Medical Informatics Europe 2002
G Surján et al. (eds)
IOS Press 2002

Patient Empowerment and the Asymmetry of Knowledge

B. SADAN, Ph.D.

The Kovens Health System Management Center, Tel Aviv University.

Abstract. eHealth consumers know more, expect more and demand more. The Internet has the potential of being a major influence on them by opening up vast opportunities for information transparency and access and the sharing of information which is essential to healthcare practice. But, these vast opportunities also pose numerous obstacles, such as the lack of common terminology or terminology standardization, the uncertain quality and reliability of the information on the Internet, the public's health literacy and the digital divide. A gradual and progressive shift from exclusive to shared knowledge and responsibility can be achieved by patient/physician collaboration.

1. Introduction

The vocabulary and behavior of the burgeoning number of eHealth consumers center on words such as "self-reliance" and "empowerment". Not surprisingly, the result, is an erosion in the traditional physician-patient relationship [1].

Cyberdialogue estimates that about 36.7 million adults now search for healthcare information online, and predicts that the number will continue to grow at "roughly twice the rate of the overall on line population" By 2005, Cyberdialogue expects that 88.5 million adults will use the Internet to search for health information, to shop for health products or to communicate with health providers or insurers through online channels [2].

A major factor in this evolution is connectivity, a trend whose growth is well documented. While it took television 26 years to achieve mass penetration among American consumers, the Internet has reached mass penetration in only seven [1].

These emerging eHealth consumers know more, expect more and demand more. They arrive at doctors offices armed with direct-to-consumer ads from pharmaceutical companies. They have researched their symptoms in the different health consumer web sites and they have access to information about clinical outcomes and financial performances previously available only to insiders. In his recent speech on "Using Medical Information on the Internet", George D. L. Lundberg, former editor-in-chief of JAMA said: "I see the Internet as one of the three biggest advances in science in the last 500 years as it applies to medical care". [3]

2. Obstacles and Opportunities

The health care industry that once relied primarily upon one-on-one interactions between patients and clinicians is now a system of integrated health care delivery networks and managed care providers. It has been estimated that about 150 people have access to a patient's medical record during one hospitalization. It is sobering to consider that, other than the physician, none of the staff have taken an oath of confidentiality. A number of Western countries have passed laws guaranteeing patients the right to claim proprietary over their medical data. This legislation has also been intended to regulate confidentiality and the authority to access. As long as medical records were kept almost exclusively in hospital archives, the situation could be contained for the most part. With the explosion of technical development, these medical data have been transferred to and are being stored in computerized databases. Together with the obvious advantage of their efficient retrieval by the patients' physicians and other caregivers whenever necessary, this conversion has facilitated access to highly confidential information by unauthorized parties and has complicated its regulation.

An example of how the application of a computer program has impacted personal health information recently appeared in the press. Two American pharmaceutical chains sent patients' prescription records to a database marketing firm which then mailed reminders to these patients to refill prescriptions, taking the opportunity to include advertisements for new drugs. The patients had not been informed that their medical information was being made available to commercial parties, and only after follow-up news stories had ignited public outrage did the pharmaceutical chains withdraw the program. [6]

This is not an isolated event. It is no secret that personal medical information is now bought and sold on the open market. Companies use it to make decisions for hiring and firing employees and to identify customers potentially most suitable for new products. The justification for providing such access to medical information is that it benefits the public safety, controls costs, and contributes to medical research. In other words, the sacredness of confidentiality is being traded off for other interests.

3. Lack of Data Standardization

Insurance companies, hospitals, clinical laboratories, pharmacies, and physicians generate large amounts of health data. Combining administrative and clinical data from various treating organizations on a routine and ongoing basis would provide superior measures of health care results, productivity, effectiveness, safety and cost.

Without going into the intricate and vast subject of privacy, these data cannot be integrated because each institution and sometimes different clinical sections, even within the same institution, inevitably describe clinical information in different ways. Thus, standard health terminology is an essential common denominator for an advanced health information system, particularly for the application of electronic health records [7]. To operate an electronic health record system, the users will need access to a generalized but consistent vocabulary for the ease and accuracy of application as well as efficient data exchange.

4. Lack of Objective Medical Criteria

Whether the situation is complicated or straightforward in terms of therapeutic indications, the existence of treatment options is, for the patient, a potential source of confusion at best and mistrust at worst. The problem is often confounded by the lack of objective criteria for therapeutic choices.

