

3.2.2 Confidentiality Postmortem

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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.
- (b) When required by law.
- (c) When in the physician's judgment disclosure will avert harm to, or benefit, identifiable individuals or the community.
- (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

Background report(s):

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

CEJA Report 5-A-00 Confidentiality of health information postmortem

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REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 5-A-00

Subject: Confidentiality of Health Information Postmortem

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Presented to: Reference Committee on Constitution and Bylaws
(Jimmie A. Gleason, MD, Chair)

Introduction

1 Medical professionals have long considered confidentiality of patients' medical information of
2 paramount concern. The patient-physician relationship is, in large part, based on a trust that the
3 information obtained within the relationship will remain confidential. However, confidentiality
4 protections are not absolute and there are a variety of exceptions based on individual and public
5 health concerns. Recently, attention has focused on the limits of the physician's duty to preserve
6 confidentiality after a patient's death. The Proposed Rule of the Department of Health and
7 Human Services on "Standards for Privacy of Individually Identifiable Health Information"
8 recommends that privacy protections of medical information cease two years after death.¹
9

10 The Council offers the following report to identify limitations to confidentiality of medical
11 information postmortem and situations in which physicians may disclose relevant information to
12 third parties. For the purposes of this discussion, postmortem medical information refers to any
13 information contained within a deceased patient's medical record, including information entered
14 into the record after death. The report begins by discussing the premise and scope of
15 confidentiality and then outlines factors physicians should consider in determining whether they
16 may disclose information postmortem.
17

Premise and Scope of Confidentiality

18
19
20 There are a number of bases for protecting confidentiality of medical information. One basis is
21 the inherent value of privacy. The value of privacy derives, in part, from the tendency to fashion
22 one's own identity and to control how much information about one-self to conceal or reveal to
23 others.² Because health information often includes some of the most intimate details of a
24 person's life, it may play a particularly significant role in self-identity. Another more commonly
25 cited rationale is the practical benefit of maintaining patient confidences. Confidentiality
26 protections help assure patients that they can entrust to their physicians private information that is
27 important to the provision of care. However, patient confidentiality is not absolute. Society has a
28 legitimate interest in permitting (and sometimes promoting) breaches of confidentiality. For
29 instance, physicians are required to report certain communicable diseases, gunshots or other
30 wounds, and evidence of child abuse or neglect.³ In Opinion 5.05, "Confidentiality," the Council
31 acknowledges the potential for limited disclosure: "[t]he obligation to safeguard patient
32 confidences is subject to certain exceptions which are ethically and legally justified because of
33 overriding social considerations."⁴ Thus, the extent to which physicians have an obligation to

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1 maintain confidentiality of medical information may be superceded by other interests and
2 concerns.

3 4 Confidentiality of Medical Information Postmortem

5
6 The inherent value of privacy and the practical benefits of maintaining confidentiality for the
7 living also provide a foundation for protecting medical information postmortem. In
8 contemporary U.S. society, some individual interests survive death. For example, the practice of
9 honoring wills functions to respect the interests of the deceased in controlling the distribution of
10 property. Likewise, protecting confidentiality after death functions to respect the former interests
11 of the deceased in controlling personal health information.

12
13 Because privacy and confidentiality focus on living individual's control over information, the
14 obligations a physician may have to a deceased patient are less clear. One might argue that
15 disclosing information postmortem is of little consequence because the dead cannot be harmed or
16 have no interest in confidentiality. But this stance ignores the potential harm to deceased
17 patients' identity with respect to their legacy. Cicero wrote: "The life of the dead consists in
18 being present in the minds of the living."⁵ Similarly, those who were close to the deceased hold
19 interests in preserving the memory of their loved ones.

20
21 In addition to the inherent value of privacy, protecting confidentiality postmortem may also have
22 practical benefits. To expand on the above example, the practice of honoring wills promotes both
23 the interests of the deceased and also the interests of the living. People make wills on the
24 assumption that their wishes will be implemented after their death. In other words, people living
25 now have a current interest in ensuring that wills, in general, are enforced. Similarly, maintaining
26 confidentiality of medical information postmortem assures living patients that the information
27 they impart to their physician will not be disclosed after death. Disclosure of such information on
28 a regular basis may weaken both the institution of confidentiality as well as public trust in
29 physicians.

