Computers in Patient Education and Monitoring

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Computing technologies offer much promise in the field of medicine. Every discipline in medicine has been affected by the proliferation of computerized technology. Clinicians face challenges in balancing constraints of time and personnel resources when caring for and educating patients. The potential value of computer technology is tremendous and expectations run high among providers and patients. Computers can help patients to synthesize knowledge from information and to retain information about diseases. Computer and communication technologies can extend the caregiver's reach with remote patient monitoring. Health care providers' roles are changing because of the availability of health information on the Internet. Computer-based patient education can help improve the patient's awareness and understanding of his or her disease(s), which can help make the patient more of a partner in the patient-physician relationship. Currently, there are some limitations to and issues about using computers for patient education and monitoring, but I expect those limitations and issues to be substantially mitigated in the future. *Key words: computers, education, monitoring, communication, telemedicine, medical informatics.* [Respir Care 2004;49(5):480–487.

Introduction

Computer technologies have the potential to profoundly change the practice of medicine and substantially impact patients' lives.[1,2] Over the past decade, computers and related communication technologies have become more affordable and more prevalent. Computer technologies are becoming smaller, faster, and more efficient. In 1965 Gordon Moore predicted that engineering improvements would double computer speed about every 18 months ("Moore's law"); that has held true since 1965 and further improvements in processing power and decreases in computer size are expected to maintain change at that pace into the future.[3–5] In part because of those improvements, computing technologies now offer powerful new information management capabilities. Miniaturization of technology allows computing devices to be used in small spaces and in many environments. Handheld, wearable, and implantable computerized devices that wirelessly transmit monitored physiologic data will improve patient monitoring capabilities.[6–9]

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The expansive growth and availability of networking and communications technologies will also continue to advance patient education and patient monitoring technologies.[7]

Kevin Kelly published "New Rules for the New Economy" in 1997 and in it he wrote about the new "network economy":

> Curious things happen when you connect all to all. Mathematicians have proven that the sum of a network increases as the square of the number of members. In other words, as the number of nodes in a network increases arithmetically, the value of the network increases exponentially. Adding a few more members can dramatically increase the value for all members.[10]

The availability of today's robust networks and smaller, more affordable computers has impacted the way medicine is practiced and the way health care consumers get medical information and seek treatment.[11] However, until these expanding technology resources are accessible to everyone who needs them, their total potential value goes unrealized. Likewise, if resources are available but the quality and accessibility of information are poor,[12] then the benefits of such technology cannot be fully realized.

Contemporary Terminology for Contemporary Technology

"E-health" is a relatively new term that describes the use of computerized information and communication technologies in health care, including patient education and monitoring.[13] Gunther Eysenbach, the editor of the *Journal of Medical Internet Research*, described e-health as:

> . . . an emerging field in the intersection of medical informatics, public health, and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development but also a state of mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology.[14]

Figure 1 illustrates e-health and its relationships to patient education and monitoring.

"Interactive health communication" is a subset of "e-health". In 1999 the Science Panel on Interactive Communication and Health,[15] convened by the United States Department of Health and Human Services, defined interactive health communication as "the interaction of an individual—consumer, patient, caregiver, or professional—with an electronic device or communication technology to access or transmit health information or to receive guidance on a health-related issue."[15]

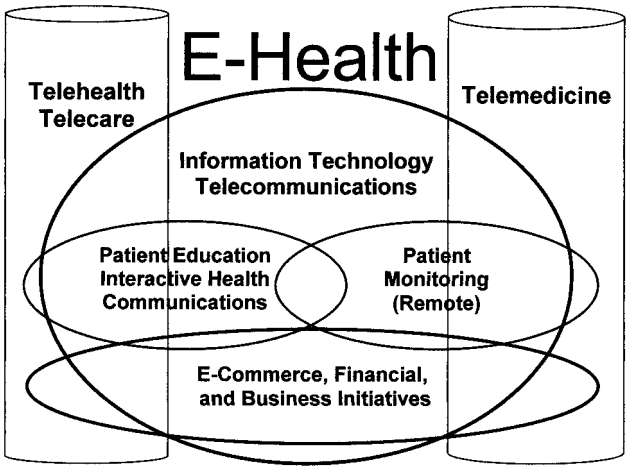

Fig. 1. E-health and the relationships of patient education and monitoring.

