

Patients' Use of the Internet for Medical Information

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OBJECTIVES: To determine the percentage of patients enrolled in a primary care practice who use the Internet for health information, to describe the types of information sought, to evaluate patients' perceptions of the quality of this information, and to determine if patients who use the Internet for health information discuss this with their doctors.

DESIGN: Self-administered mailed survey.

SETTING: Patients from a primary care internal medicine private practice.

PARTICIPANTS: Randomly selected patients ($N = 1,000$) were mailed a confidential survey between December 1999 and March 2000. The response rate was 56.2%.

MEASUREMENTS AND MAIN RESULTS: Of the 512 patients who returned the survey, 53.5% (274) stated that they used the Internet for medical information. Those using the Internet for medical information were more educated ($P < .001$) and had higher incomes ($P < .001$). Respondents used the Internet for information on a broad range of medical topics. Sixty percent felt that the information on the Internet was the "same as" or "better than" information from their doctors. Of those using the Internet for health information, 59% did not discuss this information with their doctor. Neither gender, education level, nor age less than 60 years was associated with patients sharing their Web searches with their physicians. However, patients who discussed this information with their doctors rated the quality of information higher than those who did not share this information with their providers.

CONCLUSIONS: Primary care providers should recognize that patients are using the World Wide Web as a source of medical and health information and should be prepared to offer suggestions for Web-based health resources and to assist patients in evaluating the quality of medical information available on the Internet.

KEY WORDS: Internet; primary care; health information.
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The use of the Internet as a source of medical information has become increasingly popular as more patients "go online." According to a recent United States survey, 52 million adults have used the World Wide Web to obtain health or medical information.¹ By 2005, an estimated 88.5 million adults will use the Internet to research health information and/or health-related products and to communicate with providers.² Access to large amounts of medical information is available through an estimated 20,000 to 100,000 health-related Web sites.^{2,3}

Patient-provider relationships will probably change, and medical providers will face new challenges as patients obtain health information from the Internet, share only some of this with their physicians, or potentially turn to the Internet instead of consulting a health care provider.⁴

Although information is available on the use of the Internet for health information, few studies have specifically examined Internet use among patient populations,⁴⁻⁷ and no previous reports have focused on a primary care patient population. The goals of this study were to 1) determine the percentage of patients from an internal medicine private practice who use the Internet to obtain healthcare information, 2) describe the types of information sought, 3) evaluate patients' perceptions of the quality of information available on the Internet compared to their medical providers, and 4) determine if patients who use the Internet for health information discuss this information with their doctors.

METHODS

We mailed a confidential, self-administered survey to 1,000 patients selected at random from the billing files of a primary care internal medicine private practice located in Providence, RI. The practice consisted of 5 general internists with approximately 6,000 active patients. The mailing list was limited to patients age 18 to 65 years with at least 1 patient encounter during the previous 3 years including regular follow-up, new patient, and urgent visits. The survey was first mailed in December, 1999; nonresponders received a second mailing in January and a third mailing in March of 2000. As an incentive to returning the survey, all respondents were entered into a lottery for a gift certificate to a local shopping center, and as an additional incentive, a voucher for free parking on the hospital campus was included with the third mailing. A cover letter explaining voluntary participation and confidentiality was included with each mailing, and both patients who used and those who did not use the Internet were asked to respond. The study was approved by the hospital institutional review board.

The survey required approximately 10 minutes to complete. Prior to distribution, the survey was pilot-tested

to gauge participant comprehension of questions and time needed for completion. The survey contained questions regarding demographics, use of the Internet for medical reasons including information regarding specific conditions and medications, and frequency of use. Respondents were asked to rate the usefulness of the Internet and other sources of health information available to consumers and to list health care topics that they had searched for over the past 6 months. Additionally, respondents were asked about their perception of the quality of health information on the Internet ("In general, how would you rate the quality of health information available on the Internet?"), and were asked to compare this quality with the quality of information provided by their doctor ("Compared to information learned from your doctor, how would you rate the quality of health information available on the Internet?"). Although respondents were not asked for specific Web sites that they had used, they were asked their opinions about how they judged whether a site was reliable ("Which of the following do you feel makes an Internet health site a 'reliable' source for health-care information?"). Finally, respondents were asked if they shared the information acquired online with their medical providers ("Do you discuss health information learned from the Internet/World Wide Web with your doctor?").

Bivariate associations of Internet use with patient characteristics were tested with the independent samples *t* test (continuous variables) and the Pearson χ^2 test (categorical variables). Independent variables with *P* values of $<.20$ were entered in a multiple logistic regression model where use of the Internet was the dependent variable. Nonsignificant contributors to the model were removed through an iterative process. All statistics were performed using Stata (version 6; Stata Corp., College Station, Tex).

