Consumer Health, Patient Education, and The Internet

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Abstract

Health Care in America involves a dynamic interplay between the health care consumer and several public and private entities. Studies
published by the Institute of Medicine show that the care these individuals
receive is less than efficacious. This paper reports on how the proactive health care
consumer can use the Internet to make sure the care they receive is safe, effective, patient-centered, timely, efficient, and equitable. To ensure this goal becomes a reality, programs need to be developed that train health care consumers to manage their care using the Internet, and foster a collaborative relationship with their health care provider.

Marshall McLuhan[1] predicted in 1964 that our current and future electronic technologies would create a "global village" where individual differences, beliefs, and practices would creature fission rather than fusion among the populations of the world. As we move deeper into the 21st century, the Internet has single handedly turned the world into a global village. Searchers can visit portals, web sites, chat rooms, and message boards that promote diverse beliefs and practices, while casting aspersions on the more traditional, authoritarian modes of communication and practice.

THE INTERNET: THE GREAT EQUALIZER?

Studies [2,3] purport that between 52 and 70 million Americans use the Internet to search between 10,000-100,000 [4,5] medically related web sites for information pertaining to their health. The average online health consumers are white, affluent, well educated and under the age of 65. This fact points out that ethnic groups, the less affluent, the less educated, and older Americans are in danger of being cut off from one of the most provocative communication mediums the 21st century has to offer[6].

The pervasiveness of the Internet enables health consumers to have access to information 24 hours a day, 7 days a week. Moreover, the Internet has the ability to break down traditional barriers of power by providing consumers with access to information that can be used to influence how decisions are made regarding their health care. For instance, the consumer can access: general medical references; synthesis of clinical medical studies', recommendations for care using evidence based medicine, report cards on hospitals, physicians, and health plans; and documentation on the variability of care across the United States. Recently, the Institute of Medicine (IOM)[7] reported that to improve the quality of care and better serve the needs of the consumer, the following principles must be inherent in the health care process: health care must be safe, effective, patient centered, timely, efficient and equitable. In the section that follows, this paper will focus will focus on these six principles. Intertwined within the discussion will be an explication of how the health consumer can use the Internet to make sure the care they receive adheres to these principles.

SAFETY

More people die annually in America from medically related errors than from breast cancer (42,297), AIDS (16,516) and motor vehicle accidents (43,458). With an estimated 98,800 fatal incidents, medical errors are the 8th leading cause of death in America[8]. Moreso, as the use of prescription drugs continues to rise, it is important to note that 7,000 Americans die annually from medication errors or from the adverse effect a drug has on their system. This fact takes on greater importance as the health consumer is continually bombarded by commercials for new drugs on the television, radio, and Internet. It is also important to note that each new drug has the power to cure or do irreparable harm.

Medical errors also include medical procedures that are performed on patients who were either not aware of the

risks, or did not believe the risks were serious. For example, one of fastest growing vision restoration procedures is Lasik surgery. Lasik surgery claims to free patients who suffer nearsightedness, farsightedness, and astigmatism from the drudgery of having to wear contacts or glasses. It has been estimated that in the year 2001 alone, over 1 million health consumers will have this procedure performed on their eyes[9,10]. However, what many of those 1 million consumers do not know is that the procedure is not as safe, simple and risk free as advertised. Specifically, this procedure can cause permanent, irreversible damage to a health consumers' vision, such as double or triple vision, problems driving at night, and severe dryness. In fact, the problem with dryness is so severe, Lasik patients report that sleeping can be difficult because their eyes become so dry that closing them for long periods causes severe pain. Pain that can only be relieved by peeling the eye lids open on an hourly basis and applying drops to lubricate the eye and quell the pain[11].