Interactive health communication applications that interface with end-users (consumers/patients)[15] are patient-education tools that can contribute to health improvement of patients, across socioeconomic lines, by fostering self-care and self-advocacy (Table 1). Patients get rapid reinforcement of the learning obtained via interactive health communication.[15,16] Those applications can also provide "just in time" training for clinicians.

"Telemedicine" and "telehealth" are also terms that describe the application of computing and communication technology for delivering medical services, health information, and health care at a distance.

The American Academy of Family Physicians Telehealth Discussion Paper defines telehealth as: "The integration of information technologies, medical and health technologies, telecommunication technologies and human-machine interface technologies to deliver health care and to promote the health status of people."[17]

Table 1. Interactive Health Applications

Examples
Health-related Web sites
Online chat groups
Listservs and news groups
Stand-alone kiosks
CD-ROM applications
Functions
Relay information
Enable informed decision-making
Promote healthy behaviors
Promote peer information-exchange and emotional support
Promote self-care
Manage demand for health services

Often the term "telehealth" connotes medical services provided not only over geographic distance but across social and cultural barriers as well. These terms usually refer to the use of self-supporting infrastructures for delivery of services.[18] E-health describes the provision of health services over the Internet rather than via a proprietary or solitary network. Until recently, telehealth and telemedicine have been largely non-Internet services, characterized as "point-to-point."[18] References to telehealth and telemedicine applications have been shifting toward the use of terminology consistent with the definition of e-health. In fact, *Telemedicine Journal* was recently renamed *Telemedicine Journal and E-Health*.

Many traditional telehealth programs use the Internet for communications and information functions. For example, the Comprehensive Health Enhancement Support System (CHESS) is a computer-based system that provides patients with high-quality, targeted information about diseases. The system has an easy-to-use interface and incorporates decision support and social support. A randomized, controlled study found that CHESS improved patient quality of life and promoted more efficient use of health care resources.[19,20]

The use of computers in patient education and patient monitoring are 2 distinct subjects but are closely related when viewed as part of e-health strategies. Patients who use computer-based education and actively participate in their ongoing health monitoring become more engaged in the health care process and thus becomes more of a partner in the physician-patient relationship.[21–25]

Computers and Care of Chronic Illness: The Next Big Internet Wave?

The United States health care infrastructure is largely oriented toward acute and subacute illness, not toward managing chronic illness.[26] As the United States population ages, attention needs to be shifted toward chronic illnesses. Meeting the needs of the chronically ill is one of the major challenges facing the United States health care system.[27]

Chronic illness, both in the United States and worldwide, substantially impacts the medical profession, patients, and the structure of health care delivery.[28] Not only are chronic diseases the leading killers in the United States (responsible for 7 out of 10 deaths), they are the most prevalent, costly, and preventable of all health problems.[28,29] Although chronic illnesses afflict $< 50\%$ of the American public, they account for $> 75\%$ of the national spending on health care.[28,30] That distribution of health care costs will continue to strain the United States health care system as the first wave of "baby-boomers" reaches the age of 65.[30] The number of Americans over the age of 65 is expected to double during the next 30 years. In addition, there is a trend of declining numbers of trained health care workers available to provide care to those patients.[30,31] The current United States health care infrastructure, based on a managed care and fee-for-service model, does not provide enough financial incentive for adequate care and services for patients with chronic conditions. Much of the care that is provided those patients is fragmented, difficult to find, and sometimes inappropriate.[30]

Computers Provide Value to Patient Education

The acceptability and usefulness of computers in patient education has long been recognized.[20,31,32] Changes in health care legislation, including the reimbursement of education interventions, have increased the attention paid to providing patient education. Effective patient education is an essential component of patient health promotion and disease management programs.[20] Many health care practitioners report not having enough time during a patient visit to provide adequate education.[7,20,33] Computerized patient education applications can be effective at synthesizing information into knowledge.[20,22] When the quality of the information a patient receives improves, the patient's awareness of treatment goals increases and the patient's compliance with the treatment plan improves,[34] which improves patient satisfaction, which could in turn reduce the incidence of malpractice claims and thus indirectly impact health care costs.[34,35]

