

CHAPTER 3: OPINIONS ON PRIVACY, CONFIDENTIALITY & MEDICAL RECORDS

The Opinions in this chapter are offered as ethics guidance for physicians and are not intended to establish standards of clinical practice or rules of law.

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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

3.1.2 Patient Privacy & Outside Observers to the Clinical Encounter

Individuals legitimately present during patient-physician encounters include those directly involved in the patient's care, and can include other members of the health care team or employees of pharmaceutical or

medical device companies when they are present to provide technical assistance, in keeping with ethics guidance.

When individuals who are not involved in providing care seek to observe patient-physician encounters, e.g., for educational purposes, physicians should safeguard patient privacy by permitting such observers to be present during a clinical encounter only when:

- (a) The patient has explicitly agreed to the presence of the observer(s). Outside observers should not be permitted when the patient lacks decision-making capacity, except in rare circumstances and with the consent of the parent, legal guardian, or authorized decision maker.
- (b) The presence of the observer will not compromise care.
- (c) The observer understands and has agreed to adhere to standards of medical privacy and confidentiality.

Under no circumstances should physicians accept payment from outside observers to allow those observers to be present during a clinical encounter.

AMA Principles of Medical Ethics: I,IV,VIII

3.1.3 Audio or Visual Recording Patients for Education in Health Care

Audio or visual recording of patients can be a valuable tool for educating health care professionals, but physicians must balance educational goals with patient privacy and confidentiality. The intended audience is bound by professional standards of respect for patient autonomy, privacy, and confidentiality, but physicians also have an obligation to ensure that content is accurate and complete and that the process and product of recording uphold standards of professional conduct.

To safeguard patient interests in the context of recording for purposes of educating health care professionals, physicians should:

- (a) Ensure that all nonclinical personnel present during recording understand and agree to adhere to medical standards of privacy and confidentiality.
- (b) Restrict participation to patients who have decision-making capacity. Recording should not be permitted when the patient lacks decision-making capacity except in rare circumstances and with the consent of the parent, legal guardian, or authorized decision maker.
- (c) Inform the patient (or authorized decision maker, in the rare circumstances when recording is authorized for minors or patients who lack decision-making capacity):
 - (i) about the purpose of recording, the intended audience(s), and the expected distribution;
 - (ii) about the potential benefits and harms (such as breach of privacy or confidentiality) of participating;
 - (iii) that participation is voluntary and that a decision not to participate (or to withdraw) will not affect the patient's care;
 - (iv) that the patient may withdraw consent at any time and if so, what will be done with the recording;

- (v) that use of the recording will be limited to those involved in health care education, unless the patient specifically permits use by others.
- (d) Ensure that the patient has had opportunity to discuss concerns before and after recording.
- (e) Obtain consent from a patient (or the authorized decision maker):
 - (i) prior to recording whenever possible; or
 - (ii) before use for educational purposes when consent could not be obtained prior to recording.
- (f) Respect the decision of a patient to withdraw consent.
- (g) Seek assent from the patient for participation in addition to consent by the patient's parent or guardian when participation by a minor patient is unavoidable.
- (h) Be aware that the act of recording may affect patient behavior during a clinical encounter and thereby affect the film's educational content and value.
- (i) Be aware that the information contained in educational recordings should be held to the same protections as any other record of patient information. Recordings should be securely stored and properly destroyed, in keeping with ethics guidance for managing medical records.
- (j) Be aware that recording creates a permanent record of personal patient information and may be considered part of the medical record and subject to laws governing medical records.

AMA Principles of Medical Ethics: I,IV,V,VIII

3.1.4 Audio or Visual Recording of Patients for Public Education

Audio and/or visual recording of patient care for public broadcast is one way to help educate the public about health care. However, no matter what medium is used, such recording poses challenges for protecting patient autonomy, privacy, and confidentiality. Filming cannot benefit a patient medically and may cause harm. As advocates for their patients, physicians have an obligation to protect patient interests and ensure that professional standards are upheld. Physicians also have a responsibility to ensure that information conveyed to the public is complete and accurate (including the risks, benefits, and alternatives of treatments).

