Original Research

What Makes Teens Start Using and Keep Using Health Information Web Sites? A Mixed Model Analysis of Teens with Chronic Illnesses

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Abstract

Objective: Publically available health Web sites may be able to provide support for teens with chronic disease in their transition to autonomy. This study examines teen use of health Web sites and identifies barriers and promoters of use. **Materials and Methods:** One hundred eighty (n=180) teens, aged 13–18, were recruited from asthma and diabetes specialty clinics and given a resource sheet listing selected publically available Web sites. Web sites were categorized as general health, teen health, disease specific (asthma or diabetes), and disease management. One hundred twenty-nine (n=129) participants completed a 3-month follow-up semi-structured telephone interview that assessed subsequent use of resource sheet Web sites and collected verbatim comments regarding use. **Results:** Sixty percent visited at least one Web site from the resource sheet. General health (38.8%) and teen health Web sites (38.0%) were most likely to be visited. Reasons for not visiting any site were categorized as lack of time, lack of interest, lack of Internet access, and lack of medical need. Teen health sites had the highest intention for continued use. Comments associated with willingness to continue use were categorized into the following themes: usefulness, ease, medical need, teen-specific features, and frequency of updates. Neither health literacy nor demographic factors were significantly associated with use. **Conclusions:** Making a first Web site visit generally leads to a desire for continued use, but teens will not make the first effort of visiting a Web site unless they are engaged and interested in their own health management. Teens are most willing to become regular users of Web sites that they perceive to be useful and to be targeted toward them.

Key words: Internet, adolescents, asthma, diabetes

Background

As youths with chronic conditions reach adulthood, they face increasing responsibility for managing their own health.^{1,2} This management often requires understanding and implementing a complex set of health behaviors including diet and exercise monitoring, symptom monitoring, medication taking, and information seeking. To support these activities, many healthcare providers and payers have augmented their traditional, face-to-face disease management programs with Web-based tools. Such systems can provide validated health information that can be tailored to the needs of patients; however, the tools on these Web sites are often only available to patients enrolled with specific payers or providers.³

Publically available health information Web sites can provide information to youths without access to provider-based programs or augment the information teens receive from proprietary sites. Such Web sites are generally operated by government agencies, disease-specific organizations, healthcare providers, and corporate entities and are designed for multiple purposes including promoting awareness, providing factual data, promoting products, or linking users to one another. They offer health information and disease management support to anyone with Internet access. This would include an estimated 93% of U.S. teens.⁴ Unfortunately, quality and accuracy vary across such Web sites. Users must, therefore, simultaneously find, understand, and evaluate the information that they access, and this process relies heavily on the literacy, health literacy, and information-processing skills of the users.⁵⁻⁷ Given that an estimated one of every three adolescents and young adults have health literacy limitations that could impact their ability to evaluate and apply health information that they find on the Internet, the ability of public Web sites to improve teen health is uncertain.^{8,9}

This study examines the use of selected publically available health Web sites by teens with asthma and diabetes and explores literacy and other potential barriers and promoters of online health resource use, using a combination of quantitative and qualitative measures.

Methods

SAMPLE

Adolescents, aged 13–18 years, were recruited from the asthma and diabetes specialty care clinics affiliated with Nationwide Children's Hospital in Columbus, Ohio. There were four clinics engaged: the endocrinology and pulmonology clinics located on the main

campus of the hospital and two satellite clinics in suburban communities. Patients were excluded if they and/or their parent did not have sufficient English communication skills to provide informed consent/assent for participation or, for youths under age 18, if no parent was present to provide informed consent. Participants completed assessments that measured demographics, reading level,¹⁰ health literacy,^{11,12} Internet access and use,¹³ and perceptions of health technology.¹⁴ The study was approved by the Institutional Review Board at Nationwide Children's Hospital.

Each participant was given a resource sheet listing selected publically available disease-specific and general health Web sites (Table 1). Using a standardized script, the research assistant reviewed the resource sheet with the participant and answered any questions that arose. Web sites were selected for inclusion based on Health on the Net standards and were approved by clinical specialists in our research team.¹⁵ Web resources on the sheet were divided into four categories: general health information, teen-specific health information, disease-specific health information, and disease management support.

