The Doctor as the Second Opinion and the Internet as the First

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Abstract

People who use the Internet for health information often obtain their first opinion that way, and then, if they go to a doctor, the doctor's advice is relegated to the second opinion. Using the Internet, or Dr. Google, as a first opinion can be problematic due to misinformation, misinterpretation of valid information, and the fears that can arise due to lack of medical knowledge, inexperience, and limited perspectives. When patients do visit their doctor for a second opinion, some do not disclose the fact they already received their first opinion and often their doctors do not ask. The result is that patients may suffer needlessly if their fears, concerns, misunderstandings, and misinterpretations are not addressed by the healthcare providers with the expertise and skills to assist them. A pernicious disconnect exists between many patients who use the Internet for health information and the medical professionals who care for them. The medical profession can alleviate this disconnect by taking the lead in establishing guidelines for systematically talking to patients about, and guiding, their Internet research. Human-computer interaction professionals can collaborate with the medical community in ensuring credible health Web sites become the gold standard that patients use to achieve better health.

Keywords

Health, medicine, doctors, patients, Internet, Web site, user experience, context of use, health literacy, search, Dr. Google, health communication, patient-provider communication, human-computer interaction professionals

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

In many domains, the Internet has dramatically changed how people get the information and services they need. For example, in finance and travel, the Internet provides consumers with the information and self-service model that they can use to make decisions and perform transactions without interacting with a broker or travel agent.

In healthcare, the traditional doctor-patient relationship has not been disintermediated by the Internet. Instead, a distinct shadow system exists largely in parallel with the professional healthcare system: The use of the Internet by healthcare consumers for diagnosis, education, and support.

The Use of the Internet for Healthcare

Eighty-four percent of American adult Internet users, or about 160 million people, looked for health or medical information online in 2007, up from 80 percent in 2006, according to a 2007 Harris poll [8]. The Pew Internet and American Life Project similarly reports that 80 percent of Internet users in the United States have researched health and medical advice online [2]. As

Internet use increases globally, the use of the Internet for health is likely to increase as well.

The initial use of the Internet for health was for online support groups [14]. As the Internet evolved, patients expanded their Internet use to learn about a disease or condition, to determine whether professional medical care is needed, to get a diagnosis, to learn what treatment options exist, and for peer support from people with similar conditions [16]. Most recently, Web 2.0 health Web sites, which include user-generated content and collaborative features, are encompassed in the definition of Health 2.0 [18, 19].

The Affect of Poor Health-Literacy Skills

Health literacy denotes the skills necessary to understand and use health information. Most patients who engage in online activities do so without the knowledge, experience, and objectivity of medical providers and without sufficient health literacy skills. The result is that many patients cannot understand or act on medical information, whether received online or during a doctor's visit [12]. Health literacy skills include many that are pertinent to the use of the Internet, such as locating and evaluating information for credibility and quality and analyzing relative risks and benefits of treatment options [3].

Poor health literacy is compounded by the uneven quality of online information, lack of education or guidance about how to use the Internet for health purposes, and the desire for miracle cures and easy solutions. While highly reliable health information is available online, other information is of poor quality, misleading, or outright dangerous [5]. For example, a recent YouTube video viewed thousands of times

depicts a treatment that incorrectly claims to reverse the effects of Alzheimer's disease [6]. In another instance, a woman's extensive online search located a cure for her husband's ALS (Lou Gehrig's disease) in another country even though doctors have yet to sanction a cure [Berman, personal communication, October 21, 2008].

While some people start looking for health information at well-known and established Web sites, such as MayoClinic.com and WebMD.com, most health information seekers, just like seekers of other types of information, start at a general search engine such as Google or Yahoo [2]. This has led to common references to Dr. Google and comments that "Google is the de facto second opinion" [6, 17, 19].

Often health information searches display mixed quality results that include advertisements and sponsored links; these are sometimes barely discernable from links to reliable resources. People choose the links to follow with little guidance other than their ranking in the results page. Using the resulting Web sites, people may reach conclusions or act on what they read without the knowledge, experience, objectivity, or health literacy skills to make an informed decision.

Yet more than half of health-information seekers report that their most recent online health information session affected how they care for themselves or someone else [2]. They may make decisions in isolation, without the awareness of or feedback from the very people who can best make accurate diagnoses and guide informed decisions: medical professionals.

The Internet Has Become Many People's First Medical Opinion

Many people reflexively turn to the Internet to look up symptoms, diagnose a problem, and determine what to do about it, including the basic question as to whether professional medical care is needed at all in addition to Dr. Google [2]. For many of these health-information seekers, the Internet is not their second opinion [19], but their first. When they receive professional medical care after first using the Internet, the physician's advice becomes, in fact, a second opinion.