Another example would be a patient who has been prescribed the drug Lipitor. This consumer has several options when using the Internet to find information about the drug. The first logical site to visit would be Medline Plus[12], which is the National Library of Medicine's Online Database to health information. On this site, a health consumer can search the United States Pharmacopoeia for information on prescription drugs, their dosage levels, side effects, contraindications and any interactions that may occur when a drug is taken with other substances. Another useful site is Drugfacts [13]. Each site provides the health consumer with a wealth of information on the drug Lipitor. Using the tools at each site, a health consumer may read that along with lowering cholesterol and triglyceride (fat-like substances) levels in the blood, Lipitor can cause headaches, skin rashes, dizziness and liver function test abnormalities. Furthermore, the health consumer who begins taking the drug may read that they should refrain from ingesting high doses of grapefruit juice or niacin, as both substances can cause unwanted side effects.

To further promote levels of safety, health consumers can use the Internet to investigate their hospitals, health plans, and physicians. Before being admitted into a hospital, a health care consumer can visit the Joint Commission on Accreditations of Health Care Organizations site[14], which provides guidelines for the health consumer to use when evaluating a hospital. Furthermore, many state agencies are beginning to track information on hospital performance, making it available on the Internet. For example, Pennsylvanians can access the Pennsylvania Health Care Cost Containment Council[15] which provides information on how well Pennsylvania hospitals perform 21 of the most common medical procedures. The council also provides evaluative information on the state's major health care providers. For health consumers outside Pennsylvania, Health Grades[16] provides statistical information on hospital performance, while the National Committee for Quality Assurance (NCQA)[17] provides information on health care providers on a state by state basis.

A health consumer has several alternatives to evaluate the qualifications of a physician. To learn whether a physician is a member of the American Medical Association (AMA), health consumers can visit the AMA web site[18] and use Physician Select. To investigate whether a physician is board certified, the American Board of Medical Specialties web site[19] allows health consumers to research whether their current physician is board certified or to find a list of board certified physicians by specialty practicing in their local area. Finally, to find more detailed information on a physician, and whether a physician has been involved in legal litigation, a health consumer has three options. The first option is to visit the Association of State Medical Board Executives DocFinder[20]. This site continues to grow as more and more states make information about their physicians available. A second option is to use Ralph Nader's Public Citizen Health Research Group[21] web site, which not only grades a states' attempt to make physician information available to the public, but it provides direct access to physician information made available by state licensure boards. In each of these examples, the Internet can be used by the health consumer to find information that lessens the associated risk and uncertainty, and increases the level of safety as they consider using the facilities, services and providers that make up the health care system.

Use of the Internet will not prevent health consumers from having the wrong leg amputated, or the wrong knee operated on. Furthermore, it may not prevent consumers from receiving the wrong medication. However, what the Internet does provide is a fast, efficient and powerful tool for the consumer to use to investigate a hospital's safety record, a physician's background and qualifications, and the types of medications and treatments being recommended. The health consumer can use this gathered information to examine levels of safety in having an operation at a specific hospital, taking a prescribed medication, or the risks involved in having a procedure performed, such as Lasik surgery.

Veterans in the field of medical informatics will point out that much of this information is available in print form. However, to get at this information, the health consumer is required to visit medical libraries and sift through large volumes of highly specialized, arcane professional literature. The Internet equals the playing field by providing the health consumer with a means of quickly locating information so they can discuss issues related to their health with their physicians from a position of greater understanding.