At the conclusion of the study visit, participants were each given a diary to record their use of online health information, including the sites listed on the resource sheet, over the subsequent 3 months. To minimize patient attrition from the study and maximize patients' retention of information about their online activity, we made four follow-up contacts with participants (two telephone calls and two mailings) reminding them to continue tracking their use. At 3 months, participants were called and asked to complete a semistructured interview describing their use of health Web sites over the past 90 days. Up to five attempts were made to contact each participant.

The semistructured interview was conducted using an interview guide that assessed whether the teen had tried any of the Web sites on the sheet and if not, why not. If the person reported having used at least one site, the interview continued and the participant was asked which sites were visited, how often, the level of satisfaction with each experience, and best and worst features of the sites. Finally, participants were asked whether they intended to use the sites in the future and to explain why or why not. Responses to all items were recorded verbatim.

Table 1. Sample Web Sites from the Online Health Resource Sheet

Sample general health sites	www.CDC.gov www.WebMD.com
Sample teen health sites	www.teenhealthfx.com www.kidshealth.org/teen
Sample disease-specific (asthma)	www.airsquare.ca www.webMD.com/asthma
Sample disease-specific (diabetes)	www.childrenwithdiabetes.com www.diabetes.org

ANALYSIS

We first calculated the overall use rate and the use rate in each category of Web site. We tested the association between participant characteristics using a chi-squared test. Fisher's exact test was used when cell sizes were insufficient for chi-squared. We then used a grounded theory approach to identify themes for two core areas: decision to not use any sites and decision to continue or discontinue use after an initial exposure. Grounded theory is a systematic approach to generate theory from qualitative data such as interview, focus groups, and discussion. It uses a process of iterative review and comparison of verbatim text to identify concepts and groups of concepts (categories or themes) relevant to the research question.¹⁶ For this study, each of the authors independently reviewed the interview transcripts, identified key themes, and coded each response as to its associated theme. The authors then discussed their coding to reach consensus on a set of standardized themes. Responses were then recoded as needed. Representative quotes for each theme were identified for illustrative purposes.

Results

STUDY SAMPLE

A total of 129 of the 180 recruited study participants completed the 90-day follow-up interview (71.7%). Completion rate did not differ by age or race. Overall, 72.4% of older teens (16–18) completed a follow-up call compared with 71.1% of teens aged 13–15 ($p=0.86$) and 72.2% of Whites compared with 72.0% of non-Whites ($p=0.81$). Girls trended toward higher completion compared with boys (77.8% vs. 65.6%, $p=0.07$). Table 2 provides the demographic characteristics of the final sample. Sixty percent of those contacted reported that they had used at least one of the Web sites from the resource sheet. No significant difference in self-reported use was found by health literacy, reading level, age, race, Internet experience, or disease (asthma vs. diabetes); however, Black teens, teens with asthma, Internet users, and teens with adequate health literacy trended toward greater use. General health information sites and teen health information sites were most likely to be used (39% and 38%, respectively). Disease-specific information sites were accessed by 31% of respondents, but only 13% accessed disease management support sites (Table 3).

REASONS FOR LACK OF USE

Four themes were identified in the responses of those who reported not using any of the Web sites on the resource sheet: time, Internet/computer access, interest, and need. Lack of time and lack of access were the two most commonly reported barriers, followed by lack of interest.

Lack of time. Although many of the comments were generic such as "I didn't have any time to do that," others offered further explanation indicating competing priorities. For example, one respondent stated that she had "no time because of softball," and another stated "I had a bunch of papers to do for school so I didn't have time."

Table 2. Sample Description

CHARACTERISTIC	NUMBER	PERCENT	PERCENT REPORTING ANY USE AT FOLLOW-UP
Disease			
Asthma	63	48.8	65.1
Diabetes	66	51.2	56.1
Gender			
Male	59	45.7	57.6
Female	70	54.3	62.9
Race			
White	93	72.1	58.1
Black	25	19.4	68.0
Other	11	8.5	63.6
Age			
13–15	74	57.4	60.8
16–18	55	42.6	60.0
Reading level			
Less than 6th grade	22	17.1	50.0
≥6th grade and less than HS	18	14.0	72.2
High school or higher	89	69.0	60.7
Health literacy			
Adequate	109	84.5	62.4
Less than adequate	20	15.5	50.0
Internet user			
No	10	7.7	50.0
Yes, ever	49	38.0	57.1
Yes, daily	70	54.3	64.3

Lack of access. Several of the respondents commented that they did not have access to a computer or the Internet during the follow-up period. Comments in this area ranged from simple access issues such as “I don’t have a computer” or “We don’t have Internet” to qualitative assessments of their access such as “our Internet is very slow.” Some respondents gave additional explanations for lack of access, including “I’m grounded right now so I couldn’t use any of the sites” and “My Internet is out and we can’t afford it.”

