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## ON THE COVER

David Rosenman,  
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*Fruit Drawn While  
Studying Pathology  
With Jerome, 1997.*  
Charcoal on paper.  
68 × 84 cm.

## The Internet: Ushering in a New Era of Medicine

Pam R. Rajendran

MEDICINE HAS BEEN CHANGED DRAMATICALLY BY THE INTERNET'S ABILITY to disseminate rapidly vast amounts of information and facilitate the instantaneous exchange of ideas. The Internet has become a source of medical information for approximately 98 million people in the United States.<sup>1</sup> For physicians, the Internet has increased the efficiency of patient care and has enabled collaborative research among investigators who are scattered geographically.<sup>2</sup>

The Internet has transformed the patient-physician relationship by empowering patients with information. Because physicians are no longer the primary gatekeepers of medical information, shared decision making is now emerging as the hallmark of the patient-physician relationship. Although patients now possess much more medical information, the physician's insight and input are essential to ensure that the patient can accurately comprehend the data gathered from the Internet. This added dynamic of the patient-physician relationship will fundamentally change the traditional office visit.

There are, however, virtually no restrictions on who can distribute information or conduct business on the Internet. This lack of regulation has created vast amounts of contradictory and erroneous information, which can be dangerous for patients. In addition, many dubious direct-to-consumer businesses are proliferating on the Internet. These include the auctioning of organs online<sup>3</sup> and patient-ordered diagnostic tests conducted in shopping malls with test results distributed via the Internet.<sup>4</sup> Through direct-to-consumer marketing, the Internet can promote harmful self-diagnosis and self-treatment by patients. It is therefore paramount that physicians play an active role in monitoring these potential dangers.

This month, MSJAMA examines the impact of the Internet on patients, physicians, medical law, and medical education. The Internet is changing communication both among patients and among physicians, as well as between these 2 groups. New legal and ethical issues are emerging because of this development. The Internet is also altering medical education, transforming some memorization-based components of the medical school curriculum into a dynamic and interactive learning experience.<sup>5</sup>

Looking forward, the Internet has great potential to improve the health care system. It can help standardize care for all patients by enabling rapid distribution of the latest medical information. The Internet can also reduce health care costs by allowing for more efficient management of patient data. As the Internet begins to reengineer the health care system, physicians must utilize the benefits it offers to enhance all aspects of patient care.

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## The Internet and Medicine: Building a Community for Patients With Rare Diseases

Mary Patsos, *President, Takayasu's Arteritis Association*

THE EVOLUTION OF THE INTERNET HAS TRANSFORMED THE definition of community for the patient with a rare disease. With the availability of Web pages, bulletin board services, chat rooms, forums, webcams, electronic mailings, video and audio clips, patients with rare diseases finally have a medium to voice their feelings of alienation, bewilderment, and apprehension. They are no longer limited to communicating via traditional face-to-face meetings, telephone, and mail services. With the Internet, members of this neglected and vulnerable population have at their fingertips the tools necessary to relieve fears and answer questions about their specific disease.

In 1993, I became a member of the rare-disease community when I was diagnosed with Takayasu arteritis after 2 triple-vessel heart bypass operations. Takayasu arteritis is a rare, chronic, inflammatory disease primarily of the aorta and its branches. The subclavian, renal, carotid, and the ascending aorta arteries can also be involved. Takayasu arteritis affects more females than males and usually begins in the second or third decade of life.<sup>1</sup> It is common for patients to exhibit absent pulses, vascular bruits, and symptoms of arterial involvement. This unusual disease has an incidence of 1.2 to 2.6 per million per year worldwide and is more common in Asian populations.<sup>1</sup> There can be varying presentations of symptoms and often delays in diagnosis due to the erratic course of the disease.

While I was recuperating from my second operation, I realized that education, patient advocacy, research, and support were either inadequate, neglected, or outdated. I decided to form a nonprofit, tax-exempt, public charity, the Takayasu's Arteritis Association (TAA), to establish a community for patients with Takayasu arteritis, as well as family members, health professionals, and the general public.<sup>2</sup> While developing my association's goals and objectives, it became clear that the Internet would be an immensely powerful and vital tool for communication and education. The Internet has addressed my unique needs as a patient with Takayasu arteritis and as a president of a charitable organization. As a patient, I have enjoyed its convenience and accessibility as well as the diverse opportunities it provides for interpersonal communication, empowerment, and validation. As the president of the TAA, I have used the Internet to disseminate accurate and current health information and to advocate patient empowerment.

