Advances in Health Information Technology for Patients

by Holly Brugge Jimison, PhD, and Paul Phillip Sher, MD

Patients now have access to a wide variety of health-related educational material via computers and other sources. To ensure quality, security, and data integrity, it is likely that these databases of patient health information will become part of the information that HIM professionals manage and coordinate for patient use in the clinical setting. This article describes the health information resources available to patients.

Health information enables patients to be more active participants in the treatment process, which can lead to better medical outcomes.[1,2] Health education is also an important aspect of doctor-patient communication. In recent years, information technology has had a major impact on the delivery of health information to patients. This technology, both hardware and software, is part of an increasing trend to empower consumers to take a more active role in their own healthcare and to provide the necessary information to enhance their decision making. Self-care and home care, combined with information and communications technologies, will allow patients to better manage both diseases and overall health.

"Low Technology" Resources

A variety of resources for patient education utilize traditional communications. These include paper handouts, brochures, booklets, newspapers, magazines, television, telephone, and videotapes. Most of these resources require less of an initial outlay of funding, but are difficult to store and inventory and are not easily updated.

Brochures and Pamphlets

Paper-based brochures and pamphlets are traditional resources providing information to consumers. Government agencies and non-profit organizations publish many of these to educate the consumer on some aspect of health and wellness or to promote greater understanding of specific diseases. HMOs and individual physicians provide similar information such as medication instructions or surgical procedures. These patient education materials are designed as stand-alone products to be taken home by patients. These materials can be effective if cultural sensitivity, language, readability and literacy demands are taken into consideration in their production.

Media (Newspapers, Magazines, Television)

The news media (newspapers, magazines, and television) also help to disseminate healthcare information. National and local newspapers and television have regular health columns and programming and also report on the latest medical research. Television news has highlighted and promoted important health issues such as smoking, cancer (breast and prostate, in particular), and heart disease. Popular magazines have addressed similar issues. Investigative reporting provides consumers with information on all aspects of health and healthcare, including alternative or nontraditional therapies often not discussed by traditional physicians.

Telephone

The use of the telephone to provide health information has taken several forms. Phone services provide prerecorded health information on a wide variety of health-related subjects. Hospitals or libraries purchase these services for their customers. Utilizing a touch-tone menu, consumers can access prerecorded topics. The telephone has also been used to establish nurse/physician advice lines. These serve as a less costly link between the consumer and healthcare provider and act as a triage mechanism to determine which patients need to be seen by a healthcare professional and which can be treated with advice over the phone.

Videotape and Videodisc

Video is a useful medium for training, education, and the dissemination of healthcare information. Using //xpedio/groups/secure/documents/graphic and stories to convey information can be more effective than print materials, although typically, patient education videos must be viewed in the clinic—not sent home with patients. Interactive videodisc systems allow the additional features of browsing, interaction, and tailoring the presentation to patients. Several interactive video systems have been designed to help patients understand the risks, benefits, and potential outcomes as preparation for participating in treatment decisions with their doctor.[3]

Computer Technology and Telecommunications

Advances in computer technology and communications have provided consumers with access to enormous amounts of information. Computers are becoming commonplace at home and at work. Many software packages are designed for use in patients' homes, libraries, and physicians' offices. These are typically available on CD-ROM or computer disk. Lately, these commercial products have been superceded by services on the Internet. The World Wide Web (the multimedia portion of the Internet) provides access to vast quantities of health information both for patients and health professionals. Major online services offer extensive medical resources for consumers. These include reference materials and databases, as well as access to support groups, forum discussions of health-related topics, and e-mail. Patients can also download information to their own systems. Specialized disease-specific electronic bulletin boards are devoted to specific health issues, functioning as electronic patient support groups.

The trend with both computer and telecommunication hardware and software is to merge all communications technologies together seamlessly. In the future, the home will likely contain a computer, fax, built-in telephone communication, and video conferencing capabilities, coordinated with television. Consumers will have the capability to communicate interactively to acquire health information and even consult with healthcare professionals (telemedicine).

Products/Services

The number of commercial computer products for consumer health information is overwhelming. A consumer health informatics directory[4] lists more than 600 software products related to healthcare. The products cover the full range of patient education, health promotion, and decision-making software. Some products offer only text information; others use multimedia with color graphics and video. Still others appeal to younger users by providing information through entertainment in the form of games or simulations.