Less than a decade ago computers were used to facilitate patient education primarily as stand-alone information kiosks displaying computer-aided instruction programs. From the confines of a physician's office or waiting room patients could review and print computer-generated patient handouts with relevant information about diseases and conditions.[36] Computerized educational material available to patients was primarily static data stored in a centralized, non-networked manner, on diskettes, video laser disks, CD-ROMs, or local hard drives.[37] Computer-generated booklets with personalized information were found to reduce the number of hospital admissions and improve morbidity among hospital out-patients with asthma.[38] In a randomized, controlled study, Etter and Perneger increased smoking cessation with a computer-tailored cessation program.[39] More recent computer-assisted instruction programs include numerous online technologies, CD-ROMs, virtual reality, and simulation testing, using multimedia workstations. Computerized multimedia programs are particularly effective with pediatric asthma patients.[40] The multimedia format lends additional appeal to the materials, improves patient compliance with therapy, and promotes self-management among asthmatic children.[40,41] Additionally, supplementing conventional asthma care with Internet-based multimedia programs benefits asthmatic chil-

dren by increasing their knowledge about asthma and reducing the burden of the disease.[42]

Studies have focused primarily on the efficacy of computer tools for patient education. Additional studies are needed to evaluate the quality of the information that is available to patients on the Internet.[43]

The World Wide Web Takes Over Health Information

With the ubiquity of the Internet and the ever-growing accessibility of the Web, much of the future computerized patient education will be in Web-based technologies. Substantial resources can be required to develop CD-ROM education modules, by comparison with the relatively low cost of publishing content on the Web. The ease of Web publishing makes it an attractive means of developing patient education materials. The convenience of publishing health content on the Web has made an overwhelming amount of patient health information readily available. Approximately 93 million Americans use the Internet to get health-related information.[44]

Many patients and health consumers have greatly benefited from Internet access to health information. However, though there is a wealth of data on the Internet, there are some barriers to health information for consumers.[43,45]

Quality Assurance: Health Information on the Web

The ease of Web publishing has led to the problem of determining the quality of health information found on the Internet.[45–47] In a review of Web sites related to asthma education, Croft and Peterson found that at the Web sites they studied, asthma education materials differ markedly in quality and content. They concluded that patient education materials currently available on the Web fail to meet patients' information needs.[45] Many authors of Internet health information are not trained in medicine or health education, and much Web health information is related to product marketing.[7,33] A research review of the content at Web sites related to chronic obstructive pulmonary disease (COPD) compared commercial sites to noncommercial sites and found that information on commercial sites was much more likely to be of poorer quality.[48] A *Washington Post* article had the following nontrivial information and commentary about incorrect and potentially damaging information on medical Web sites:

> One of the most basic statistics—the survival rate for people with this form of cancer—varied tremendously among Web sites, from 5% to 85%. The majority of oncologists predict a survival rate of 70% to 75% for this cancer. The Web site maintained by the Encyclopedia Britannica erroneously listed a mortality rate of "about 95% even with radical therapy." . . . The parents of a child diagnosed with Ewing sarcoma may be devastated by a finding on the Internet of a 95% mortality rate. . . . [They] even may be driven to consider refusing therapy if they are convinced that conventional medical science yields such a dismal prognosis. Alternatively they may believe that an organization that lists an 85% cure rate may provide better therapy than one that posts a cure rate more in line with the peer-reviewed published trials.[49]

There is some evidence that Internet information can lead to harm, as reported in an editorial in the *British Medical Journal.* Several cases are documented in which deaths occurred after individuals followed alternative treatment routines based on advice found on Web sites.[50] These cases led to the development of a controversial, online database to record adverse events.[50] To combat the problems of poor-quality Web information there are several sources to turn to:

- The Science Panel on Interactive Communication and Health has published a checklist to help assess health information at Web sites.[51]
- The National Cancer Institute has also published a checklist, called "Ten Things to Know About Evaluating Medical Resources on the Web."[52]
- *JAMA* has guidelines for Web-publishing health information.[53]
- The Health On the Net Foundation, which is based in Switzerland, has published a set of ethical principles (the Health On the Net [HON] Code of Conduct) for Web publishers of health information.[54] A health information Web site can use the HON Code of Conduct logo if they agree to adhere to the Code, but there is no process for enforcing the adherence to the principals.[7,51]

Though there is currently no way for consumers to be sure of the value of health information they retrieve from the Internet, there are ways to protect consumers from the hazards of misinformation. Health care professionals need to realize that many patients retrieve information from the Internet and that it is important to discuss that information with patients and to try to prevent them from acting on misinformation.[25,55–59]