The fundamental advantage offered by the Internet is its ability to seamlessly connect information dispersed across time zones and continents. The small and geographically scattered population of patients with Takayasu arteritis has in the Internet a central place for interaction and education. The medium addresses many patients' factual questions and psycho-

logical concerns. Due to the complexities of the disease, it is common for patients to see many specialists, who often have diverse opinions in diagnosis and treatment. This makes it especially critical for patients to have trustworthy and reliable Internet sites to help them clarify uncertainties and misinformation. In addition, the mounting pressures and demands on the time of health professionals, often leaves communication gaps between physician and patient. Support groups for patients with rare diseases must therefore compensate for this lack of education and support services. In filling these gaps in patient care, Web sites can serve as valuable channels of communication. Through Web sites that focus on rare diseases, complex information conveyed to patients by their physicians can be explained in simpler, more understandable terms. At the same time, the Web sites serve as lively forums for discussion about the needs and activities of the community of patients with rare diseases.

With all of the fanfare surrounding the power and potential of the Internet, it may present some pitfalls for the rare-disease community. Issues of cost, privacy, and fraudulency need constant attention. Rare-disease communities may be discounted unless they continue to fight for regulations and legislation that will make the Internet accessible and affordable. For example, the introduction of high-speed cable and phone-line connections should not restrict access of the financially burdened patients to extensive library files, the latest research, or other online resources.

According to an old adage, "Man loves company even if only that of a small burning candle."<sup>3</sup> The process of exchanging ideas via the Internet can be therapeutic for people with rare diseases. Practical ideas as well as emotional support emerge from Internet discussions among members of rare-disease communities, since by comparing treatment courses, patients may get ideas for their own treatment. The Internet has already helped to create important new communities for patients with rare diseases, the medical community, and the general public. By using the Internet, many more rare-disease communities will be able to share experiences, resources, ideas, coping skills, helpful hints, financial support, and hope. In combination, these efforts will guarantee the success of our missions and contribute to the growth of a truly new form of community.

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## The National Library of Medicine's Web Site for Physicians and Patients

Donald A. B. Lindberg, MD, *Director, National Library of Medicine, National Institutes of Health*

IT IS INCREASINGLY A FAMILIAR PICTURE: THE PATIENT WALKING into the physician's office clutching a sheaf of computer printouts from the Internet. It quickly becomes apparent that the patient spent the previous evening surfing the Internet for the latest information on a particular disease and is now prepared to barrage the physician with questions. The National Library of Medicine (NLM) is responsible for much of this scenario. Quite possibly the patient obtained this information from MEDLINE, or the newer MEDLINEplus. It is also possible that the patient brought some of the misinformation promulgated on the Internet.

The *Index Medicus*, from which MEDLINE was derived, began in 1879. The NLM first employed computers in 1964, to prepare the *Index Medicus* for printing. Online searching of the MEDLINE database was introduced in 1971. In the years that followed, medical librarians (and the occasional physician) came to the NLM to take a class in how to search MEDLINE. GratefulMed was introduced in 1986 to permit searching MEDLINE directly from personal computers. Today, hundreds of millions of MEDLINE searches are conducted each year by users around the world.<sup>1</sup> At least 30% of users are the general public, some of whom may be your patients.<sup>1</sup>

In November 1998, the NLM decided to change its century-old practice of providing databases primarily for the use of health care professionals. The result is a new service, MEDLINEplus, which is different from MEDLINE in that it connects the user to information written especially for the general public on more than 400 health topics. The information comes from the US National Institutes of Health (NIH) and other federal agencies, professional associations and nonprofit health organizations. Using strict guidelines, NLM's librarians select Web pages that are educational, appropriate to the audience, well organized, easy to use, and do not promote a product or service. The source of the information must be dependable, with an advisory board whose names are listed. The Web site must be consistently available and its links reliably maintained. In addition to health topics, MEDLINEplus also connects the user to medical dictionaries, hospitals, directories of physicians and dentists, an extensive medical encyclopedia, and consumer information about thousands of prescription drugs. In the last year usage has increased from 650 000 to 2.3 million "page hits" per month.

