

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS[□]

CEJA Report 2 - I-01

Subject: Privacy in the Context of Health Care

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

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7 SCOPE

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9 The Council recognizes that the topic of privacy has received considerable attention by Congress;
10 medical privacy and confidentiality of identifiable health information have been subject to federal
11 legislation. The Health Insurance Portability and Accountability Act (HIPAA) was enacted in
12 1996 and included provisions directing Congress to pass privacy legislation by August 1999.
13 After Congress was unable to pass the legislation which was intended to regulate the use of health
14 information created or maintained by health care providers,² the Secretary of Health and Human
15 Services (HHS) issued a set of privacy rules. The specific rules that were developed created a
16 considerable amount of concern among health care professionals as to whether the privacy
17 protections might hinder the patient-physician relationship more than enhance it. Recently, HHS
18 addressed some of these concerns in order to balance the need to respect patient privacy and
19 confidentiality with the need to ensure efficient medical care.³ Essentially, the rules attempt to
20 strike a balance between privacy protection and public health considerations, including access to
21 records for public health uses including public health, research, and investigation of abuse,
22 neglect, and violence.⁴

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

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28 CONCEPTUAL DEFINITIONS OF PRIVACY

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

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

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

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

21 22 Privacy as it relates to confidentiality

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

32
33 Privacy and confidentiality are companion concepts. Both are in the opposite realm of what is
34 defined as “public,” and relinquishing personal privacy is always a precondition for establishing
35 confidentiality. However, it is also important to note that they differ. In particular, privacy can
36 refer to singular features of persons such as thoughts or feelings. Most importantly, it has been
37 considered as a right or interest. In contrast, confidentiality always refers to a relational context
38 whereby a person makes a promise, that information divulged by another person will not be
39 further disseminated.

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

47 48 ETHICAL FOUNDATIONS AND IMPLICATIONS

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

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

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

16
17 As briefly discussed above, the concept of privacy is linked to confidentiality as a means of
18 protecting patients’ informational privacy. In effect, confidentiality concerns the communication
19 of private and personal information from one person to another, where it is expected that the
20 recipient of the information will not disclose it to a third party. This concept is reiterated in
21 Principle IV of the AMA’s *Code of Medical Ethics*, which states, “A physician...shall safeguard
22 patient confidences and privacy within the constraints of the law.”⁸ The belief that information
23 will be appropriately handled extends to another key ethical concept, that of trust – or reliance
24 upon the moral character and competence of another person.⁶ When patients trust their health
25 care providers, their decisions are an expression of their autonomy. In contrast, when a lack of
26 trust exists, a breakdown in communication is more likely to occur, such that choices are not
27 adequately presented to a patient or the patient is reluctant to express preferences.

28 29 CONCLUSION

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

38 39 Recommendation

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

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43 In the context of health care, emphasis has been given to confidentiality, which is defined
44 as information told in confidence or imparted in secret. However, physicians also should
45 be mindful of patient privacy, which encompasses information that is concealed from
46 others outside of the patient-physician relationship.

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48 Physicians must seek to protect patient privacy in all of its forms, including 1) physical,
49 which focuses on individuals and their personal spaces, 2) informational, which involves
50 specific personal data, 3) decisional, which focuses on personal choices, and 4)
51 associational, which refers to family or other intimate relations. Such respect for patient

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

3
4 Privacy is not absolute, and must be balanced with the need for the efficient provision of
5 medical care and the availability of resources. Physicians should be aware of and respect
6 the special concerns of their patients regarding privacy. Patients should be informed of
7 any significant infringement on their privacy, of which they may otherwise be unaware.

REFERENCES

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¹ Report of the Council on Ethical and Judicial Affairs. “Filming Patients in Health Care Settings.” (CEJA Report 3-A-01).

² Christiansen, John R., Esq. “Health Information Technology and Privacy: The Legal Perspective.” *MD Computing*. (July/August 1999): 15-16.

³ HIPAA guidelines. www.hhs.gov/ocr/hipaa September 18, 2001.

⁴ M. J. Friedrich. “Health Care Practitioners and Organizations Prepare for Approaching HIPAA Deadlines.” www.jama.com. October 3, 2001.

⁵ Hippocratic Oath. <http://www.humanities.cuny.cuny.edu/history/reader/hippoath.htm>

⁶ Beauchamp, Thomas and James Childress. *Principles of Biomedical Ethics*. Fifth edition. Oxford; Oxford University Press. (2001).

⁷ American Medical Association. *The Ethical Force Program: Creating Performance Measures for Ethics in Health Care*. (January 2001): 7-9.

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