2.1.3 Withholding Information from Patients

Truthful and open communication between physician and patient is essential for trust in the relationship and for respect for autonomy. Withholding pertinent medical information from patients in the belief that disclosure is medically contraindicated creates a conflict between the physician's obligations to promote patient welfare and to respect patient autonomy.

Except in emergency situations in which a patient is incapable of making an informed decision, withholding information without the patient's knowledge or consent is ethically unacceptable. When information has been withheld in such circumstances, physicians' should convey that information once the emergency situation has been resolved, in keeping with relevant guidelines below.

The obligation to communicate truthfully about the patient's medical condition does not mean that the physician must communicate information to the patient immediately or all at once. Information may be conveyed over time in keeping with the patient's preferences and ability to comprehend the information. Physicians should always communicate sensitively and respectfully with patients.

With respect to disclosing or withholding information, physicians should:

- (a) Encourage the patient to specify preferences regarding communication of medical information, preferably before the information becomes available.
- (b) Honor a patient's request not to receive certain medical information or to convey the information to a designated surrogate, provided these requests appear to represent the patient's genuine wishes.
- (c) Assess the amount of information the patient is capable of receiving at a given time, and tailor disclosure to meet the patient's needs and expectations in keeping with the individual's preferences.
- (d) Consult with the patient's family, the physician's colleagues, or an ethics committee or other institutional resource for help in assessing the relative benefits and harms associated with delaying disclosure.
- (e) Monitor the patient carefully and offer full disclosure when the patient is able to decide whether to receive the information. This should be done according to a definite plan, so that disclosure is not permanently delayed.
- (f) Disclose medical errors if they have occurred in the patient's care, in keeping with ethics guidance.

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

Background report(s):

CEJA 3-A-16 Modernized Code of Medical Ethics

CEJA 2-A-06 Withholding information from patients (therapeutic privilege)

2.1.3 Withholding Information from Patients

Truthful and open communication between physician and patient is essential for trust in the relationship and for respect for autonomy. Withholding pertinent medical information from patients in the belief that disclosure is medically contraindicated creates a conflict between the physician's obligations to promote patient welfare and to respect patient autonomy. [New content sets out key ethical values and concerns explicitly.]

Except in emergency situations in which a patient is incapable of making an informed decision, withholding information without the patient's knowledge or consent is ethically unacceptable. When information has been withheld in such circumstances, physicians should convey that information once the emergency situation has been resolved, in keeping with relevant guidelines below. [New content addresses gap in current guidance.]

The obligation to communicate truthfully about the patient's medical condition does not mean that the physician must communicate information to the patient immediately or all at once. Information may be conveyed over time in keeping with the patient's preferences and ability to comprehend the information. Physicians should always communicate sensitively and respectfully with patients.

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

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 2-A-06

Subject: Withholding Information from Patients (Therapeutic Privilege)

Presented by: Priscilla Ray, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws

(Joseph H. Reichman, MD, Chair)

INTRODUCTION

Some physicians have withheld medical information from patients when they have believed full disclosure to be medically contraindicated, to avoid potential harm to the patient's physical or psychological well-being. This practice, commonly referred to as "therapeutic privilege," is distinct from circumstances when it is not feasible to disclose information to a patient, such as emergency situations or other instances when a patient lacks the capacity of making decisions (see E-8.08, "Informed Consent" and E-8.081, "Surrogate Decision Making"). It also is distinct from disclosure issues that arise from medical errors, which the Council addressed in a previous report (see E-8.121, "Ethical Responsibility to Study and Prevent Error and Harm").

Intentionally withholding information may be viewed as presenting a conflict between a physician's ethical imperative to protect patients and a physician's ethical obligation to be truthful and to provide patients with relevant medical information. Moreover, it abrogates the process of shared decision-making and conflicts with contemporary expectations that physicians will respect patients' autonomy and enable them to take an active role in making treatment decisions that reflect their interests and preferences. It is in this context that this report re-examines the ethical propriety of withholding medical information from patients.

ETHICAL ANALYSIS

Non-disclosure of medical information was once uncontroversial when paternalism afforded physicians broad discretion in making treatment decisions on behalf of their patients. Stemming from the Hippocratic tradition, physicians were ethically obligated to promote their patients' welfare by providing care in accordance with their own judgment regarding the most appropriate course of treatment. Physicians could opt not to share potentially distressing diagnostic or prognostic medical information with patients if they believed that disclosure might prove detrimental to patients' well-being. Accordingly, the selective withholding of medical information

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^{*} 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.

