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Health Information on the Internet

In this piece, we describe how the Internet is dramatically altering the way patients seek and obtain health information. In a future Topic of the Month we will discuss the implications for physicians and their relationships with patients.

The goal of patient education, whether delivered online or through more traditional means, is to provide patients with accurate information that addresses their individual needs and interests, is appropriate to their educational level, and empowers them to become more active participants in decisions regarding their health. The Internet can support these goals, but safeguards need to be in place to protect patients' interests.

Types of resources

By the end of 2000, there were more than 17,000 health-related websites, according to the Pew Internet Project. Site sponsors include integrated delivery systems and hospitals, managed care organizations, health professions schools and medical societies, government agencies, pharmaceuticals, publishers and journals, online services, advocacy groups and others.

Patient education resources on the Internet are divided into two distinct categories: non-interactive and patient-interactive. Non-interactive resources are primarily text-based, using materials drawn from either second-hand information from articles in journals or newsletters or original content created for the website. Non-interactive resources can be developed relatively easily and at low cost.

Patient-interactive resources vary in composition, but the key component is that the patient contributes some form of original content and receives a response immediately or subsequently after some period of time. Examples of patient-interactive resources include chat rooms, bulletin boards, expert Q&A, and others forms of multimedia. They are typically found on large-scale health information websites along with non-interactive resources. Some sites specialize in peer information exchange and emotional support for people with medical needs.

Internet usage

As the Internet becomes more popular, more patients are using it to look for health care information. Estimates of the number of patients seeking web-based health information vary. A Harris Interactive poll in March 2001 found 93 million "Cyberchondrics" (63% of all U.S. adults), who search for information on average three times a month. A second report by The Pew Internet & American Life Project published in November 2000 identified 52 million "health seekers" (55% of the Internet-user population); 55% of these "health seekers" say access to the Internet has improved the way they get medical and health information. Among the health seekers, 29% go online weekly for medical information and 30% monthly. Everyone agrees that the number will continue to rise.

Respondents to the Pew survey gave several reasons why they like the Internet for health information: the convenience of being able to seek information at any hour; access to large amounts of information; the ability to do research anonymously; and the ease of looking up sensitive topics that are difficult to talk about.

Physicians also are using computers and the Internet more over time, for a variety of purposes including patient education. A

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survey by the AMA found that Internet use grew from 20% of all physicians in 1997 to 70% in 2000. Additionally, findings from the AMA study indicate that the percentage of online physicians who consider the Internet as a useful resource for patient education has increased to 39%, compared to only 25% in 1997.

Internet issues: quality and confidentiality

The health information that patients obtain on the Web can have a profound effect on their decisions regarding care and treatments, including whether to go to and how to question the doctor, and how to treat an illness. In the survey by The Pew Internet & American Life Project, 47% of the patients who sought health information for themselves and 36% of the patients who sought health information for someone else (immediate family) stated that the material affected their health care decisions. Also 92% of all health seekers say they information they found during their last online search was useful, and 80% learned something new.

An important concern is the quality and accuracy of health information on the web. Again according to the Pew Internet Project, most health seekers are concerned about the reliability of the information source, and over half check to see who is providing the information. Only 52% of those who visited health sites think that almost all or most health information they see online in credible. A recent study by the Rand Corporation confirmed that most online health information is accurate, but it's often elusive, incomplete and incomprehensible (JAMA, May 23/30, 2001). The researchers found that using simple search engines, such as Yahoo or Ask Jeeves, is inefficient and the reading level of most material is quite high. Also, only half of the topics that the researchers thought were important for consumers were covered more than minimally. Just over half of the sites revealed conflicts in the information provided, e.g., a side effect is said to be likely and unlikely in the same site.

High quality Internet sources should have the following characteristics: unbiased, staffed by experts, explicit about funding and sponsorship, clear about data of materials, and provide references and sources. Several organizations (including Health on the Net Foundation, American Medical Association, Internet Healthcare Coalition, Hi-Ethics, MedCertain) have developed criteria to guide and evaluate the content on health-related websites. Still, there is no national or universally accepted set of guidelines or regulations for evaluating their quality and accuracy. Patients must scrutinize the information they gather, attempt to locate the quality standards regarding the information they view, and ultimately rely upon their physician to interpret the information.

Another concern is patient confidentiality. The Pew Internet Project survey found that health seekers appreciate the ability to do research anonymously, and to learn about sensitive topics that are difficult to talk about. So they are very anxious to have their privacy protected. Congress has attempted to address these concerns with the Health Insurance Portability and Accountability Act of 1996 (HIPAA). The first set of guidance materials is being released this summer. However, many websites do not fit within the three categories of organizations that are covered by the HIPAA regulations: health care providers, insurance companies, and health data clearinghouses (organizations that process and transmit insurance-claim data). No clarifications regarding patient education resources such as health assessments, applications for clinical trials, or chat rooms have been issued yet. For now, patients are

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advised to read the privacy guidelines of the websites they visit and reply upon their own judgement.

As more and more patients become "empowered," the traditional role of the physician as the primary and sole source of information will be fundamentally altered. Physicians will have to help patients to sort through the information that they acquire but be sensitive to each patient's interests and educational level. Physicians must convey to patients that gathering information on the Internet can be valuable but solely basing health care decisions on such information is not prudent.

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