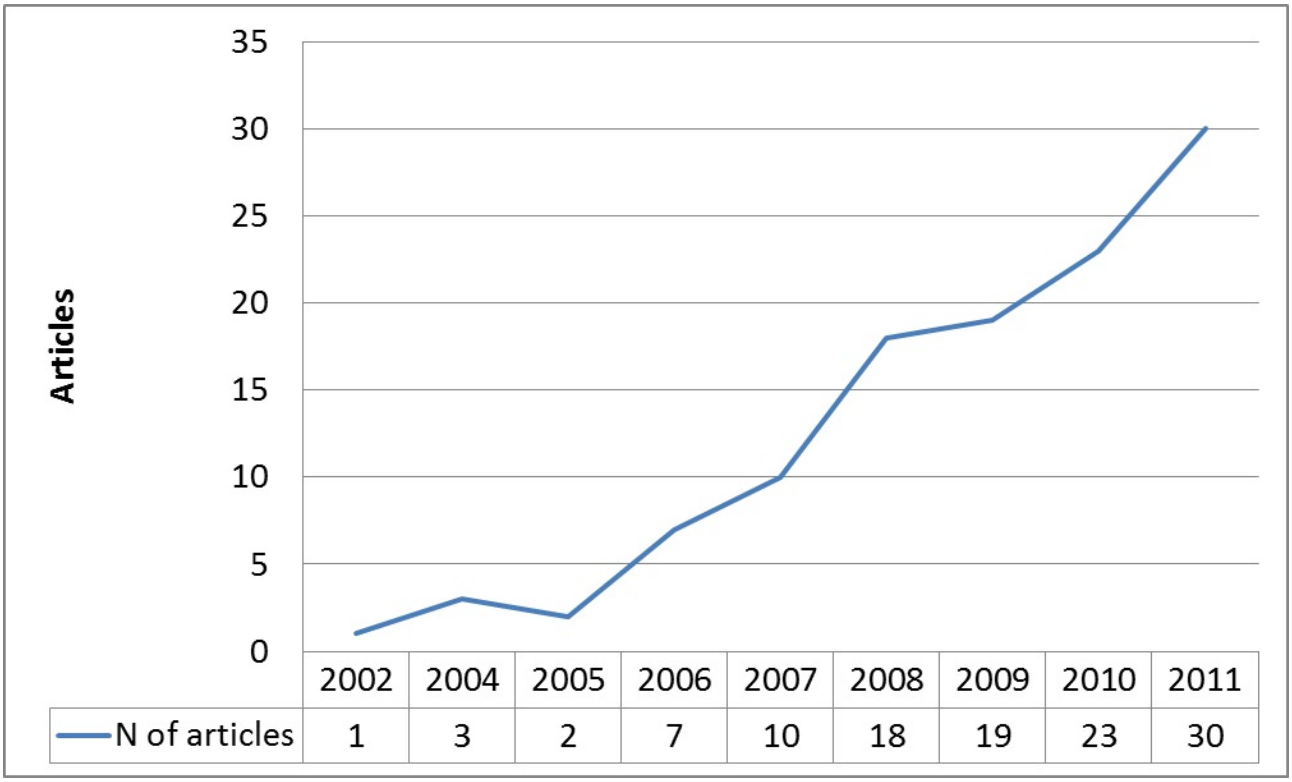
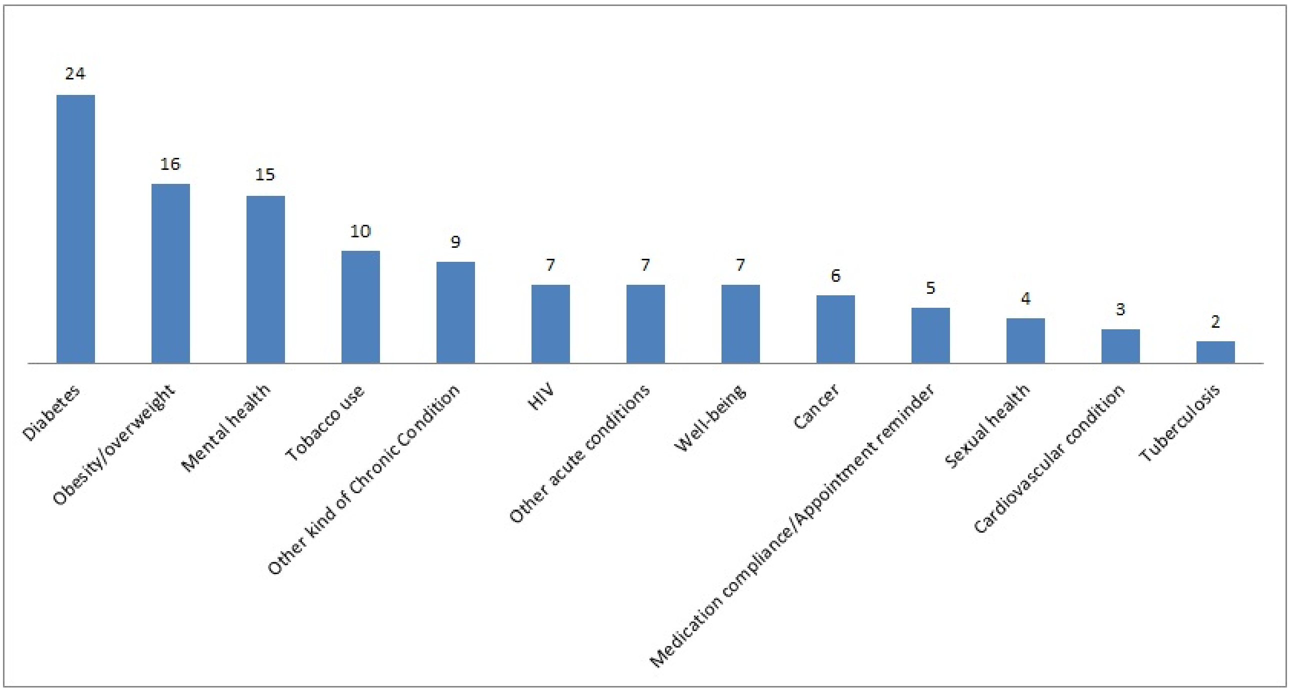


Figure 3. Conditions addressed by mHealth applications in mHealth research.



Discussion

This systematic literature review has found encouraging trends pointing toward the development of mHealth as an autonomous field of study, which is of interest to different disciplines. In the case of social sciences for instance, this is shown by the publication of a special issue of the *Journal of Health Communication* dedicated entirely to mHealth in May 2012. We took this into account but did not include it in the current review because of the date of publication.

The increase in the number of articles over the past decade indicates an increasing interest in peer-reviewed scientific literature on the topic. In particular, the number of articles almost doubled from 2007 to 2008. All continents engaged in research on mHealth during the last 5 years. Many different conditions were addressed by the studies analyzed, with an evident focus on chronic conditions. More recently, the development of the interventions became more accurately described and grounded on past evidence or theory. In the last decade, the first in the history of mHealth, new methodologies were applied to the field, and while the majority of the studies were pilot studies or clinical trials, some new approaches were introduced. At the same time, the samples used in such studies grew, thus pointing toward a more reliable assessment. Newer and more advanced technologies were tested; however, the potential of smartphones does not seem to have been fully exploited yet. Indeed, half of the included studies applied very basic features of mobile phones, such as text messaging, which corroborates evidence already established in the field [7]. One third of the studies used features from add-ons, and only a few other examples used video, images, or MMS. Mobile technology interventions were directed to different impact areas, and most frequently to health promotion and self-management. Interestingly, research moved from an evaluation of the technology itself to an assessment of its impact on health outcomes, and an increase in the number of interventions with an overall positive impact was observed. These observations point toward a field that is becoming more structured, coherent, and solid. Among the outcome measures used, both self-reported and objective measures could be found, and in some cases were combined. In the last 5 years, the use of self-reported measures increased. Clinical measures only were observed as outcomes in almost one third of the studies, and an increasing trend was evident. Consistent with the observed trend towards an assessment of the impact of technology, we noticed an increase in psychosocial and clinical measures, sometimes in combination with users' assessment of the technology, and a decrease of assessments of the technology alone.

Recommendations

Although these findings are encouraging and can be seen as indicators of a promising field, they highlight certain gaps that future research should address. So far, the focus of mHealth interventions has been on chronic conditions, similar to eHealth [134]. However, it would be advisable to explore the impact of mobile health for acute conditions as well. Because of their wireless cellular communication capability, mobile phones allow users to have continuous, interactive communication from any location. In our view, this characteristic of mobile phones makes them an ideal tool to address in real-time the specific needs of patients experiencing acute conditions.

Another recommendation is to address methodological issues such as whether clinical trials are the most suitable design to use at every stage of research in this field. The studies we analyzed showed a diversification toward the second half of the decade, which seems to reflect more positive outcomes and a stronger evidence-based development of the interventions. Consistent with the conclusions of other authors [3,5,7,135], we believe the field will greatly profit from a diversification in research methodologies and that the multidisciplinary approach offered by different areas could be a fertile ground for the development of the field, both from a theoretical and methodological perspective.

Our last recommendation is for research to fully exploit the potential of technologies, especially of smartphones. We expected in our review to find more results detailing applications of new built-in features, which are the "specialty" of smartphones. However we found that only a few interventions aimed at assessing the impact of native applications for smartphones had been reported so far in the literature. Moreover, in all the cases, the apps were not available to the public but had been created ad hoc for research purposes**.**

This last recommendation brings up a new topic of discussion. Currently, there are more than 15,000 health-related apps (free and paid) on app stores, but we were not able to find any study assessing any of them. So what is publicly available has not been evaluated, and what has been evaluated is not publicly available. At least three possible scenarios could explain the lack of scholarly interest in studying the effects of interventions based on publicly available apps. First, no one, so far, has conducted such studies. If this is true, it provides great opportunities for investigation in this area, since some basic features of mobile health such as text messaging have already proved to be effective. A second scenario could be that it is still too early for results of such assessments to have been published. However, this seems to be less plausible, because iPhones and similar devices have already been on the market for 5 years. Finally, it could be that studies evaluating the impact of native applications have indeed been published, but not in the peer-reviewed scientific literature. A search of the gray literature, such as more consumer-oriented magazines, websites, or blogs (eg, iMedicalApps) could then yield some results. If this last, and more plausible, explanation is true, then we need to document the exploitation of smartphones in a way that is easily accessible to the scientific community. If only a minority of good quality applications and solutions seek clinical mHealth research to prove effectiveness, we should question why this is happening. It is thus essential to understand why scientific literature is not keeping up with advancements of the field, to find where any discussion is taking place, and to find the evidence of apps' effectiveness, which seems to be missing [3].

Limitations

A limitation of our study, which is common to most systematic literature reviews, resides in the fact that the last articles analyzed were published in February 2012. In this constantly evolving field, this could make a difference, especially because we are well aware that the publication process is often lengthy and time-consuming, and therefore we could have missed some studies on smartphones.

A second possible limitation lies in the choice of databases. For our systematic search, we focused on more medical and social sciences–oriented databases. However a preliminary search conducted on a more technology-oriented database (ACM) resulted in a long list of peer-reviewed articles mainly focused on system design, which we would have excluded from the final sample since our research interest was on the impact of mobile technology on health outcomes.

Conclusion

With this systematic literature review, we sought to map a field that is becoming more and more visible in the literature. This review is an essential first step to the understanding of strengths and limitations in mHealth research.

Some questions remain about the lack of information on the newest technological opportunities and on the best methodologies to assess mHealth's impact on health outcomes. Is scientific literature the appropriate place to find studies on the effectiveness of mobile applications? Are we exploiting all the potential of smartphones? Why is the scientific research not keeping up with the market evolution? Further research will help to answer these questions.

Authors' Contributions

All authors took part in the design of the search strategy. MF and ND conducted the search, extracted the data, and analyzed the content. MF drafted the manuscript and together with ND contributed to the writing of the final manuscript. MF revised the manuscript with the input and advice from all authors.

Conflicts of Interest

None declared.

