Patient Use of the Internet for Information in a Lung Cancer Clinic*

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Study objectives: To determine how frequently patients attending a lung cancer clinic use the Internet for their own health information, to determine whether there are demographic differences between Internet users and nonusers, and to determine how patients compare the quality of Internet information with other sources of lung cancer information.

Design: Sequentially administered patient questionnaire. One hundred eighty-four patients were surveyed, and 139 patients (75.5%) completed the questionnaire.

Setting: A multidisciplinary thoracic oncology clinic in a Midwestern University hospital.

Patients or participants: Patients attending the multidisciplinary thoracic oncology clinic over a 3-month period.

Measurements and results: The Internet was the most commonly used nonphysician source of information among our patients. Sixteen percent of the patients sought information on the Internet, but 60% expressed interest in using the Internet for information. Users were on average of higher income level and educational attainment but did not differ from nonusers by community size. Internet users rated the quality of information available on the Internet of similar quality to information from all sources.

Conclusions: Older patients are increasing using the Internet for self-education in lung cancer. While certain barriers continue to exist, patients from rural areas use the Internet to the same degree, as do patients from urban areas. Patients do, however, overrate the quality of information on the Internet.

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Key words: computer networks; lung cancer; patient education

Abbreviation: ISP = Internet service provider

Patients are increasingly involved in their own medical decisions, and well-informed and educated patients are better prepared to participate as partners in making medical decisions. This involvement is even more important in diseases such as lung cancer with many challenging diagnostic and therapeutic choices. The Internet is a potentially powerful and important tool for patient education, and medical information sites represent a large proportion of Web sites.1 Surveys of Internet users demonstrate they have great interest in accessing medical information on the Internet.2 However, these data are skewed toward current Internet users, and more specific patient surveys suggest that only 11 to 25% of patients currently use the Internet to research information on their own health.3–6

The Internet also presents some unique problems. First, access to the Internet is not universal even in the United States. Access may be limited because of computer availability, limited Internet service provider (ISP) availability, or limited individual computer skills. Previous surveys suggested that some of this “digital divide” may be related to educational and income levels or to user age.3,6 User age is obviously an important factor in health-related information sites because most patients with serious or chronic illness are older. Contrary to the role of age in these patient surveys is the finding that users > 55 years of age constitute one of the fastest-growing user groups in the United States.7 Thus, it is not clear whether age remains a limiting factor for patient Internet use. In addition to personal demographics, rural populations may be further restricted because of limited ISPs in their communities. If this is true, patients living in rural areas would use the Internet less often for their own health information compared to patients living in more urban areas.

The second unique challenge to the Internet as an effective patient-health information resource relates

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to information quality. Medical information on the Internet can be highly variable in quality. Even information directed at health professionals often fails to meet minimal quality standards. While several groups have developed basic standards for medical information quality, very few sites meet these standards, and the public is highly unlikely to be aware of the standards. We have very little data comparing how the general public views the quality of Internet information compared to other traditional resources available to them. Finally, providing Internet access for patients can be costly, and we have limited data on whether patients without such access would be interested in it.

We undertook the current study to address these questions of access, use, and user-quality rating. We studied patients attending a lung cancer clinic in our university medical center. Because most patients considered for a diagnosis of lung cancer are > 45 years old, it allowed us to study a motivated (because of potentially serious illness) but older patient population. In addition, our population is drawn from throughout our state, and a large component is from rural areas or small towns. Finally, we asked patients to evaluate all information resources. This allowed us to compare the patients’ perspective of Internet resources compared with more traditional resources.

Materials and Methods

The study was completed in the University of Iowa Health Care Holden Comprehensive Cancer Center Multidisciplinary Thoracic Oncology Clinic. This is a clinic dedicated to providing care for patients with presumptive or diagnosed thoracic malignancies. Patients from throughout Iowa, western Illinois, and northern Missouri are referred to the clinic for evaluation, diagnosis, and treatment. Based on their presenting complaints, they may be seen by pulmonary medicine, thoracic surgery, or medical oncology. All patients reporting to the clinic over a 3-month period were asked to participate in the study by a clinic nurse or physician assistant. If they had not previously participated and agreed, they were provided an 18-item questionnaire to complete anonymously when they registered and waited to see the physician. The completed questionnaires were placed in a sealed box that was emptied and collected after each clinic. The data were extracted by one of the investigators (P.C.F.) and collected in an Excel spreadsheet (Microsoft; Redmond, WA). All data were expressed as mean ± SD. Comparisons were done using χ² test. Significant differences were defined as p < 0.05.