RESULTS

Of the 1,000 surveys mailed, 88 were not deliverable by the Post Office and 1 survey was delivered to a patient who did not qualify for inclusion on the basis of age. Of the remaining 911 surveys, 516 were returned, but 4 were not included in the analysis (1 was illegible; 1 patient was unable to complete secondary to disability; and 2 were completed by family members instead of patient). Thus, the overall response rate was 56.2 percent, and 512 respondents were analyzed.

Demographics of Respondents and Internet Users

The mean age for survey respondents and nonrespondents was 47 years (\pm SD 12) and 44 years (\pm SD 12), respectively ($P < .01$); 56% of respondents were females versus 45% of nonrespondents ($P < .01$). The characteristics of the 512 respondents are shown in Table 1. Of the respondents, 53.5% (274 of 512) stated that they used the Internet for health information. The mean age of respondents who used the Internet for medical information was

Table 1. Characteristics of Survey Respondents

Characteristic	Patients Using Internet for Health Information	Patients Not Using Internet for Health Information
Mean age, y \pm SD	45.8 \pm 11.3	49.3 \pm 11.9
Female gender, n (%)	158(58)	132(55)
Race, n (%)		
White	246(91)	204(86)
Nonwhite	23(9)	33(14)
Annual income, n (%)		
$<$ \$50,000	82(33)	126(57)
\geq \$50,000	170(67)	94(43)
Education, n (%)		
Less than undergraduate degree	100(37)	155(65)
Undergraduate degree or higher	168(63)	82(35)

45.8 years (\pm SD 11.3) compared to 49.3 years (\pm SD 11.6) for those who did not ($P \leq .001$). A higher proportion of patients who used the Internet were college educated ($P \leq .001$) and had annual household incomes greater than \$50,000 ($P \leq .001$). In the multiple logistic regression model, Internet use was associated with age less than 60 years (odds ratio [OR], 3.08; 95% confidence interval [CI], 1.75 to 5.42), college education (OR, 2.33; 95% CI, 1.56 to 3.49), and household income level \geq \$50,000 per year (OR, 2.00; 95% CI, 1.33 to 3.00).

Nineteen percent (51 of 271) of those using the Internet for health information indicated that they used the Internet at least once a week, while 35% (95 of 271) used the Internet at least monthly.

Types of Health Information Sought

Respondents used the Internet for a variety of health-related reasons. Sixty-eight percent (185 of 271) indicated that they sought information about nutrition or diet. Fifty-eight percent (157 of 272) noted using the Internet to investigate drug side effects or complications of medical therapy, 41% (112 of 273) to find information on complementary or alternative medicine, and 41% (111 of 270) to obtain second opinions about medical conditions. Only 9 individuals stated that they had ever purchased alternative and/or complementary remedies from a Web site and only 1 respondent obtained a medical prescription from an online doctor.

As shown in Figure 1, patients used the Internet for information on a broad range of medical topics. Many of the items that respondents searched for were common medical conditions addressed by primary care physicians.

Patients' Perceptions of Quality of Health Information on the Internet

Respondents rated the usefulness of various sources of health information available to consumers including

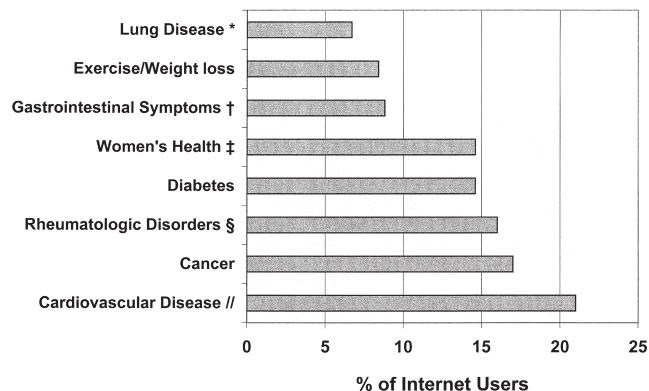


FIGURE 1. Health care topics sought on the Internet. Based on write-in responses by respondents ($N = 225$) including but not limited to the following: *asthma, sarcoidosis, emphysema; †gastrointestinal symptoms and disorders including reflux, gallbladder disease, inflammatory bowel disease, irritable bowel syndrome, *Helicobacter pylori*, hepatitis; ‡endometriosis, pregnancy, menopause, prenatal care; §rheumatologic disorders including arthritis, fibromyalgia, chronic fatigue syndrome, Lyme disease; ¶cardiovascular disease including heart disease, hypertension, heart attack, heart failure, stroke.

the Internet (see Table 2). Patients both using and not using the Internet for health information rated "physician or nurse" as the most useful source of health information. Not surprisingly, those using the Internet for health information noted the Internet as the second most useful source, while "television news" was the second most useful source for those not using the Internet for health information.