EFFECTIVENESS

The practice of medicine follows a familiar pattern: a person feels sick, they make an appointment to see their physician, the physician gives them a physical examination, and asks them a set of questions. If warranted, the physician orders a series of tests and tells the patient they will be contacted with the results. Many times the results reveal an illness that can be cured with rest and an antibiotic. Other times they point to a more serious problem, like prostate or breast cancer. During any medical intervention, the health consumer must be concerned with how the physician arrived at their diagnosis. Moreover, the health consumer needs to ask: did the physician perform their duties and decide on a treatment based on "personal experience, or did they rely on studies in the medical literature"?[22](p32) These concerns are important because as Weinberg states: "Most people view the medical care they receive as a necessity provided by doctors who adhere to scientific norms based on previously tested and proven treatments. . . however, the type of medical service provided is often found to be as strongly influenced by subjective factors related to attitudes of individual physicians as by science".[23](p7) Wennberg calls physician subjectiveness the 'practice style factor', which are formed by a physician's experience; where they went to school; the geographic location where they practice; preferences for certain treatments, and lack of knowledge, which may also be influenced by the lack of certainty among medical professionals in terms of how effective a treatment will be in restoring a patient's health. Practice style factors lead to a great deal of variation among physicians in terms of the frequency that treatments and diagnostic tests are used across the United States. For example, the Dartmouth Atlas of Health Care[24] points out that men living in Baton Rouge, Louisiana, who are diagnosed with prostate cancer are more than twice as likely to receive a radical prostatectomy than men living in Pittsburgh, Pennsylvania, even though Pittsburgh has the second largest population of seniors next to Daytona County, Florida. Wennberg goes on to state that practice style factors or "local medical opinions regularly differ to the point that four times more people in one region get a surgery than do their neighbors".[25] Variation differences tell us that many health consumers are receiving treatments that can be based more on doctor preferences and less on evidence that the treatment works and is the best course of action for the patient.

The health consumer has several options when using the Internet to help evaluate the decisions made by their doctors and the treatments they recommend. The first option is the use of clinical practice guidelines, which are "systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances".[26] Clinical Guidelines can be accessed via the National Guidelines Clearinghouse.[27] These guidelines are built "on syntheses of the evidence, but go one step further to provide formal conclusions or recommendations about appropriate and necessary care for specific types of patients.[28] Guidelines can also be retrieved from the Canadian Medical Association[29], the Agency for Health Care Policy and Research[30], the University of California School of Medicine[31], and for those patients diagnosed with cancer, the National Comprehensive Cancer Network.[32]

The second option consists of using the Internet to find evidence on the practicality and usefulness of clinical interventions[33]. Several sites provide access to concise and regularly updated summaries and journal articles of the best available evidence on how well a specific treatment works. These sites include: the ACP Journal Club and Evidence Based Medicine[34], The Bandolier[35], Clinical Evidence[36], and the Cochran Collaboration[37]. The information available at these sites helps health consumers become knowledgeable in regards to a treatment's effectiveness and the associated risks. Moreover, this information can help the consumer take a more active role in the management of their health care by collaborating with, rather than passively obeying, their physicians on important decisions related to their care. However, when considering the consumer's role in the decision making process, an important corollary needs to be made that clearly delineates the boundary between patient and physician: "the patient is always right, but sometimes the doctor knows best".7(p32) There will be times when the consumer will request services that are not necessarily in their best interest. It is on these occasions that the physician must inform the consumer of the consequences that could result from a specific course of action, and if warranted, decline from providing services they feel are nonbeneficial. It is important to point out that the amount of variability that

exists between the use of different treatments should be based on patient needs and expectations and not on the subjective preferences of the physician.7(p74) As health consumers become more informed and begin to take a more active role in their health care, the practice of medicine can move towards a more patient centered orientation.

PATIENT CENTERED

In the previous section, the focus was on how patients can be more active and informed in their own care. For this to happen, physicians need to modify the care to the patient, not the patient to the care.22 Self help expert, Tom Ferguson stated that as patients gain a more active voice in caring for themselves, older health care delivery models will become obsolete. The current model of medical care, which Ferguson [38,39],5 calls the industrial age model, is based on a pyramid which has tertiary care on top, secondary care in the center, and primary care on the bottom. According to Ferguson, as the Internet continues to influence the practice of medicine, this industrial model will be replaced by an information age model. This model will take the form of an inverted pyramid and will contain six layers. These six layers from top to bottom include: individual self care, friends and family, self help and community networks, health care professionals as facilitators, health care professionals as partners, and health care professionals as authorities.

