3.1.1 Privacy in Health Care

Protecting information gathered in association with the care of the patient is a core value in health care. However, respecting patient privacy in other forms is also fundamental, as an expression of respect for patient autonomy and a prerequisite for trust.

Patient privacy encompasses a number of aspects, including personal space (physical privacy), personal data (informational privacy), personal choices including cultural and religious affiliations (decisional privacy), and personal relationships with family members and other intimates (associational privacy).

Physicians must seek to protect patient privacy in all settings to the greatest extent possible and should:

(a) Minimize intrusion on privacy when the patient's privacy must be balanced against other factors.

(b) Inform the patient when there has been a significant infringement on privacy of which the patient would otherwise not be aware.

(c) Be mindful that individual patients may have special concerns about privacy in any or all of these areas.

AMA Principles of Medical Ethics: I,IV

Background report(s):

CEJA Report 3-A-16 Modernized *Code of Medical Ethics*

CEJA Report 2-I-01 Privacy in the context of health care

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AMA Principles of Medical Ethics: I,IV

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS[]

CEJA Report 2 - I-01

Subject: Privacy in the Context of Health Care

Presented by: Frank A. Riddick, Jr., MD, Chair

Presented to: Reference Committee on Amendments to Constitution and Bylaws (Robert T. Gibbons, MD, Chair)

Recently, the Council on Ethical and Judicial Affairs (CEJA) presented a Report addressing ethical concerns raised by filming patients in health care settings.[1] In so doing, it came to the attention of the Council that, although Opinions included in the AMA's *Code of Medical Ethics* allude to the concept of privacy, none speaks to the issue directly. Therefore, the Council offers the following Report to provide general ethical guidance on the issue of privacy.

SCOPE

The Council recognizes that the topic of privacy has received considerable attention by Congress; medical privacy and confidentiality of identifiable health information have been subject to federal legislation. The Health Insurance Portability and Accountability Act (HIPAA) was enacted in 1996 and included provisions directing Congress to pass privacy legislation by August 1999. After Congress was unable to pass the legislation which was intended to regulate the use of health information created or maintained by health care providers,[2] the Secretary of Health and Human Services (HHS) issued a set of privacy rules. The specific rules that were developed created a considerable amount of concern among health care professionals as to whether the privacy protections might hinder the patient-physician relationship more than enhance it. Recently, HHS addressed some of these concerns in order to balance the need to respect patient privacy and confidentiality with the need to ensure efficient medical care.[3] Essentially, the rules attempt to strike a balance between privacy protection and public health considerations, including access to records for public health uses including public health, research, and investigation of abuse, neglect, and violence.[4]

Regardless of the effectiveness of the current federal privacy regulations, underlying these regulations are important ethical concepts of which all physicians should be respectful and which, therefore, warrant further analysis by the Council.

CONCEPTUAL DEFINITIONS OF PRIVACY

In the United States, privacy is linked to freedom from intrusion by the state or other persons. It also is understood to refer to a domain of personal decisions about important matters. In less legalistic forms, privacy can be viewed as a necessary condition for maintaining intimate relationships that entail respect and trust, such as love or friendship.

[] Reports of the Council on Ethical and Judicial Affairs are assigned to the reference committee on Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.

Respect and trust are also important in professional relationships, such as between patients and physicians. Moreover, in the health care setting, privacy has come to be linked most directly with one's ability to make decisions related to one's body without intrusion by others.

According to two leading bioethicists, several forms of privacy are particularly relevant in the context of health care, 1) physical, which focuses on individuals and their personal spaces, 2) informational, which involves specific personal data, 3) decisional, which focuses on personal choices, and 4) associational, which refers to family or other intimate relations. Such respect for patient privacy is a fundamental expression of patient autonomy and is a prerequisite to building the trust that is at the core of the patient-physician relationship.[6]

From the perspective of the HIPAA regulations, informational privacy has been the focus of most debates since it relates to matters such as the disclosure of health information, more specifically disclosure of health information via electronic transmission, and the use of electronic communication. However, to view privacy as merely limiting access to information about an individual misses significant components of privacy that are of particular concern in the context of health care.[6] Specifically, physical privacy is an issue that has been neglected in recent debates but remains important to many patients. Although there are limitations to the physical privacy in a health care setting, physicians can strive to protect it, for example by providing care in a more private area when possible.