Computers for Remote Patient Monitoring: Telemedicine

Telemedicine is another subcomponent of e-health (Table 2). The use of computers for remote patient monitoring

Table 2. Telemedicine Applications

Travel medicine (on cruise ships, airlines)
Rural medicine
Sleep medicine
Aerospace medicine
Emergency medicine
Pharmacy
Neonatology
Dermatology
Radiology
Surgery
Chronic diabetes care
Chronic asthma care
Chronic mental health care
Counseling and mental health therapy
Intensive care monitoring
Public health monitoring
Nursing home monitoring
Hospice care
Disaster relief
Terrorism response
In prisons
At schools
Internationally

began in space exploration. The National Aeronautics and Space Administration introduced computerized physiologic monitoring in the 1960s, when telemetric monitoring was done during the Apollo space missions. That application used satellite technology and was a direct precursor to one of the first applied telemedicine projects, the Space Technology Applied to Rural Papago Advanced Health Care[60] project, in which health care was provided via satellite communication to the Papago Indians on their remote reservation.

Telemedicine is "the use of electronic signals to transfer medical data (photographs, radiographs, audio, patient records, videoconferences, etc) from one site to another via the Internet, Intranets, [personal computers], satellites, or videoconferencing telephone equipment in order to improve access to health care."[61]

Telemedicine, from its infancy, was designed to provide medical services by overcoming geographic and economic barriers. That focus continues as remote monitoring of patients' respiratory conditions becomes more commonplace. The advent of the Internet and less expensive computers has driven down the cost of telemedicine and remote respiratory monitoring. In many cases common computer software and hardware can replace expensive proprietary telemedicine devices. As this trend continues, it will be important for clinicians to resist the temptation to set up ad hoc monitoring or telemedicine programs only because that becomes easy to do. Data protection and security must be assured when establishing these technologies.

Remote patient monitoring is another aspect of e-health that serves patients by extending the clinician's reach. Remote monitoring provides the patient with a better opportunity to maintain quality of life, and patients who are more involved with their own care become stakeholders in their outcomes.

Technologies of Remote Patient Monitoring

There are 2 general types of remote patient monitoring: "real-time" and "store-and-forward." Real-time technology transfers audio, video, and text immediately and directly to the receiving computer. Store-and-forward technology stores data from the patient monitoring device and later sends it to the receiving computer (a server or data storage facility).[9] Real-time telemedicine interaction between clinicians and patients has been reimbursable by Medicare, whereas store-and-forward interactions have not.[9] There are many different devices for gathering and transmitting patient data. Some are stand-alone appliances that plug into a telephone connection and can send video and audio in addition to heart sounds and blood pressure readings. Other devices are Internet-enabled and can send data in real-time or store and forward it to a Web site or online database. The transmission and storage of such remotely monitored data must comply with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) regulations.

Remote patient monitoring is well suited to bridge the gaps of care and management of the growing number of chronic disease patients. Internet-based store-and-forward video has been used to monitor pediatric asthma patients as a means of improving inhaler technique and to follow and monitor the patient's quality of life. In one study the monitoring technology improved inhaler use scores, decreased emergency department visits, and decreased the use of rescue therapy; but quality of life was unchanged. The monitoring technique appeared to be well accepted and was effective for assessing children's use of asthma medications and asthma monitoring tools.[62]

Clinicians often rely on patients' accounts in their daily diaries to evaluate the efficacy of prescribed treatment. In a randomized, controlled, clinical trial of school-age children Burkhart et al found that electronically monitored peak flows were only moderately correlated to the patients' self-reports in diaries. Education of parents regarding the need for supervision and treatment-plan adherence is critical in self-management programs.[63]

Kamps et al concluded that asthmatic children's diaries are unreliable and that electronic peak flow meters should be used with children who require monitoring.[64] Handheld devices will become more useful and popular in the near

future as the technology improves. They are now used for capturing and storing patient data, which can be wirelessly transmitted to a desktop computer for analysis. As more wireless devices are incorporated into remote monitoring, the integration of medical applications with technologies will become more commonplace. Cellular telephones and other wireless devices for capturing monitored data will offer even fewer restrictions for patients in the future.[64] Finkelstein et al found that even patients who had no experience with computerized devices could handle and respond well to the requirements of an Internet-based home telemonitoring program.[65,66] Remote patient monitoring and self-testing of pulmonary function among asthma patients in that study group was shown to be valid and comparable to testing done under the supervision of a trained medical professional.[65] There are specialized technologies that permit even delicate and sensitive diagnostic processes such as heart and lung auscultation to be conducted remotely.[67] Anderson et al suggest that, even without specialized equipment, mobile phones can noninvasively monitor tracheal breath sounds in patients who suffer exercise-induced asthma and other chronic airway diseases.[68]