In the old industrial model, the physician is the first point of contact and the patient takes a passive role in the decisions regarding the care they receive. To maintain their authoritarian role, the physician must be familiar with between 200-300 illnesses and their treatment. This is quite a burden to carry, because in today's information age, it is quite unrealistic to assume that the physician can maintain working knowledge of the burgeoning biomedical literature available. This has lead to the growth of the information age model, where the health consumer enters the model at the top layer of individual self-care. Here, consumers can begin to develop a level of expertise regarding their medical problem by making use of use of search engines[40,41] and other specialty[42] and illness specific web sites[43] to locate information on their illness, identify various treatment regimens, review their effectiveness, retrieve and review clinical guidelines27,29,30,31,32, and even participate in clinical trials.[44]

In Layer Two, the consumer relies on the wisdom of their friends and family to learn more about their illnesses and find guidance on where to turn next to find more answers. Layer Three interactions are marked by the consumers participation in self help groups and online communities that impart experiential knowledge about an illness. Ferguson5 and Borkman[45] explain that self help groups are important because they provide health consumers with in-depth knowledge of what it is like to experience an illness from a deeply personal point of view. For example, doctors are concerned with treating a set of symptoms, but unless they have suffered from the illness themselves, they have no idea what it is like to live with a disease such as cancer, and how it can effect a consumer's lifestyle and their relationship with family, friends and colleagues at work. Self help groups provide consumers with in-depth knowledge of what it is like to live with an illness, undergo a specific therapy, how they will feel at specific points in the therapy, and even experiential information on the effectiveness of specific treatments. Self help groups[46] are easy to identify and many provide access to listservers[47] where members of the group exchange relevant experiential based information via e-mail and online chats.

The remaining layers in the model deal with a consumer's relationship with health care professionals. In Layer Four, the health consumer makes contact with a physician or related health care professional who works with the consumer as a coach or facilitator. This leads to a collaborative effort (Layer Five) where the health care consumer and physician work together to negotiate decisions based on the consumers needs, preferences and, most important of all, clinical evidence. In Layer Six, the consumer engages a health care professional as an authoritarian in a crisis or emergency situation, where they have been rushed unconscious to the emergency room, become handicapped, or considered incompetent. Ferguson39 reported that many encounters between the patient and physician are still defined as Layer Six interactions. To remedy this problem, patients must take on the role of self-helper, while physicians must be willing to accept a more collaborative arrangement between themselves and their patients.

Studies[48,49,50,51,52,53] showed that when the patient takes the initiative or is given the freedom to ask questions, discuss and investigate treatment options, express their opinions and concerns, and state preferences they will experience measurably better health outcomes than more passive health consumers.49 This new active of the consumer role should not be seen as a threat to the physician, but as an advantage

where consumers can help their physicians remain current in the burgeoning world of medical information. The physician can use their experience and knowledge to guide the health consumer in making choices that are suited to their needs and preferences. In the end, this can help the healing process take place in a more timely fashion.

TIMELY

A person who is sick, newly diagnosed, or must decide between various treatment options can ride an emotional roller coaster filled with uncertainty and fear. To allay these feelings, a health consumer needs information and some reassurance that something can be done to alleviate their suffering in a timely fashion. However, due to demands placed on today's health care professionals, this vital information is not always forthcoming, or it is not presented in a manner in which the consumer can understand. This has a tendency to heighten a consumers' level of uncertainty, causing undo stress and exacerbating present symptoms. To eliminate their levels of uncertainty and fear, the health consumer has several available options to pursue when using the Internet to find more information. First the Internet, when used judiciously, can help consumers identify a set of symptoms and then link those symptoms to a possible illness. The consumer can then use this information to work with their physician to reach a decision on the next best possible course of action. Second, the newly diagnosed patient can use the Internet to learn more about an illness. This knowledge will allow consumers to ask more intelligent questions of their health care providers. Third, the Internet can be used to investigate current and alternative treatment regimes and the existing clinical evidence that shows which treatments work best based on consumer preferences and their specific case histories7. Finally, the Internet can be used to help the already healthy consumer find information that allows them to maintain a healthy lifestyle. When used as a tool to gather health related information, the Internet can help health care consumers get the care and treatment they need in a timely manner.