- 1 could be viewed as fulfilling physicians' obligations both to act beneficently² and to promote patients' overall well-being.³
- This practice of non-disclosure was well established in the foundational works of Western medical ethics, such as Percival's *Medical Ethics*, which promoted the beneficent withholding of medical information to minimize patients' distress. 4 Similarly, the 1847 AMA Code of Medical Ethics stated that physicians had a "sacred duty...to avoid all things which have a tendency to discourage the patient and depress his spirits." These guidelines helped to establish legal precedents that allowed physicians to withhold potentially harmful information from their patients in the event that full disclosure would impede patients' abilities to render rational decisions or harm them in other ways.6

 In recent decades, medical paternalism has given way to the contemporary concepts of patient autonomy and shared decision-making.⁷ Today, physicians are called upon to promote patients' well-being by openly discussing the balance between anticipated benefits of a given intervention and its potential harms.⁸ In some instances, a case-specific balance of benefits and harms may appear to some physicians as justification to withhold medical information, with the beneficent desire to protect patients from potential harms. However, a physician's concealment of medical information may not prove beneficent if it contravenes a patient's own wishes.

Many patients want detailed medical information, even if it means receiving adverse diagnostic or prognostic information. Physicians' communication of detailed medical information has been shown to ease patients' anxiety and improve health outcomes. Moreover, increased levels of communication and information sharing may also contribute to higher levels of patient satisfaction and potentially decrease malpractice liability. Conversely, the lack of adequate information may preclude patients from receiving necessary medical attention or making optimal life decisions on the basis of their individual needs and personal values. 13,14

Withholding pertinent medical information from patients without their knowledge or consent may also have negative long-term consequences for the medical profession. The patient-physician relationship is founded upon trust, because patients must rely upon their physicians to provide the information needed to make a properly informed decision.¹⁵ Lack of candid disclosure can compromise this relationship if patients suspect (or later discover) that information is being withheld from them.¹⁶ Thus, individual physicians' purportedly benevolent acts of deception risk undermining not only individuals, but also public confidence and trust in the medical profession.¹⁷

In practice, medical information should never be permanently withheld from the patient because doing so represents a clear violation of patients' trust. However, physicians' obligation of beneficence may allow (or compel) them to postpone the full disclosure of information to patients whose capacity to make competent medical decisions may be compromised, or when disclosure is otherwise medically contraindicated. ¹⁸ Delayed disclosure, however, is not justified when physicians merely intend to prevent a patient's refusal of medically necessary treatments, ¹⁹ or to instill hope for the future. ²⁰

Little is known of the extent to which disclosure of alarming medical information may ultimately harm patients.²¹ Physicians are encouraged to consult colleagues or hospital ethics committees

- 1 when considering the need to temporarily withhold medical information from their patients. Such
- 2 consultations reflect respect for patients' right of self-determination and can be of real help to
- 3 physicians in assessing available alternatives to postponement of communicating medical
- 4 information.

When physicians determine that a patient should not receive all relevant medical information at a given time, they need to continue to provide appropriate care for and monitor the patient to identify an appropriate time to offer full disclosure. This should be done according to a definite plan, so that disclosure is not permanently withheld.

PROMOTING PATIENT-PHYSICIAN COMMUNICATION

Physicians' concerns about disclosure of potentially harmful information should lead them to encourage patients to make choices regarding the receipt of medical information before potentially harmful information becomes available.²² Physicians should tailor their disclosure of medical information in response to the needs, expectations and preferences of individual patients.²³

 To respect patients' rights of decisional autonomy, physicians must offer all patients the opportunity to receive relevant medical information.²⁴ This may be accomplished by asking patients to specify the scope of information they wish to receive and their preferred methods for receiving it. Physicians should then honor these preferences to the extent practicable.

Some patients may want certain medical information to be withheld.²⁵ Others may wish to involve family members in the decision-making process or, alternatively, to appoint family members or trusted caregivers to act as their proxy.²⁶ Physicians should respect the wishes of competent patients, including accommodation of their cultural and religious beliefs.²⁷ However, physicians should consider patients' decisions sensitively to ensure that their requests are not coerced and genuinely represent the patients' preferences.¹³ Additionally, physicians should educate patients and their proxies about the importance of disclosure and shared decision-making.¹³

When communicating medical information, physicians should assess the amount of information that patients want and are capable of receiving at a given time.²⁸ Clinical judgment is required to determine the appropriate means for communicating relevant information, taking patients' personalities and clinical histories into account when possible.² Information should be presented in a way that patients can understand and use in making medical decisions.¹³ Finally, physicians should attempt to confirm that this information has been understood—for example, by asking them to repeat what they have been told—and providing further clarification as necessary.^{29,30}

Physicians should communicate all requested medical information sensitively and respectfully,³¹ while seeking to minimize any negative effects upon the patient.³² By listening to patients' concerns and responding to their individual needs, physicians can promote the patient-physician relationship³³ and protect against the iatrogenic suffering of patients.³⁴ Physicians can also minimize potential harms by monitoring patients' well-being and by helping them to access appropriate support services, when needed.²¹

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- 3 Withholding relevant medical information from patients without their knowledge or consent, in an
- 4 attempt to minimize potential physical or psychological harms, has been called "therapeutic
- 5 privilege." This practice creates a conflict between physicians' concurrent obligations to act
- 6 beneficently and to respect patients' autonomy. Whenever possible, physicians should minimize
- 7 the withholding of medical information by accommodating patients' informational preferences.