Wellness, Preventive Care, Health Risk Appraisal, and Nutrition

A variety of software is available for health promotion, health risk appraisal, nutrition analysis, and fitness. Health promotion and risk analysis software is designed to help people understand health risks and to provide methods for reducing or eliminating the risky behavior by computerized appraisal. These systems provide tailored printouts and can be used by individuals or employees as the starting point to target populations for health promotion, to develop individualized self-help programs, or to identify possible candidates for more aggressive intervention. Several of the wellness programs concentrate on diet and nutrition and include modules on diet, recipe analysis, menu planning, body composition, and energy expenditure.

Patient Education Handouts

Physicians have traditionally provided patient education and instruction materials in the form of handouts or brochures on specific topics of interest. Commercial products now offer these as electronic databases with print-on-demand capabilities. A few also offer the capability to tailor the printout to the clinic, individual physician, and individual patient with fairly easy editing.

General Health References

A number of products are available as general home healthcare references. Although mainly text, they also include video, audio narration, and animation. Health resource libraries often subscribe to larger databases that are too costly for the average consumer. These databases collect information from journals, newspapers, and other media into a single source. In evaluating these systems, it is important to note how the developers guarantee the reliability of the information. Most organizations will have a team of clinical advisers to review all materials.

Self-care and Triage

Quite often a patient's main question is whether to see a doctor, wait and see if a symptom gets better on its own, or to try to take care of the problem at home. Some of the products ask the patient to enter symptoms and background information, and then provide advice on possible diagnoses, whether to see a doctor (and how soon), or how best to relieve symptoms at home. Software is also available for home emergency medical advice. However, these programs are usually meant to be used in advance as a tutorial with graphics and animation to demonstrate techniques.

Drug Information

Drug reference programs offer consumers information on prescription and nonprescription medications. These programs typically provide nontechnical information on thousands of brand- name and generic drugs, covering topics such as why a drug is prescribed, dosage and usage information, adverse reactions, warnings, precautions, and possible interactions with other drugs, foods, and beverages. Many of the home reference systems have built-in modules with drug information.

Preparation for Office Visits; History Taking and Health Records

Preparing in advance for medical appointments can play an important role in effective physician-patient communication. Several computer programs have been developed to help by organizing information, educating consumers, and keeping a record of important issues that need to be addressed during the encounter. These programs allow a user to maintain a comprehensive medical record at home.

Decision-making Assistance for Treatment Options

Informed medical decision making is at the heart of consumer health informatics. A number of programs have been developed to help patients choose among treatment options for specific diseases. Relevant information about the benefits and harms of each alternative therapy is presented, sometimes using video clips of other patients discussing their decision making and the outcomes they experienced. An important feature of these programs is that patients are encouraged to consider quality-of-life issues associated with possible health outcomes and to consider what factors are important to them as they prepare to participate in their treatment decisions.

Informed Consent

Newer procedures to handle informed consent include specialized software that augments both the education and consent processes. Programs in this category run the range from entirely text-based, automated versions of the traditional paper system to those containing video clips and multimedia descriptions of medical procedures. Currently, a paper consent form is usually printed out at the end of use. However, we anticipate that computers will soon be used to record consent through audio or electronic signature as well.

Advance Directives

There are a few examples of computer software to assist in end-of-life decisions. These systems typically use interactive video to educate patients about advanced life support while determining patient desires for end-of-life care. The documentation of patient knowledge, understanding, and wishes for end-of-life care is an important part of the medical record.

Online Resources: The Internet and World Wide Web

The Internet provides extensive health information resources. Table 1 lists some of the sites that consumers can access for comprehensive information.