References

1. Free C, Phillips G, Felix L, Galli L, Patel V, Edwards P. The effectiveness of M-health technologies for improving health and health services: a systematic review protocol. BMC Res Notes 2010;3:250 [FREE Full text] [doi: 10.1186/1756-0500-3-250] [Medline: 20925916]
2. Riley WT, Rivera DE, Atienza AA, Nilsen W, Allison SM, Mermelstein R. Health behavior models in the age of mobile interventions: are our theories up to the task? Transl Behav Med 2011 Mar 1;1(1):53-71 [FREE Full text] [doi: 10.1007/s13142-011-0021-7] [Medline: 21796270]
3. Whittaker R. Issues in mHealth: findings from key informant interviews. J Med Internet Res 2012;14(5):e129 [FREE Full text] [doi: 10.2196/jmir.1989] [Medline: 23032424]
4. Fogg BJ, Adler R. Texting 4 Health: A Simple, Powerful Way to Change Lives (Stanford University) (Stanford University). Stanford, CA: Captology Media; 2009.
5. Sherry JM, Ratzan SC. Measurement and evaluation outcomes for mHealth communication: don't we have an app for that? J Health Commun 2012 May;17 Suppl 1:1-3. [doi: 10.1080/10810730.2012.670563] [Medline: 22548591]
6. Guy R, Hocking J, Wand H, Stott S, Ali H, Kaldor J. How effective are short message service reminders at increasing clinic attendance? A meta-analysis and systematic review. Health Serv Res 2012 Apr;47(2):614-632. [doi: 10.1111/j.1475-6773.2011.01342.x] [Medline: 22091980]
7. Evans WD, Abroms LC, Poropatich R, Nielsen PE, Wallace JL. Mobile health evaluation methods: the Text4baby case study. J Health Commun 2012;17 Suppl 1:22-29. [doi: 10.1080/10810730.2011.649157] [Medline: 22548595]
8. Collins English Online Dictionary. 2013. "Smartphone" URL: http://www.collinsdictionary.com/dictionary/english/smartphone?showCookiePolicy=true [accessed 2013-04-10] [WebCite Cache ID 6Fm8JS74o]
9. Smith A. Americans and their cell phones. Washington, DC: Pew Internet & American Life Project; 2011 Aug 15. URL: http://pewinternet.org/Reports/2011/Cell-Phones.aspx [accessed 2013-04-10] [WebCite Cache ID 6Fm0QlEp8]
10. International Communications Union. 2012. URL: http://www.itu.int/ITU-D/ict/publications/material/LDB_ICT_2012.pdf [accessed 2013-04-10] [WebCite Cache ID 6Fm0SamWW]
11. Chomutare T, Fernandez-Luque L, Arsand E, Hartvigsen G. Features of mobile diabetes applications: review of the literature and analysis of current applications compared against evidence-based guidelines. J Med Internet Res 2011;13(3):e65 [FREE Full text] [doi: 10.2196/jmir.1874] [Medline: 21979293]
12. Krishna S, Boren SA, Balas EA. Healthcare via cell phones: a systematic review. Telemed J E Health 2009 Apr;15(3):231-240. [doi: 10.1089/tmj.2008.0099] [Medline: 19382860]
13. Klasnja P, Pratt W. Healthcare in the pocket: mapping the space of mobile-phone health interventions. J Biomed Inform 2012 Feb;45(1):184-198 [FREE Full text] [doi: 10.1016/j.jbi.2011.08.017] [Medline: 21925288]
14. Research2guidance. 2013. The research mobile specialists URL: http://www.research2guidance.com/ [accessed 2013-04-07] [WebCite Cache ID 6Fhsvb7a4]
15. Boulos MN, Wheeler S, Tavares C, Jones R. How smartphones are changing the face of mobile and participatory healthcare: an overview, with example from eCAALYX. Biomed Eng Online 2011;10:24 [FREE Full text] [doi: 10.1186/1475-925X-10-24] [Medline: 21466669]
16. Terry M. Medical Apps for Smartphones. Telemed J E Health 2010 Feb;16(1):17-22. [doi: 10.1089/tmj.2010.9999] [Medline: 20070172]
17. Aguilera A, Muñoz RF. Text messaging as an adjunct to CBT in low-income populations: A usability and feasibility pilot study. Professional Psychology: Research and Practice 2011 2011;42(6):472-478. [doi: 10.1037/a0025499]
18. Anhøj J, Møldrup C. Feasibility of collecting diary data from asthma patients through mobile phones and SMS (short message service): response rate analysis and focus group evaluation from a pilot study. J Med Internet Res 2004 Dec 2;6(4):e42 [FREE Full text] [doi: 10.2196/jmir.6.4.e42] [Medline: 15631966]

19. Arsand E, Tatara N, Østengen G, Hartvigsen G. Mobile phone-based self-management tools for type 2 diabetes: the few touch application. J Diabetes Sci Technol 2010 Mar;4(2):328-336 [FREE Full text] [Medline: 20307393]
20. Beebe LH, Smith K, Bennett C, Bentley K, Walters AB, Hancock B, et al. Keeping in touch. Cell phone use in people with schizophrenia disorders. J Psychosoc Nurs Ment Health Serv 2010 Apr;48(4):32-37. [doi: 10.3928/02793695-20100304-99] [Medline: 20349885]
21. Blasco A, Carmona M, Fernández-Lozano I, Salvador CH, Pascual M, Sagredo PG, et al. Evaluation of a telemedicine service for the secondary prevention of coronary artery disease. J Cardiopulm Rehabil Prev 2012;32(1):25-31. [doi: 10.1097/HCR.0b013e3182343aa7] [Medline: 22113368]
22. Bopp JM, Miklowitz DJ, Goodwin GM, Stevens W, Rendell JM, Geddes JR. The longitudinal course of bipolar disorder as revealed through weekly text messaging: a feasibility study. Bipolar Disord 2010 May;12(3):327-334 [FREE Full text] [doi: 10.1111/j.1399-5618.2010.00807.x] [Medline: 20565440]
23. Bramley D, Riddell T, Whittaker R, Corbett T, Lin RB, Wills M, et al. Smoking cessation using mobile phone text messaging is as effective in Maori as non-Maori. N Z Med J 2005 Jun 3;118(1216):U1494. [Medline: 15937529]
24. Brendryen H, Drozd F, Kraft P. A digital smoking cessation program delivered through internet and cell phone without nicotine replacement (happy ending): randomized controlled trial. J Med Internet Res 2008 Jan;10(5):e51 [FREE Full text] [doi: 10.2196/jmir.1005] [Medline: 19087949]
25. Burns MN, Begale M, Duffecy J, Gergle D, Karr CJ, Giangrande E, et al. Harnessing context sensing to develop a mobile intervention for depression. J Med Internet Res 2011 Jan;13(3):e55 [FREE Full text] [doi: 10.2196/jmir.1838] [Medline: 21840837]
26. Carroll AE, DiMeglio LA, Stein S, Marrero DG. Using a cell phone-based glucose monitoring system for adolescent diabetes management. Diabetes Educ 2011;37(1):59-66. [doi: 10.1177/0145721710387163] [Medline: 21106908]
27. Charpentier G, Benhamou PY, Dardari D, Clergeot A, Franc S, Schaepelynck-Belicar P, TeleDiab Study Group. The Diabeo software enabling individualized insulin dose adjustments combined with telemedicine support improves HbA1c in poorly controlled type 1 diabetic patients: a 6-month, randomized, open-label, parallel-group, multicenter trial (TeleDiab 1 Study). Diabetes Care 2011 Mar;34(3):533-539 [FREE Full text] [doi: 10.2337/dc10-1259] [Medline: 21266648]
28. Chi BH, Stringer JS. Mobile phones to improve HIV treatment adherence. Lancet 2010 Nov 27;376(9755):1807-1808. [doi: 10.1016/S0140-6736(10)62046-6] [Medline: 21071073]
29. Cho JH, Lee HC, Lim DJ, Kwon HS, Yoon KH. Mobile communication using a mobile phone with a glucometer for glucose control in Type 2 patients with diabetes: as effective as an Internet-based glucose monitoring system. J Telemed Telecare 2009;15(2):77-82. [doi: 10.1258/jtt.2008.080412] [Medline: 19246607]
30. Cocosila M, Archer N, Haynes RB, Yuan Y. Can wireless text messaging improve adherence to preventive activities? Results of a randomised controlled trial. Int J Med Inform 2009 Apr;78(4):230-238. [doi: 10.1016/j.ijmedinf.2008.07.011] [Medline: 18778967]
31. Cocosila M, Archer N, Yuan Y. Would people pay for text messaging health reminders? Telemed J E Health 2008 Dec;14(10):1091-1095. [doi: 10.1089/tmj.2008.0047] [Medline: 19119832]
32. Cummings E, Hauser J, Cameron-Tucker H, Fitzpatrick P, Jessup M, Walters EH, et al. Enhancing self-efficacy for self-management in people with cystic fibrosis. Stud Health Technol Inform 2011;169:33-37. [Medline: 21893709]
33. da Costa TM, Salomão PL, Martha AS, Pisa IT, Sigulem D. The impact of short message service text messages sent as appointment reminders to patients' cell phones at outpatient clinics in São Paulo, Brazil. Int J Med Inform 2010 Jan;79(1):65-70. [doi: 10.1016/j.ijmedinf.2009.09.001] [Medline: 19783204]
34. de Oliveira R, Cherubini M, Oliver N. MoviPill? Improving Medication Compliance for Elders Using a Mobile Persuasive Social Game. In: Proceedings of the 12th ACM International Conference on Ubiquitous Computing. 2010 Presented at: 12th ACM International Conference on Ubiquitous Computing; September 26-29, 2010; Copenhagen p. 251-260.
35. Depp CA, Mausbach B, Granholm E, Cardenas V, Ben-Zeev D, Patterson TL, et al. Mobile interventions for severe mental illness: design and preliminary data from three approaches. J Nerv Ment Dis 2010 Oct;198(10):715-721 [FREE Full text] [doi: 10.1097/NMD.0b013e3181f49ea3] [Medline: 20921861]
36. Dunton GF, Liao Y, Intille SS, Spruijt-Metz D, Pentz M. Investigating children's physical activity and sedentary behavior using ecological momentary assessment with mobile phones. Obesity (Silver Spring) 2011 Jun;19(6):1205-1212. [doi: 10.1038/oby.2010.302] [Medline: 21164502]
37. Faridi Z, Liberti L, Shuval K, Northrup V, Ali A, Katz DL. Evaluating the impact of mobile telephone technology on type 2 diabetic patients' self-management: the NICHE pilot study. J Eval Clin Pract 2008 Jun;14(3):465-469. [doi: 10.1111/j.1365-2753.2007.00881.x] [Medline: 18373577]
38. Ferrer-Roca O, Cárdenas A, Diaz-Cardama A, Pulido P. Mobile phone text messaging in the management of diabetes. J Telemed Telecare 2004;10(5):282-285. [Medline: 15494086]
39. Finkelstein J, Wood J, Cha E. Introducing a BlackBerry eLearning Platform for Interactive Hypertension Education. In: Proceedings of the 2nd International Conference on Mobile, Hybrid, and On-Line Learning. 2010 Presented at: 2nd International Conference on Mobile, Hybrid, and On-Line Learning; Feb. 10-16, 2010; Washington, DC p. 77-81.
40. Fjeldsoe BS, Miller YD, Marshall AL. MobileMums: a randomized controlled trial of an SMS-based physical activity intervention. Ann Behav Med 2010 May;39(2):101-111. [doi: 10.1007/s12160-010-9170-z] [Medline: 20174902]

41. Free C, Whittaker R, Knight R, Abramsky T, Rodgers A, Roberts IG. Txt2stop: a pilot randomised controlled trial of mobile phone-based smoking cessation support. Tob Control 2009 Apr;18(2):88-91. [doi: 10.1136/tc.2008.026146] [Medline: 19318534]
42. Free C, Knight R, Robertson S, Whittaker R, Edwards P, Zhou W, et al. Smoking cessation support delivered via mobile phone text messaging (txt2stop): a single-blind, randomised trial. Lancet 2011 Jul 2;378(9785):49-55 [FREE Full text] [doi: 10.1016/S0140-6736(11)60701-0] [Medline: 21722952]
43. Fukuoka Y, Kamitani E, Dracup K, Jong SS. New insights into compliance with a mobile phone diary and pedometer use in sedentary women. J Phys Act Health 2011 Mar;8(3):398-403. [Medline: 21487139]
44. Fukuoka Y, Vittinghoff E, Jong SS, Haskell W. Innovation to motivation--pilot study of a mobile phone intervention to increase physical activity among sedentary women. Prev Med 2010;51(3-4):287-289 [FREE Full text] [doi: 10.1016/j.ypmed.2010.06.006] [Medline: 20600263]
45. Gerber BS, Stolley MR, Thompson AL, Sharp LK, Fitzgibbon ML. Mobile phone text messaging to promote healthy behaviors and weight loss maintenance: a feasibility study. Health Informatics J 2009 Mar;15(1):17-25 [FREE Full text] [doi: 10.1177/1460458208099865] [Medline: 19218309]
46. Gold J, Aitken CK, Dixon HG, Lim MS, Gouillou M, Spelman T, et al. A randomised controlled trial using mobile advertising to promote safer sex and sun safety to young people. Health Educ Res 2011 Oct;26(5):782-794 [FREE Full text] [doi: 10.1093/her/cyr020] [Medline: 21447750]
47. Gold J, Lim MS, Hocking JS, Keogh LA, Spelman T, Hellard ME. Determining the impact of text messaging for sexual health promotion to young people. Sex Transm Dis 2011 Apr;38(4):247-252. [doi: 10.1097/OLQ.0b013e3181f68d7b] [Medline: 20966830]
48. Granholm E, Ben-Zeev D, Link PC, Bradshaw KR, Holden JL. Mobile Assessment and Treatment for Schizophrenia (MATS): a pilot trial of an interactive text-messaging intervention for medication adherence, socialization, and auditory hallucinations. Schizophr Bull 2012 May;38(3):414-425. [doi: 10.1093/schbul/sbr155] [Medline: 22080492]
49. Grassi A, Preziosa A, Villani D, Riva G. A Relaxing Journey: the Use of Mobile Phones for Well-Being Improvement. Annual Review of CyberTherapy and Telemedicine 2007;5:123-131.
50. Haapala I, Barengo NC, Biggs S, Surakka L, Manninen P. Weight loss by mobile phone: a 1-year effectiveness study. Public Health Nutr 2009 Dec;12(12):2382-2391. [doi: 10.1017/S1368980009005230] [Medline: 19323865]
51. Hanauer DA, Wentzell K, Laffel N, Laffel LM. Computerized Automated Reminder Diabetes System (CARDS): e-mail and SMS cell phone text messaging reminders to support diabetes management. Diabetes Technol Ther 2009 Feb;11(2):99-106. [doi: 10.1089/dia.2008.0022] [Medline: 19848576]
52. Hoffman JA, Cunningham JR, Suleh AJ, Sundsmo A, Dekker D, Vago F, et al. Mobile direct observation treatment for tuberculosis patients: a technical feasibility pilot using mobile phones in Nairobi, Kenya. Am J Prev Med 2010 Jul;39(1):78-80. [doi: 10.1016/j.amepre.2010.02.018] [Medline: 20537846]
53. Hurling R, Catt M, Boni MD, Fairley BW, Hurst T, Murray P, et al. Using internet and mobile phone technology to deliver an automated physical activity program: randomized controlled trial. J Med Internet Res 2007;9(2):e7 [FREE Full text] [doi: 10.2196/jmir.9.2.e7] [Medline: 17478409]
54. Istepanian RS, Zitouni K, Harry D, Moutosammy N, Sungoor A, Tang B, et al. Evaluation of a mobile phone telemonitoring system for glycaemic control in patients with diabetes. J Telemed Telecare 2009;15(3):125-128. [doi: 10.1258/jtt.2009.003006] [Medline: 19364893]
55. Joo NS, Kim BT. Mobile phone short message service messaging for behaviour modification in a community-based weight control programme in Korea. J Telemed Telecare 2007;13(8):416-420. [doi: 10.1258/135763307783064331] [Medline: 18078554]
56. Juzang I, Fortune T, Black S, Wright E, Bull S. A pilot programme using mobile phones for HIV prevention. J Telemed Telecare 2011;17(3):150-153. [doi: 10.1258/jtt.2010.091107] [Medline: 21270049]
57. Kalichman SC, Kalichman MO, Cherry C, Swetzes C, Amaral CM, White D, et al. Brief behavioral self-regulation counseling for HIV treatment adherence delivered by cell phone: an initial test of concept trial. AIDS Patient Care STDS 2011 May;25(5):303-310 [FREE Full text] [doi: 10.1089/apc.2010.0367] [Medline: 21457056]
58. Katz DL, Nordwall B. Novel interactive cell-phone technology for health enhancement. J Diabetes Sci Technol 2008 Jan;2(1):147-153 [FREE Full text] [Medline: 19885191]
59. Katz KS, Rodan M, Milligan R, Tan S, Courtney L, Gantz M, et al. Efficacy of a randomized cell phone-based counseling intervention in postponing subsequent pregnancy among teen mothers. Matern Child Health J 2011 Dec;15 Suppl 1:S42-S53. [doi: 10.1007/s10995-011-0860-3] [Medline: 21809218]
60. Kearney N, McCann L, Norrie J, Taylor L, Gray P, McGee-Lennon M, et al. Evaluation of a mobile phone-based, advanced symptom management system (ASyMS) in the management of chemotherapy-related toxicity. Support Care Cancer 2009 Apr;17(4):437-444. [doi: 10.1007/s00520-008-0515-0] [Medline: 18953579]
61. Khokhar A. Short text messages (SMS) as a reminder system for making working women from Delhi Breast Aware. Asian Pac J Cancer Prev 2009;10(2):319-322 [FREE Full text] [Medline: 19537904]