MEDLINEplus health topics also contain 1 or more links to preformulated MEDLINE searches focused on various aspects of each topic. These searches yield a manageable number of current references (usually 20 to 50). The references are English-language articles from journals that are gener-

ally available from a local medical library. The search is formulated to retrieve articles likely to be of interest to the general public. In the extensive MEDLINEplus section on diabetes, for example, a user without any knowledge of how to search MEDLINE can retrieve useful medical information. Planned improvements to the site include a daily medical news feature and local sources of health information and assistance, and more Spanish and other non-English-language materials.

The efforts of the NLM to keep the public informed about medicine have not stopped with MEDLINEplus. In February 2000, in cooperation with the NIH, a new Web-based database, ClinicalTrials.gov, was launched. The catalyst for this site was a 1997 law<sup>2</sup> that required a registry for both federally and privately funded clinical trials for serious diseases or conditions. More than 5200 such studies are currently listed in ClinicalTrials.gov. For each clinical trial, the database includes a statement of purpose, the recruiting status, criteria for patient participation, location, and contact information. An important feature of the database is an extensive series of links to other online health resources that help place clinical trials in the context of patients' overall medical care. As with MEDLINEplus, no registration is required to use ClinicalTrials.gov, and complete privacy is assured to all users.

Additional information available online and supported by the NLM include:

The "Visible Humans"—two very large datasets of sub-millimeter anatomical data that are being used (without charge) by 1,240 licensees in 41 countries.

"Images from the History of Medicine"—a viewable file of the 60,000 images from NLM's historical collection.

"Profiles in Science"—a digital recreation of the scientific findings and unpublished writings, letters, photographs, and laboratory notes of great scientists.

While medical misinformation on the Internet is plentiful, the NLM provides physicians and their patients a central resource for authoritative health data. The most comprehensive database of the medical literature, MEDLINE, has been joined by MEDLINEplus. Now health care providers and the general public alike have access to an unbiased, noncommercial source of medical information.

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## Access vs Quality Assurance: The e-Health Conundrum

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THE RISE OF E-HEALTH<sup>1</sup> IS INEXORABLE, AND ITS INHERENT e-commerce message is consistently upbeat. Microsoft tells consumers that with its new e-health systems “[t]he patient is definitely in charge”<sup>2</sup> while Intel markets digital credentialing to physicians under the bullet “provide better patient care.”<sup>3</sup> However, there seems to be little reflection on the accuracy of such predictions or their deeper professional implications. Indeed, the American Medical Association (AMA) Web page devoted to e-health, entitled “Finding solutions to the e-health puzzle: AMA puts the pieces together for you and your patients,”<sup>4</sup> is disturbingly silent as to the legal and ethical issues that must be navigated during this fundamental re-engineering of the delivery system.

At the core of the e-health debate is the tension between access and quality assurance. e-health destroys the single-point, gatekeeper model of access, promising multiple entry points and, thereafter access to health care that is nonlinear and less hierarchical.<sup>1</sup> Established information brokers, including health care professionals, risk disintermediation, replaced by direct distribution of information to patients, while conventionally aggregated medical functions (such as health data collection and diagnosis) face disaggregation by home-based devices and automated teller machine-like models of medical practice. These technologies should decrease costs and improve access, yet pose serious issues for quality assurance systems. Systems based on licensure or malpractice law are premised on a single point of entry identifiably located in physical space and will be ineffective to police a delivery system that is no longer based on physicality or the preeminence of the traditional patient-physician relationship.<sup>5</sup>

Ethical structures may not fare any better. Transferring the core tenets of the patient-physician relationship to managed care has been difficult enough.<sup>6</sup> But e-health poses even more difficult problems. Choice and communication (aided by the promise of extracting administrative costs from the health-care delivery system) should dramatically improve access. Yet, e-health’s lack of physicality, its depersonalization, anonymity, and even coldness challenge usual conceptions of competence and compassion. Further, multipoint entry into the delivery system makes continuity difficult to achieve, while health advice sites based on e-commerce paradigms involve considerable conflicts of interest.<sup>7</sup> Finally, e-health marketing practices and privacy concerns frequently seem to involve the commodification of patients and patient data.

e-Health has great potential for good. Highly efficient national medical markets, around-the-clock service and the seamless integration of products and services no longer

should be the stuff of dreams. The ability to heavily personalize computer-mediated relationships may rehabilitate patient-physician relationships eroded by years of managed care, while the Web’s ability to deliver rich information directly to consumers could reverse centuries of damaging informational asymmetry between patient and physician.

