Medical Internet Ethics: A Field in Evolution

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Abstract

As in any new field, the merger of medicine, e-commerce and the Internet raises many questions pertaining to ethical conduct. Key issues include defining the essence of the patient-provider relationship, establishing guidelines and training for practicing online medicine and therapy, setting standards for ethical online research, determining guidelines for providing quality healthcare information and requiring ethical conduct for medical and health websites. Physicians who follow their professional code of ethics are obligated not to exploit the relationship they have with patients, nor allow anyone else working with them to do so. Physicians and therapists are obligated to serve those who place trust in them for treatment, whether in face-to-face or online Internet encounters with patients or clients. This ethical responsibility to patients and clients is often in direct conflict with the business model of generating profits. Healthcare professionals involved in Medical Internet Ethics need to define the scope of competent medical and healthcare on the Internet. The emerging ethical issues facing medicine on the Internet, the current state of medical ethics on the Internet and questions for future directions of study in this evolving field are reviewed in this paper.

Keywords:

Internet; Ethics, Medical; Ethics, Professional; Physician-Patient Relation; Code of Ethics; Research Ethics

Materials and Methods

Available, published articles were located with an OVID MEDLINE search for "Internet" and "Ethics, Medical," "Internet" and "Ethics, Professional." Additional articles and information were retrieved from pertinent online medical journals, related organization websites and relevant medical listserves: MWM-L (Medical Web Masters List), ISMHO (International Society of Mental Health Online), and AIR-L (Association of Online Researchers, AoIR).

Introduction

The primary objective of the medical profession is to render service to humanity; reward or financial gain is a subordinate consideration.

AMA Principles of Medical Ethics [1]

The Internet

The Internet is a new medium, one that blends numerous previous methods of human communication into one. This medium also allows for new forms of communication such as specialized resources, self-assessment tools, videos, online support groups, bulletin boards, and chat rooms.

This new "CyberSpace Frontier," much like the American Wild West of old, is relatively unregulated. It is easy to create a professional-appearing cybershingle on the Internet, so that legitimate practitioners and charlatans alike can create a cyberpresence. This new frontier has the potential of providing the public with a wealth of legitimate information about their health, and also of exposing them to volumes of unregulated, misleading information. Unregulated websites promoting unproven cures, creating false hopes and espousing incorrect information have proliferated. "The Good, The Bad and The Ugly" can equally create websites.

Medical Ethics

For many physicians the decision to enter medicine is akin to answering "a calling." This calling involves a dedication similar to that seen in the clergy or public service. Under the ancient tenets of the Hippocratic oath, physicians vow to uphold the injunction, *"primum nom nocre,"* first do no harm. The profession of medicine demands a commitment to service, patient advocacy, and social responsibility. This commitment has traditionally taken precedence over economic interests. [2]

Medicine's code of ethics is far more stringent than the law. The American Medical Association has established a code of conduct for their members that defines conflict of interests. This code confirms the primary goal of the medical profession to render service to humanity emphasizing that *reward or financial gain is a subordinate consideration* and *under no circumstance may physicians place their own financial interests above the welfare of their patients.* [1]

However, online entrepreneurs, business and medical, continue to try and cash in on the Internet, with its promise of great potential wealth, often placing their own financial interests above the welfare of patients. These actions are in direct conflict with the AMA's Principles of Medical Ethics and other codes of conduct. Unethical behavior has been a major impetus for establishing Medical Internet Ethics.

A Field in Evolution—Medical Internet Ethics

In this field of Medical Internet Ethics, there are five distinct areas that require codes of ethical conduct to be established:

- Defining the essence of the Doctor-Patient, Patient-Provider, Client-Therapist Relationships
- Establishing guidelines and regulations for practicing online medicine and therapy
- Setting standards for conducting online ethical research
- Determining guidelines for providing quality medical and health (healthcare) information on the Internet
- Requiring ethical conduct for healthcare websites

Discussion

The Patient-Provider Relationship

The Internet is changing the patient-provider relationship, whether physician-patient, or client-therapist, and the paradigm under which medicine and therapy has been practiced for centuries; one based on the presumption that in order to treat, the physician or provider must see the patient to diagnose. Healthcare professionals need to define the patient-provider relationship for online care.