62. Koller S, Hofmann-Wellenhof R, Hayn D, Weger W, Kastner P, Schreier G, et al. Teledermatological monitoring of psoriasis patients on biologic therapy. Acta Derm Venereol 2011 Oct;91(6):680-685 [FREE Full text] [doi: 10.2340/00015555-1148] [Medline: 21879250]
63. Kollmann A, Riedl M, Kastner P, Schreier G, Ludvik B. Feasibility of a mobile phone-based data service for functional insulin treatment of type 1 diabetes mellitus patients. J Med Internet Res 2007 Jan;9(5):e36 [FREE Full text] [doi: 10.2196/jmir.9.5.e36] [Medline: 18166525]
64. Koshy E, Car J, Majeed A. Effectiveness of mobile-phone short message service (SMS) reminders for ophthalmology outpatient appointments: observational study. BMC Ophthalmol 2008 Jan;8:9 [FREE Full text] [doi: 10.1186/1471-2415-8-9] [Medline: 18513438]
65. Kristjánsdóttir Ó, Fors EA, Eide E, Finset A, van Dulmen S, Wigers SH, et al. Written online situational feedback via mobile phone to support self-management of chronic widespread pain: a usability study of a Web-based intervention. BMC Musculoskelet Disord 2011 Jan;12:51 [FREE Full text] [doi: 10.1186/1471-2474-12-51] [Medline: 21352516]
66. Kunawararak P, Pongpanich S, Chantawong S, Pokaew P, Traisathit P, Srithanaviboonchai K, et al. Tuberculosis treatment with mobile-phone medication reminders in northern Thailand. Southeast Asian J Trop Med Public Health 2011 Nov;42(6):1444-1451. [Medline: 22299414]
67. Kunutsor S, Walley J, Katabira E, Muchuro S, Balidawa H, Namagala E, et al. Using mobile phones to improve clinic attendance amongst an antiretroviral treatment cohort in rural Uganda: a cross-sectional and prospective study. AIDS Behav 2010 Dec;14(6):1347-1352. [doi: 10.1007/s10461-010-9780-2] [Medline: 20700644]
68. Lakkis NA, Atfeh AM, El-Zein YR, Mahmassani DM, Hamadeh GN. The effect of two types of sms-texts on the uptake of screening mammogram: a randomized controlled trial. Prev Med 2011 Oct;53(4-5):325-327. [doi: 10.1016/j.ypmed.2011.08.013] [Medline: 21871480]
69. Lee HJ, Lee SH, Ha KS, Jang HC, Chung WY, Kim JY, et al. Ubiquitous healthcare service using Zigbee and mobile phone for elderly patients. Int J Med Inform 2009 Mar;78(3):193-198. [doi: 10.1016/j.ijmedinf.2008.07.005] [Medline: 18760959]
70. Leong KC, Chen WS, Leong KW, Mastura I, Mimi O, Sheikh MA, et al. The use of text messaging to improve attendance in primary care: a randomized controlled trial. Fam Pract 2006 Dec;23(6):699-705 [FREE Full text] [doi: 10.1093/fampra/cml044] [Medline: 16916871]
71. Lester RT, Ritvo P, Mills EJ, Kariri A, Karanja S, Chung MH, et al. Effects of a mobile phone short message service on antiretroviral treatment adherence in Kenya (WelTel Kenya1): a randomised trial. Lancet 2010 Nov 27;376(9755):1838-1845. [doi: 10.1016/S0140-6736(10)61997-6] [Medline: 21071074]
72. Lim EJ, Haar J, Morgan J. Can text messaging results reduce time to treatment of Chlamydia trachomatis? Sex Transm Infect 2008 Dec;84(7):563-564. [doi: 10.1136/sti.2008.032441] [Medline: 18723584]
73. Lim MS, Hocking JS, Aitken CK, Fairley CK, Jordan L, Lewis JA, et al. Impact of text and email messaging on the sexual health of young people: a randomised controlled trial. J Epidemiol Community Health 2012 Jan;66(1):69-74. [doi: 10.1136/jech.2009.100396] [Medline: 21415232]
74. Lim MS, Sacks-Davis R, Aitken CK, Hocking JS, Hellard ME. Randomised controlled trial of paper, online and SMS diaries for collecting sexual behaviour information from young people. J Epidemiol Community Health 2010 Oct;64(10):885-889. [doi: 10.1136/jech.2008.085316] [Medline: 19767322]
75. Lim S, Kang SM, Shin H, Lee HJ, Won Yoon J, Yu SH, et al. Improved glycemic control without hypoglycemia in elderly diabetic patients using the ubiquitous healthcare service, a new medical information system. Diabetes Care 2011 Feb;34(2):308-313 [FREE Full text] [doi: 10.2337/dc10-1447] [Medline: 21270188]
76. Logan AG, McIsaac WJ, Tisler A, Irvine MJ, Saunders A, Dunai A, et al. Mobile phone-based remote patient monitoring system for management of hypertension in diabetic patients. Am J Hypertens 2007 Sep;20(9):942-948. [doi: 10.1016/j.amjhyper.2007.03.020] [Medline: 17765133]
77. Macedo LG, Maher CG, Latimer J, McAuley JH. Feasibility of using short message service to collect pain outcomes in a low back pain clinical trial. Spine 2012 Jun 1;37(13):1151-1155. [doi: 10.1097/BRS.0b013e3182422df0] [Medline: 22146289]
78. Maguire R, Miller M, McCann LA, Lesley T, Kearney N, Meurig S. Managing chemotherapy symptoms via mobile phones. Nursing Times 2008;104(22):28-29.
79. Mao Y, Zhang Y, Zhai S. Mobile phone text messaging for pharmaceutical care in a hospital in China. J Telemed Telecare 2008 Jan;14(8):410-414. [doi: 10.1258/jtt.2008.080406] [Medline: 19047450]
80. Martínez-Ramos C, Cerdán MT, López RS. Mobile phone-based telemedicine system for the home follow-up of patients undergoing ambulatory surgery. Telemed J E Health 2009;15(6):531-537. [doi: 10.1089/tmj.2009.0003] [Medline: 19566396]
81. Mattila E, Lappalainen R, Pärkkä J, Salminen J, Korhonen I. Use of a mobile phone diary for observing weight management and related behaviours. J Telemed Telecare 2010;16(5):260-264. [doi: 10.1258/jtt.2009.091103] [Medline: 20483880]
82. McCall K, Keen J, Farrer K, Maguire R, McCann L, Johnston B, et al. Perceptions of the use of a remote monitoring system in patients receiving palliative care at home. Int J Palliat Nurs 2008 Sep;14(9):426-431. [Medline: 19060793]
83. McCann L, Maguire R, Miller M, Kearney N. Patients' perceptions and experiences of using a mobile phone-based advanced symptom management system (ASyMS) to monitor and manage chemotherapy related toxicity. Eur J Cancer Care (Engl) 2009 Mar;18(2):156-164. [doi: 10.1111/j.1365-2354.2008.00938.x] [Medline: 19267731]

84. Meltzer EO, Kelley N, Hovell MF. Randomized, cross-over evaluation of mobile phone vs paper diary in subjects with mild to moderate persistent asthma. Open Respir Med J 2008 Jan;2:72-79 [FREE Full text] [doi: 10.2174/1874306400802010072] [Medline: 19412327]
85. Milne RG. Reducing non-attendance at specialist clinics: an evaluation of the effectiveness and cost of patient-focussed booking and SMS reminders at a Scottish health board. Int J Consum Stud 2010 Aug;34(5):570-580. [doi: 10.1111/j.1470-6431.2010.00903.x]
86. Morak J, Schindler K, Goerzer E, Kastner P, Toplak H, Ludvik B, et al. A pilot study of mobile phone-based therapy for obese patients. J Telemed Telecare 2008;14(3):147-149. [doi: 10.1258/jtt.2008.003015] [Medline: 18430285]
87. Morris ME, Kathawala Q, Leen TK, Gorenstein EE, Guilak F, Labhard M, et al. Mobile therapy: case study evaluations of a cell phone application for emotional self-awareness. J Med Internet Res 2010 Jan;12(2):e10 [FREE Full text] [doi: 10.2196/jmir.1371] [Medline: 20439251]
88. Mosso JL, Gorini A, De La Cerda G, Obrador T, Almazan A, Mosso D, et al. Virtual reality on mobile phones to reduce anxiety in outpatient surgery. Stud Health Technol Inform 2009;142:195-200. [Medline: 19377147]
89. Nakajima R, Nakamura K, Takano T, Seino K, Inose T. Improvements in health by consultations using mobile videophones among participants in a community health promotion programme. J Telemed Telecare 2007;13(8):411-415. [doi: 10.1258/135763307783064403] [Medline: 18078553]
90. Nguyen HQ, Gill DP, Wolpin S, Steele BG, Benditt JO. Pilot study of a cell phone-based exercise persistence intervention post-rehabilitation for COPD. Int J Chron Obstruct Pulmon Dis 2009 Jan;4:301-313 [FREE Full text] [Medline: 19750190]
91. Noh JH, Cho YJ, Nam HW, Kim JH, Kim DJ, Yoo HS, et al. Web-based comprehensive information system for self-management of diabetes mellitus. Diabetes Technol Ther 2010 May;12(5):333-337. [doi: 10.1089/dia.2009.0122] [Medline: 20388042]
92. Pallavicini F, Algeri D, Repetto C, Gorini A, Riva G. Biofeedback, Virtual Reality and Mobile Phones in the Treatment of Generalized Anxiety Disorder (GAD): a Phase-2 Controlled Clinical Trial. Journal of CyberTherapy & Rehabilitation 2009;2(4):315-327 [FREE Full text]
93. 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 Jan;11(1):e1 [FREE Full text] [doi: 10.2196/jmir.1100] [Medline: 19141433]
94. Pérez F, Montón E, Nodal MJ, Viñoles J, Guillen S, Traver V. Evaluation of a mobile health system for supporting postoperative patients following day surgery. J Telemed Telecare 2006;12 Suppl 1:41-43. [doi: 10.1258/135763306777978506] [Medline: 16884576]
95. Pinsker M, Schindler K, Hayn D, Kastner P, Riedl M, Ludvik B. Experiences Using Mobile Phones as Patient-Terminal for Telemedical Home Care and Therapy Monitoring of Patients Suffering from Chronic Diseases. Lecture Notes in Computer Science 2008;5105:1305-1312. [doi: 10.1007/978-3-540-70540-6_195]
96. Pop-Eleches C, Thirumurthy H, Habyarimana JP, Zivin JG, Goldstein MP, de Walque D, et al. Mobile phone technologies improve adherence to antiretroviral treatment in a resource-limited setting: a randomized controlled trial of text message reminders. AIDS 2011 Mar 27;25(6):825-834. [doi: 10.1097/QAD.0b013e32834380c1] [Medline: 21252632]
97. Prabhakaran L, Chee WY, Chua KC, Abisheganaden J, Wong WM. The use of text messaging to improve asthma control: a pilot study using the mobile phone short messaging service (SMS). J Telemed Telecare 2010;16(5):286-290. [doi: 10.1258/jtt.2010.090809] [Medline: 20576744]
98. Puccio JA, Belzer M, Olson J, Martinez M, Salata C, Tucker D, et al. The use of cell phone reminder calls for assisting HIV-infected adolescents and young adults to adhere to highly active antiretroviral therapy: a pilot study. AIDS Patient Care STDS 2006 Jun;20(6):438-444. [doi: 10.1089/apc.2006.20.438] [Medline: 16789857]
99. Quinn CC, Clough SS, Minor JM, Lender D, Okafor MC, Gruber-Baldini A. WellDoc mobile diabetes management randomized controlled trial: change in clinical and behavioral outcomes and patient and physician satisfaction. Diabetes Technol Ther 2008 Jun;10(3):160-168. [doi: 10.1089/dia.2008.0283] [Medline: 18473689]
100. Quinn CC, Gruber-Baldini AL, Shardell M, Weed K, Clough SS, Peeples M, et al. Mobile diabetes intervention study: testing a personalized treatment/behavioral communication intervention for blood glucose control. Contemp Clin Trials 2009 Jul;30(4):334-346. [doi: 10.1016/j.cct.2009.02.004] [Medline: 19250979]
101. Quinn CC, Shardell MD, Terrin ML, Barr EA, Ballew SH, Gruber-Baldini AL. Cluster-randomized trial of a mobile phone personalized behavioral intervention for blood glucose control. Diabetes Care 2011 Sep;34(9):1934-1942 [FREE Full text] [doi: 10.2337/dc11-0366] [Medline: 21788632]
102. Rami B, Popow C, Horn W, Waldhoer T, Schober E. Telemedical support to improve glycemic control in adolescents with type 1 diabetes mellitus. Eur J Pediatr 2006 Oct;165(10):701-705. [doi: 10.1007/s00431-006-0156-6] [Medline: 16670859]
103. Reid SC, Kauer SD, Dudgeon P, Sanci LA, Shrier LA, Patton GC. A mobile phone program to track young people's experiences of mood, stress and coping. Development and testing of the mobiletype program. Soc Psychiatry Psychiatr Epidemiol 2009 Jun;44(6):501-507. [doi: 10.1007/s00127-008-0455-5] [Medline: 19011723]
104. Reid SC, Kauer SD, Hearps SJ, Crooke AH, Khor AS, Sanci LA, et al. A mobile phone application for the assessment and management of youth mental health problems in primary care: a randomised controlled trial. BMC Fam Pract 2011 Jan;12:131 [FREE Full text] [doi: 10.1186/1471-2296-12-131] [Medline: 22123031]

