Cancer Patients Connect on the Internet

By Norra MacReady

few clinicians in any specialty have not seen a patient who at some time has asked, “I read about this online; what do you think?” According to data gathered by the Pew Research Center’s Internet and American Life Project, 80% of Internet users, or 59% of American adults, surf the net for health information. This group includes cancer patients: Research by Wen-Ying Sylvia Chou, Ph.D., and colleagues at the National Cancer Institute showed that 52% of 998 cancer survivors surveyed cited the Internet as their primary source of health information.

But some doctors dismiss patients’ Internet-related questions with what Carma Bylund, Ph.D., director of the Communication Training and Research Laboratory at Memorial–Sloan Kettering Cancer Center, calls “the warning”: “You’ve got to be careful what you read on the Internet.”

Bylund believes that attitude is misguided. “I know there are doctors who tell their patients not to go on the Internet, but to me that doesn’t seem very useful, because basically the underlying message is, ‘If you do go on the Internet, don’t talk to me about anything you read,’ which really isn’t a very patient-centered approach,” she said. “I think a better way is to validate the patients’ efforts and direct them to some better websites, rather than taking this blanket approach that the Internet is all bad.”

Indeed, many clinicians and investigators are now enlisting the Internet as a tool for enhancing doctor–patient communications and reducing the isolation that many patients and caregivers may experience.

**Snapshot of Internet Users**

The image of the net-savvy individual as a more assertive patient is perhaps not surprising when one considers who is most likely to go online for health-related information: well-educated people younger than 65 years. “Health literacy and general education go hand in hand, so the more educated you are, the more health literate you’re likely to be, and I would say that people who are more comfortable on the Internet tend to have a higher degree of health literacy,” says Kimberly Stump-Sutliff, RN, an associate medical editor and writer for the American Cancer Society.

According to Chou, who is program director at the NCI’s Health Communication and Informatics Research Branch, age also appears to influence one’s use of online resources, with people 65 and older tending to not be as active on the Internet—precisely the part of the population that cancer most afflicts, as Stump-Sutliff pointed out. “Cancer tends to be a disease of older people, and older people in general are not as comfortable on the Web as even a grade-school kid.”

These differences have led to what some investigators have termed a “digital divide,” or a gap between the Internet haves and have-nots. As Chou and her associates have observed, people who use the Internet as a source of health-related information are much more likely to have at least a high school education. They also use the Internet for other health-related purposes, such as making doctor appointments, renewing prescriptions, and viewing laboratory results.

But some evidence indicates that the divide may be narrowing, especially as users of Facebook and other online social networking media expand across races, reaching people with low socioeconomic status and less access to health care. According to data from the Pew Internet and American Life Project, approximately 60% of all white, black, and Latino Internet users visited social networking sites in 2010. In the NCI survey of cancer survivors, Chou and her coauthors saw no differences in health-related Internet use by race or ethnicity, health status, or time since cancer diagnosis. “Ethnic minorities are as likely to participate in social media, and sometimes even more so, than whites,” said Chou. “This finding has led to attempts to use social media for health-promotion messages, but so far the results of those efforts have been mixed.”

**Internet Improves Doctor–Patient Relationship**

Not all doctors are naysayers about social media; some turn patients’ questions about Web-based information into an oppor-
tunity to improve their relationship with patients. “We have found that even though people’s first source of information may be the Internet, their most trusted source is still their provider,” Chou said.

“Whenever I teach or talk to doctors about this, I like to make the point that even if what the patient brings in doesn’t make sense or doesn’t apply to their situation, just saying, ‘It’s great that you’re taking an active interest in your health’ is really important,” said Bylund. “In our research on patients in general, we have found that when doctors validate their efforts to look up information, even if they didn’t agree with that information, the patients were more satisfied. We later replicated that finding in a study of just cancer patients.” In other words, taking the time to validate a patient’s concerns can enhance the doctor–patient relationship. According to Mitch Golant, Ph.D., senior vice president of research and training at the Cancer Support Community in Los Angeles, “There’s a lot of value in patients being informed about their treatment options, and making treatment decisions based on the patient’s goals and objectives is a very meaningful way of engaging the patient with the doctor. Websites and information can help frame that discussion.”

Doctors can play an important role in helping patients evaluate the credibility of the information they obtain and the sites they frequent, said Golant. Often the names on a site’s advisory board, if it has one, lend credibility to the site and reassure both doctors and patients. “Are there medical professionals, such as oncologists, who are reviewing the site for content? If so, how often? If not, does the site offer disclosures about the limitations on the information it provides? How frequently is the information updated, and what sources or resources are used to update that information?”

In general, says Stump-Sutliff, the most trustworthy sites are those produced by people or organizations who have “no vested interest in getting you to read their information: They’re not trying to sell you something, and they’re not necessarily trying to get you to go there for treatment.” Also, she said, “Just by looking at the URL, you can get a clue who is behind the site. Internet addresses ending in .edu, .org, and .gov tend to be better-critiqued or better-reviewed sources of information, whereas sites that end in .com or .net may not be monitored as closely or may be written by someone who is less knowledgeable.”

So are patients missing out if they are not regular Internet users? “Possibly, but there are other ways people can get that information if they aren’t that comfortable using the Internet or don’t have good Internet access,” Stump-Sutliff said. “You can get the same information that’s on the ACS website by calling our 1-800 number, and many places have similar types of access. People may be missing out on the convenience of the Internet, but there are ways for them to get the information they need, and clinicians should know how to help them find it.”

Peer-to-Peer Health Care
For people with illnesses such as cancer, perhaps the greatest power of the Internet lies in its ability to connect them with like-minded individuals anywhere in the world. “Within the last 6-7 years, we’ve been seeing another level of use in which people are not just getting information from the Internet. They’re also putting their information and engaging in this very participatory process,” said Chou.

The Cancer Support Community has been using this feature of the Internet at least since 1998, when it began an online support group for cancer patients. The group, which convenes for 90 minutes weekly, is professionally facilitated, is accessed with a password, and is held in real time. Golant estimated that 150–200 people visit the group in any given week. “It’s not just a chat room; it actually is an online support group,” he said. “We’ve been looking at the transcripts of those interactions for the last 12 years, and you can really see the benefit of patients’ being able to support one another. That’s the true value of the Internet: It can help people who live too far and are too ill to access support in any other way.” Another benefit, he said, is the anonymity it affords, which appeals to patients who live in small communities, where they may not want people to know they have cancer.” The organization now runs a similar support group for caregivers.

Apparently, some people are reaching out even when they have no assurance of an audience, said Chou. In a study of cancer survivors who posted videos on YouTube, “we found that they feel this urge to tell their story. I think it provides them a forum to share their personal experiences with cancer, even if they don’t know who out there may be listening.” She has noticed one striking similarity in people’s narratives: “They always go back to the moment when they found out they had cancer, even if they don’t know who out there may be listening.” She has noticed one striking similarity in people’s narratives: “They always go back to the moment when they found out they had cancer, even if they’re healthy now. That moment of finding out seems to have a kind of transformative impact.

“There’s a potentially healing or cathartic element that seems to be very strong,” Chou said. “They seem to be saying, ‘It’s time for me to tell my story.’ That’s something social media have given everyday individuals: the opportunity to have a voice.”

© Oxford University Press 2012. DOI: 10.1093/jnci/djs130