EFFICIENCY

As consumers use the Internet to procure health related information, the practice of medicine in America can begin to take place in a more efficient manner. As health consumers make use of clinical guidelines and web sites that disseminate evidence based information on treatments and their effectiveness, variability among doctors can be lessened. Furthermore, as Kendall and Levine[54] pointed out, consumers can begin to use the Internet to learn how they can avoid the risk of disease or injury; how to detect a problem before it becomes more difficult to treat, and how they can get their health back when they become sick or injured. Using the Internet in this fashion, allows health consumers to take a more proactive stance toward their health. For example, consumers who are diagnosed with an illness can follow a set of guidelines that pilot their physicians in the further diagnosis and treatment of the illness. These guidelines can protect the consumer from having to undergo unnecessary tests and treatments. Furthermore, use of treatments by physicians based on sound medical evidence will only lead to a health care system that is more efficient and less wasteful of not only the resources of the consumer, but those of public and private health care entities.

EQUITY

The Internet does not discriminate based on age, sex, religious belief and national origin. It is a service available to all individuals who own a computer, or reach the Internet via a public accessible computer, 7 days a week, 24 hours a day. Therefore, because of its pervasive, democratic nature, the Internet is the perfect tool for breaking down the barrier between people who have the information they need to make decisions regarding the type of health care they receive, and those who do not. However, even though the Internet has the power to equalize the barriers between the information haves and have nots, and improve the overall health care process, two factors need to be considered before health can be considered safe, effective, patient centered, timely, efficient, and equitable. These factors are education and the Internet's acceptance among health professionals as an important information resource for the dissemination of health care information to the health consumer.

EDUCATION

For health consumers to use the Internet judiciously, they need to be educated on how to use Internet search tools to locate relevant information. Philosophically, learning to use the Internet to help manage one's health is like learning how to read all over again. To achieve this goal, the author proposes that health consumers be given instruction providing them with a mental model of what the Internet is and how it works, a firm grounding in search engine technology and how they can be used to locate health related information; techniques to evaluate information found on a web site; and guidance in finding information on the quality of the hospitals, health plans, physicians, and treatments they will encounter as they receive care. With this knowledge, the

health care consumer will be armed with the abilities they need to locate information to help them make important decisions regarding their health care. However, it is important for every health care consumer to realize that they cannot make these decisions without the help of a knowledgeable and collaborative health care professional.

HEALTH CARE PROFESSIONALS

Stories abound of doctors confronted by patients, reamfuls of information gleaned from the Internet in hand, who challenge the physician's knowledge by asking: “why didn't you tell me about this?” As more and more individuals use the Internet to gather health related information, this scenario is likely to continue unless health care professionals take a more proactive role in helping health care consumers use the Internet to find medical information. In one scenario, a physician who diagnoses a patient with prostate cancer, can guide that patient to a set of web sites they have personally evaluated and contain relevant information about the disease, its treatments, the side effects of those treatments, and the prognosis for recovery. Alternatively, physicians and physician practices can begin to build their own web sites that contain links to recommended web sites. On these sites, physicians can build their own digital libraries. These digital libraries can contain links to more detailed sites and even links to articles the physician has read and believe will be beneficial to the patient's understanding of their medical problems and their treatment. This action can work in a two fold fashion: first it can help doctors who are already pressed for time educate their patients using a medium that more and more of their patients will use to find medical information. Second, this action can work to reassure patients and make them feel they are getting the information and attention they need to make accurate decisions regarding their health. In taking a more proactive role in terms of the Internet and its use, physician's can work collaboratively with their patients towards the creation of a health care environment that is safe, effective, patient centered, timely, efficient, and equitable.

With the rise of the Internet, now more than ever, the health care consumer has instant access to information and products that claim to cure everything from the common cold to various forms of cancer. This new found ability, all at once, puts the health care consumer in both a privileged and precarious position. Privileged because with an appropriate mental model of how the Internet works and how it can be used to locate health related information, an online health consumer has the power to become an expert in a selected health related topic. Precarious, because the consumer can fall prey to medical quacks[55], outdated and erroneous information, and a wide array of products and devices that do not work as advertised, or adversely affect individual health.[56] Ultimately, the dynamic between the health care consumer and the Internet, can profoundly impact the quality of care received, relationships with health care providers, and the roles played in the management of individual health care.

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