Summary

Computers have changed the ways medicine is practiced and patients are cared for. Relationships between patients and providers have also changed substantially because of the availability of health information on the Internet. Reflecting on trends and projections for the future challenges to our health care system, it is apparent that our approach to caring for chronically ill patients is in need of serious attention. Respiratory therapists are among the health professionals most affected by these worrisome trends, and they have an important role in helping patients prevent chronic disease. Chronic cardiopulmonary diseases will continue to rank high on the list of costly chronic afflictions. Computing technologies can provide interactive and meaningful patient education and effectively communicate the message of prevention and inform patients of the health hazards of smoking and other causes of chronic illness. Computers can also effectively extend the clinician's reach via telecare, telemedicine, and telehealth, to which patients have shown receptiveness and good response. Computer and communication technologies can help bridge gaps and cross barriers and will play an important role in the evolution of health care, so health care professionals must understand the capabilities and shortcomings of those technologies. Ongoing clinician education is necessary for them to stay abreast of changes and advances in computer and communication technologies. Respiratory care patients and practitioners will find value in the use of these technologies. As professionals who are familiar with both hospital and home-care technologies, respiratory therapists are positioned to show leadership in this area of medicine, which is ever changing and full of opportunities for patients and caregivers alike.

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Discussion

Nelson: What actually constitutes *practice of medicine*? How close to practicing medicine are some of these Web sites that give suggestions? Each of the 50 United States has a medical practice act, but has anyone looked at how close these Web sites are dancing to that line?

Belda: Most medical Web sites include disclaimers that advise consumers not to act on the advice provided without first consulting their physician, but there are some Web sites that actually provide real-time consultation. That goes beyond the usual static Web information and moves more towards telemedicine. Web sites need to be clear that they are only providing information and not prescribing treatments or medications.

With respect to the practice of telemedicine the approach taken to reviewing such practice is based on the number of patients. If interaction with patients in other states is occasional, then it is rarely scrutinized, but many states require licensing if a practice sees a large number of out-of-state patients.

Giordano:* I think that the most promise right now, just personal opinion, is the disease-management aspects, since chronic disease drives up so much of the cost in health care. Within the context of COPD, I think it could be especially useful for the respiratory therapist and the physicians and pulmonologists who attend these patients. We know the people in the home do not necessarily have access to respiratory therapists, but we also know that, even though COPD is incurable, the exacerbations *are* curable. If we could do a better job of avoiding exacerbations, then we could deliver on the promise to save money and improve quality of life.

I'm excited about the possibilities for telemedicine and its relevance to respiratory care. The AARC [American Association for Respiratory Care] is, as a matter of fact, putting on a workshop at the National COPD Conference next month that will deal with monitoring the COPD patient and telemedicine. So I think this is an area that we should all look into and certainly our constituents should look into, because right now COPD, in direct and indirect costs, costs over $30 billion a year. That's from NHLBI [National Heart, Lung, and Blood Institute], who got it from CDC [Centers for Disease Control].

Hopper: The daycare place that I bring my 3-year-old to has Web cameras, so from work I can see what he's up to. The picture is not high-quality, but it's almost live and it refreshes every few seconds. Whenever I see that, it makes me think of when I did respiratory home care; most times I would get called out at night for some simple little thing, such as a hose that had come undone, or something was empty and needed filling, or a tube kinked. Are you aware of any home-care companies that use Web cameras? They only cost $20 or $30. The patient could walk around with the camera and show the respiratory therapist the oxygen concentrator, cylinder, or ventilator. Is anything like that going on?

Belda: I don't know of anything like that in practice currently, but you're absolutely right: with a wireless device the patient could walk around the house with it to show the therapist what's happening. That's a very good point.