RECOMMENDATIONS

The Council on Ethical and Judicial Affairs recommends:

(1) That the following statement be adopted as new policy, to be subsequently issued as a new ethical opinion:

Withholding pertinent medical information from patients under the belief that disclosure is medically contraindicated, a practice known as "therapeutic privilege," creates a conflict between the physician's obligations to promote patients' welfare and respect for their autonomy by communicating truthfully. Therapeutic privilege does not encompass withholding medical information in emergency situations, or reporting medical errors (see E-8.08, "Informed Consent," and E-8.121, "Ethical Responsibility to Study and Prevent Error and Harm").

Withholding medical information from patients without their knowledge or consent is ethically unacceptable. Physicians should encourage patients to specify their preferences regarding communication of their medical information, preferably before the information becomes available. Moreover, physicians should honor patient requests not to be informed of certain medical information or to convey the information to a designated proxy, provided these requests appear to genuinely represent the patient's own wishes.

All information need not be communicated to the patient immediately or all at once; physicians should assess the amount of information a patient is capable of receiving at a given time, delaying the remainder to a later, more suitable time, and should tailor disclosure to meet patients' needs and expectations in light of their preferences.

Physicians may consider delaying disclosure only if early communication is clearly contraindicated. Physicians should continue to monitor the patient carefully and offer complete disclosure when the patient is able to decide whether or not to receive this information. This should be done according to a definite plan, so that disclosure is not permanently delayed. Consultation with patients' families, colleagues or an ethics committee may help in assessing the balance of benefits and harms associated with delayed disclosure. In all circumstances, physicians should communicate with patients sensitively and respectfully.

(New HOD/CEJA Policy)

(2) That amendments to Opinion E-8.08, "Informed Consent," proposed below be made at the time the statement above is issued as a new opinion:

E-8.08, "Informed Consent"

The patient's right of self-decision can be effectively exercised only if the patient possesses enough information to enable an <u>intelligent informed</u> choice. The patient should make his or her own determination on treatment. The physician's obligation is to present the medical facts accurately to the patient or to the individual responsible for the patient's care and to make

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1	recommendations for management in accordance with good medical practice. The physician
2	has an ethical obligation to help the patient make choices from among the therapeutic
3	alternatives consistent with good medical practice. Informed consent is a basic social-policy in
4	both ethics and law that physicians must honor, for which exceptions are permitted: (1) where
5	the unless the patient is unconscious or otherwise incapable of consenting and harm from
6	failure to treat is imminent. In special circumstances, it may be appropriate to postpone
7	disclosure of information, (see Opinion E-8.122, "Withholding Information from Patients"). or
8	(2) when risk disclosure poses such an immediate and serious psychological threat of detriment
9	to the patient as to be medically contraindicated Social policy does not accept the paternalistic
10	view that the physician may remain silent because divulgence might prompt the patient to
11	forego needed therapy. Rational, informed patients should not be expected to act uniformly,
12	even under similar circumstances, in agreeing to or refusing treatment.
13	
14	Physicians should sensitively and respectfully disclose all relevant medical information to
15	patients. The quantity and specificity of this information should be tailored to meet the
16	preferences and needs of individual patients. Physicians need not communicate all information
17	at one time, but should assess the amount of information that patients are capable of receiving
18	at a given time and present the remainder when appropriate. (I, II, III, IV, V, VIII)
19	
20	Issued March 1981. Updated June 2006, based on the Report "Withholding Information from
21	Patients (Therapeutic Privilege)."
22	
23	(Modify HOD/CEJA Policy)
24	
25	(3) That the remainder of the report be filed.

Fiscal Note: Staff cost estimated at less than \$500 to implement.

(3) That the remainder of the report be filed.