105. Riley W, Obermayer J, Jean-Mary J. Internet and mobile phone text messaging intervention for college smokers. J Am Coll Health 2008;57(2):245-248. [doi: 10.3200/JACH.57.2.245-248] [Medline: 18809542]
106. Rizvi SL, Dimeff LA, Skutch J, Carroll D, Linehan MM. A pilot study of the DBT coach: an interactive mobile phone application for individuals with borderline personality disorder and substance use disorder. Behav Ther 2011 Dec;42(4):589-600. [doi: 10.1016/j.beth.2011.01.003] [Medline: 22035988]
107. Rodgers A, Corbett T, Bramley D, Riddell T, Wills M, Lin RB, et al. Do u smoke after txt? Results of a randomised trial of smoking cessation using mobile phone text messaging. Tob Control 2005 Aug;14(4):255-261 [FREE Full text] [doi: 10.1136/tc.2005.011577] [Medline: 16046689]
108. Rollo ME, Ash S, Lyons-Wall P, Russell A. Trial of a mobile phone method for recording dietary intake in adults with type 2 diabetes: evaluation and implications for future applications. J Telemed Telecare 2011;17(6):318-323. [doi: 10.1258/jtt.2011.100906] [Medline: 21844173]
109. Scherr D, Zweiker R, Kollmann A, Kastner P, Schreier G, Fruhwald FM. Mobile phone-based surveillance of cardiac patients at home. J Telemed Telecare 2006;12(5):255-261. [doi: 10.1258/135763306777889046] [Medline: 16848939]
110. Scherr D, Kastner P, Kollmann A, Hallas A, Auer J, Krappinger H, MOBITEL Investigators. Effect of home-based telemonitoring using mobile phone technology on the outcome of heart failure patients after an episode of acute decompensation: randomized controlled trial. J Med Internet Res 2009;11(3):e34 [FREE Full text] [doi: 10.2196/jmir.1252] [Medline: 19687005]
111. Schiel R, Kaps A, Bieber G, Kramer G, Seebach H, Hoffmeyer A. Identification of determinants for weight reduction in overweight and obese children and adolescents. J Telemed Telecare 2010;16(7):368-373. [doi: 10.1258/jtt.2010.091005] [Medline: 20679405]
112. Seid M, D'Amico EJ, Varni JW, Munafo JK, Britto MT, Kercsmar CM, et al. The in vivo adherence intervention for at risk adolescents with asthma: report of a randomized pilot trial. J Pediatr Psychol 2012 May;37(4):390-403. [doi: 10.1093/jpepsy/jsr107] [Medline: 22167121]
113. Shapiro JR, Bauer S, Hamer RM, Kordy H, Ward D, Bulik CM. Use of text messaging for monitoring sugar-sweetened beverages, physical activity, and screen time in children: a pilot study. J Nutr Educ Behav 2008;40(6):385-391 [FREE Full text] [doi: 10.1016/j.jneb.2007.09.014] [Medline: 18984496]
114. Sharma R, Hebbal M, Ankola AV, Murugabupathy V. Mobile-phone text messaging (SMS) for providing oral health education to mothers of preschool children in Belgaum City. J Telemed Telecare 2011;17(8):432-436. [doi: 10.1258/jtt.2011.110416] [Medline: 22025742]
115. Spaniel F, Vohlídka P, Hrdlicka J, Kozený J, Novák T, Motlová L, et al. ITAREPS: information technology aided relapse prevention programme in schizophrenia. Schizophr Res 2008 Jan;98(1-3):312-317. [doi: 10.1016/j.schres.2007.09.005] [Medline: 17920245]
116. Stapleton S, Adams M, Atterton L. A mobile phone as a memory aid for individuals with traumatic brain injury: a preliminary investigation. Brain Inj 2007 Apr;21(4):401-411. [doi: 10.1080/02699050701252030] [Medline: 17487638]
117. Sternfeld B, Jiang SF, Picchi T, Chasan-Taber L, Ainsworth B, Quesenberry CP. Evaluation of a cell phone-based physical activity diary. Med Sci Sports Exerc 2012 Mar;44(3):487-495. [doi: 10.1249/MSS.0b013e3182325f45] [Medline: 21857369]
118. Strandbygaard U, Thomsen SF, Backer V. A daily SMS reminder increases adherence to asthma treatment: a three-month follow-up study. Respir Med 2010 Feb;104(2):166-171. [doi: 10.1016/j.rmed.2009.10.003] [Medline: 19854632]
119. Stuckey M, Fulkerson R, Read E, Russell-Minda E, Munoz C, Kleinstiver P, et al. Remote monitoring technologies for the prevention of metabolic syndrome: the Diabetes and Technology for Increased Activity (DaTA) study. J Diabetes Sci Technol 2011 Jul;5(4):936-944 [FREE Full text] [Medline: 21880237]
120. Tasker AP, Gibson L, Franklin V, Gregor P, Greene S. What is the frequency of symptomatic mild hypoglycemia in type 1 diabetes in the young?: assessment by novel mobile phone technology and computer-based interviewing. Pediatr Diabetes 2007 Feb;8(1):15-20. [doi: 10.1111/j.1399-5448.2006.00220.x] [Medline: 17341287]
121. Treasure J, Macare C, Mentxaka IO, Harrison A. The use of a vodcast to support eating and reduce anxiety in people with eating disorder: A case series. Eur Eat Disord Rev 2010;18(6):515-521. [doi: 10.1002/erv.1034] [Medline: 20669153]
122. Tsai C, Lee G, Raab F, Norman G, Sohn T, Griswold W, et al. Usability and Feasibility of PmEB: A Mobile Phone Application for Monitoring Real Time Caloric Balance. In: Proceedings of Pervasive Health Conference and Workshops, 2006. 2006 Presented at: Pervasive Health Conference and Workshops; Nov. 29-Dec. 1, 2006; Innsbruck URL: http://dx.plos.org/10.1371/journal.pone.0044740
123. Turner J, Larsen M, Tarassenko L, Neil A, Farmer A. Implementation of telehealth support for patients with type 2 diabetes using insulin treatment: an exploratory study. Inform Prim Care 2009;17(1):47-53. [Medline: 19490773]
124. Vidrine DJ, Arduino RC, Gritz ER. Impact of a cell phone intervention on mediating mechanisms of smoking cessation in individuals living with HIV/AIDS. Nicotine Tob Res 2006 Dec;8 Suppl 1:S103-S108. [Medline: 17491177]
125. Vidrine DJ, Marks RM, Arduino RC, Gritz ER. Efficacy of cell phone-delivered smoking cessation counseling for persons living with HIV/AIDS: 3-month outcomes. Nicotine Tob Res 2012 Jan;14(1):106-110 [FREE Full text] [doi: 10.1093/ntr/ntr121] [Medline: 21669958]
126. Vilella A, Bayas JM, Diaz MT, Guinovart C, Diez C, Simó D, et al. The role of mobile phones in improving vaccination rates in travelers. Prev Med 2004 Apr;38(4):503-509. [doi: 10.1016/j.ypmed.2003.12.005] [Medline: 15020186]

127. Vogel PA, Launes G, Moen EM, Solem S, Hansen B, Håland AT, et al. Videoconference- and cell phone-based cognitive-behavioral therapy of obsessive-compulsive disorder: a case series. J Anxiety Disord 2012 Jan;26(1):158-164. [doi: 10.1016/j.janxdis.2011.10.009] [Medline: 22119331]
128. Wang DH, Kogashiwa M, Ohta S, Kira S. Validity and reliability of a dietary assessment method: the application of a digital camera with a mobile phone card attachment. J Nutr Sci Vitaminol (Tokyo) 2002 Dec;48(6):498-504. [Medline: 12775117]
129. Wangberg SC, Arsand E, Andersson N. Diabetes education via mobile text messaging. J Telemed Telecare 2006;12 Suppl 1:55-56. [doi: 10.1258/135763306777978515] [Medline: 16884582]
130. Whittaker R, Dorey E, Bramley D, Bullen C, Denny S, Elley CR, et al. A theory-based video messaging mobile phone intervention for smoking cessation: randomized controlled trial. J Med Internet Res 2011 Jan;13(1):e10 [FREE Full text] [doi: 10.2196/jmir.1553] [Medline: 21371991]
131. Whittaker R, Maddison R, McRobbie H, Bullen C, Denny S, Dorey E, et al. A multimedia mobile phone-based youth smoking cessation intervention: findings from content development and piloting studies. J Med Internet Res 2008 Jan;10(5):e49 [FREE Full text] [doi: 10.2196/jmir.1007] [Medline: 19033148]
132. Woolford SJ, Clark SJ, Strecher VJ, Resnicow K. Tailored mobile phone text messages as an adjunct to obesity treatment for adolescents. J Telemed Telecare 2010;16(8):458-461 [FREE Full text] [doi: 10.1258/jtt.2010.100207] [Medline: 20959393]
133. Zanner R, Wilhelm D, Feussner H, Schneider G. Evaluation of M-AID, a first aid application for mobile phones. Resuscitation 2007 Sep;74(3):487-494. [doi: 10.1016/j.resuscitation.2007.02.004] [Medline: 17452068]
134. Ahern DK, Kreslake JM, Phalen JM. What is eHealth (6): perspectives on the evolution of eHealth research. J Med Internet Res 2006;8(1):e4 [FREE Full text] [doi: 10.2196/jmir.8.1.e4] [Medline: 16585029]
135. Nilsen W, Kumar S, Shar A, Varoquiers C, Wiley T, Riley WT, et al. Advancing the science of mHealth. J Health Commun 2012 May;17 Suppl 1:5-10. [doi: 10.1080/10810730.2012.677394] [Medline: 22548593]

Abbreviations

ACM: Association for Computing Machinery
CINAHL: Cumulative Index to Nursing and Allied Health Literature
MMS: multimedia messaging service
SMS: short message service

Edited by G Eysenbach; submitted 09.11.12; peer-reviewed by Z Hajar, R Whittaker; comments to author 22.01.13; revised version received 05.03.13; accepted 28.03.13; published 21.05.13.

Please cite as:
Fiordelli M, Diviani N, Schulz PJ
Mapping mHealth Research: A Decade of Evolution
J Med Internet Res 2013;15(5):e95
URL: http://www.jmir.org/2013/5/e95/
doi:10.2196/jmir.2430
PMID:23697600

Original Paper

Global Reach of Direct-to-Consumer Advertising Using Social Media for Illicit Online Drug Sales

Tim Ken Mackey[1,2], MAS; Bryan A Liang[1,3], MD, JD, PhD

[1]Institute of Health Law Studies, California Western School of Law, San Diego, CA, United States
[2]University of California, San Diego-San Diego State University, Joint Doctoral Program in Global Health, La Jolla, CA, United States
[3]San Diego Center for Patient Safety, Department of Anesthesiology, University of California, San Diego, San Diego, CA, United States

Corresponding Author:
Tim Ken Mackey, MAS
University of California, San Diego-San Diego State University
Joint Doctoral Program in Global Health
3588 Health Sciences Drive, Mail Code: 0901
La Jolla, CA, 92093-0507
United States
Phone: 1 1 951 491 4161
Fax: 1 858 822 2399
Email: tmackey@ucsd.edu

Abstract

Background: Illicit or rogue Internet pharmacies are a recognized global public health threat that have been identified as utilizing various forms of online marketing and promotion, including social media.

Objective: To assess the accessibility of creating illicit no prescription direct-to-consumer advertising (DTCA) online pharmacy social media marketing (eDTCA2.0) and evaluate its potential global reach.

Methods: We identified the top 4 social media platforms allowing eDTCA2.0. After determining applicable platforms (ie, Facebook, Twitter, Google+, and MySpace), we created a fictitious advertisement advertising no prescription drugs online and posted it to the identified social media platforms. Each advertisement linked to a unique website URL that consisted of a site error page. Employing Web search analytics, we tracked the number of users visiting these sites and their location. We used commercially available Internet tools and services, including website hosting, domain registration, and website analytic services.

Results: Illicit online pharmacy social media content for Facebook, Twitter, and MySpace remained accessible despite highly questionable and potentially illegal content. Fictitious advertisements promoting illicit sale of drugs generated aggregate unique user traffic of 2795 visits over a 10-month period. Further, traffic to our websites originated from a number of countries, including high-income and middle-income countries, and emerging markets.

Conclusions: Our results indicate there are few barriers to entry for social media–based illicit online drug marketing. Further, illicit eDTCA2.0 has globalized outside US borders to other countries through unregulated Internet marketing.

(J Med Internet Res 2013;15(5):e105) doi:10.2196/jmir.2610

KEYWORDS

health policy; pharmacies; social media; Internet; social marketing; marketing of health services; online pharmaceutical services

Introduction

An estimated 2.4 billion persons worldwide used the Internet in 2011 [1,2]. This increasing use of the Internet and its related technologies has enabled the rise of social media platforms, including Facebook, Twitter, MySpace, and Google+. Collectively, these types of interactive systems are also known as *Web 2.0*. The phenomenon is global, with close to 4 of 5 active worldwide Internet users regularly visiting social media, and social media platforms representing the top online destinations in a cross-section of 10 developed countries and emerging markets (including Brazil, Mexico, India, and China) [1,3,4].