Results

Of the 184 patients provided the questionnaire, 139 patients (75.5%) returned completed questionnaires to us. The mean age of our patients was 58.5 ± 15.4 years with 61% male and 39% female. As reflects our patient population, 64.7% of the patients came from communities of < 25,000 people, with 11.2% coming from a rural area, 11.2% coming from communities of < 1,000 people, 14.3% coming from communities of 1,001 to 5,000 people, and 27.8% coming from communities with 5001 to 25,000 people. Seventy-eight patients (56.5%) stated that they had a computer in the home, and 52 patients (87% of those with computers) had Internet access. Of those with Internet access, Internet usage averaged 8.4 ± 9.6 h/wk. Median income for our patients was between $25,000/yr and $50,000/yr, and educational level ranged from less than high school to postgraduate school (Table 1).

Patients identified nine different sources of information when we asked them, “Where have you received information about your disease?” Most participants listed at least two sources of information in response to this question. The most common source of information was either their referring physician (47%) or the subspecialist physician (82%). The Internet was the third most common source (16%), ahead of family and friends (14%), medical journals (6%), magazines (6%), television (3%), medical libraries (1%), and the public library (1%). We next compared the demographics of the two groups that either used or did not use the Internet for information. As others have reported, we did find that the two groups significantly differed in educational level and annual income, with both a higher educational level and higher annual income being associated with more Internet use (Figs 1, 2). The Internet users were slightly younger on average (52 ± 13 years vs 60 ± 16 years), but this difference was not statistically significant. They also had a higher percentage with a computer in the house (100% vs 34%) and Internet access at home (100% vs 25%). However, there was no difference between the two groups when compared by community size (Table 2). In fact, more than one third of the Internet users identified themselves as living in a rural area.

To evaluate how patients rated the quality of Internet-based information, we asked the patients to

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evaluate the quality of all the information using a 4-point scale of poor, good, excellent, and outstanding. We then compared the group responses with the evaluation of Internet-based resources submitted only by patients who had used the Internet. There was no significant difference between the group ratings of all resources compared with the rating of Internet-only resources (Fig 3). Based on the fact that most patients listed their primary or their subspecialty physician as their information source, this means that most patients rated the quality of Internet information as equivalent to the information from the physician. We next asked the patients to describe how well informed they felt about their disease using the same 4-point scale. Again, those patients using the Internet were no different from those that did not use the Internet, with most patients answering good or excellent (79% in the Internet group and 71.8% in the traditional resource group). As a final measure of patient satisfaction with Internet-based information, we asked all patients how likely they were to use a computer with Internet access if it were available in the clinic. Patients who did not use the Internet were much less likely to use a computer in the clinic (16% very likely) than were patients who had used the Internet (65% very likely) [Fig 4]. This again supports a very high satisfaction by patients who used the Internet.

**DISCUSSION**

Clinical care is optimized, especially with complex problems like bronchogenic carcinoma, when the patient is actively involved in the decisions regarding their own health care. An educated patient is best prepared to actively participate in his or her own care. The Internet represents a revolution in information access for patients and provides an unprece-
If a computer with Internet access was available in the clinic for self-education, would you use it?

![Graph](Image)

**Figure 4. Patients express significant interest in using the Internet for self-education while in the clinic, especially among patients with experience using the Internet.**

...dented opportunity for patient self-education. However, we are only beginning to learn how patients will use the Internet to supplement traditional sources of information. We undertook this study to address several questions about patient utilization of the Internet for self-education. We focused on patients attending our multidisciplinary lung cancer clinic because it allowed us to study an actual patient group and not the unselected general population. Using general survey data, > 55% of Internet users report using the Internet for health-related information. However, these numbers are higher than published surveys of actual patient populations. Part of this difference may be explained by the finding that older and less educated patients utilize the Internet less often. Because our patients, by the nature of their disease, are on average an older population but have a serious and potentially life-threatening disease, we could investigate Internet utilization in a motivated older patient group.

The second issue we investigated related to access. Our patient population is drawn from rural areas and small towns, which may have limited ISPs. No one has specifically looked at whether a “digital divide” exists based on community size and potential access to ISPs. Overall, 16% of our patients reported using the Internet to learn about their disease. This result is similar to the 10 to 25% of patients previously reported to use the Internet for self-education; however, the Internet was the most commonly used nonphysician resource in our study. This is in contrast to the study by Vordermark et al., who reported that the Internet was the least utilized resource. Part of this difference may be explained by the fact that the study by Vordermark et al. was performed in Germany and ours in the United States. Alternatively, the difference may be due to increased accep-

...tance of the Internet as a relevant resource for patients over time because their study was done in the late 1990s. Similar to earlier studies, patients who used the Internet in our study were slightly younger than those that did not; however, the mean age even among those patients that used the Internet in our study was 51.7 years. These results are consistent with the general observation that users aged 55 to 64 years are the fastest-growing Internet user group, and we are likely to continue to see increased numbers of our older patients using the Internet for self-education. The finding that 60% of our patients and 60 to 78% of patients in previous studies expressed interest in using the Internet for self-education further supports this potential for growth.