To achieve the promise of e-health, ethical and legal structures must be refurbished to further demand the provision of quality medical information, untainted by patient sorting costs or provider self-interest. Regulatory systems must be changed so that they are no longer premised on ties with some physical place. Legal and ethical constructs must be informed by e-health codes of conduct and computer-mediated data quality solutions.<sup>8</sup> Different groups of health care professionals may cling to narrow conceptions of the “practice of medicine” However, the future of meaningful quality assurance is dependent on accepting that, at least from the patient’s perspective, medical advice sites, drug manufacturers, and health insurers all practice medicine and must be held to the highest standards.

In other areas of the economy where e-commerce came first and law struggled to keep up, legislatures have been convinced to pass arguably anticonsumer legislation in such areas of intellectual property and software licensing. With e-health the early signs are more positive, as the US Department of Health and Human Services has sought valiantly to reconcile cost extraction and patient rights in its privacy regulations.<sup>9</sup> The serious challenges posed by e-health should not be underestimated as information, diagnosis, treatment, and care are delivered through unfamiliar channels. However, there is still time to reengineer legal and ethical codes to marry increased access to quality assurance and avoid the abyss of a computer-mediated sequel to the worst and most dehumanizing aspects of managed care.

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# Cybermedical Skills for the Internet Age

Jordan M. Prutkin, Yale University School of Medicine

DURING THE LAST 10 YEARS THE INTERNET HAS GROWN FROM a small network that allowed the exchange of information between academic, military, and government officials to a global infrastructure that has radically changed the way people obtain information. The practice of medicine has not escaped this revolution. As a result, physicians must now become facile with the world of "cybermedicine."

Medicine in the electronic age will include more flexible communication with patients, easier retrieval of medical information, faster access to patient data, and streamlining of medical office management. But capitalizing on the power of the Internet requires both technical proficiency as well as an understanding of why these technologies are important from a societal perspective.

The most important of these "cybermedical" skills may be proficiency in using e-mail for communication with patients. As opposed to the early acceptance of the telephone to answer patients' questions, many physicians are leery of professional e-mail.<sup>1</sup> However, because patients are demanding this service, physicians will need to develop appropriate standards regarding e-mail communication. One compelling reason to use e-mail, rather than the telephone, is that it provides unambiguous documentation that can be placed in the medical record.

Another immediate concern is patients using of the Internet for medical information. In this age of consumerism and personal activism, patients regularly visit physicians' offices with information obtained from the Internet. According to a recent telephone survey, 41 million people in the United States use the Internet for health information.<sup>2</sup> Physicians must discern which of this is accurate and which may be harmful, and they must understand how patients obtain this information so as to better evaluate its source. A recent study regarding the quality of cancer information on the Internet showed that grossly erroneous information can be obtained from even reputable Web sites.<sup>3</sup> Such readily available misinformation could have grave consequences if patients decide to pursue improper treatment.

To address this problem, physicians could design their own Web sites that include links to other sites that they feel provide quality information to patients. A 1999 study showed that more than half of US Internet users would be willing to visit a Web site designed by their physician, but only 9% actually knew if their physician had a Web site.<sup>4</sup>

Soon there will be greater availability of computerized medical records accessible from remote locations.<sup>5</sup> These databases will expand further as the price of computer memory continues to fall, data compression technology is enhanced, and security standards are developed. A patient may no longer have separate medical charts located at different

providers' offices; rather there might be 1 computerized record containing routine information such as periodic health exams and also adjunct data such as electrocardiograms and radiographic films. Physicians, by learning how to input and access these databases, will facilitate communication with other providers, curtail the unnecessary duplication of tests, and reduce time spent locating medical records.

Physicians will increasingly have access to telemedicine, loosely defined as using telecommunication and other electronic means to provide medical care when the provider and patient are located at a distance from each other.<sup>6</sup> Real-time audio and video communication, transmission of radiographic films, and, eventually, even robotic surgeries between long distances might become common practice. Physicians should learn how to take advantage of this technology, and while preliminary studies have shown patient satisfaction with telemedicine,<sup>7</sup> steps should be taken to maintain the quality of care.