Physicians involved in recording patients for public broadcast should:

- (a) Participate in institutional review of requests to record patient interactions.
- (b) Require that persons present for recording purposes who are not members of the health care team:
 - (i) minimize third-party exposure to the patient's care; and
 - (ii) adhere to medical standards of privacy and confidentiality.
- (c) Encourage recording personnel to engage medical specialty societies or other sources of independent expert review in assessing the accuracy of the product.

- (d) Refuse to participate in programs that foster misperceptions or are otherwise misleading.
- (e) Restrict participation to patients who have decision-making capacity. Recording should not be permitted when the patient lacks decision-making capacity except in rare circumstances and with the consent of the parent, legal guardian, or authorized decision maker.
- (f) Inform a patient (or authorized decision maker) who is to be recorded:
 - (i) about the purpose for which patient encounters with physicians or other health care professionals will be recorded;
 - (ii) about the intended audience(s);
 - (iii) that the patient may withdraw consent at any time prior to recording and up to an agreed on time before the completed recording is publicly broadcast, and if so, what will be done with the recording;
 - (iv) that at any time the patient has the right to have recording stopped and recording personnel removed from the area;
 - (v) whether the patient will be allowed to review the recording before broadcast and the degree to which the patient may edit the final product; and
 - (vi) whether the physician was compensated for his participation and the terms of that compensation.
- (g) Ensure that the patient has had the opportunity to address concerns before and after recording.
- (h) Ensure that the patient's consent is obtained by a disinterested third party not involved with the production team to avoid potential conflict of interest.
- (i) Request that recording be stopped and recording personnel removed if the physician (or other person involved in the patient's care) perceives that recording may jeopardize patient care.
- (j) Ensure that the care they provide and the advice they give to patients regarding participation in recording is not influenced by potential financial gain or promotional benefit to themselves, their patients, or the health care institution.
- (k) Remind patients and colleagues that recording creates a permanent record and may in some instances be considered part of the medical record.

AMA Principles of Medical Ethics: I,IV,VII,VIII

3.1.5 Professionalism in Relationships with Media

Ensuring that the public is informed promptly and accurately about medical issues is a valuable objective. However, media requests for information about patients can pose concerns about patient privacy and confidentiality, among other issues.

Physicians who speak on health-related matters on behalf of organizations should be aware of to institutional guidelines for communicating with media, where they exist. To safeguard patient interests when working with representative of the media, all physicians should:

- (a) Obtain consent from the patient or the patient’s authorized representative before releasing information.
- (b) Release only information specifically authorized by the patient or patient’s representative or that is part of the public record.
- (c) Ensure that no statement regarding diagnosis or prognosis is made except by or on behalf of the attending physician.
- (d) Refer any questions regarding criminal activities or other police matters to the proper authorities.

AMA Principles of Medical Ethics: IV

3.2.1 Confidentiality

Patients need to be able to trust that physicians will protect information shared in confidence. They should feel free to fully disclose sensitive personal information to enable their physician to most effectively provide needed services. Physicians in turn have an ethical obligation to preserve the confidentiality of information gathered in association with the care of the patient.

In general, patients are entitled to decide whether and to whom their personal health information is disclosed. However, specific consent is not required in all situations.

When disclosing patients’ personal health information, physicians should:

- (a) Restrict disclosure to the minimum necessary information; and
- (b) Notify the patient of the disclosure, when feasible.

Physicians may disclose personal health information without the specific consent of the patient (or authorized surrogate when the patient lacks decision-making capacity):

- (c) To other health care personnel for purposes of providing care or for health care operations; or
- (d) To appropriate authorities when disclosure is required by law.
- (e) To other third parties situated to mitigate the threat when in the physician’s judgment there is a reasonable probability that:
 - (i) the patient will seriously harm him/herself; or
 - (ii) the patient will inflict serious physical harm on an identifiable individual or individuals.

For any other disclosures, physicians should obtain the consent of the patient (or authorized surrogate) before disclosing personal health information.