A continuing challenge related to the Internet in the health-care field is usability and quality. While traditional medical print media maintains quality control using a peer review process and editorial oversight, most continuing medical education Internet sites fail to meet even minimal quality standards. Similarly, patient information sites often fail to provide high quality or conventional information for patients. This means that the reader must assume more responsibility for assessing the quality of information presented on an Internet medical site. In addition, medical Internet sites are often written in English only and at a reading level significantly above the reading level of the average American. This means that even when the content is accurate, it may not be communicated well to the patient using the site. We have somewhat mixed results when evaluating patients’ perception of the quality of health-related information on the Internet. In a recent study from California, a randomly selected sample stated that they trusted the information from health-care professionals more than the information from the Internet. However, actual patients seem to place more trust in Internet information. In the study by O’Connor and Johanson of patients in a GI clinic, 86% of the Internet users were “somewhat or very certain” that the “medical information they got on the Internet was of good quality.” Our patients were less certain of the quality, but still rated the quality of Internet information equivalent to what they received from their physicians. It appears, therefore, that patients in general overrate the quality of medical information available to them on the Internet.

While our study did not address the issue of efficacy, this will obviously become increasingly important in determining how patients and health-care providers use the medical Internet in the future. Ultimately, the purpose of providing information for patients is to improve their care, outcomes, or quality...
of life. Studying outcomes from patient education is challenging, and studies to date have had promising but limited results. In both diabetes and cardiac surgery, Internet-based patient information appears to provide increased social support, coping strategies, and decreased anxiety. In pediatric asthma, one Internet-based educational program was as effective as traditional education at a lower cost in personnel, while a second increased the impact of the educational intervention. There are no current studies addressing the effect of Internet-based education on outcome in patients with lung cancer.

In conclusion, patients have identified a need for additional education resources, and they see the Internet as an important information resource. In addition, age and access barriers are rapidly disappearing and patients express increasing interest in using the Internet for their own health-related information. However, patients seem to have a misplaced faith in the quality of health-related information available on the Internet. Several challenges remain for the health professions. How do health professionals assert some control over quality control or direct patients to appropriate resources? How do we develop objective evidence about the efficacy of Internet-based patient educational materials to assure that they fulfill their promise? It is clear that the health profession needs to be actively involved in seeking the answers to these questions.

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APPENDIX: INTERNET INFORMATION SURVEY

Please take a few minutes to fill out this brief survey. If you have filled it out before, you do not have to fill it out again. The purpose of this survey is to learn about the various sources of information people use to learn about their disease outside the clinic. This information will help us better educate patients in the future. This survey is anonymous, and we will not keep any records that could be used to identify you. Your care in this clinic will not be affected whether or not you complete this questionnaire.

If you have any questions, please ask one of the nurses in the clinic or call Dr. Peterson at 319-356-1012.

Age: __ Sex: Male Female (please circle)

Disease/condition (or “Why are you here?”):

Is this your first visit to this clinic? Yes No (please circle)

Size of the town you currently live in: (please mark your choice)

Rural
< 1,000
1,001–5,000
5,001–25,000
> 25,000

Occupation: 

Do you have a computer at home? Yes No (please circle)

Do you have access to the Internet? Yes No (please circle)

If yes, please indicate where: Home Work Other (please list):

Approximately how many hours do you spend on the Internet per week?

If there were a computer with Internet access in the clinic for finding medical information, how likely would you use it? (please answer even if you have never used the Internet)

Not at all Somewhat likely Very likely

Where have you received information about your diagnosis? (check all that apply)

Friends or family Public library Television

Magazines Medical journals Local doctor

Doctor at UHHC Internet or World Wide Web Other (please list):

If you have used the Internet or World Wide Web, please tell us the names or addresses of any sites that you have used, or how you found your information on the Internet.

How would you rate the quality of all the information you found? (please mark your choice)

Poor Good Excellent Outstanding

How would you rate the quality of just the information you found on the Internet or World Wide Web? (please mark your choice)

Poor Good Excellent Outstanding

If you found information on the Internet, what factors influenced your decision to look at a particular site?

Ease of use Graphics

Recently written Qualifications of authors

From a government or university Web site Volunteer health site (example, American Cancer Society)

Other (please list):

How well do you feel informed about your disease/condition prior to your visit today?

Poor Good Excellent Outstanding

The next two questions are optional.

Annual household income: (please mark your choice)

<$10,000 $10,001–$25,000 $25,001–$50,000 > $50,000

Highest educational level: (please mark your choice)

Some high school Graduated high school

Some college Graduated college

Postgraduate work

Thank you for taking the time to answer our questions.

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