A recent study in the British Medical Journal assessed the variation among individual general practitioners who faced the same problem twice in actual practice and under unbiased conditions [8]. Twenty-eight Norwegian general practitioners were consulted during normal surgery hours by an actor pretending to be a patient with angina pectoris. Six weeks later, the same general practitioners were again consulted by a different actor portraying a similar case. The result was a significant variation in the decisions made by individual physicians. There was no satisfactory explanation for these differences having occurred.

Another example of this problem recently appeared in the New England Journal of Medicine [9]. Twenty-two board-certified cardiologists were given an abstract of clinical and diagnostic data on 596 patients with coronary problems. Each panelist was asked to either recommend or to not recommend coronary angiography for the individual patient. Each case was judged by two of the expert panelists as well as by the referring physician. The conclusion of the study was that the rate of agreement between two board-certified cardiologists on whether to recommend coronary angiography for the same given patient was not much better than chance.

A particularly painful example of lack of objective medical criteria may be occurring right now under our eyes. For years, women over 40 years of age lived by the medical dogma that a yearly mammogram could detect breast cancer early enough to save them from death. In the early 90's, however, doubts grew about whether the test really helped women in this age group and now some experts question whether it saves anyone at any age. This shows both the uncertainty of scientific progress and the vagaries of scientific "truths" [4].

Various guidelines and protocols have been offered to overcome the problem of variability in clinical decisions, but a survey of medical experts who write guidelines for treating conditions such as heart disease, depression and diabetes has found that nearly 9 out of 10 of them have some financial ties to the pharmaceutical industry, and that these ties are almost never disclosed. It has long been known that contact with the pharmaceutical industry can influence an individual doctor's prescribing patterns and that financial support from drug manufacturers can affect the course of academic research as well. Eleven of the 44 practice guidelines were underwritten by pharmaceutical companies and carried statements to that effect. But, of the 44 guidelines, just one reported a potential conflict of interest [5].

This situation highlights the need for information transparency and the need of patients to know the hidden ties behind clinical recommendations. Making this information available will not decrease research and sponsorships: to the contrary, it will help to ease the pressure of researchers to comply with the sponsor's commercial motivations.

5. Health Literacy

Patients with the greatest health care needs may be least able to read and comprehend information that is necessary for them to function successfully as patients [10]. The Literacy Report of the Council on Scientific Affairs [9] makes the important point that communication with patients is facilitated when clinicians tailor health information to patients' literacy and comprehension levels. The report also notes that the National Adult Literacy survey from the US Department of Education found that nearly half of American adults have low-level reading skills [10]. In fact, the mean reading level of US adults is at grade 8, and the mean reading level of Medicaid enrollees is at grade 5.

Health literacy is a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment. Patients with adequate health literacy can read, understand, and act on health care information. There is disparity, however, between the skills needed for adequate health literacy and the literacy skills of many Americans. Numerous studies have documented [10] that health material and consent forms are often written at levels exceeding the average patient's reading skills. A study in general medical clinic at 2 public hospitals evaluated 402 patients with hypertension and 114 with diabetes mellitus and found that the patients' functional health literacy strongly correlated with knowledge of their illness.

According to the Council on Scientific Affairs], there are 5 principal reasons why health policy makers should care about the health literacy issue. First, low-literacy patients, by definition, can not be empowered consumers in a market-driven health care system. Second, patients who do not understand health care professionals' instructions will not receive quality medical care. Third, health professionals and hospitals can be liable for adverse outcomes by patients who do not understand health information. Fourth, poor literacy can result in substantial but avoidable costs for the Healthcare system's health care providers and the patients together with their families. Fifth, the poor literacy patients are the ones more likely be heavily dependent for their health care on public policy makers. [10]

6. Internet Access and the Digital Divide

A substantial digital divide continues to characterize computer and Internet use. The expanding use of the Internet has been paralleled by a growing interest in determining how effectively health information can be communicated through computer technology and the Internet and how likely the public would be to seek it. In the Nov/Dec 2000 issue of Health Affairs, Brodie et al [13] concluded that Americans with lower income are much less likely to use a computer or have Internet access than their higher income counterparts, as might be expected, and we see a similar digital divide among Americans with different levels of education. The widening of gaps makes it unclear how rapidly equal Internet penetration will be achieved.

