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Ethical Issues in Consumer Health Informatics

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Principles of Ethics as a Framework for Consumer Health Informatics

Medical ethics are used to guide conduct and action. Many stakeholders come into play when considering how consumers obtain their health information. In addition to the consumer, we must consider the spectrum of clinicians (physicians, nurse educators, physical therapists, dieticians, etc.), as well as those people and organizations who create information materials for consumers (e.g., pharmaceutical companies, publishers, government groups, Web companies). With the growth in use of the Web for health information, it becomes critical to consider the ethical roles and responsibilities of the various stakeholders. Five guiding ethical principles form the basis for evaluating moral conduct in health care: autonomy, veracity, beneficence, nonmaleficence, and justice [1–3,22,23].

- **Autonomy**: self-determination, right to privacy, individual freedom, fundamental to informed consent
- **Veracity**: telling the truth, keeping promises, open patient–physician relationship
- **Beneficence**: doing good, promoting the well-being of others, professional obligation to help those in need
- **Nonmaleficence**: avoiding harm to others; protecting patients from danger, pain, and suffering (Hippocratic oath)
- **Justice**: fairness, respect for equality of all humans, equitable allocation of scarce resources, consideration of social policy.

Autonomy is relevant because it is the patient who is making choices about his or her own health care based on good quality information. Inasmuch as the physician and patient decision aids provide information about available treatment options, the principle of veracity is also important. The respect for autonomy and duty to inform truthfully are intimately related and concordant in patient decision aids and Web sites. As agents for the benefit of the patient, in the course of treatment both information tools and physicians must be beneficent and nonmaleficent. The moral obligations of fairness, respect, equality, and equity all play a role in the recommendation of treatments in the context of shared decision making and within computer tools for consumers.

Relating Ethical Principles to Consumer Health Informatics

In this chapter we discuss ethical issues relating to how consumers use Internet technology for health information, obtaining medicine or therapy and social support. Several topics at the forefront of consumer health informatics have important ethical implications. For example, the privacy and security of a consumer's medical information is a clear concern to the vast majority of consumers. Privacy and security of information are explicit goals of the ethical principle of autonomy. The quality and reliability of the information found on the Web is highly variable and difficult for consumers to judge. Conflict of interest on health Web sites is a rampant problem. Oftentimes it is difficult to distinguish sites that are selling or promoting a medical product from those attempting to provide unbiased material and recommendations. Health Web site developers have an ethical responsibility to convey accurate and current information. Interestingly, even for organizations without a product or advertising, creating and maintaining Web sites takes significant funding and effort to do well. Beyond fundamental honesty, some interesting questions would be to determine how good is "good enough" or how current is "current enough." Similarly, from the programmer's point of view, there is a question as to how much testing to ensure accurate performance is required to be "good enough." Oftentimes, ethical goals are confronted by practical business goals, and it is important to create clear policy to promote ethical principles. This type of policy can be set as voluntary guidelines or as regulations enforced by a governmental organization.

Ethical issues are particularly challenging in the environment of consumer health applications for several reasons: health is important and the stakes are high, consumers are not the experts in the domain of knowledge required to judge value and to protect themselves, Web sites can be created quickly and inexpensively by nearly anyone, both regulation and verification by experts are difficult because of an extremely large number of sites and the dynamic nature of material on the Web; and finally the technologies are constantly changing, creating new capabilities with further ethical implications.

Ethics and Quality Assurance on Consumer Health Sites

Judging the quality of information we receive in our daily lives is always difficult. Our information comes from a variety of sources (TV, newspapers, magazines, professional journals, books, and the Internet). However, judging the quality of health materials on the Web is particularly challenging for consumers. There are minimal monetary and skill barriers to creating Web sites, and it is fairly easy to make a site look quite professional and indistinguishable from those of larger, well-established organizations. Not all sites are "peer reviewed," published, or created by professionals with expertise in the topic covered. Because the quality of health information is so critical for consumers, several organizations have created guidelines for judging the quality of information on the Web for consumers [4–6,24]. Some of the criteria included in all of these guidelines are topical relevance, currency of the information, accuracy, and authoritativeness or objectivity.