The increased use of the Internet and social media technology has also been associated with direct-to-consumer advertising (DTCA) to market health-related products [5,6]. From 1996 to 2005, DTCA pharmaceutical expenditures in the United States experienced rapid increases estimated at 330% with a total of

US $4 billion in spending for 2009 [7,8]. However, recent market surveys indicate that American DTCA expenditures have recently experienced modest declines largely because of the global economic recession and patent expiration of blockbuster drugs [1,2]. Despite the overall declines in DTCA expenditures, Internet-based DTCA (eDTCA) has experienced increases in investment and attention, indicating a transition in marketing strategies from traditional media (eg, TV, radio, and print) to digital media [1,3,4].

Importantly, DTCA is generally banned in all developed countries, with the exception of the United States and New Zealand [5,6]. In the US, the Food and Drug Administration (FDA) has made efforts to provide industry guidance regarding off-label promotion over the Internet, but has yet to issue explicit guidance on regulation of other forms of Internet advertising, specifically social media-based promotion [7,8]. This lack of adequate DTCA regulation in the largest country where it is permitted may be leading to global dissemination through digital platforms that are not restricted by geopolitical borders [5,6]. This growing eDTCA use and limited FDA online advertising guidance also coincides with the increasing use of the Internet for sourcing of health information. A Pew Internet survey indicates 72% of US users search for health and medical information online, and approximately one-third of users attempt to use the Internet to self-diagnose their health issues [9].

The increased access and use of unregulated eDTCA by illicit actors, specifically online drug sellers, is even more disturbing. This includes social media-based eDTCA (eDTCA2.0) to market a wide variety of medical products that are of questionable quality, origin, and authenticity [5,6,10-12]. The use of eDTCA by these actors is problematic because it often contains content that is misleading, fraudulent, and otherwise illegal [5,13]. This includes the marketing and sale of prescription drugs as "no prescription necessary," use of unsubstantiated medical questionnaires in lieu of a prescription, and marketing products as generic even if there is not an equivalent generic formulation [5,13,14].

Importantly, illicit online pharmacy activities and lack of appropriate eDTCA marketing regulation is compounded by an absence of online pharmacy regulation globally [14]. A recent World Health Organization (WHO) survey of member states found that 66% of respondents failed to specifically regulate Internet pharmacy operations [14]. This is further exacerbated by results from a recent FDA survey indicating that 23% of Internet consumers reported purchasing prescription drugs online [15]. In addition, there are globally established public health risks associated with illicit online sellers that have recently been further highlighted by national drug regulators, international organizations such as the WHO, the United Nations Office of Drugs and Crime, the International Criminal Police Organization, and other diverse stakeholders [16,17]. Hence, although there has been increasing global attention, the combination of unregulated online pharmacies and their use of digital marketing poses unique public health and patient safety risks, the scope and reach of which have yet to be adequately assessed.

Consequently, we wished to explore the potential ease of creation and reach of global, illicit online pharmacy eDTCA. Specifically, we differentiate illicit online drug sellers from licit sellers by defining illicit as those marketing and offering for sale prescription pharmaceutical products without the need for a prescription. Since the vast majority of countries require regulated pharmaceutical products be dispensed with a valid prescription from an authorized health professional, purported "no prescription" online sales are illegal and illicit activity. We also note pharmaceutical products dispensed with a valid prescription by an unlicensed or otherwise unauthorized provider may also constitute a violation of applicable laws, rules, and regulations. Further, because of the potential global reach of social media marketing in enabling this illicit trade, we also wished to assess the financial cost to develop illicit no prescription eDTCA2.0 marketing in these popular platforms and its potential global reach using commercially available Web tools and services. Finally, we were interested in determining whether our social media study sites would be taken down or blocked by service providers.

Methods

Our overall strategy was to create an illicit online pharmacy social media presence in identified leading social media platforms. The primary outcomes of the study were to determine the up-front financial cost, determine if we could generate Internet/user traffic, and if so, its volume and geographic distribution.

We first identified the top 4 social media platforms by traffic volume allowing user-generated eDTCA2.0 content at no cost or charge (ie, site tools that did not require sponsored or ad-based social media promotion; eDTCA sites) [18,19]. For each of these platforms, we created a fictitious advertisement marketing the sale of no prescription pharmaceuticals online (illicit eDTCA ad; see Figure 1). The advertisement was created with Adobe Photoshop CS4 software (San Jose, CA, USA). Content was consistent with prior studies identifying consumer-targeted messaging used by illicit online drug sellers, including the keywords no prescription, no RX, discounts, 100% satisfaction guaranteed, and other forms of potentially illegal, fraudulent, and misleading forms of marketing [20,21]. Images, icons, and a fictitious "lowest price" seal were also used, consistent with other forms of misleading promotion that we have observed being employed by suspect online drug sellers [5,10,16]. A stock image of a health professional was purchased for the advertisement to substantiate simulated commercial marketing.

To operationalize our online social media presence to measure user traffic and distribution, we purchased unique URLs with descriptive terms associated with illicit online drug sales and website space that terminated on these URLs (Table 1). Each unique URL corresponded to the specific social media advertisement, so that all visits to a particular Web address were linked to 1 social media platform point of advertisement. When clicked, rather than linking to an actual illicit online drug seller, all advertisements linked to static text content residing on the URL indicating "site unavailable."

Table 1. Unique URLs linked to illicit Internet-based direct-to-consumer advertising (eDTCA) sites.

Study site URLs[a]	eDTCA platform and associated link
www.norxsafedrugsnow.com	Facebook (http://www.facebook.com/pages/No-Prescription-Online-Pharmacy/178946562182447)
www.norxneededsafedrugs.com	Twitter (@NoRXPharmacy)
www.norxneededcheapandsafedrugs.com	MySpace (http://www.myspace.com/norxonlinepharmacy)
www.norxneededcheapdrugs.com	Google+ (used with Gmail account: norxonlinepharmacy@gmail.com which was suspended)

[a] URLs hosted using Go Daddy services [22].

To assess geographic distribution, we also purchased commercially available site analytic services to track the number and location of visitors to each site. All these services (eg, URLs/domain names, website hosting, and site analytic services) were purchased from the popular Internet service and hosting site Go Daddy [22] given its convenience, market-leading presence, and large-scale commercial and personal usage. Go Daddy administers over 55 million domain names, has 11 million customers, and is the largest Internet Corporation for Assigned Names and Numbers (ICANN) domain registrar worldwide [22,23].

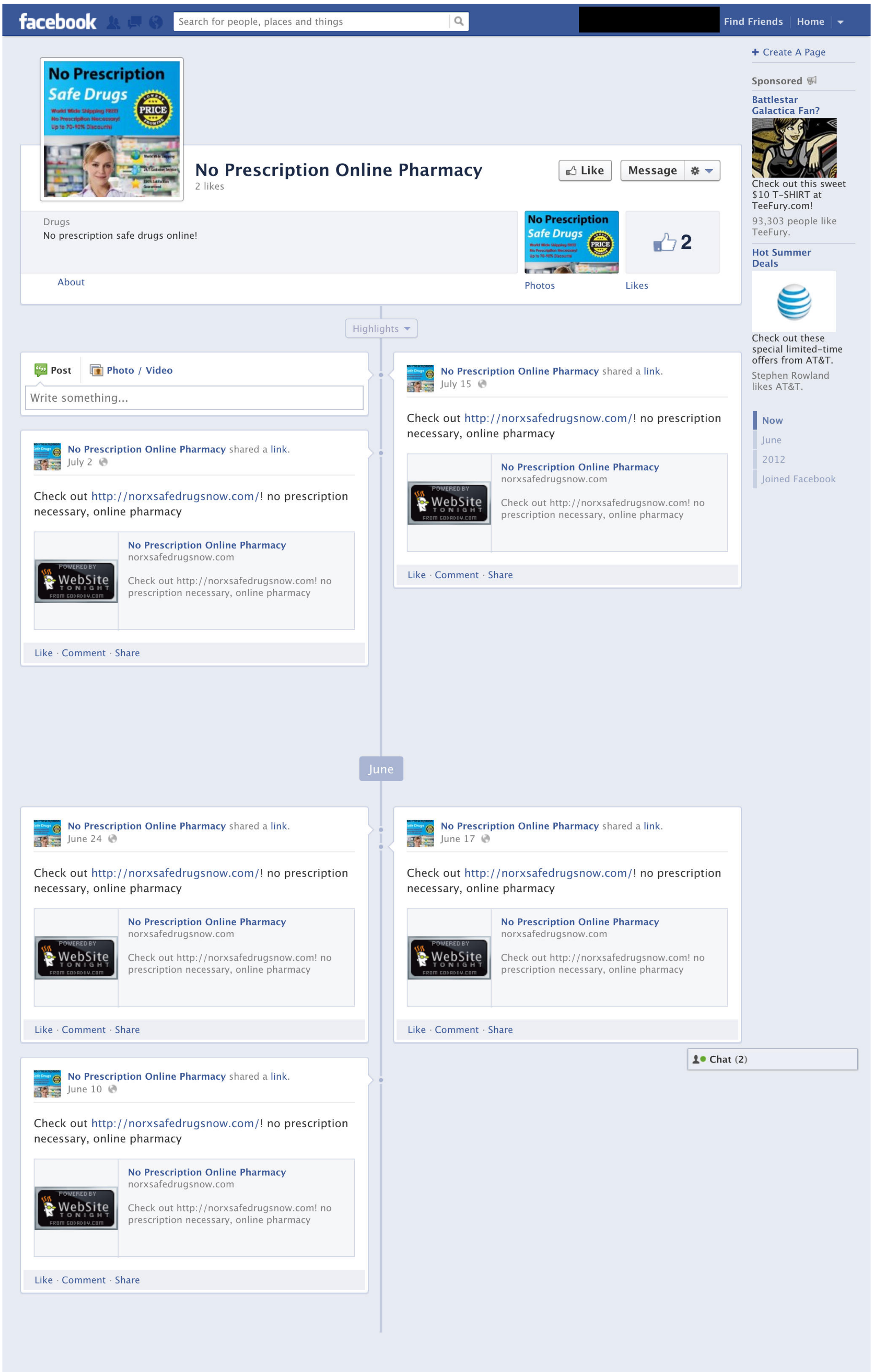
Using these illicit eDTCA ads with clear characteristics of questionable authenticity and legality, we then created user accounts on eDTCA sites using a fictitious email address. Sites were created using the descriptive term “NoRX Online Pharmacy” in site user registration fields. In addition, we registered our eDTCA Facebook site as a Brand or Product page under the category “Drugs.” These registration categories indicate Facebook has systems that specifically enable promotion of health/pharmaceutical-related products.

We then posted the illicit eDTCA ad to each eDTCA site and associated it with a link to the unique URLs/websites hosted by the Go Daddy services (Figures 2-4). On a weekly basis, we posted updates/messages advertising a no prescription online pharmacy and provided a link to the corresponding unique URLs/websites. Site analytics were reviewed on a biweekly basis with results aggregated into monthly traffic and geographic statistics. Employing the website analytic services, we tracked the 2 main study outcome measures: user traffic visiting illicit eDTCA ad-linked URLs, and the location of source Internet protocol (IP) addresses. User traffic is divided into 2 categories: the total number of visits to the site (including returning visitors), and unique user traffic, ie, the number of unique visitors to the site (excluding returning visitors). These definitions are used by site analytics tools and are consistent with industry standards.

Illicit eDTCA ads and websites went live on September 24, 2011, and data were collected for the period beginning September 24, 2011 and ending July 24, 2012. Data were presented by Go Daddy analytics anonymously, and no user or user-identifiable information was collected. Informed consent was exempted pursuant to US federal regulations 45 CFR § 46.101(b)(4), (c)(2), and (d), and this study protocol was approved by the California Western School of Law Institutional Review Board.

Figure 1. Illicit Internet-based direct-to-consumer advertising (eDTCA) ad created for study.

Figure 2. Facebook eDTCA site.



No Prescription Online Pharmacy

2 likes

Drugs

No prescription safe drugs online!

Battlestar Galactica Fan?

Check out this sweet $10 T-SHIRT at TeeFury.com!

93,303 people like TeeFury.

Hot Summer Deals

Check out these special limited-time offers from AT&T.

Stephen Rowland likes AT&T.

No Prescription Online Pharmacy shared a link.

July 15

Check out http://norxsafedrugsnow.com/! no prescription necessary, online pharmacy

No Prescription Online Pharmacy

norxsafedrugsnow.com

Check out http://norxsafedrugsnow.com! no prescription necessary, online pharmacy

Like · Comment · Share

No Prescription Online Pharmacy shared a link.

July 2

Check out http://norxsafedrugsnow.com/! no prescription necessary, online pharmacy

No Prescription Online Pharmacy

norxsafedrugsnow.com

Check out http://norxsafedrugsnow.com! no prescription necessary, online pharmacy

Like · Comment · Share

No Prescription Online Pharmacy shared a link.

June 24

Check out http://norxsafedrugsnow.com/! no prescription necessary, online pharmacy

No Prescription Online Pharmacy

norxsafedrugsnow.com

Check out http://norxsafedrugsnow.com! no prescription necessary, online pharmacy

Like · Comment · Share

No Prescription Online Pharmacy shared a link.

June 17

Check out http://norxsafedrugsnow.com/! no prescription necessary, online pharmacy

No Prescription Online Pharmacy

norxsafedrugsnow.com

Check out http://norxsafedrugsnow.com! no prescription necessary, online pharmacy

Like · Comment · Share

No Prescription Online Pharmacy shared a link.