AMA Principles of Medical Ethics: III,IV,VII,VIII

3.2.2 Confidentiality Post Mortem

In general, patients are entitled to the same respect for the confidentiality of their personal information after death as they were in life. Physicians have a corresponding obligation to protect patient information, including information obtained post mortem. However, the obligation to safeguard confidentiality post mortem is subject to certain exceptions that are ethically and legally justifiable because of overriding societal concerns.

Physicians may disclose autopsy results to the surrogate or other decision maker who gave consent for the procedure.

Otherwise, physicians may disclose a deceased patient's personal health information only:

- (a) In accord with the patient's explicit prior consent or directive. Physicians should respect the individual's specific preferences regarding disclosure; or
- (b) When required by law; or
- (c) When in the physician's judgment disclosure will avert harm to, or benefit, identifiable individuals or the community; or
- (d) For purposes of medical research or education if personal identifiers have been removed.

In all circumstances, physicians should:

- (e) Consider the effect disclosure is likely to have on the patient's reputation.
- (f) Restrict disclosure to the minimum necessary information.

When disclosing a deceased patient's health information would result in personal gain for the physician (financial or otherwise), the physician must seek specific consent to the disclosure from the patient's authorized decision maker.

AMA Principles of Medical Ethics: IV

3.2.3 Industry-Employed Physicians & Independent Medical Examiners

Physicians may obtain personal information about patients outside an ongoing patient-physician relationship. For example, physicians may assess an individual's health or disability on behalf of an employer, insurer, or other third party. Or they may obtain information in providing care specifically for a work-related illness or injury. In all these situations, physicians have a responsibility to protect the confidentiality of patient information.

When conducting third-party assessments or treating work-related medical conditions, physicians may disclose information to a third party:

- (a) With written or documented consent of the individual (or authorized surrogate); or
- (b) As required by law, including workmen's compensation law where applicable.

When disclosing information to third parties, physicians should:

- (c) Restrict disclosure to the minimum necessary information for the intended purpose.
- (d) Ensure that individually identifying information is removed before releasing aggregate data or statistical health information about the pertinent population.

AMA Principles of Medical Ethics: IV

3.2.4 Access to Medical Records by Data Collection Companies

Information contained in patients' medical records about physicians' prescribing practices or other treatment decisions can serve many valuable purposes, such as improving quality of care. However, ethical concerns arise when access to such information is sought for marketing purposes on behalf of commercial entities that have financial interests in physicians' treatment recommendations, such as pharmaceutical or medical device companies.

Information gathered and recorded in association with the care of a patient is confidential. Patients are entitled to expect that the sensitive personal information they divulge will be used solely to enable their physician to most effectively provide needed services. Disclosing information to third parties for commercial purposes without consent undermines trust, violates principles of informed consent and confidentiality, and may harm the integrity of the patient-physician relationship.

Physicians who propose to permit third-party access to specific patient information for commercial purposes should:

- (a) Only provide data that has been de-identified.
- (b) Fully inform each patient whose record would be involved (or the patient's authorized surrogate when the individual lacks decision-making capacity) about the purpose(s) for which access would be granted.

Physicians who propose to permit third parties to access the patient's full medical record should:

- (c) Obtain the consent of the patient (or authorized surrogate) to permit access to the patient's medical record.
- (d) Prohibit access to or decline to provide information from individual medical records for which consent has not been given.
- (e) Decline incentives that constitute ethically inappropriate gifts, in keeping with ethics guidance.

AMA Principles of Medical Ethics: I,II,IV

3.3.1 Management of Medical Records

Medical records serve important patient interests for present health care and future needs, as well as insurance, employment, and other purposes.

In keeping with the professional responsibility to safeguard the confidentiality of patients' personal information, physicians have an ethical obligation to manage medical records appropriately.

This obligation encompasses not only managing the records of current patients, but also retaining old records against possible future need, and providing copies or transferring records to a third party as requested by the patient or the patient's authorized representative when the physician leaves a practice, sells his or her practice, retires, or dies.