Sixty-two percent (168 of 269) of respondents using the Internet for health information rated the quality as "excellent" or "very good," and 32% (85 of 269) felt the quality was "good." Only 6% (16 of 269) felt the quality of

information was "fair" and none of the respondents rated the information as "poor." Sixty percent (155 of 259) of the respondents using the Internet for medical information felt the information on the Internet was the "same as" or "better than" that from their doctor. Fifteen percent (39 of 259) rated the quality as "worse than" their provider and 25% (65 of 259) were "not sure" or had "no opinion." In bivariate analysis, no personal characteristics were associated with the quality rankings of health information available on the Internet. Education level was the only characteristic that approached statistical significance ($P = .097$), suggesting that higher quality ratings were given by less-educated responders.

When patients were asked to identify factors associated with a "reliable" Internet health site, sponsorship by a medical society was chosen by seventy-two percent of respondents (197 of 274). Other important factors included "site recommended by a physician or health care professional," 60% (165 of 274), "sponsored by a university," 59% (162 of 274), and "sponsored by a hospital/HMO," 51% (140 of 274). Less-frequently selected factors were "sponsored by a nonprofit organization," 30% (81 of 274), "site recommended on TV, radio, newspaper, or magazine," 18% (49 of 274), "sponsored by a pharmaceutical company," 16% (44 of 274) and "site advertised on TV, radio, newspaper, magazine, or Internet," 13% (35 of 274).

Discussion of Internet Searches with Doctors

Fifty-nine percent (158 of 269) of those using the Internet for medical or health information stated that they did not discuss this information with their doctor. Neither gender, education level, nor age less than 60 years was associated with patients sharing or not sharing information with their doctors. However, respondents who shared information obtained on the Internet with their providers

Table 2. Evaluation of Usefulness of Various Sources of Medical Information

Source of Medical Information	Patients Using Internet for Health Information, Mean Score*	Patients Not Using Internet for Health Information, Mean Score*
Physician or nurse	6.09	6.19
Internet/World Wide Web	5.05	2.29 [†]
Educational program or newsletter sponsored by hospital or HMO	4.50	4.54
Television news	4.22	4.98 [†]
Medical journals	4.03	3.11 [†]
Family	3.95	4.80 [†]
Health or fitness magazine	3.84	3.67
Newspapers	3.83	4.29 [‡]
Friends	3.79	4.38 [†]
News magazine	3.67	3.49
Radio	3.42	3.87 [‡]

* Mean score based on scale from 1 ("not at all useful") to 7 ("extremely useful").

[†] $P < .001$ for difference between groups by t test.

[‡] $P < .05$ for difference between groups by t test.

rated the quality of health information on the Internet higher than those who did not share with their providers (OR, 1.84; 95% CI, 1.06 to 3.21).

Eleven percent (29 of 266) of those using the Internet for health care information indicated that they had used the Internet instead of seeing or speaking with their doctors. These respondents had also used the Internet for a variety of medical topics. However, compared to all respondents, a greater percentage indicated using the Internet for second opinions (69% vs 41%) and for information on complementary or alternative medicine (83% vs 41%). The 2 most common reasons respondents gave for using the Internet instead of their providers were that it was "more convenient to get 'on-line' advice" and "less expensive to get advice 'on-line.'" Of these 29 patients, several respondents wrote in additional reasons for using the Internet instead of their doctor. These included: "wanted to see if my problem warranted seeing my doctor," "doctor wasn't open to discussion of my suggestions," "little faith in doctors," "not sure doctor understands my concerns," and "want more of an education on topic than doctor has time to give."

DISCUSSION

In this survey of established patients in an internal medicine private practice, more than half of respondents reported having used the Internet for health information. Even with the most conservative estimate, assuming all nonresponders did not use the Internet, at least 27% of patients from this primary care population have used the Internet for medical information. These patients were seeking information on a wide variety of topics, including treatment side effects, second opinions, complementary or alternative medicines, and specific diagnoses. In addition, the majority of respondents appeared confident that they were accessing reliable information, and most did not share this information with their doctors.

To date, few studies have examined patient use of the Internet to obtain medical information. Mandl et al. conducted a survey on Internet use in a more socio-economically diverse population in a pediatric emergency room setting.⁵ Of the 214 individuals who completed the survey, only 31.3% (patients and parents) noted using the Internet specifically for medical information. The study did not evaluate how they perceived the quality of health information available on the Internet or how that quality compared to their healthcare providers.