June 10

Check out http://norxsafedrugsnow.com/! no prescription necessary, online pharmacy

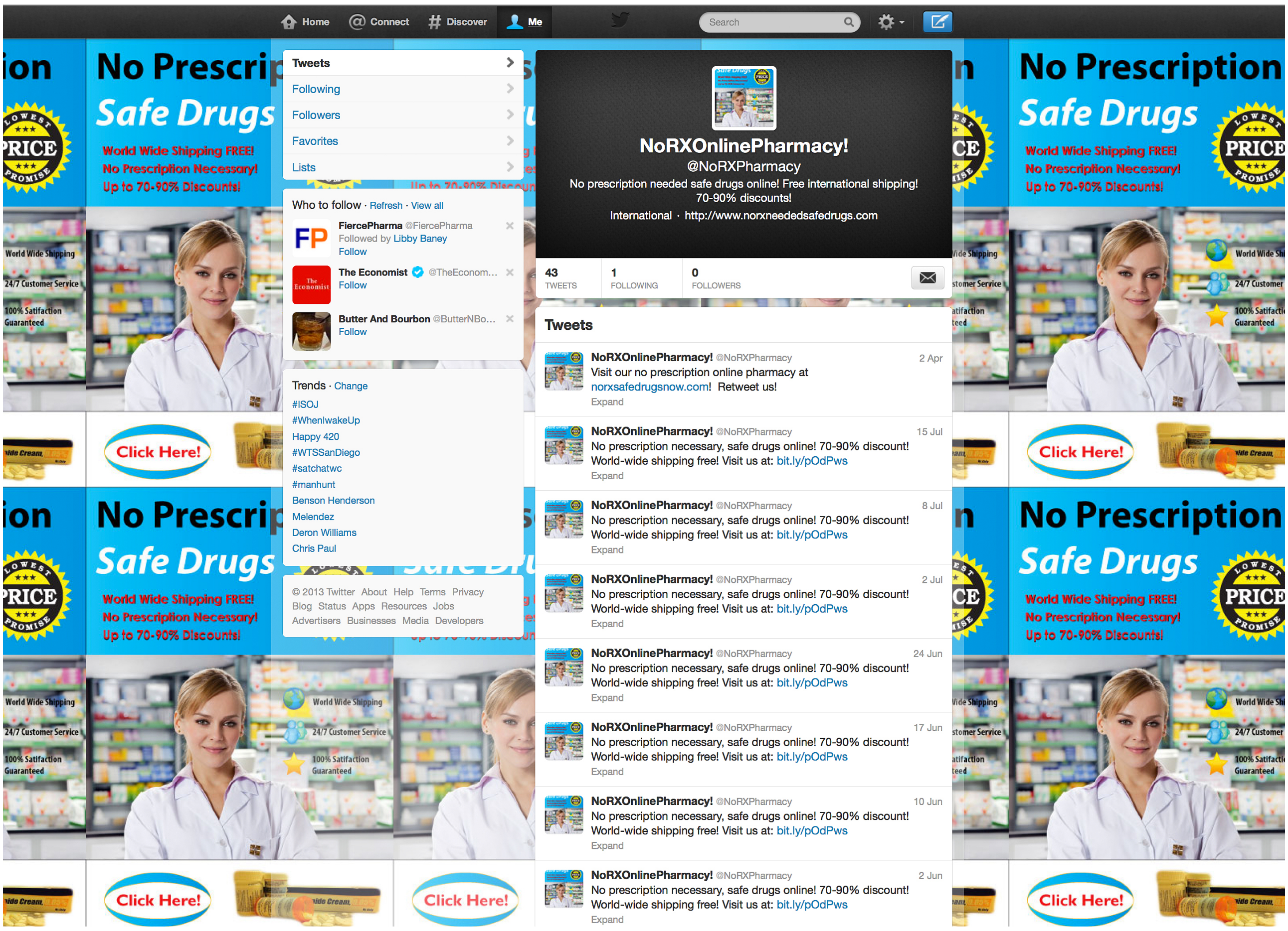
No Prescription Online Pharmacy

norxsafedrugsnow.com

Check out http://norxsafedrugsnow.com! no prescription necessary, online pharmacy

Like · Comment · Share

Figure 3. Twitter eDTCA site.



NoRXOnlinePharmacy!
@NoRXPharmacy
No prescription needed safe drugs online! Free international shipping! 70-90% discounts!
International · http://www.norxneededsafedrugs.com

NoRXOnlinePharmacy! @NoRXPharmacy 2 Apr
Visit our no prescription online pharmacy at norxsafedrugsnow.com! Retweet us!
Expand

NoRXOnlinePharmacy! @NoRXPharmacy 15 Jul
No prescription necessary, safe drugs online! 70-90% discount! World-wide shipping free! Visit us at: bit.ly/pOdPws
Expand

NoRXOnlinePharmacy! @NoRXPharmacy 8 Jul
No prescription necessary, safe drugs online! 70-90% discount! World-wide shipping free! Visit us at: bit.ly/pOdPws
Expand

NoRXOnlinePharmacy! @NoRXPharmacy 2 Jul
No prescription necessary, safe drugs online! 70-90% discount! World-wide shipping free! Visit us at: bit.ly/pOdPws
Expand

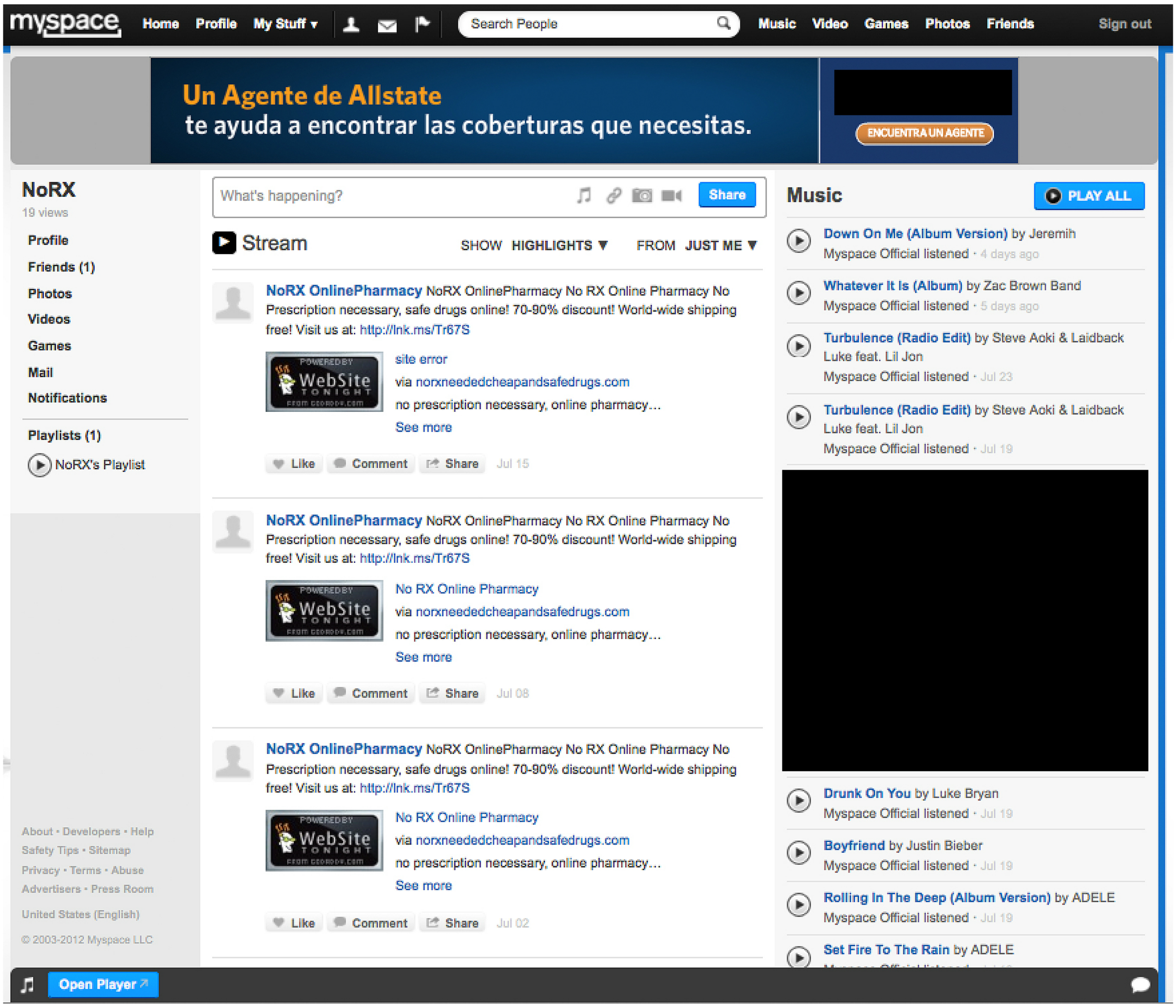
NoRXOnlinePharmacy! @NoRXPharmacy 24 Jun
No prescription necessary, safe drugs online! 70-90% discount! World-wide shipping free! Visit us at: bit.ly/pOdPws
Expand

NoRXOnlinePharmacy! @NoRXPharmacy 17 Jun
No prescription necessary, safe drugs online! 70-90% discount! World-wide shipping free! Visit us at: bit.ly/pOdPws
Expand

NoRXOnlinePharmacy! @NoRXPharmacy 10 Jun
No prescription necessary, safe drugs online! 70-90% discount! World-wide shipping free! Visit us at: bit.ly/pOdPws
Expand

NoRXOnlinePharmacy! @NoRXPharmacy 2 Jun
No prescription necessary, safe drugs online! 70-90% discount! World-wide shipping free! Visit us at: bit.ly/pOdPws
Expand

Figure 4. MySpace eDTCA site.



[redacted]

NoRX OnlinePharmacy NoRX OnlinePharmacy No RX Online Pharmacy No Prescription necessary, safe drugs online! 70-90% discount! World-wide shipping free! Visit us at: http://lnk.ms/Tr67S

site error
via norxneededcheapandsafedrugs.com
no prescription necessary, online pharmacy...
See more

Jul 15

NoRX OnlinePharmacy NoRX OnlinePharmacy No RX Online Pharmacy No Prescription necessary, safe drugs online! 70-90% discount! World-wide shipping free! Visit us at: http://lnk.ms/Tr67S

No RX Online Pharmacy
via norxneededcheapandsafedrugs.com
no prescription necessary, online pharmacy...
See more

Jul 08

NoRX OnlinePharmacy NoRX OnlinePharmacy No RX Online Pharmacy No Prescription necessary, safe drugs online! 70-90% discount! World-wide shipping free! Visit us at: http://lnk.ms/Tr67S

No RX Online Pharmacy
via norxneededcheapandsafedrugs.com
no prescription necessary, online pharmacy...
See more

Jul 02

Down On Me (Album Version) by Jeremih
Myspace Official listened · 4 days ago

Whatever It Is (Album) by Zac Brown Band
Myspace Official listened · 5 days ago

Turbulence (Radio Edit) by Steve Aoki & Laidback Luke feat. Lil Jon
Myspace Official listened · Jul 23

Turbulence (Radio Edit) by Steve Aoki & Laidback Luke feat. Lil Jon
Myspace Official listened · Jul 19

[redacted]

Drunk On You by Luke Bryan
Myspace Official listened · Jul 19

Boyfriend by Justin Bieber
Myspace Official listened · Jul 19

Rolling In The Deep (Album Version) by ADELE
Myspace Official listened · Jul 19

Set Fire To The Rain by ADELE

Results

We identified the top 4 social media platforms enabling eDTCA2.0: Facebook, Twitter, MySpace, and Google+. Financial costs for creating illicit eDTCA ads across these platforms were relatively minor. In total, our outlays were less than US $400, with a cost of approximately US $80/eDTCA site (excluding the cost of existing software used to create the illicit eDTCA ad), inclusive of the fees for domain registration, website hosting and design tools, and website analytics (1-year service term), plus approximately US $60 for a limited commercial license for use of the health professional image used in the eDTCA2.0 ads.

We found that there appears to be little regulation of eDTCA2.0 content by social media platforms. Facebook, Twitter, and MySpace content created for the purposes of this study continue to remain accessible as of April 19, 2013, despite highly questionable and likely illegal content. Terms and conditions of use of these social media sites may also have been violated during the study, although no enforcement resulted (see Multimedia Appendix 1). Only our Google+ site was suspended by the service provider for undisclosed reasons. When trying to log into our Google+ account, we received a notification that our account had been disabled on October 26, 2011 (approximately 4 weeks after the site became active), at which point we terminated data collection. However, no reason was given for disabling our account. Others have had clearly legal Google+ accounts disabled during our study period for no apparent reason [24].

Fictitious illicit eDTCA ads linked to the remaining eDTCA sites (Facebook, Twitter, and MySpace) marketing illegal sale of prescription drugs generated total user traffic in the aggregate of 4107 visits, and unique user traffic in the aggregate of 2795 visits over a 10-month period from September 24, 2011 to July 24, 2011 for all websites. Select descriptive statistics on Web traffic over the study period had a mean monthly user traffic volume of 111 to 141 visits (upper and lower limits) and 78 to 97 visits for unique user traffic volume (Table 2).

Our unique URLs/websites linked to illicit eDTCA ads posted on our Twitter eDTCA site generated the most user and unique user traffic volume of all platforms over the study period (Figure 5).

Country-level location data of user visits to the unique URLs/websites linked to illicit eDTCA ads resulted in user traffic from a total of 18 unique countries, including high-income, upper-middle income, lower-middle income, and emerging markets (Figure 6). The United States generated the highest percentage of visitors (54.0% of total traffic). Emerging markets of China and the Russian Federation ranked second (26.0%) and fourth (6.5%), respectively, with another high-income market country, the United Kingdom, ranking third (8.9%) in total visitors. Collectively, these top 4 countries generated the vast majority of user traffic (95.6%). Certain country visitors were unique to types of social media platforms, including Sweden (Facebook) and South Korea (Twitter; see Table 3).

Table 2. Illicit eDTCA unique user descriptive statistics.

Social media	Visits (n)	Mean	Median	Mode	Min	Max	Other information
Facebook	859	78.09	83	89	41	102	2 likes
Twitter	1069	97.18	99	117	40	124	1 following
MySpace	867	78.81	90	95	18	96	N/A

Table 3. Illicit eDTCA user location data.