Privacy as it relates to confidentiality

Confidentiality is one of the oldest medical ethical precepts, dating back to the Hippocratic Oath: "What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself, holding such things shameful to be spoken about."[5] Drawing from its rich history, confidentiality remains widely acknowledged as a fundamental ethical tenet of medicine, as patients must be willing to confide sensitive and personal information to health care professionals.[6] Therefore, its value in the context of the patient-physician relationship stems partly from the need for patients to trust their physicians, and for physicians to express their loyalty to patients.

Privacy and confidentiality are companion concepts. Both are in the opposite realm of what is defined as "public," and relinquishing personal privacy is always a precondition for establishing confidentiality. However, it is also important to note that they differ. In particular, privacy can refer to singular features of persons such as thoughts or feelings. Most importantly, it has been considered as a right or interest. In contrast, confidentiality always refers to a relational context whereby a person makes a promise, that information divulged by another person will not be further disseminated.

Even though many patients view confidentiality as an unwavering safeguard, there are of course exceptions. Similarly, privacy is not absolute. The provision of affordable and efficient care often requires that patients come to health care facilities, rather than receive care in their home. In such settings, space is relatively scarce, and unavoidably patients must share many common areas, and even rooms. Disclosure of personal information will be required for effective treatment, and many health care providers, and ancillary parties will know any decisions made.

ETHICAL FOUNDATIONS AND IMPLICATIONS

According to the concept of autonomy, an individual has the ability to act freely in accordance with a self plan,[6] and can participate in the decisions that influence his or her "fundamental sense

of personhood."[7] The principle of respect for autonomy can be viewed in two ways: as either a negative or a positive obligation. As a negative obligation, the principle states that autonomous actions should not be subjected to the constraints of others. Respect for autonomy as a positive obligation requires promoting decisions based on choices that reflect an individual's values and preferences. [6]

Clearly, autonomy has direct bearing on the manner in which a patient receives care. Physicians respect patient autonomy by ensuring that a patient is given appropriate information on which a decision regarding medical care can be based. Furthermore, in the context of health care, the concept of autonomy often intersects with the concept of privacy. For instance, the lack of physical privacy can influence a patient's actions or decisions. A patient may be preoccupied with his or her environment because it lacks privacy to the point where it is not possible for the patient to engage in an open discussion. This would result in undermining the informed consent process, such that decisions made by the patient would be a poor reflection of his or her true values or preferences.

As briefly discussed above, the concept of privacy is linked to confidentiality as a means of protecting patients' informational privacy. In effect, confidentiality concerns the communication of private and personal information from one person to another, where it is expected that the recipient of the information will not disclose it to a third party. This concept is reiterated in Principle IV of the AMA's *Code of Medical Ethics,* which states, "A physician…shall safeguard patient confidences and privacy within the constraints of the law."[8] The belief that information will be appropriately handled extends to another key ethical concept, that of trust – or reliance upon the moral character and competence of another person.[6] When patients trust their health care providers, their decisions are an expression of their autonomy. In contrast, when a lack of trust exists, a breakdown in communication is more likely to occur, such that choices are not adequately presented to a patient or the patient is reluctant to express preferences.

CONCLUSION

Aside from the legal protections that are offered by the right to privacy, there are such important ethical elements that it ought to receive careful consideration in the context of health care. Indeed, whether it is physical, informational, decisional, or associational, each manifestation of privacy has direct repercussions on the ability of a patient to act autonomously. Moreover, it is important to recognize that confidentiality speaks primarily to the issue of informational privacy, but that the notion of trust, which is a cornerstone of the patient-physical relationship, requires that a patient's privacy be respected in all of its aspects.

Recommendation

The Council recommends that the following be adopted and the remainder of the report be filed:

> In the context of health care, emphasis has been given to confidentiality, which is defined as information told in confidence or imparted in secret. However, physicians also should be mindful of patient privacy, which encompasses information that is concealed from others outside of the patient-physician relationship.
>
> Physicians must seek to protect patient privacy in all of its forms, including 1) physical, which focuses on individuals and their personal spaces, 2) informational, which involves specific personal data, 3) decisional, which focuses on personal choices, and 4) associational, which refers to family or other intimate relations. Such respect for patient

privacy is a fundamental expression of patient autonomy and is a prerequisite to building the trust that is at the core of the patient-physician relationship.

Privacy is not absolute, and must be balanced with the need for the efficient provision of medical care and the availability of resources. Physicians should be aware of and respect the special concerns of their patients regarding privacy. Patients should be informed of any significant infringement on their privacy, of which they may otherwise be unaware.

REFERENCES

The Council wishes to acknowledge the contributions of Matthew Wynia, MD, MPH, and Mary Kuffner, JD, in the development of this Report.

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[8]American Medical Association. *The Code of Medical Ethics*. 2000.