Lack of interest. The third most common response theme was lack of interest in using the Internet for this purpose. Teens in this group offered generic statements suggesting that the use of the Internet for

health information or management of their health in general was not a priority. Representative quotes included “I totally forgot all about it,” “I haven’t really thought about it or anything,” “(I’m) not really interested,” and “because it wasn’t important.”

Lack of need. Only three participants stated that they did not need health information. Participants in this group offered explanations including “I didn’t really feel like I had any questions at the time” and “because I’ve decided my asthma is under good control.”

INTENTION TO CONTINUE OR DISCONTINUE USE

Of the 78 teens who visited at least one site, 86% stated that they would visit at least one site again within the next 6 months. Intention to continue use was highest for teen health sites, with 88% of those who had used a teen health site saying that they would use the site again at least once in the next 6 months. Teens planned to use disease management sites most frequently. Twenty-nine percent of teens who visited a disease management site intended to use it more than once a month in the next 6 months. Again literacy and demographic characteristics were not significant predictors of intent to continue or discontinue use. *Table 4* details the intended use rates for each type of Web site.

Themes associated with willingness to continue use were usefulness, ease of use, medical need, interaction with other teens, and frequency of information updates, all indicating teens’ general positive opinions of the sites.

Usefulness. Usefulness was the most common reason that teens stated that they intended to continue using sites, appearing in more than three-quarters of responses. Users stated that they intended to keep using Web sites because they were “helpful,” “useful,” and “informational.” Users also recognized the value of health information provided beyond information about their own condition. One user stated “Great information helps with school work, for other instances you need to know health information.” Two teens offered contrasting views about usefulness as shown in comments such as “I didn’t learn anything I didn’t already know” and “They need more interesting facts instead of boring ones and I already know all of them,” but these opinions were in a clear minority.

Table 3. Reported Use on Follow-Up by Web Site Category

WEB SITE TYPE	NUMBER WITH ANY USE	PERCENT
General health information	50	38.8
Teen health information	49	38.0
Disease-specific information	40	31.0
Disease management	17	13.2
Any site from list	78	60.5

Table 4. Intent to Continue Use of Visited Web Sites in the Next 6 Months

	GENERAL HEALTH N= 50 N (%)	TEEN HEALTH N= 49 N (%)	DISEASE SPECIFIC N= 40 N (%)	DISEASE MANAGEMENT N= 17 N (%)
Will not use again	10 (20.0)	6 (12.2)	7 (17.5)	3 (17.6)
Will use less than once a month	17 (34.0)	16 (32.6)	13 (32.5)	6 (35.3)
Will use once a month or more	23 (46.0)	27 (55.1)	20 (50.0)	8 (47.1)

Ease of use. A majority of teen users also reportedly found the Web sites easy to use. Several teens explicitly noted that a site “was easy to use,” and another explained that he/she would continue using the sites “because they worked well. They did what they were supposed to do.” In contrast, only two teens reported that they did not find the sites easy to use, with one noting that he/she “couldn’t understand it” and another explaining that “it confused me.”

Medical need. Ten percent of respondents specifically noted that their health status was part of the decision to continue using Web sites. For example, one respondent said “I think it might help me later because of how I’ve been having problems. The diary ones (websites) might help prevent the asthma from happening.” Another said his/her reason for continued use was that “I am still trying to control my asthma. Still having problems so (I’m) finding a way to control it.” Two teens again provided contrasting views noting they did not perceive a continuing need to use the Web sites. One explained that he/she would not visit the site again, “because I don’t think I’ll need to find any more information,” and the other noted that his/her “asthma has been well-controlled lately.”