Country	Classification[a]	Social media site, n (%)			
		Facebook	Twitter	MySpace	Total
United States	High income	702 (34.2)	818 (37.7)	650 (30.0)	2170 (54.3)
China	Upper-middle income/emerging market	240 (23.1)	412 (39.7)	387 (37.2)	1039 (26.0)
United Kingdom	High income	105 (8.8)	145 (9.6)	106 (8.2)	356 (8.9)
Russian Federation	Upper-middle income/emerging market	67 (5.6)	76 (5.0)	117 (9.0)	260 (6.5)
Unknown	—	38 (3.2)	12 (0.8)	7 (0.5)	57 (1.4)
Germany	High income	7 (0.6)	9 (0.6)	8 (0.6)	24 (0.6)
Japan	High income	5 (0.4)	15 (1.0)	4 (0.3)	24 (0.6)
Netherlands	High income	4 (0.3)	5 (0.3)	5 (0.4)	14 (0.4)
France	High income	4 (0.3)	4 (0.3)	4 (0.3)	12 (0.3)
Ukraine	Lower-middle income/emerging market	2 (0.2)	2 (0.1)	2 (0.2)	6 (0.2)
Israel	High income	2 (0.2)	2 (0.1)	2 (0.2)	6 (0.2)
Czech Republic	High income	2 (0.2)	2 (0.1)	2 (0.2)	6 (0.2)
Moldova, Republic of	Lower-middle income	3 (0.3)	2 (0.1)	2 (0.2)	7 (0.2)
Canada	High income	3 (0.3)	1 (0.1)	1 (0.1)	5 (0.1)
Sweden	High income	2 (0.2)	0 (0.0)	0 (0.0)	2 (0.1)
Australia	High income	1 (0.1)	1 (0.1)	1 (0.1)	3 (0.1)
Taiwan	High income[b]	1 (0.1)	1 (0.1)	1 (0.1)	3 (0.1)
Romania	Upper-middle income	1 (0.1)	1 (0.1)	1 (0.1)	3 (0.1)
Korea, Republic of	High income	0 (0.0)	2 (0.1)	0 (0.0)	2 (0.1)

[a] Country income classification based on World Bank List of Economies [25]. Country emerging market classification based on the International Monetary Fund's World Economic Outlook Update [26].

[b] Taiwan is not listed as a separate country, but it is separately classified by the World Bank as a high-income country [27].

Figure 5. Unique user traffic statistics for eDTCA sites (provided by Go Daddy website analytics tool).

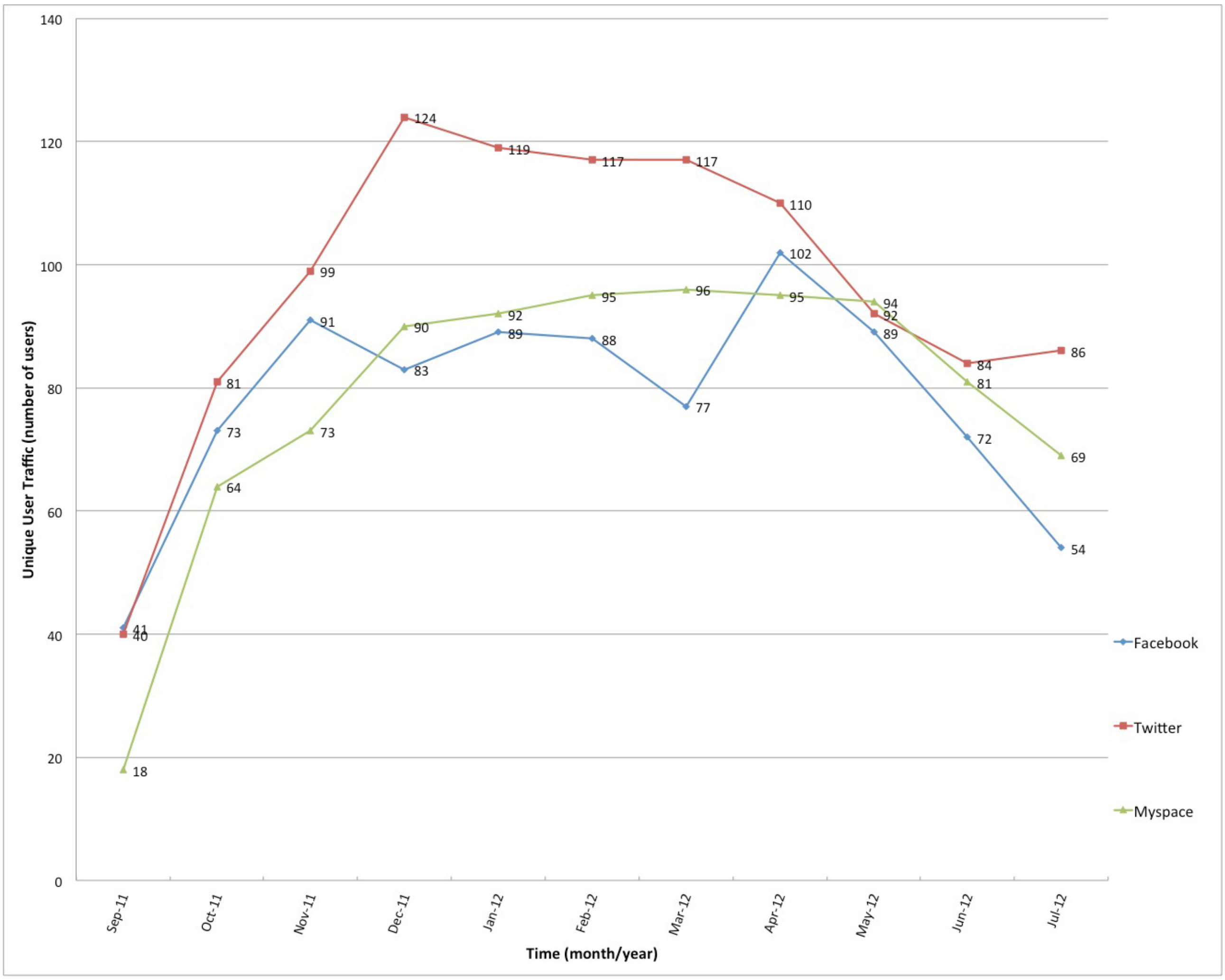
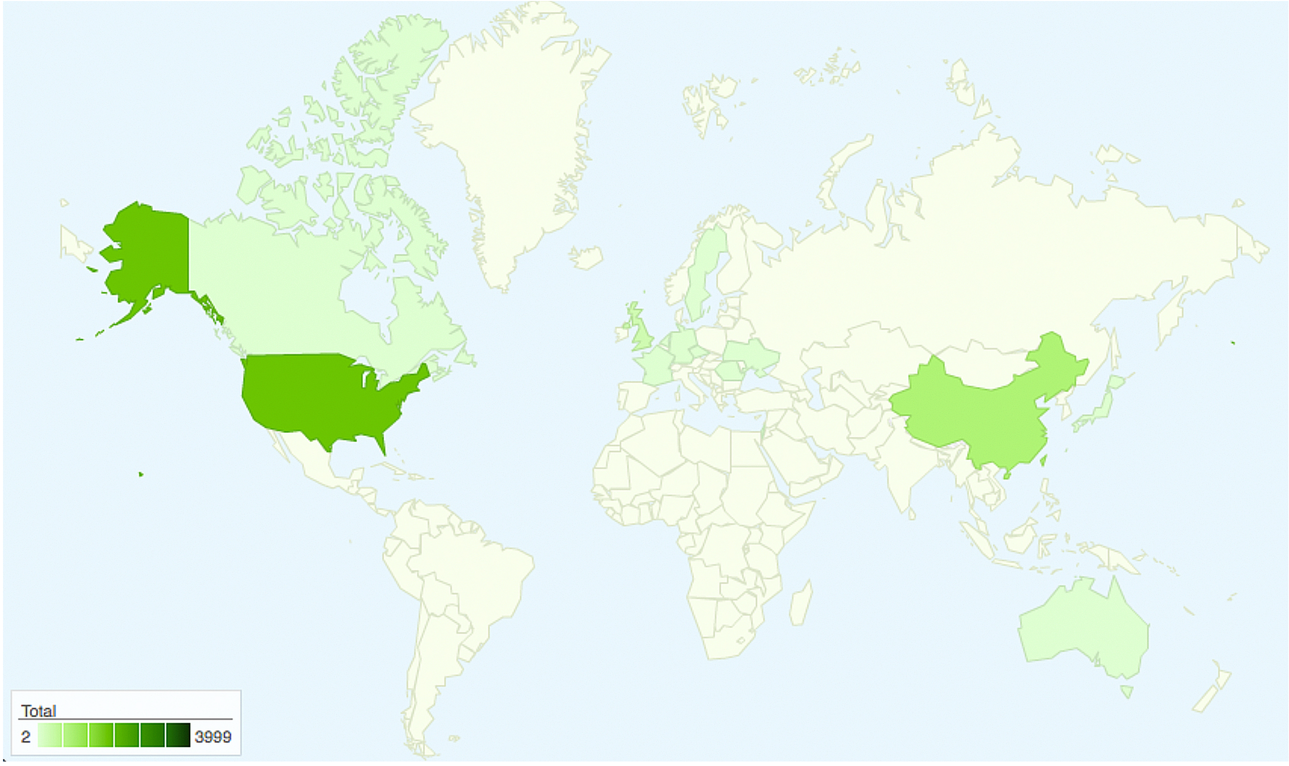


Figure 6. Geographic heat map of user traffic (source: Google Fusion Tables).



Discussion

Implications

It is inexpensive and easy to create an illicit online pharmacy marketing presence using eDTCA2.0. Moreover, there appears to be few barriers of entry and continued market presence of illegally marketed no prescription drugs using eDTCA2.0 on Facebook, Twitter, and MySpace.

These results are consistent with previous studies identifying an increasing presence of eDTCA2.0 use by illicit online drug sellers for a variety of medical products [5,6,10-12,28], but expand earlier work by finding consistent cross-platform presence in key social media platforms. This ease of creating a potential pharmaceutical criminal presence on globally accessible social media is highly alarming given its increasing utilization by online users and current lack of effective regulation [29]. Importantly, we believe these results are the first to demonstrate the use of social media platforms and Web tools to inexpensively create illicit eDTCA2.0 marketing and sites that are readily available and accessible to a worldwide audience.

Supporting study findings of ease of accessibility and affordability, social media eDTCA site registration was available at no cost, and illicit eDTCA ads creation and website maintenance were accomplished at a nominal cost for domain registration, website hosting and design tools, and website analytics—all conveniently packaged by the same provider. Access to social media allowed us to generate user traffic without employing forms of search engine optimization and search engine marketing services, avoiding these additional costs.

Our illicit eDTCA ads and websites generated relatively limited traffic compared with other traditional sources of e-commerce, such as legitimate pharmacy websites. This was likely due to a lack of site optimization and investment in Internet marketing, and our nonfunctional sites—we did not actually illicitly sell drugs online. Further, illustrating the ubiquity of illicit eDTCA2.0 presence, when registering our eDTCA sites, we discovered numerous other illicit online drug sellers utilizing social media platforms that competed directly with our study sites The presence of these more established illicit sites, and their aggressive forms of eDTCA marketing (ie, use of more explicit images/claims), further limited visibility and user traffic to our sites. However, despite these challenges, our illicit eDTCA ads and eDTCA sites were still able to generate traffic from global users.

Beyond safety concerns from consumer purchase of medicines from illicit online drug sellers, global dissemination of our eDTCA ads potentially violates DTCA prohibitions in virtually all countries other than the United States and New Zealand. Hence, global dissemination of eDTCA appears unrestricted and lacks necessary effective regulation and enforcement. Study results indicate our illicit eDTCA ads, which were clearly false and misleading, were accessed by users in diverse countries including high-income and middle-income countries, and other emerging markets.

We also observed user traffic that was highly concentrated in countries known to have illicit online drug sales and counterfeit drug trafficking activity, including China and Russia, and high-income consumption markets of the United States and the United Kingdom, where counterfeit seizures and incidents have been reported [13,16]. As well, the United States had the highest user traffic, which is also consistent with data supporting a high-proportion of US-based Internet and social media users and high prescription drug expenditures [29,30]. For further information on geographical findings, see Multimedia Appendix 1.

Although previous studies have reported findings supporting the negative impact of transborder promotion of traditional forms of DTCA (eg, satellite TV broadcasts and print content) [31-34], our study provides evidence of the globalization of illicit, broad-based digital forms of social media marketing. The results from this study can provide important information to global policymakers about necessary elements for appropriate illicit eDTCA regulation. For example, the use of high-risk keywords and terms in usernames and eDTCA2.0 content makes one direct solution clear: requiring social media service providers to monitor for content associated with illicit online drug selling activity during registration and in content generated by users via their sites, tools, and applications. We note that during the course of the study registration, use, and promotion, we consistently used terms that could easily identify the eDTCA site as being involved in potentially illegal activity (eg, “no prescription” and “no RX”). Social media providers should actively monitor for these keywords and proactively shut down users that are in violation of their general terms of use prohibiting illegal activity.

In addition, social media sites should partner with public health agencies and law enforcement by providing Internet surveillance data on suspect online drug sellers and patient safety events. Social media platforms can also follow recommendations of established organizations, such as the National Association of Boards of Pharmacy (NABP) Verified Internet Pharmacy Practice Sites (VIPPS) accreditation program, which accredits online pharmacies that meet pharmacy compliance and licensure requirements in the United States, provides consumer education on safe online drug purchasing, and is the only accreditation program recommended by the FDA [5,10]. This could also include social media surveillance reporting for possible inclusion on the NAPB Not Recommended Sites list that identifies risky online drug sources [10].

Complementing public protection activities, social media sites should not be immune to potential prosecutorial action associated with enabling criminal activity and failing to police obvious false, fraudulent, and illicit marketing that can directly harm patients and consumers. This type of enforcement is consistent with a US $500 million penalty levied by the US Department of Justice against Google regarding allegations of profits from AdWords associated with illegal online drug sales [35]. Large social media companies, such as Facebook, should be legally required to use a portion of their resources for simple public safety enforcement of rules already extant in their policies. In this sense, social media platforms should recognize the goal of promoting public health is consistent with ensuring users are provided a safe online experience.

Limitations

Our study has certain limitations. We note that data collected from commercially available and convenient Internet services could not be externally validated. However, reliance upon IP address sources would reasonably be considered reliable, especially from known service providers, although IP blocking and redirecting software may be utilized by users and could affect results. Also, we were unable to ascertain why our Google+ study site was suspended. Google+ was a relatively new social media platform at the time of this study; hence, other explanations may be responsible for access issues rather than illicit content, particularly in the context of other clearly legal Google+ accounts disabled without reason. We also did not discern website referral patterns or visitor types of our social media sites, and user traffic could encompass human users and forms of Web technologies (eg, Web bots, crawlers, and indexing services). However, even if all the user traffic generated by our eDTCA sites did not consist of human users, the results still demonstrate our content is being accessed, crawled, indexed, and mapped for use on the Internet. Finally, user traffic was not high volume compared with other e-commerce sites; hence, limiting the generalizability of the study results. Yet our limited costs, knowledge, and mild advertising content still generated global visits.