Several organizations are working to determine the essence of the patient-provider relationship. The mental health community has been leading the efforts to define and determine the therapeutic benefits of online therapist-client relationships. The International Society for Mental Health On-line (ISMHO), the Psychiatric Society for Informatics (PSI), and the National Board of Certified Counselors (NBCC) are examining online services and working to establish guidelines for e-psychiatry, e-therapy and web-counseling. In January 2000 the ISMHO and the PSI endorsed Principles for the Online Provision of Mental Health Services defining the online client-therapist relationship and what constitutes providing online mental health services. [3] The NBCC has established standards for the ethical practice of web-counseling. [4]

Organizations in the medical community are exploring the nature of the physician-patient relationship. The AMA's Committee on Ethical and Judicial Affairs will determine the essential elements of the physician-patient relationship and how the traditional relationship can be translated for use within the new technology. [5]

Online Medicine/Online Therapy

Online physicians and therapists are innovators, expanding the boundaries of physician-patient, or client-therapist relationships and exploring the types of interactions and services that can be provided over the Internet. Key to adapting principles of medical ethics to the Internet is determining what obligation exists between the physician or therapist and website visitor. This may not be easy. One of the early pioneers in health websites, Dr. C. Everett Koop, felt no doctor-patient obligation towards visitors to his website, because they were not "his" patients. [6] Does a physician consultant to a website have an ethical obligation to visitors? At what point is there a patient-provider relationship? Do any of the ethical guidelines that guide and protect the patient-provider relationship apply in cyberspace? Or is it reduced to a medical/healthcare provider-consumer one? Under professional codes of conduct, healthcare providers are obligated to serve those who trust them to treat them. This obligation is part of the face-to-face encounters with patients or clients and logically should be extended to online Internet encounters. But, what are the limits of online medicine or online therapy? Does an online relationship require an off line one as well? What is the ethical obligation of unsolicited e-mail? These are important questions that must be carefully considered and answered by medical ethicists to establish guidelines for Medical Internet Ethics.

Another issue regarding online practice is whether healthcare providers need a special license to practice on the Internet. In the field of telemedicine many states require licensure in their state before an out-of-state physician can electronically provide services to patients. [7] Some propose an independent, international body to assess "cyberdocs" and issue a special license to practice in cyberspace. [8] Medicine may be better served by adopting the consensus reached in e-psychiatry; the idea that the patient travels along the information highway to visit their provider in his/her office, the same way as he/she would to travel to see the provider if the provider was in another state. Viewed this way, online practices would not require special state licensure. [9]

Once guidelines for online medicine and therapy have been established, special training programs for online practitioners could be instituted to educate potential e-providers about online medical ethics obligations and Internet legalities.

Research on the Internet

Several issues are important regarding Internet research.
- Determining the validity of online surveys
- Researching vs. "Lurking" in online settings
- Right to privacy vs. collecting research information
- Ethics of soliciting for research participants, online

Many traditional research techniques do not adapt well for use on the Internet. The anonymity of the Internet makes it difficult to obtain a truly randomized, unbiased study population for an online survey. It is impossible to know why someone did not complete a survey. Perhaps they did not notice the form, perhaps they did not want to participate, or perhaps they were afraid of being tracked. Thus, results are biased for those that have the inclination, the ability or the time to complete a survey. [10]

With the new forms of communication—chatrooms, message boards and listserves—creating new online arenas to study, one fundamental issue is whether these online arenas are considered public or private. Many researchers believe that they can design studies to monitor discussion groups as long as they do not identify subjects in research projects. Can a researcher "lurk" in a chatroom to collect research data? Are researchers obligated to disclose their presence if they are "observing" in chatrooms, knowing their presence may alter participant's behavior? Does participating in public forums imply informed consent? These are other ethical questions that will need to be answered.