Interaction with other teens. As noted earlier, teens were most likely to report intent for continued use of teen sites. Interaction with other teens was a highly valued feature. One teen site user said, “It was about other teens. Sometimes you feel alone and the stories helped.” Similar comments included “I like to find people and stories with people like me,” and “I like hearing other kids talk about their diabetes.” Teens also liked interactive features designed for them including quizzes and virtual environments.

Frequent updates. The belief that new information was regularly added to a Web site was mentioned by several teens and appeared to provide a reason for going back to a site. One asthma patient stated that she would go back “to see if I find new information, to see if others have more research on asthma instead of my opinion.” Another said, “I think it’s updated often enough that you can go back frequently for more information.”

Discussion

Six in 10 teens with a chronic illness visited at least one Web site from a health resource sheet listing publically available general and

disease-specific Web sites. Black youth, females, asthmatics, and regular Internet users trended toward higher use but these relationships were not statistically significant. Over 80% of those who visited a site intended to go back at least once in the next 6 months. General health information sites had the highest initial use rate and sites specifically designed for teens were associated with the greatest intent for continued use. Although demographic characteristics were not significant predictors of use, themes regarding personal interest in health information use and perceptions of Web site characteristics appeared to be associated with use decisions.

Based on our semistructured interviews, the greatest barrier to Web site use was a general lack of interest in health information seeking. This mind set was manifested in responses about not having time, not having interest, not having medical need, and losing the materials provided. This result is not surprising because adolescence is often a period of poor disease control for both asthma and diabetes. This poor control has been attributed to a variety of factors including low self-efficacy, desire to be “normal,” rebellion, and insufficient developmental status.^{1,17,18} Avoidance of online health information and the low willingness to even try disease management sites may be another symptom of this underlying issue.

Interestingly, although 89% of teens in our study reported having access to the Internet and 54% reported using the Internet daily, one of the most commonly stated reasons for not using any of the recommended Web sites was lack of access. This suggests that self-reported Internet access may not be a good measure of having sufficient access to be a user of online health information.

The strongest promoters of continued use were perceptions of ease of use and usefulness. This finding is consistent with the broader technology acceptance literature.^{14,19,20} In addition, teens were more likely to continue using Web sites that met their current health needs and that were targeted to them in both style and content.

The role of literacy and health literacy in adolescent health is an area of growing interest.²¹ Our results show that lower literacy youths are as likely as their higher literacy counterparts to use publically available online health resources. This finding is both encouraging and disconcerting. It is encouraging because even those with reading levels below sixth grade were willing and able to access health information online. This supports the continued use of the Internet as a medium for sharing health information in educationally and socially diverse populations. Alternatively, the fact that lower literacy youths are visiting health Web sites in large numbers raises concerns about

their ability to find, evaluate, and apply the information appropriately in healthcare decision making.

We note that the findings of this study may not be broadly generalizable because of the population studied. Our sample was composed of teens who were receiving care in a specialty care clinic. Consequently, our population may have better knowledge, higher health-related motivation, better healthcare access, and higher socioeconomic status than teens with asthma and diabetes that are managed in nonspecialty clinics or emergency departments. However, the themes we found related to limited Internet access and to low interest in health management could be even more pronounced in the general population of adolescents with chronic disease. We also note that all of the behaviors and attitudes we studied were measured through self-report. It is possible that our reported use rates reflect a degree of social desirability bias with teens reporting use that did not actually occur. These numbers should therefore be considered high-end estimates of potential use.

Based on the comments made by individuals in our sample, teens with Internet access are most willing to become regular users of Web sites that they perceive to be useful and to be targeted toward them. Making a first visit most often leads to a desire for continued use; however, teens are not willing to make the first effort of visiting a Web site unless they are engaged and interested in their own health management. Simple use of demographic or educational characteristics is not sufficient to understand whether a population will use online health information resources. It is also important to understand potential psychological readiness for disease self-management to help predict use.

Acknowledgments

This work was funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (Grant No. 1R03HD053715-01A2). Special thanks to Dr. Kelly J. Kelleher for his thoughtful comments and to the members of the TeenLit grant team.

Disclosure Statement

No competing financial interests exist.

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Received: September 27, 2010

Revised: December 28, 2010

Accepted: January 3, 2011