Finally, the near future will see quick tests of patients' DNA using cDNA microarrays.<sup>8</sup> These data could then be compared with central databases of genetic information such as Genbank, the database of the Human Genome Project. Chip analysis will provide physicians with more information about a patient's health, including their sensitivity to certain medications and propensity for developing certain diseases. While learning how to use this technology, physicians will also need to understand its medical, legal, and ethical ramifications.

Because physicians need to develop the skills to practice medicine using these technologies, it should be the responsibility of medical schools to ensure that students are competent to use them. For those who have already started their medical careers, specialty and state medical societies should offer classes on the Internet and other new medical technologies. Because of what the Internet can offer, including quicker access to more information, society can only benefit from physicians cultivating a facility with these new technologies.

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# Medical Education and the Internet: This Changes Everything

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THE UBIQUITOUS AND MULTIMEDIA NATURE OF THE WEB environment has already made a significant impact on medical education. In addition to facilitating the creation and distribution of innovative educational content, it creates a virtual arena for instant global communication and collaboration. Moreover, the Internet can provide tools to address some of the unique challenges posed by medical education. First, students and resident house staff need to learn, but real world mistakes that result from learning are unacceptable. Second, relevant medical knowledge, like the Internet, is evolving and expanding rapidly. Third, medical students must develop a sophisticated constellation of skills and knowledge—from communications and practical skills to pattern recognition and problem solving skills. Finally, students and residents must learn how to teach, as patient education will be one of their primary activities.

## Delivering on the Promise

Our surveys indicate that most US medical students have Internet access at home, and virtually all have broadband access at school (*Medschool.com*, unpublished data, August 1999). Most students and house staff now have access to online textbooks and journals at home and school, thus reducing trips to the library. In addition, evolving wireless and personal digital assistant (PDA) applications are making it possible to deliver computer-assisted instruction (CAI) programs in a mobile format.

In addition to convenience, the Internet allows for the development of a global learning community. Communication and collaboration tools like moderated discussion forums, e-mail, chat, instant messaging, and Internet telephony facilitate discussion, debate, and learning among student peers and faculty.

The increasing availability of broadband Internet connections allows for the transmission of larger amounts of data, improving the Internet's ability to capture and transmit the drama of real patient stories. Multiple media formats like animations, video, and audio can be combined to provide an integrated learning experience that cannot be duplicated in a traditional classroom environment. This learning experience itself can be integrated with traditional teaching modalities like didactic lectures and small group learning. Any educational or reference material can be hyperlinked into the learning experience, allowing the student to explore independently as necessary.

The Internet also allows for the repackaging of education content to be used for multiple purposes. For example, a patient video about asthma can be deployed in instructional modules on topics such as ventilation/perfusion mismatch and the differential diagnosis of wheezing. Instructors can therefore

"build once, use many" and even share. The future will likely give rise to a decentralized learning network where faculty and students alike can search and download learning objects and even whole coursework from the computers of other faculty and universities.<sup>1</sup>

CAI can also free up for faculty for intensive activities like small group discussion and student tutoring. For example, a school may decide to record and archive a set of core didactic lectures that would free the faculty from giving the same lecture every year.

## Current Challenges

The development and integration of Web-based learning into mainstream medical school curricula has been sluggish. Most of the 124 US medical schools currently use computers for educational support.<sup>2</sup> However, only 19 schools (15%) report offering a complete course using any form of distance learning including non-Internet methods such as teleconferencing and videotape. In contrast, two thirds of all 4-year undergraduate institutions in the United States have implemented distance learning.<sup>3</sup>

Factors that may slow adoption of the Internet as an interactive educational tool include institutional inertia, faculty unfamiliarity with the Internet, lack of funds, and poor faculty incentives to develop online learning. In addition, standards for online learning are just emerging and do not currently address the specific needs of medical education.<sup>4</sup> Moreover, home broadband access, which is needed to deliver more sophisticated CAI, is currently limited.<sup>5</sup> Finally, there are attribution, copyright, and intellectual property issues that must be addressed.

## Looking Forward

Despite the current obstacles, the Internet has rapidly become indispensable to medical education. Current efforts are underway to develop more sophisticated CAI, including integrated medical curricula using streaming media and patient case simulators with branched decision points. For students, faculty, and medical schools committed to educational innovation and excellence, this continues to be an exciting time for experimentation and discovery.

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