In some cases, the first opinion is the only opinion used. People may make significant health decisions, often in their best interest, or learn how to treat a health problem on their own. A symptom checker can advise when immediate attention is needed for a possibly serious health problem, but a doctor provides further exploration of symptoms and signs, an appropriately focused physical exam, and any testing that may still be necessary before an assessment and differential diagnosis can be accurately produced.

Doctors can misdiagnose, too, but the Internet has many limitations as a screening tool. The worst scenarios occur when people are satisfied with Dr. Google and do not seek further medical help when it is, in fact, warranted. No data exists about the frequency with which a doctor's appointment is needed but not scheduled.

In many cases, the first opinion from the Internet leads directly or indirectly to seeking the second opinion. Patients may receive advice from a Web site to seek professional medical treatment or may be so overwhelmed, frustrated, confused, or frightened by

what they find online that they decide to see a doctor [2]. In either case, frequently the Internet-provided first opinion is not communicated to the doctor. The lack of communication occurs in both directions; patients often do not talk about their research and diagnosis, and doctors rarely inquire about their patients' Internet use, focusing instead in the conventional manner of addressing symptoms and making a diagnosis [6].

Why Physicians Don't Ask

One reason physicians don't ask patients whether they have consulted online health sources is that doing so is not part of their training [4]. Initiatives such as managed care and pay-for-performance may have the unintended adverse consequence of reducing the already often limited provision of patient education [1, 15]. Another reason physicians don't ask is lack of time during appointments.

Yet another reason is the negative image of patients who are confrontational because they already are convinced of their diagnosis or who walk in armed with the "enthusiastically clutched ream of Internet printouts" [20]. Some physicians may feel that a patient's Internet research is not relevant since they, as professionals, must rely on their own expertise, patient interviews, and diagnostic procedures regardless of what the patient found online [6, 7].

Why Patients Don't Tell

The negative image of the patient who has reams of printouts or who confronts the doctor is more mythical than real. In fact, many patients never bring printouts, and more significantly, they don't disclose their online health research to their doctor, even when they have found that first opinion, or are confused or scared by what they read [2].

The reasons for lack of disclosure include not wanting to appear stupid, not being comfortable with the pronunciation or definition of medical terminology, wanting to test the doctor's knowledge or diagnostic skills, or wanting to see if the doctor's opinion agrees with their own or with Dr. Google's [11]. Other major reasons are that patients aren't asked and that they don't know how to raise the subject and fear being thought disrespectful if they do.

Many patients don't want to voice their worst fears or come across as a cyberchondriac, a term that was coined to describe people who believe they have a disease that they read about online [6]. Their disinclination to talk about what they read is compounded by the vulnerability patients experience by having to ask health-related questions while attired in a paper gown and knowing that there is limited time for their appointment.

The Consequences

Thus, patients' Internet research and their visits to their doctors are largely disconnected even though patients, doctors, and most creators of health Web sites all share the same purpose: to help patients become healthier. Since a strong doctor-patient relationship is partially based on trust, undisclosed research can erode the patient's trust in the doctor without the doctor even being aware of it. It also disrupts continuity of care in the patient-treatment process.

A common example of this is when the fears and concerns a patient had prior to the visit are not

addressed and incite more worry or further research. For instance, a patient with a pre-conceived diagnosis who receives a different diagnosis from the doctor may be skeptical of the accuracy of the doctor's diagnosis if the original one was not explicitly discussed.

Because the lack of health-literacy skills can lead to poor comprehension and retention of information during a doctor's visit, many patients leave a doctor's visit confused and ill-informed. While there are ways the consultation can be restructured to mitigate this [15], many patients leave their doctor without the answers they sought or with new questions, and, hence, immediately go online to conduct a search for Dr. Google's third opinion. Without recommendations or assistance from the doctor in locating high quality and relevant information, patients conduct their research in isolation. Once again, the doctor didn't ask, and the patient didn't tell.

True Story: A Mother Incorrectly Diagnoses Whooping Cough
Mary Ann P. went online because her 10-year-old daughter had a cough that persisted for six days and kept her out of school [Mary Ann P., personal communication, January 9, 2009]. She was looking for potential home remedies to help calm the cough so that her daughter would be more comfortable, be able to rest, and recover.

On the Internet, she discovered that her daughter's symptoms were similar to those of whooping cough. One Web site she consulted even had an audio clip of a coughing child with whooping cough, which sounded just like her daughter's cough. Based on what she read and heard online, Mary Ann also wondered if the

effectiveness of her daughter's babyhood immunization was fading.