REFERENCES

- ¹ Meisel, A. The 'exceptions' to the informed consent doctrine: Striking a balance between competing values in medical decision making Wis. L. Rev. 1979; 413 at 460 n. 153.
- ² Novack, D., et al. Physicians' attitudes toward using deception to resolve difficult ethical problems. JAMA. 1989;261(20):2980-85.
- ³ Barber, B. Informed Consent to Medical Therapy and Research. New Brunswich, NJ: Rutgers University Press. 1980: 37.
- ⁴ Wolpe, P. R. The Triumph of Autonomy in American Bioethics: A Sociological View. in *Bioethics and* Society. Devries, R., Subedi, J. (eds). Upper Saddle River, New Jersey: Prentice Hall. 1998;39.
- ⁵ Boyle, R. Communication, Truthtelling, and Disclosure from *Introduction to Clinical Ethics*. Fletcher, J., et al (eds). Frederick, Md.: University Publishing Group. 1997:56-57.
- ⁶ 464 F.2e 772 (D.C. Cir 1972); Natanson v. Kline, 350 P.2d 1903 (Kan. 1960).
- ⁷ CEJA Opinion E-8.08, "Informed Consent."
- ⁸ CEJA Opinion E-10.015, "The Patient-Physician Relationship."
- ⁹ Marzanski, M. Would you like to know what is wrong with you? On telling the truth to patients with dementia. Journal of Medical Ethics. 2000;26:108-13.
- ¹⁰ Silverstein, M., et al. ALS and life-sustaining therapy: patients desires for information, participation in decision-making, and life-sustaining therapy. Mayo Clin Proc. 1991;66:906-13.
- ¹¹ Kaplan, S., et al. Characteristics of physicians with participatory decision-making styles. *Ann Intern Med.* 1996; 124: 497-504.
- ¹² Levinson W. Physician-patient communication: A key to malpractice prevention. *JAMA*;1994:272:1619-
- ¹³ Herbert, P., Hoffmaster, B., Glass, K., Singer, P. Bioethics for physicians: 7. Truth telling. Can Med Assoc J. 1997;156(2): 225-8.
- ¹⁴ Weeks, J., et al. Relationship between cancer patients' predictions or prognosis and their treatment preferences. *JAMA*. 1998;279(21):1709-14.
- ⁵ CEJA Opinion E-10.01, "Fundamental Elements of the Patient-Physician Relationship"
- ¹⁶ Conn, J., Gillman, M., Conway, S. Ethics in practice: Revealing the diagnosis of androgen insensitivity syndrome in adulthood. *BMJ*. 2005;331:628-30.
- Bok, S. Lying: Moral choice in public and private life. New York: Vintage Books, 1979;28.
- ¹⁸ Cote, A. Telling the truth? Disclosure, therapeutic privilege and intersexuality in children. *Health Law* Journal. 2000;8:199-216.
- ¹⁹ Wynia, M. Invoking therapeutic privilege. AMA Virtual Mentor. Accessible at: http://www.amaassn.org/ama/pub/category/print/11937.html.
- ²⁰ Annas, G. Informed consent, cancer, and truth in prognosis. *NEJM*. 1994;330:233-35.
- ²¹ Buckman, R. How to Break Bad News: A Guide for Health Care Professionals. Baltimore: The Johns Hopkins University Press. 1992; 53
- ²² Patterson, E. Therapeutic justification for withholding medical information: What you don't know can't hurt you, or can it? Nebraska Law Rev. 1985;65:721.
- ²³ Weston W. Informed and shared decision-making: The crux of patient-centred care. *CMAJ*. 2001;165(4):434-9.
- ²⁴ Freedman, B. Offering truth: one ethical approach to the uninformed cancer patient. *Arch Intern Med.* 1993:153:572-6.
- ²⁵ Pietsky, D. The breakthrough. *Ann Intern Med.* 1996;124:345-7.
- ²⁶ Surbone, A. Letter from Italy: Truth telling to the patient. *JAMA*. 1992:268:1661-2.
- ²⁷ Etchells E, Sharpe G, Burgess M, et al. Bioethics for clinicians: 2. Disclosure. *CMAJ* 1996; 155: 387-391.
- ²⁸ British Medical Association. *Human Genetics, Choice and Responsibility*. Oxford: Oxford University Press. 1998:86-8..

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- ²⁹ Schillinger D, Piette J, Grumbach K, Wang F, Wilson C, Daher C, Leong-Grotz K, Castro C, Bindman AB. Closing the loop: physician communication with diabetic patients who have low health literacy. *Arch Intern Med.* 2003 Jan 13;163(1):83-90.
- ³⁰ National Quality Forum (NQF). *Implementing a National Voluntary Consensus Standard for Informed Consent: A User's Guide for Healthcare Professionals*. Washington, DC: National Quality Forum; 2005.
 ³¹ Jackson, J. On the morality of deception- does method matter? A reply to David Bakhurst. *Journal of*

Medical Ethics. 1993;19:183-7.

³² Weiss, G. Patients' Rights: Who should know what?. *Medical Economics*. 2002;19:97.

- ³³ Buckman, R. *How to Break Bad News: A Guide for Health Care Professionals*. Baltimore: The Johns Hopkins University Press. 1992; 11.
- ³⁴ Da Silvia, et al. Not telling the truth in the patient-physician relationship. *Bioethics*. 2003;17:417-24.