Ford: In the San Diego area it's called "e-health." To some extent this is a matter of people thinking they have to keep up with the technology—like "*You're* getting an MRI, so *I'm* getting an MRI," and basically that's where everyone is going. Companies are using "e-health" as a marketing strategy throughout San Diego. But many of the patients at my hospital are uninsured. We're the hospital for the county jail, although the jail guys probably have Internet access. Did you find any data on how many households have access to the Internet?

Belda: The latest report I've seen on Internet access stated that over 60% of United States households had it in

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2003.[1] The Pew Internet Research Center has pretty good studies on the availability and use by demographics and locations.[1]

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Stewart: We did a telemedicine program last year for our congestive heart failure patients, many of whom do not have Internet access, which required us to install the equipment in their homes. We treat about 75 of those patients every month, and we couldn't afford to put the technology in every patient's home to do the level of monitoring we wanted to, so at some point there's a break-even if the objective is to reduce costs by avoiding emergency room admissions. We've got to find a way to do that. We loved the program. The patients weighed themselves, listed the time they took their medications, answered some questions, and if the patient indicated anything that seemed odd, we'd pick up the phone and call to check on him or her. But obtaining the funding for the technology was the most difficult thing.

Belda: With that equipment how long was the training period for those patients?

Stewart: Most of it was telephone technology and most patients were able to learn how to enter their information in a couple of sessions, during clinic visits. The instructions and questions are simple and very specific, such as "Enter your weight now." and "What Time Did You Take Your Medication?" So that is pretty simple for them. It would be very feasible with patients who understand how to use the Internet and have access to it, but this particular population, at least where I'm from, doesn't have that level of access, so the system had to be telephone-accessed and we had to provide it to them.

Pierson:* I don't know how to frame this as a question, but I have a concern that I want to articulate. Your presentation very effectively illustrated for us the enormous amount of information that is now available and accessible on the Internet and out there, flowing. I am concerned about the issue of quality. You showed us the checklist that consumers or visitors of Web sites could use, kind of like a *Consumer's Digest* checklist for evaluating a new car, to make sure the information you see at a Web site is valid. That has some resemblance to what we do in publishing the Journal and peer review, but it's not exactly the same thing. If I'm a clinician looking for answers to clinical questions or seeking education, or if I'm a patient seeking information about my care and my disease, I think there's going to be the need to deal with a phenomenon that I see, and that is the implications of the fact that enthusiasm and expertise are not exactly synonymous. A lot of the information currently available on the Internet reflects the enthusiasm of the people posting the information but may not necessarily represent the level of expertise that I as a clinician or my patient deserve and should be able to find. How can we reconcile the need to get reliable, good information off the Internet with the tremendous amounts of it that are out there, and how can the user of the Internet and the accessor of this information get some assurance of its veracity?

Belda: There are processes in place, including the Health On the Net Foundation Web site "ribbons" and other identifiers that providers and patients should look for. But to really address that issue would require very-high-level representation and some sort of consortium I think. I suspect that, with the way technology has changed, even just in the last 7 years with respect to the Web, it's no longer as easy as it once was to freely post anything on the Internet and have it appear as if the information came from a premier medical library or institution. I think that as time and technology progresses, the various medical experts who have chosen not to participate with e-health initiatives will become engaged in them. I suspect that many potential medical leaders have been holding out and not yet participating, perhaps because of a lack of resources or time or the computer knowledge needed to create and maintain a Web site, perhaps because of general conservatism, or perhaps because there is such a strong potential for illegitimate information to be confused with legitimate, valuable knowledge on the Internet.

The "dot.com" fanaticism and eventual implosion of Internet commerce sites in the late 1990s affected commercial Web sites and trickled down to consumers as well. With all of the new startup companies that were created by the "promise" of the Internet, traditional "brick-and-mortar" stores began expecting major losses to Internet companies, because they were perceived to be more agile and had fewer expenses. When those major losses didn't materialize and the Internet bust occurred for most of those small Web startups, consumers and traditional businesses took notice and much of the Internet enthusiasm was exposed as overreaching hype. Consumers began to look more critically at what true value existed for them, and the traditional brick-and-mortar businesses took advantage of the new "value added" approach of providing Web commerce in tandem with their traditional stores.

I believe that as a more conservative and careful approach to medical-information-sharing catches on, we will see more reliable means for sharing and obtaining relevant medical information on the Web. Technology will help with this, but developing a wary, self-initiated health consumer will also be a critical part of making this process safe and successful.

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