Researchers may want to follow a visitor's path through a site, and extrapolate the thought process behind their pattern. The capabilities exist to include highly sophisticated tracking methods for following visitors at a website. Sophisticated tracking mechanisms using Java technology may be acceptable for use at a standard website, but should be implemented with caution at medical sites. Because of the potentially sensitive nature of medical/health information, visitors to medical/health websites should have their privacy respected and not unknowingly have their viewing habits and choices recorded and analyzed. Does visiting a website imply informed consent to have private information tracked?

Using the Internet for patient recruitment came under scrutiny when a prominent medical website was criticized for not disclosing a financial arrangement between a research organization and the physician involved in the website. [6] Equally concerning is the development of an online tracing system to identify and recruit patients with rare diseases. [11] Strict guidelines will need to be implemented to prevent insurers, employers and unscrupulous entrepreneurs from harnessing technology for profit, to the detriment of privacy.
The American Psychological Association has established ethical principles for conducting ethical research that could be adapted for online research. [12] In light of the growing concern about controversial online research practices, the Association of Internet Researchers (AoIR) is working to establish guidelines for conducting online research.

Guidelines for Quality Medical and Health Websites

The nice thing about standards is that there are so many of them to choose from.

Andrew S. Tanenbaum

Online ethics on commercial medical websites came to the forefront in the fall of 1999 after several prominent medical and health websites exhibited questionable ethical behavior. Medical ethicists and patient advocates called for a code of conduct for medical and health websites after complaining that Internet healthcare companies neither disclosed their relationship with advertisers nor clearly distinguished medical content from promotional materials on their websites. [13]

One of the first codes of conduct for health and medical websites was created by the Health on the Net Foundation (HON) in 1996. The HON code is well-recognized in the medical Internet community with a membership of over 3,000 websites in 36 countries. [14] Also in 1996, The British Healthcare Internet Association published their Quality Standards for Medical Publishing on the Web. [15]

In 1997 the American Psychological Association's (APA) Ethics Committee provided guidelines to their members for dealing with services provided by telephone, teleconferencing and the Internet, [16] and the *Journal of the American Medical Association* proposed guidelines for medical websites. [17] Dr. George Lundberg depicted the roots of the medical Internet as compromising medical ethics, journalism ethics, business ethics and the ethics of medical editing, when Medscape published their advertising policy, "The Ethics of the Medical Internet," in September 1999. [18]

During 2000 there was a flurry of activity surrounding Medical Internet Ethics. In March the AMA published guide-lines for their medical and health websites. [19] In May the Internet Healthcare Coalition (IHC) released the Internet Healthcare Coalition's eHealth Ethics Initiative International Code of Ethics. At a conference in October representatives from the eHealth Ethics Initiative of the Internet Healthcare Coalition, Health on the Net Foundation (HON) and Hi-Ethics (Health Internet Ethics) agreed to "create a coordinating committee to establish the common glossary of definitions and terms." [20] In September the MedCERTAIN consortium sponsored a workshop to establish a set of consensus quality criteria for health related websites where a Collaboration statement of purpose and the Consensus Recommendations on Trustmarks were drafted. [21] Also in September URAC ("American Accreditation HealthCare Commission," see www.urac.org,

to explain the discrepancy in their name) appointed members to its Health Web Site Advisory Committee, with representatives from many of the prominent healthcare organizations. In February 2001, URAC released their Draft Health Web Site Accreditation Standards for public comment and by March 2001 started accepting pre-applications for web site accreditation. [22]

With so many organizations vying to set "the" standard for reviewing and judging quality in medical websites, healthcare providers and consumers alike are left asking: Which is the most authoritative? Who has the "best" code? Who is ensuring that the websites are in compliance with their own codes? Who has the fewest competing interests? Which organization is the most ethical—putting patients and consumers first, ignoring outside competing interests and monetary incentives? Which organization should I believe? In this emerging field of online medicine, there is a great prestige factor as well as great financial incentives to be "the" organization recognized as assigning quality seals, providing site accreditation, or training for online healthcare practitioners (think "certification fees"). MedCERTAIN and URAC are both striving to emerge as "the" organization to assign quality seals or provide for a web site accreditation program, respectively. [23, 24]

One can hope that the agreement of reached by several organizations at recent meetings and conferences is an indication of movement in the right direction towards finally adopting one common Medical Internet Ethics code.