The accuracy of health information on a Web site, insofar as it can be ascertained, is a basic concept relating to quality. Some professional health sites (both for-profit and nonprofit) have professional writers with domain expertise and also a board of reviewers to ensure accuracy of their material. Oftentimes, consumers are advised to judge sites with .gov or .edu extensions as having more accurate and unbiased information, as compared with .com sites. Naturally, although this heuristic may be useful as a first pass, it is oversimplified. Unless a health Web site has funding for both quality development and maintenance of content, it is very easy for information to go through a careful quality assurance process and still become outdated [21]. For the consumer of information, trying to find proxies for quality can be difficult. The following are some criteria that have been suggested:

- Credentials of information provider (Is there an advisory board?)
- Qualifications of advice providers (Are they licensed health care professionals?)
- Credibility of content (no wild promises)
- Full disclosure of sponsor of Web site (purpose of the Web site)
- Attribution clearly noted, including copyright.

From the consumer's point of view, topical relevance is certainly important when assessing the usefulness and quality of a Web site. The relevance of a site is context specific and depends on the particular question an individual consumer has in mind. To find appropriate materials, sites must be clearly organized and/or have intelligent search functions. In addition, the relevance of material on a Web site depends on the degree to which it is tailored to the individual and appropriate to his or her specific needs. Most health material on the Web is generic and not interactively tailored to individuals. This basically replicates what could be found in a textbook or brochure. The final aspect of relevance to an individual has to do with whether the material is action oriented and helps the consumer either make a healthcare decision that may lead to an action or a health behavior change.

Currency or the timeliness of information on a Web site itself is an important consideration. It is often difficult to have a generalized policy on how often health materials need to be updated. However, most professional sites ensure at least quarterly review of all materials. Consumers may judge the currency of Web site information by looking for date stamps or a notice of date of creation and/or update. On the ethical front, it is important to note that some Web sites use algorithms to update their time stamp automatically even if the material has not been changed or even reviewed, giving the impression that the information is current.

Thus, from the developer's point of view there are substantial ethical issues in creating health information sites for consumers. In addition to navigating conflict of interest, fraud, and inaccuracies, there are also the more murky decisions on the time and resources to put into Web site development and testing. Providing health information and interventions over the Internet is becoming an increasingly important component of health care. Ensuring that the materials are unbiased, accurate, relevant, and timely is fundamental to providing quality health care.

Ethics and Shared Decision Making

Shared decision making is now acknowledged by many as a viable alternative to what used to be a typical doctor-centered "paternalistic" model of care [7–11]. Shared decision making involves a two-way flow of information: from doctor to patient regarding treatment options, positive and negative effects, and the likelihood of such effects; and from patient to doctor regarding such factors as personal preferences, values, and constraints. Shared decision making also includes a shared deliberation or negotiation about the preferred treatment and a choice. Thus, shared decision making relates to the self-determination aspects of the ethical principle of autonomy.

The drive toward a paradigm of sharing treatment decision making has come about because of the realization that in many clinical situations (most often involving chronic diseases) there is no one best treatment option for all patients. Outcomes for many treatments are inherently uncertain at the individual patient level, and individual patients have differing risk tolerances, which affect their treatment preferences [8]. In circumstances in which multiple treatment options exist, making a decision often involves making tradeoffs between various attributes and outcomes. This process is value laden and based on patient preferences. In addition, it is now recognized that many patients wish to actively participate more fully in decision making and become more explicitly informed about their illness and options for treatment [12]. Nevertheless, the fact that not all patients prefer to play an active role in the decision making process or in making the final choice must not be neglected in the context of shared decision making.

The guiding ethical principles that serve as the foundations of shared decision making and patient decision aids are sometimes challenged and present dilemmas that must be addressed when they are incorporated in the patient–doctor decision making process. A useful approach to guiding ethical decision making in medicine was developed by three clinical ethicists (a philosopher—Jonsen, a physician—Siegler, and a lawyer—Winslade) [13]. The process can be thought of as the "ethics workup," similar to the "History and Physical" skills that all medical students come to use when learning how to "work up" a patient's primary complaints. Although this method has deep philosophical roots, the approach closely reflects how clinicians actually think through difficult cases. It is also appropriate for structuring knowledge content development for computer tools for patients.

The approach is to consider the following four topics as a way to organize the facts of the particular case at hand.