To manage medical records responsibly, physicians (or the individual responsible for the practice's medical records) should:

- (a) Ensure that the practice or institution has and enforces clear policy prohibiting access to patients' medical records by unauthorized staff.
- (b) Use medical considerations to determine how long to keep records, retaining information that another physician seeing the patient for the first time could reasonably be expected to need or want to know unless otherwise required by law, including:
 - (i) immunization records, which should be kept indefinitely;
 - (ii) records of significant health events or conditions and interventions that could be expected to have a bearing on the patient's future health care needs, such as records of chemotherapy.
- (c) Make the medical record available:
 - (i) as requested or authorized by the patient (or the patient's authorized representative);
 - (ii) to the succeeding physician or other authorized person when the physician discontinues his or her practice (whether through departure, sale of the practice, retirement, or death);
 - (iii) as otherwise required by law.
- (d) Never refuse to transfer the record on request by the patient or the patient's authorized representative, for any reason.
- (e) Charge a reasonable fee (if any) for the cost of transferring the record.
- (f) Appropriately store records not transferred to the patient's current physician.
- (g) Notify the patient about how to access the stored record and for how long the record will be available.
- (h) Ensure that records that are to be discarded are destroyed to protect confidentiality.

AMA Principles of Medical Ethics: IV,V

3.3.2 Confidentiality & Electronic Medical Records

Information gathered and recorded in association with the care of a patient is confidential, regardless of the form in which it is collected or stored.

Physicians who collect or store patient information electronically, whether on stand-alone systems in their own practice or through contracts with service providers, must:

- (a) Choose a system that conforms to acceptable industry practices and standards with respect to:
 - (i) restriction of data entry and access to authorized personnel;
 - (ii) capacity to routinely monitor/audit access to records;
 - (iii) measures to ensure data security and integrity; and
 - (iv) policies and practices to address record retrieval, data sharing, third-party access and release of information, and disposition of records (when outdated or on termination of the service relationship) in keeping with ethics guidance.
- (b) Describe how the confidentiality and integrity of information is protected if the patient requests.
- (c) Release patient information only in keeping with ethics guidance for confidentiality.

AMA Principles of Medical Ethics: V

3.3.3 Breach of Security in Electronic Medical Records

When used with appropriate attention to security, electronic medical records (EMRs) promise numerous benefits for quality clinical care and health-related research. However, when a security breach occurs, patients may face physical, emotional, and dignitary harms.

Dedication to upholding trust in the patient-physician relationship, to preventing harms to patients, and to respecting patients' privacy and autonomy create responsibilities for individual physicians, medical practices, and health care institutions when patient information is inappropriately disclosed.

The degree to which an individual physician has an ethical responsibility to address inappropriate disclosure depends in part on his or her awareness of the breach, relationship to the patient(s) affected, administrative authority with respect to the records, and authority to act on behalf of the practice or institution.

When there is reason to believe that patients' confidentiality has been compromised by a breach of the electronic medical record, physicians should:

- (a) Ensure that patients are promptly informed about the breach and potential for harm, either by disclosing directly (when the physician has administrative responsibility for the EMR), participating in efforts by the practice or health care institution to disclose, or ensuring that the practice or institution takes appropriate action to disclose.
- (b) Follow all applicable state and federal laws regarding disclosure.

Physicians have a responsibility to follow ethically appropriate procedures for disclosure, which should at minimum include:

- (c) Carrying out the disclosure confidentially and within a time frame that provides patients ample opportunity to take steps to minimize potential adverse consequences.

- (d) Describing what information was breached; how the breach happened; what the consequences may be; what corrective actions have been taken by the physician, practice, or institution; and what steps patients themselves might take to minimize adverse consequences.
- (e) Supporting responses to security breaches that place the interests of patients above those of the physician, medical practice, or institution.
- (f) Providing information to patients to enable them to mitigate potential adverse consequences of inappropriate disclosure of their personal health information to the extent possible.

AMA Principles of Medical Ethics: IV,VIII