Economics of E-health and Ethical Conduct

Healthcare is a late arrival to e-commerce, although most analysts agree that the long-term potential for online health is still enormous. Business-to-consumer healthcare commerce is anticipated to grow into a $70 billion industry by 2003, while business-to-business healthcare commerce is expected to become a $170 billion industry over the same period. [25] Drug companies and private companies are investing heavily to create a presence on the Internet. There are an increasing number of new online medical business models: selling professional services or healthcare products, creating a high profile health or medical portal (Drkoop.com, Intelihealth, WebMD), or providing services to physicians and healthcare providers (Medem, Medscape, MEDePass).

Even with the recent decline in the so called "dotcoms," the potential for monetary gains from healthcare sites for physicians continue to be great. Yet, according to the AMA's Patient-Physician Covenant, "Physicians, as physicians, are not, and must never be, commercial entrepreneurs, gateclosers, or agents of fiscal policy that runs counter to our trust." [26] How will physician consultants to medical e-commerce solve what appears to be an apparent conflict of interests? By redefining the physician-patient relationship to be a provider-consumer in e-commerce terms of the Internet?

Conclusion

Medical and health websites differ from other Internet sites because they deal with personal information about people's health. Many Internet users believe their movements are not being tracked, that they can "surf" anonymously at websites for information about potentially controversial subjects—AIDS, Herpes, Suicide—and not fear repercussion. Without enforceable guidelines for creating healthcare sites and ensuring privacy, and standards for conducting online research, Internet users risk their private life unexpectedly becoming public and face potential repercussions if insurance companies, employers, friends or family discover confidential information about their health.

Consequently, medical website designers, writers, backers, consultants, e-health marketers, healthcare providers and physicians must understand the unique position they are in with online healthcare consumers. All those involved in the creation, maintenance and marketing of healthcare websites should be required to adhere to a strict code of medical Internet ethics. Medical websites, more than any other type of site on the Internet, should ensure visitors' personal privacy and prevent personal medical information, including patterns of use from being sold, purchased, or inadvertently entering the hands of marketers, employers, and insurers. [19]

In order for patients to feel confident about the medical and health information they obtain at a website, a standard set of ethical guidelines for medical/health websites needs to be adopted and enforced, possibly by a new international Internet medical organization. The past unifying successes of the WHO or UNESCO could be utilized to create an International Internet Board, that could establish and enforce international Internet regulations in addition to codifying Medical Internet Ethics. The adoption of the UN-sponsored "ebXML" has shown that the United Nations can be an effective catalyst for standard-setting. [27] National efforts make it too easy for less scrupulous healthcare entrepreneurs to transparently move their Internet company to the most permissive jurisdiction they can find.

Research will need to be done to further understand the patient-provider relationship and how the practice of medicine or therapy can be translated to the Internet. An effective code of Medical Internet Ethics may eventually require additional training for healthcare providers who want to practice online medicine or therapy. New methodology for conducting online research will need to be developed along with guidelines for conducting ethical online research.

Maintaining a strong internal code of ethics by which to practice has always been a core component of medicine. Physicians should honor their professional code of ethics to serve and not exploit their patients, whether in face-to-face or online encounters. This ethical obligation to patients and

clients may be in direct conflict with the business model of generating profits. Online entrepreneurs and non-medical professionals may not understand the ethical obligations of the patient-provider relationship, and they should be educated not to exploit online patients or clients and follow a Medical Internet professional code of conduct. We should remember that the practice of medicine involves a commitment to service, not to economic interests. Patients—on or off line—ultimately come first.

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