Armed with this information, Mary Ann took her daughter to see a nurse practitioner during the so-called sick-kid drop-in hour the morning after searching online. Mary Ann didn't tell the nurse practitioner about her Internet research because she wanted her to observe her daughter's symptoms and make her own diagnosis based on her training and experience. Mary Ann also did not want to "sound stupid" if her whooping-cough suspicion was unfounded.

The nurse practitioner told Mary Ann that her daughter just had a cold and a bad cough. Mary Ann was relieved, of course, although she wondered if the time and worry from her Internet research were worthwhile. Her daughter got better quickly; if she hadn't, Mary Ann's worries about a diagnosis of whooping cough could have persisted and she would have returned to the doctor's office. If the health professional had asked, it would have been easy for Mary Ann to voice her concerns, and she might have even learned more about the diagnostic process the nurse practitioner used so she would know more about correctly diagnosing whooping cough.

True Story: A Patient Brings Critical Medical Information to a Doctor and Nurse about Treatment for Bat Bites
One morning Diana C. woke up to find a bat in her bedroom [Diana C., personal communication, April 17, 2008]. Not knowing that bats should be captured and tested for rabies, she forced it out a window. The next day she noticed marks on her shoulder. When they reddened and became itchy, she remembered the bat

and searched online. Diana identified the marks as a bat bite by measuring the distance between the teeth on a life size picture of a bat and comparing that to the marks on her shoulder. Although she knew that bat bites were uncommon where she lived, she learned that rabies transmitted by a bat bite can prove fatal if not treated within 48 hours; she went to the emergency room for appropriate treatment.

Diana told her doctors what she found online and sought confirmation that it was, in fact, a bat bite. She insisted on getting both the first doses of the vaccine plus the rabies immunoglobulin within the 48 hour post-bat exposure time frame. Diana's Internet-first opinion got her to the emergency room. The doctor's second opinion confirmed the first opinion, and the nurse used Diana's online information to guide the way she cleansed the wound. In this case, a patient significantly contributed to her own treatment by bringing accurate information to the doctor about what she needed.

True Story: Internet-Induced Panic
Based on the results of an online symptom checker, Julie Z. feared she had uterine cancer. [Julie Z., personal communication, June 3, 2008]. She was unable to make an appointment with her doctor until a week after noticing the first symptoms. While waiting, she relentlessly searched the Internet scaring herself "to death" by the information she found about severe cases.

Julie tried to talk to her doctor about the information she read online about uterine cancer, "but all he said was, 'We cannot know until we do the biopsy', which may have been medically true but didn't calm my fears," Julie related. "My anxiety led me to search obsessively. Plummeting [into] the depths of the Internet is far more responsive to my needs since I can openly search on any topic that I can think of related to my concern."

Julie's test results came back negative and her obsessive searching ended. She and Diana both shared the benefits of using the Internet to prompt them to go for medical evaluation, but Julie also suffered one of the same consequences as Mary Ann, since the information she found alarmed her. Julie's doctor could have recognized and responded more to her concerns, but Julie tried to be respectful of his time and did not disclose the extent of her fears or of her obsessive online research.

What Can Patients Do To Use the Internet More Effectively?
Patients can strive to become empowered healthcare consumers, a term that refers to patients who have effective health-literacy skills and who use the Internet judiciously and safely. The term also optimistically implies that, through their knowledge about health problems and what to do about them, the burden on the medical system may be reduced. But little training or education is available to empower healthcare consumers on how to use the Internet in conjunction with the medical profession; many, like Mary Ann, Diana, and Julie, develop these skills on their own through persistence, determination, or need.

In fact, patients rarely receive specific guidance on how to use the Internet generally or for health specifically. People rarely check for quality seals, information about sources, the date material was created, and any

funding or sponsorship on health Web sites [2]. Accrediting agencies, such as HONcode [9] and URAC [21], exist, but most people don't know about them and don't check Web sites for their seals indicating compliance with the accrediting agency's standards. As the barriers become lower for creating Web sites, quality indicators become more important for the public's protection. Yet, this works only if consumers know about and understand the indicators.

Poor health literacy impacts patients in their adherence to prescriptions and a multitude of ways related to their use of the Internet [3]. Web 2.0 and the now-touted Health 2.0 [18] are not a panacea for helping patients in their use of the Internet for health and may even be disadvantageous for patients who do not distinguish between expert- and user-generated content. Poor health literacy can be somewhat mitigated by better education from doctors and other health professionals.

Furthermore, patients can be given guidance by their healthcare providers in how to integrate their Internet research with their visits. Doctors rarely invite patients to bring Web-based information or resources with them to appointments. It would assist patients if they were told whether to bring printouts or questions arising from their Internet research, how to bring up online research with their physician, or even the optimal point in the consultation to mention the Internet. Some of this could even be mediated by a nurse or nurse practitioner, but with the doctor ultimately involved.