- *Medical indications*: a review of diagnosis and treatment options
- *Patient preferences*: how a patient values the potential health outcomes
- *Quality of life*: the objective of all clinical encounters is to improve, or at least address, quality of life for the patient
- *Contextual features*: the wider context beyond physician and patient which includes the family, law, hospital policy, insurance companies, and so forth.

These four topics are present in every clinical problem domain. In the design of computer tools for consumer use, it is important to incorporate the ethical concepts related to shared decision making in an explicit manner. These guidelines argue for interactivity, tailoring, and assessing patient preferences for potential health outcomes.

Privacy and Security of Patient Data

A recent survey on the attitudes of consumers on healthcare Web sites administered by the California Healthcare Foundation found that 88% of consumers do not want their health information shared without their consent [14]. In addition, the California Healthcare Foundation found that the privacy policies and practices of many prominent healthcare Web sites lacked proper protective measures for consumers' health information.

The Federal Trade Commission (FTC) is the governmental organization that regulates privacy practices. In its recent review of prominent Web sites, it found that several of the organizations were sharing information about their users with third parties (such as advertisers) without the permission of the users of their site. In fact, three of these sites were health Web sites [15]. The California Healthcare Foundation has also found that many Web sites, including those of pharmaceutical companies, have not ensured adequate privacy protection for consumers. The main findings of their report include [14]:

- Visitors are not anonymous, even if they think they are.
- Privacy policies fall short of truly safeguarding consumers.
- An inconsistency between policies and practices exists.
- Security is not adequate to protect health information.
- Few sites disclaiming liability for third parties can guarantee those entities are protecting visitors' health information.

The ethical principle of autonomy includes the notion of a patient's right to privacy, but clearly this principle is often violated in consumer health applications. In response to these reports and ongoing press coverage, many sites have begun to adhere to ethical codes and guidelines, signified by a posted code on their Web page. Examples of self-regulatory initiatives include [6,16–19]:

- Hi-Ethics: emphasizes privacy, security, credibility and reliability
- American Medical Association's Principles Governing Web Sites
- Health On the Net Code of Conduct: emphasizes reliability and credibility
- Internet Healthcare Coalition's eHealth Code of Ethics
- Verified Internet Pharmacy Practice Sites Program: for pharmaceutical companies

The Web sites that have adopted these voluntary guidelines and regulations have been proactive in responding to the public's concern about the privacy and security of information. The primary piece of legislation and regulation in this area is the Health Insurance Portability and Accountability Act of 1996 (HIPAA). This act creates very strict requirements for ensuring the security and privacy of patient information. Although it is not clear how HIPAA may apply to the full spectrum of health Web sites, most organizations with Web sites for patients are taking care to be in full compliance proactively.

Ethics and Etiquette of Online Virtual Communities

Online virtual communities are growing in importance in health care. Many of these communities are focused on specific diseases or conditions, where social support and problem solving are important components of care. These include both electronic bulletin boards for posting messages or real-time online chat rooms. Some of the communities are facilitated or moderated by healthcare professionals. In other cases, there may be an experienced patient who serves as a coach or facilitator. Social support and online problem solving by patients contributes significantly to improving health outcomes. However, several ethical concerns merit clarification as new participants join a group. Some sample issues are covered in the World Wide Web's Virtual Library site [20] covering the Ethics and Etiquette of Internet Resources. These include guidelines for social interactions (netiquette), copyright information, as well as advice on how to protect privacy while participating in online virtual communities. Although there may be no formal regulations for a health Web site, the guidelines around respect and privacy are similar to those for face-to-face group support meetings. Many organizations that provide forums for virtual communities employ moderators for these groups to ensure that ethical principles are followed.

Conclusion

The guiding ethical principles discussed in this chapter are considered essential as the moral underpinnings of guidelines and regulations that serve as codes of ethical conduct for all parties involved in the delivery of health information and health interventions via the Internet. We have examined the ethical issues from the perspective of patients, clinicians, Web site developers, and Web site sponsors. The dynamic nature of the Web environment, and of technology development in general, offers continual new challenges for ethicists and stakeholders in this area. It is encouraging to see the grassroots efforts of the consumer health informatics community to self-regulate and help ensure that patients have an opportunity to access unbiased, secure, and high-quality health information and interventions. The ethical challenges we face are not always clear cut, but the five guiding ethical principles have served as a useful framework for facilitating a powerful new component of health care—consumer health informatics.

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