Conclusions

The dynamic nature of the Internet and particularly social media results in tremendous challenges for future policy. As the presence, popularity, and diversity of social media continues to expand, social media use by illicit online drug sellers will continue to grow. In response, there will be a need to expand global law enforcement efforts to keep pace with and anticipate suspect online drug seller activities.

As expansion of illegal marketing of prescription drugs online moves from search engines to social media and combination forms [12], it is apparent that these illegal actors are cognizant and evolving with technology. This study highlights the ease of entry into this illicit market and lack of adequate, effective regulation and enforcement. This is an urgent public health concern because legal efforts are continuing to fall behind criminal actions that are nimble and sophisticated. Continued study of the marketing pathways and associated vulnerabilities of digital platforms, such as social media, will be necessary to keep pace with increasing criminal use of the Internet to illegally sell drugs worldwide. Global governance and cooperation is essential between law enforcement, health care stakeholders, and Internet participating parties to address the exploitation of the online sphere by criminals undermining global health.

Acknowledgments

TKM would like to thank the Partnership for Safe Medicines for their support of this research. No user or other user-identifiable information was collected for the purposes of this study and informed consent was exempted pursuant to US federal regulations 45 CFR § 46.101(b)(4), (c)(2), and (d). This study protocol was approved by the California Western School of Law Institutional Review Board.

Authors' Contributions

We note that with respect to author contributions, Tim Mackey (TM) Bryan A Liang (BAL) jointly conceived the study, TM and BAL jointly wrote the manuscript, TM and BAL jointly edited the manuscript, and BAL supervised its legal and policy analysis. BAL is the guarantor of the study. All authors had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Conflicts of Interest

All authors have completed the Unified Competing Interest form (available on request from the corresponding author) and declare the following support and relationships with parties that might have an interest in the submitted work: BAL is a member of the Core Committee, Council on Foreign Relations Global Drug Safety Roundtable, and has received funding for one address and meeting of the Roundtable. BAL was a former member of the National Academy of Sciences, Institute of Medicine, Committee on Understanding the Global Public Health Implications of Counterfeit, Falsified, and Substandard Drugs, and received funding for travel and lodging for 1 meeting of this committee. Further, BAL is a member of the US nonprofit National Patient Safety Foundation (NPSF) Research Program Committee and is a Project Liaison for that organization, which addresses key issues in drug safety. NPSF receives funding from public and private donors, including the medical industry. BAL receives $250-500 annually for reviewing Letters of Intent and full grant proposals for NPSF. BAL is also a board member and Vice President of the Partnership for Safe Medicines (PSM), a nonprofit membership, dues driven organization of nonprofit public, private, academic, and patient entities supporting drug supply safety. BAL and TKM are reimbursed for travel to 1 PSM board meeting/annual conference each year. TKM is the Carl L Alsberg MD Fellow for Safe Medicines of PSM, and receives unrestricted fellowship funding in support of TKM’s current PhD studies, including research materials and travel-related expenses associated with presentation at academic conferences. Researchers are independent of this source of funding and this source of funding had no role in the study. There was no involvement of anyone other than the authors in the conception, design, collection, planning, conduct, analysis, interpretation, writing, and discussion to submit this work. Their spouses, partners, or children have no financial relationships that may be relevant to the submitted work. TKM and BAL have no nonfinancial interests that may be relevant to the submitted work.

Multimedia Appendix 1

Additional information on website terms and conditions and study results.

[PDF File (Adobe PDF File), 33KB - jmir_v15i5e105_app1.pdf]

References

1. AdAge Insights White Paper.: Kantar Media; 2011. Pharmaceutical marketing URL: http://gaia.adage.com/images/bin/pdf/WPpharmmarketing_revise.pdf [accessed 2013-04-18] [WebCite Cache ID 6G291yFV4]
2. International Telecommunication Union. Key global telecom indicators for the world telecommunication service sector URL: http://www.itu.int/ITU-D/ict/statistics/at_glance/KeyTelecom.html [accessed 2013-03-10] [WebCite Cache ID 6F3VSJk9Q]
3. Nielsen. 2011. State of the media: social media report Q3 2011 URL: http://www.nielsen.com/us/en/reports/2012/state-of-the-media-the-social-media-report-2012.html [accessed 2013-03-11] [WebCite Cache ID 6F3VWzreu]
4. Loftus T. Wall Street Journal Blogs. 2012 Jan 04. Emerging markets tops in social media activity URL: http://blogs.wsj.com/digits/2012/01/04/study-emerging-markets-tops-in-social-media-activity/ [accessed 2013-04-18] [WebCite Cache ID 6G29MhBYL]
5. Liang BA, Mackey TK. Prevalence and global health implications of social media in direct-to-consumer drug advertising. J Med Internet Res 2011;13(3):e64 [FREE Full text] [doi: 10.2196/jmir.1775] [Medline: 21880574]
6. Liang BA, Mackey T. Direct-to-consumer advertising with interactive internet media: global regulation and public health issues. JAMA 2011 Feb 23;305(8):824-825. [doi: 10.1001/jama.2011.203] [Medline: 21343583]
7. Gottlieb S. Forbes. 2013 Feb 27. FDA wants to regulate drug firms on the Internet and it's targeting Facebook "likes" URL: http://www.forbes.com/sites/scottgottlieb/2013/02/27/fdas-wants-to-regulate-the-internet-and-now-its-taking-on-facebooks-like-button/ [accessed 2013-04-19] [WebCite Cache ID 6G29TIAho]
8. Liang BA, Mackey T. Reforming direct-to-consumer advertising. Nat Biotechnol 2011 May;29(5):397-400. [doi: 10.1038/nbt.1865] [Medline: 21552236]
9. Fox S, Duggan M. For one-third of US adults, the Internet is a diagnostic tool. Washington, DC: Pew Internet & American Life Project; 2013 Jan 15. URL: http://pewinternet.org/Reports/2013/Health-online/Part-One/Section-1.aspx [accessed 2013-04-20] [WebCite Cache ID 6G29kmfbQ]
10. Liang BA, Mackey TK. Online availability and safety of drugs in shortage: a descriptive study of internet vendor characteristics. J Med Internet Res 2012;14(1):e27 [FREE Full text] [doi: 10.2196/jmir.1999] [Medline: 22321731]
11. Liang BA, Mackey TK. Vaccine shortages and suspect online pharmacy sellers. Vaccine 2012 Jan 5;30(2):105-108. [doi: 10.1016/j.vaccine.2011.11.016] [Medline: 22094281]
12. Liang BA, Mackey TK, Lovett KM. Suspect online sellers and contraceptive access. Contraception 2012 Nov;86(5):551-556. [doi: 10.1016/j.contraception.2012.04.011] [Medline: 22633248]
13. Liang BA, Mackey T. Searching for safety: addressing search engine, website, and provider accountability for illicit online drug sales. Am J Law Med 2009;35(1):125-184. [Medline: 19534258]
14. World Health Organization. Safety and Security on the Internet: Challenges and advances in Member States. Geneva: World Health Organization; 2011. URL: http://www.who.int/goe/publications/goe_security_web.pdf [accessed 2013-04-20] [WebCite Cache ID 6G29we3Ap]
15. US Food and Drug Administration. 2012 Sep 27. BeSafeRx: Know Your Online Pharmacy - Survey Highlights URL: http://www.fda.gov/Drugs/ResourcesForYou/Consumers/BuyingUsingMedicineSafely/BuyingMedicinesOvertheInternet/BeSafeRxKnowYourOnlinePharmacy/ucm318497.htm [accessed 2013-04-20] [WebCite Cache ID 6G29z6Gju]
16. Mackey TK, Liang BA. The global counterfeit drug trade: patient safety and public health risks. J Pharm Sci 2011 Nov;100(11):4571-4579. [doi: 10.1002/jps.22679] [Medline: 21698604]
17. Mackey TK, Liang BA, Kubic TT. Foreign Affairs. 2012 May 14. Dangerous Doses: Fighting Fraud in the Global Medicine Supply Chain URL: http://www.foreignaffairs.com/articles/137634/tim-k-mackey-bryan-a-liang-and-thomas-t-kubic/dangerous-doses [accessed 2013-04-20] [WebCite Cache ID 6G2A5Ix05]
18. Madden M, Zickuhr K. 65% of online adults use social networking sites. Washington, DC: Pew Internet & American Life Project; 2011 Aug 26. URL: http://pewinternet.org/~/media//Files/Reports/2011/PIP-SNS-Update-2011.pdf [accessed 2013-03-11] [WebCite Cache ID 6F3Vcq3L4]
19. Smith A, Brenner J. Twitter Use 2012. Washington, DC: Pew Internet & American Life Project; 2012 May 31. URL: http://pewinternet.org/~/media//Files/Reports/2012/PIP_Twitter_Use_2012.pdf [accessed 2013-03-12] [WebCite Cache ID 6F3Vfvqed]

20. Ivanitskaya L, Brookins-Fisher J, O Boyle I, Vibbert D, Erofeev D, Fulton L. Dirt cheap and without prescription: how susceptible are young US consumers to purchasing drugs from rogue internet pharmacies? J Med Internet Res 2010;12(2):e11 [FREE Full text] [doi: 10.2196/jmir.1520] [Medline: 20439253]
21. Orizio G, Rubinelli S, Schulz PJ, Domenighini S, Bressanelli M, Caimi L, et al. "Save 30% if you buy today". Online pharmacies and the enhancement of peripheral thinking in consumers. Pharmacoepidemiol Drug Saf 2010 Sep;19(9):970-976. [doi: 10.1002/pds.2007] [Medline: 20652863]
22. Go Daddy. About Go Daddy URL: http://ca.godaddy.com/newscenter/about-godaddy.aspx?ci=9079 [accessed 2013-04-20] [WebCite Cache ID 6G2ALxKUO]
23. Webhosting.info. 2013. ICANN accredited registrars: largest ICANN registrars URL: http://www.webhosting.info/registrars/top-registrars/global/ [accessed 2013-04-20] [WebCite Cache ID 6G2ANwIdp]
24. Google Groups. 2011. My google account has been disabled for no reason URL: http://productforums.google.com/forum/ [accessed 2013-04-20] [WebCite Cache ID 6G2AcGUxc]
25. The World Bank. Country and lending groups URL: http://data.worldbank.org/about/country-classifications/country-and-lending-groups [accessed 2013-05-20] [WebCite Cache ID 6Gl4O5jMu]
26. International Monetary Fund. 2012 Jul 16. World economic outlook update: new setbacks, further policy action needed URL: http://www.imf.org/external/pubs/ft/weo/2012/update/02/index.htm [accessed 2013-05-18] [WebCite Cache ID 6GiP0GGld]
27. The World Bank. How we classify countries URL: http://data.worldbank.org/about/country-classifications [accessed 2013-05-18] [WebCite Cache ID 6GiPDjkoS]
28. Mackey TK, Liang BA. Oncology and the Internet: regulatory failure and reform. J Oncol Pract 2012 Nov;8(6):341-343 [FREE Full text] [doi: 10.1200/JOP.2012.000579] [Medline: 23450970]
29. US Census Bureau, Statistical Abstract of the United States: 2012. 2012 Aug 6. Adult computer and adult Internet users by selected characteristics: 2000 to 2011 URL: http://www.census.gov/compendia/statab/2012/tables/12s1158.pdf [accessed 2013-03-11] [WebCite Cache ID 6F3aIJjOP]
30. comScore. 2011 Dec 21. It's a social world: top 10 need-to-knows about social networking and where it's headed URL: http://www.comscore.com/Insights/Presentations_and_Whitepapers/2011/it_is_a_social_world_top_10_need-to-knows_about_social_networking [accessed 2013-04-20] [WebCite Cache ID 6G2AqP5PC]
31. Mintzes B, Morgan S, Wright JM. Twelve years' experience with direct-to-consumer advertising of prescription drugs in Canada: a cautionary tale. PLoS One 2009;4(5):e5699 [FREE Full text] [doi: 10.1371/journal.pone.0005699] [Medline: 19479084]
32. Mintzes B. Direct to consumer advertising of prescription drugs. BMJ 2008;337:a985. [Medline: 18765449]
33. Mackenzie FJ, Jordens CF, Ankeny RA, McPhee J, Kerridge IH. Direct-to-consumer advertising under the radar: the need for realistic drugs policy in Australia. Intern Med J 2007 Apr;37(4):224-228. [doi: 10.1111/j.1445-5994.2006.01298.x] [Medline: 17388861]
34. Law MR, Majumdar SR, Soumerai SB. Effect of illicit direct to consumer advertising on use of etanercept, mometasone, and tegaserod in Canada: controlled longitudinal study. BMJ 2008;337:a1055 [FREE Full text] [Medline: 18765444]
35. Mackey TK, Liang BA. Separating online piracy from counterfeit medicines: The need for policy reform and a call to action. Health Policy and Technology 2012 Sep 2012;1(3):120-122. [doi: 10.1016/j.hlpt.2012.07.004]

Abbreviations

DTCA: direct-to-consumer advertising
eDTCA: online direct-to-consumer advertising
eDTCA2.0: social media–based online direct-to-consumer advertising
FDA: Food and Drug Administration
ICANN: Internet Corporation for Assigned Names and Numbers
IP: Internet protocol
NABP: National Association of Boards of Pharmacy
NPSF: National Patient Safety Foundation
PSM: Partnership for Safe Medicines
VIPPS: Verified Internet Pharmacy Practice Sites

Edited by G Eysenbach; submitted 12.03.13; peer-reviewed by A Ahmadvand, I Montoya; comments to author 26.03.13; revised version received 20.04.13; accepted 07.05.13; published 29.05.13.

Please cite as:
Mackey TK, Liang BA
Global Reach of Direct-to-Consumer Advertising Using Social Media for Illicit Online Drug Sales
J Med Internet Res 2013;15(5):e105
URL: http://www.jmir.org/2013/5/e105/
doi:10.2196/jmir.2610
PMID:23718965

Publisher:
JMIR Publications
130 Queens Quay East.
Toronto, ON, M5A 3Y5
Phone: (+1) 416-583-2040
Email: support@jmir.org