Commercial vendors provide access to their own health materials and discussion groups, as well as information available on the Internet. Most of the recent work in online patient education material has occurred on the World Wide Web. Quality documents containing both text and graphics are being made public through institutions' home pages on the World Wide Web. To view some examples, use a browser to visit the sites listed in Table 1. Many hospitals, HMOs, and other provider organizations are developing their own sites with patient education components. These systems allow closer links to patient information needs and are likely to promote greater satisfaction with services.

table 1—a sample of Web sites for consumer health information

General Medical Information	
CHID (Combined Health Information Database)	http://chid.aerie.com
CNN Interactive Health	http://www.cnn.com/HEALTH/index.html
Emory University HealthWeb	http://www.gen.emory.edu/MEDWEB/keyword/consumer_health.html
Group Health Cooperative of Puget Sound	http://www.ghc.org
HealthFinder	http://www.healthfinder.gov
HealthGate	http://www.healthgate.com
New York Online Access to Health	http://www.noah.cuny.edu
Netwellness	http://www.netwellness.com
Mayo Health Oasis	http://www.mayo.ivi.com
Disease-Specific Sites	
Alzheimer's Disease	http://www.alzheimers.com
Oncolink (Cancer)	http://cancer.med.upenn.edu/
HeartPoint (Cardiac Disease)	http://www.heartpoint.com
National Institute of Diabetes and Digestive and Kidney Diseases	http://www.niddk.nih.gov/
Agencies and Societies	
Agency for Healthcare Policy and Research	http://www.ahcpr.gov
American Cancer Society	http://www.ca.cancer.org
American Lung Association	http://www.lungusa.org
Center for Disease Control (CDC)	http://www.cdc.gov

However, the growth in consumer use of the Internet has changed the traditional doctor-patient relationship. As patients come to their physicians with information found online, some physicians are spending more time discussing this information (and, in some cases, misinformation). Yet this new consumer enlightenment can also be a boon. It can provide the mechanism for physicians to help patients take control of their own healthcare. This form of empowerment and self-efficacy has been studied in relation to patient education.

Empowerment and Self-efficacy

Empowerment and self-efficacy are closely linked concepts. In general, empowerment is the process that enables people to "own" their own lives and have control over their destiny. It is closely related to health outcomes, in that powerlessness has been shown to be a broad-based risk factor for disease. Similarly, self-efficacy is a patient's level of confidence that he or she can perform a specific task or health behavior in the future. Some clinical studies have even shown self-efficacy to be the variable most predictive of improvements in patients' functional status.[5,6] Given the strong influence of empowerment and self-efficacy on health outcomes, it is important to incorporate a focus on these concepts when designing systems for patient use.

The Internet and Social Support

Out of the upheaval caused by changes in the healthcare delivery system and the shrinking time available for healthcare professionals to devote to patients, the information resources of the Internet have helped level the playing field. This democratization of health information has helped both patients and caregivers. Support groups and online self-help provide emotional and psychological support, especially for chronic and life-threatening diseases. The Internet gives instant access to patients who may be geographically remote.

The Internet and Disease Management

Information technology is also an enabling force in disease management. Home healthcare and disease management may cause a paradigm shift in the way we view the settings for healthcare. Patient care services can now be delivered through telecommunications. The Internet can provide the template for treating chronic diseases at a distance. Systems for such care

can monitor vital signs, check medication adherence, provide education and reminders, and allow healthcare professionals to observe a patient in a home setting without a home visit. Linking these systems to the patient's electronic medical record will allow customization of the patient education materials with clinical and demographic information. The goal of research in consumer health informatics is to develop sound principles to inform the design of new systems for patient use and to measure the benefits derived from the use of those systems. However, research in several areas is needed to move the field forward in providing real benefits to patients' health outcomes and in showing the effectiveness of the systems to purchasers of healthcare. Effective patient education does not simply consist of providing information to patients. It must also include activities planned to encourage patients with acute or chronic conditions to participate actively and appropriately in their treatment and rehabilitation.

Considerations for HIM Professionals

The future holds great promise for consumers becoming empowered and active participants in their medical care decisions through increased and more effective access to healthcare information. The advances in technology for communications and information processing will certainly change the way in which medicine is practiced and will also change the way in which patients receive information and interact with the medical care system. There are several implications for health information management specialists. Hospitals, clinics, and health plans will be selecting and storing electronic patient health information, as well as integrating it into routine clinical care. Electronic medical records data will be used to select and recommend information for patients. Thus, it will be important to ensure the quality, security, and integrity of health information as we strive to improve patient care and health outcomes.

Notes

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Holly Brugge Jimison *is an assistant professor in Medical Informatics and* ***Paul Sher*** *is an adjunct professor in medical informatics at Oregon Health Sciences University's Biomedical Information Communication Center in the Division of Medical Informatics.*

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