More recently, O'Connor and Johanson reported the results of a survey of gastroenterology patients.⁶ In their population, 25.5% of patients indicated searching the Internet for medical information within the past year. This is similar to the most conservative estimate of Internet health users, 27%, in the current study. Although more clinically generalizable than surveys of the general population, O'Connor and Johanson surveyed patients from a subspecialty practice and did not report the number of

patients that share information from Web searches with their medical providers.

In November of 2000, the Pew Internet and American Life Project released the results of more than 12,000 telephone surveys and estimated that 55% of fifty-two million American adults with Internet access have used the Internet for health or medical information.¹ Included in this report was a subset of 521 "special surveys" of Internet users who used the Internet for health care information. Of this population, 69% did not talk to "a doctor or nurse" about the information obtained from the Internet. This is a higher proportion than the 59% of patients in our study who did not share this information with their provider. However, the Pew study sample was a random digit telephone sample conducted among the general population, whereas the current study focused specifically on patients from a primary care practice. It is not known what percentage of the Pew study sample had established relationships with medical providers.

The Health On the Net Foundation (HON)⁸ conducts serial Web-based surveys online to assess the "use of the Internet for medical/health purposes."⁹ The HON surveys are confined to sites that have links to the HON Foundation Web site,¹⁰ and the respondents are most likely regular Web users. The results of a recent HON survey indicated that 69% of patients completing the survey discuss Web searches with their medical providers,¹¹ in contrast to the 41% of patients from the present study. However, this may be secondary to the oversampling of medical professionals completing the HON survey.

Although patients may pursue "online" information about complementary or alternative medicine treatments that many physicians do not address in the office, this study suggests that patients are also using the Internet to research information about their medical conditions, treatment side effects, and for second opinions. In the present study, many of the health topics sought by respondents were topics commonly encountered by physicians in the primary care setting. Despite the existence of many reliable medical and health-related Web sites, several reviews have demonstrated that patients may encounter potentially misleading or inaccurate information when navigating the Internet.¹²⁻¹⁵ In fact, much of the available information on the World Wide Web does not pass through a traditional editorial process, and many sites do not provide a source of authorship or origin.^{16,17}

Nearly sixty percent of the patients who used the Internet for medical information indicated that they did not share this information with their doctors. Although not specifically addressed in this study, one important reason why patients may not share Web searches with physicians is that physicians may not be asking. However, as the use of the Internet increases, it will become more important for physicians to identify patients who use the Internet and to understand how they use it as a source of medical information. The Internet has the potential to dramatically

change the doctor-patient relationship in that it offers an opportunity for patients to increase their knowledge, become more informed, and increase their involvement in their health care decision-making process.

The present study represents a small sample of Internet users from a private practice in the United States. These patients were primarily English speaking, white, educated, and from higher socioeconomic strata. Responses were self-reported and patients' actual Internet use could not be verified, nor could the validity or reproducibility of the survey be confirmed. Additionally, it is possible that those who returned the survey were more likely to use the Internet. However, the survey was mailed and not Web-based in an attempt to include those who do not use the Internet and those who use it less frequently. This study focused on established patients from an internal medicine practice and is therefore more generalizable to primary care settings than are Web-based or random-digit dialing telephone surveys.

As noted above, patients tended to give higher ratings to the quality of health information on the Internet. This raises concern, given that Berland et al. recently noted that patients using the Web for medical information may have difficulty "finding complete and accurate information" and suggested that deficiencies with health information online may "negatively influence" patients' decisions.¹⁸ Providers should recognize that in their eagerness to participate in health care decisions, patients may turn to the Internet for information. Both physicians and patients need to be aware of the sources of health information available online and the variable quality of this information.

Several researchers and organizations have assessed and proposed instruments and guidelines to assist patients and providers in evaluating the quality of medical and health information on the Internet.¹⁹⁻²⁴ Despite these efforts, the reliability and validity of these evaluation tools are still in question.²²⁻²⁵ Providers, however, can become proactive by familiarizing themselves with organizations such as the Health on the Net Foundation (www.HON.ch),⁸ the Internet Healthcare Coalition (www.ihealthcoalition.org)²⁶ and Health Internet Ethics (www.hiethics.org),²⁷ that are dedicated to the quality of health information online. Physicians may best assist their patients by acknowledging patient use of the Internet and by serving as guides to help them find reliable material. As part of the medical history, physicians should routinely inquire about their patients' use of the Internet to obtain medical information.²⁸ For patients who are already connected to the Internet, health care providers should be prepared to offer suggestions for Web-based health resources and to assist patients in evaluating the quality of medical information available on the World Wide Web.

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