Ideally, some of this information exchange can occur outside an office visit, but a mechanism is needed for that to happen. Many physicians do not even have e-mail contact with patients.

What Can Doctors Do?
Doctors can acknowledge that many of their patients go online before a visit. They can specifically address the difference between presenting symptoms and presenting a diagnosis acquired through online research. And they can ask patients about any lingering concerns about the diagnosis or treatment.

Doctors can also recommend health Web sites that will save patients time and effort. Perhaps most importantly, physicians can educate their patients about how to recognize high-quality health-related information as well as about cues that betray the absence of credibility.

Doctors are often Internet users, and the more they use it for their own and their patients' health concerns, the more knowledgeable and adept they become. They can also learn about patients' perspectives and their experiences of illness through discussion forums and patient blogs [6]. Some doctors even write their own blogs or create Web sites for their practice.

With the amount of medical literature to keep abreast of, doctors have less time than ever before. Even small amounts of time devoted to helping their patients find beneficial Web sites could benefit those patients; this could be facilitated by medical societies rather than each doctor bearing the responsibility.

Questions from patients arising from their Internet research could be addressed in advance of an appointment. In practices where patients are handed a clipboard with a form to fill in while in the waiting room, a new section could be about Internet use, specifically which Web sites they use and the questions that their

research provoked. Since doctors have different patient-interaction preferences, how to handle Internet use can be decided individually or within a practice and communicated in advance to patients. However, doctors are afraid of being inundated with information that is irrelevant or excessive. A successful strategy needs to address what patients communicate and the communication mechanism and process.

What Can Human-Computer Interaction Professionals Do?

Human-computer interaction professionals can collaborate with the medical community to develop a gold standard for consumer health Web site design. Gold-standard Web sites need to take into account the context of usage [13], e.g., the needs of healthcare consumers like Mary Ann, Diana, and Julie who seek a diagnosis or answers to their questions [2, 19]. While accrediting agencies like HONcode and URAC look at many factors in accrediting a Web site, these do not include the user experience.

Ultimately, anyone using a health Web site is trying to feel better or stay well. The design and evaluation of health Web sites, focusing on users' experience and context of usage, can lead to sites that better meet patients' needs regardless of their health-literacy skills and diagnostic or educational needs.

But while patients may be the primary users of health Web sites, doctors are the secondary users because of their role in treating patients who use these Web sites or recommending Web sites to newly diagnosed patients. Doctors' user experience as secondary users must also be considered for health Web sites to be successful. Finally, professional medical societies and

government agencies may ultimately be best suited to develop standards and guidelines, in collaboration with human-computer interaction professionals, because they have the most at stake in improving the healthcare system. Regulatory requirements will provide the most consistent consumer protection.

In addition to the improvements resulting from design and evaluation processes accommodating the needs of patients and doctors, the Web sites themselves can provide guidance on how to use their content safely, more effectively, and in conjunction with professional medical care. Beyond symptom checkers that recommend contacting a doctor or visiting an emergency room, this type of guidance is rare.

Conclusions

Today, the medical community fails to acknowledge the extent to which patients do health-related online research. More information is needed about the reasons patients rely heavily on the Internet. Why do they use it for their first opinion? And why do they not disclose to physicians what they learn online about their possible diagnoses, as well as the fears or empowerment that their online reading provokes?

Patients benefit if they are more knowledgeable and have better relationships with their doctors. Doctors benefit if their patients are more knowledgeable and less confrontational or fearful. These should become shared goals supported by medical societies and government agencies and facilitated through consumer health Web sites. These recommendations for doctors, patients, and human-computer interaction professionals can each contribute to safer use of the Internet for

health and better integration with professional medical care.

Much attention and funding has been given to electronic medical records (EMRs) initiatives because the efforts are aimed at both reducing healthcare costs and improving patient care. Yet there is debate about whether EMRs and other initiatives, such as managed care and pay-for-performance, improve the quality of patient care [10]. Funding should also be provided to study how patients' free-form use of the Internet affects patient health and healthcare costs, such as avoiding unnecessary emergency room and office visits or empowering patients.

Many questions need to be answered, such as how the use of the Internet can best help patients in the context of seeking, not just information, but better health outcomes; how to develop and promote a gold standard for health Web sites that the medical community endorses; how health literacy can be improved; and how patient-doctor consultations can better integrate patients' Internet research in ways that benefit both patient and provider. With 80 percent or more of Americans of all ages, to say nothing of Internet users in other countries, using the Internet for health, improving healthcare should be a collaborative priority of the medical and human-computer interaction communities.

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