7. Quality and Reliability of the Information on the Internet

The Internet is an increasingly important source of health-related information for consumers. One recent survey estimated that more than 60 million US residents went online in search of health information in the past year [12]. The ability to obtain accurate medical information quickly, conveniently, and privately presents to consumers an opportunity for better informed decision making and greater participation in care. Little is known, however, about whether the available material is sufficiently complete and accurate for sound consumer decision making. Several studies on single medical conditions have suggested deficiencies in the quality of Web-based health information [12]. Three unique studies were performed from July 2000 through December 2000. Their purpose was to evaluate health information on several health conditions through English- and Spanish-language search engines and web sites. The results showed that less than one-quarter of the search engine's first pages of links led to the relevant content. On average, 45% of the clinical features on English-language web sites and 22% on the Spanish-language ones were more than minimally covered and completely accurate, and that 24% of the clinical elements on English and 53% on Spanish Web sites were not covered at all. All the English and 86% of the Spanish web sites required high school level or greater reading ability.

8. Patients-Physicians as a Team

Clinicians are increasingly being encouraged to involve patients in their medical decisions. Such a partnership in decision making is very important but its needs to be based upon sharing information and mutual trust. I have earlier mentioned several of the difficulties still in existence in respect to patients' real ability to access and comprehend medical data.

The progress from the technological aspect has been tremendous but very little has been done to make the medical information not only accessible but understandable and, therefore, usable by the primary partner, namely, the patient. On the other hand, a recent study by Braddock and colleagues [14] found that 91% of patient-physician interactions failed to meet their definition of informed decision making. Their findings also suggest that physicians are doing only a fair job of educating their patients about how to arrive at well-founded clinical decisions.

In my opinion, the pendulum of patient empowerment has tilted too far and the only way for the gap in knowledge to narrow and for physicians to do better a job in involving patients in their own medical decisions is by a real sense of cooperation and real sharing of information.

Co-documentation and co-ownership of medical data will provide the patients with the opportunity to gradually assume more control even, or perhaps, especially, when they have become vulnerable and dependent for having been afflicted with a disease or condition. This approach will send the message to the medical staff that, together with the trust and confidence with which the patients have placed themselves in their hands, they are no longer indifferent to their own plight. The message to the patients is that they have not entirely abdicated their rights to decide their fate. Once the patients become masters of their medical data, they will also decide when and to whom to disclose their medical data, such as to care-providing institutions and for purposes of research. What I am advocating will entail embarking upon a long-term process, but the benefits that will result from this trend — one that has already been initiated by the posting of patient medical records on the Internet to be shared by patients and care providers alike — will be well worth the effort

References

[1] "The emergence of the E-Health consumer" 1999, A Health Care Study by Deloitte & Touche LLP & Deloitte Consulting LLC

[2] www.cyberdialogue.com/resource/data/cch/data.html

[3] www.physiciansnews.com/spotlight/700.html

[4] "The Painful Fact of Medical Uncertainty" by Gina Kolata. The New York Times, Feb. 10, 2002.

[5] Choudhry NK, Stelfox HT, Detsky AS. Relationships between authors of clinical practice guidelines and the pharmaceutical industry. J Am Med Assoc 2002;287:612-617.

[6] Lo B, Alpers A. Uses and abuses of prescription drug information in pharmacy benefits management programs. J Am Med Assoc 2000;283:801-806.

[7] Hammond WE. Call for a standard clinical vocabulary. J Am Med Assoc 1997;4;254-255.

[8] Rethans JJ, Saebu L. Do general practitioners act consistently in real practice when they meet the same patient twice? Examination of intradoctors variation using standardised (simulated) patients. Br Med J 1997;314:1170.

[9] Avian JZ, Landrum MB, Normand S-LT, Guadagnoli E, McNeil BJ. Rating the appropriateness of coronary angiography - do practicing physicians agree with an expert panel and with each other? N Engl J Med 1998;338:1896.

[10] Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association "Health Literacy Report of the Council on Scientific Affairs". J Am Med Assoc 1999;281:552-557.

[11] Berland GK, Elliot MN, Morales LS, Algazy JL, Krasvitz RL, Broder MS, Kanouse DE, Munoz JA, Puyol JA, Lara M, Watkins KE, Yang H, McGlynn EA. Health information on the Internet: accessibility, quality, and readability in English and in Spanish. J Am Med Assoc 2001;285:2612-2621.

[12] McLeod SD. The quality of medical information on the Internet. A new public health concern: Arch Ophthalmol 1998;116:1663-1665.

[13] Mollan B, Flournoy RE, Altman DE, Blendon RJ, Benson JM, Rosenbaum, MD. Health information, the Internet and the digital divide. Health Affairs- November/December 2000.

[14] Braddock CH III, Edwards KA, Hasenberg NM, Laidley TL, Levinson W. Informed decision making in outpatient practice: time to get back to basics. J Am Med Assoc 1999;282:2313-2320.