30
31 Thus, the reasons for preserving confidentiality of health information for living patients seem to
32 apply postmortem as well. However, the inability ever to obtain consent for disclosure from the
33 deceased may influence the degree to which such information should be kept confidential in the
34 face of conflicting interests. Consent, although a useful safeguard for living patients, is hardly
35 helpful in this context. Therefore, we must fashion confidentiality protections that are not unduly
36 restrictive.

37
38 One possibility is to borrow from the concept of surrogate decision making. In cases where a
39 patient receiving life-sustaining treatment loses decision-making capacity, the Council suggests
40 that decisions be made by a surrogate decision-maker. In the absence of a designated proxy (e.g.,
41 through an advance directive), the patient's family should become the surrogate decision-maker.
42 If there is no person closely associated with the patient, but there are persons who both care about
43 and have sufficient knowledge of the patient, then such persons may be appropriate surrogates.⁶
44 In this context, the surrogate example provides a useful template for identifying a proxy for
45 deceased patients.

46
47 Although this example is helpful in some cases, a variety of problems arise similar to ones that
48 exist in the context of living patients. These include the difficulty of ascertaining an appropriate
49 decision-maker, if one has not already been designated, as well as elucidating the patient's
50 preferences. However, there is an important difference in the nature of the decision to be made
51 by the surrogate of a living patient and the surrogate of a deceased one. In the former case,

1 decisions focus on treatments the patient would have chosen.⁷ In the medical context, patient
2 autonomy is an expression of choice among various potential therapeutic benefits. In the latter
3 case, decisions should reflect how the decedent would have wanted to control his or her lasting
4 identity in general, and his or her health information in particular. Although this also constitutes
5 an expression of autonomy, there are no therapeutic benefits that will come to rest with the
6 deceased regardless of a decision made by a surrogate. Simply articulating an individual's
7 attitudes and values may be adequate to infer treatment decisions but may be inadequate in
8 determining how to protect an individual's life story or narrative.⁸

9 10 Disclosure of Medical Information Postmortem

11
12 In the United States, the protection of confidential information postmortem varies from state-to-
13 state. For example, in a number of states, autopsy reports performed under the auspices of a
14 medical examiner become part of the public record.⁹ In these cases, state Freedom of Information
15 Acts commonly require that public records be available to anyone who wants them unless an
16 exception applies. Exceptions restricting public access to medical information may apply across
17 the board, as in Massachusetts, or may depend on a court to balance privacy interests in particular
18 medical records against public interest in the disclosure of those records, as in New York.¹⁰

19
20 The American Medical Association's general policy regarding disclosure states that: "Conflicts
21 between a patient's right to privacy and a third party's need to know should be resolved in favor of
22 patient privacy, except where that would result in serious health hazard or harm to the patient or
23 others."¹¹ Clearly, confidentiality protections postmortem would not be more stringent than those
24 in place during a patient's life. These protections, at their strongest, would be equal to those for
25 living patients. Specific to deceased patients, Opinion 5.057 "Confidentiality of HIV Status on
26 Autopsy Reports," notes that in the absence of law, physicians should ". . . fulfill ethical
27 obligations to notify endangered third parties (e.g., identified sexual or needle-sharing
28 partners)."¹² Thus, in this narrow case the Council recognizes a permissive notion of disclosure
29 of confidential information postmortem and a possible obligation to warn at-risk individuals.

30
31 When deciding whether it is permissible to disclose medical information postmortem, one should
32 weigh the interests in preserving confidentiality against the interests in disclosing the information.
33 In most cases this determination will be based on ethical or legal criteria similar to those used to
34 make judgments about the release of confidential information for living patients.¹³ We will
35 assume that if information about a living patient ethically may be disclosed, the same information
36 may likewise be disclosed after that patient has died.

37 38 A. Disclosure of Information Pertinent to the Health of Other Individuals

39
40 There are at least two sets of circumstances where information concerning a deceased patient
41 might be sought. The first is when disclosure would provide information directly pertinent to the
42 health of a particular individual(s). The second, which will be dealt with later, is when the
43 information sought would be used for research, education or other purposes not directly affecting
44 a particular individual's health.

45
46 The familial nature of genetic information creates the potential of gaining genetic information
47 about blood relatives of the deceased. Similarly, information relating to an infectious disease
48 may be of significant use to at-risk third parties. In the case of living patients, the treating
49 physician could discuss disclosure with the affected patient or encourage the patient to avoid
50 endangering others.¹⁴ Clearly, encouraging disclosure or avoidance is no longer an option
51 postmortem. In this context, physicians considering disclosure should examine whether the

1 potential for harm is likely to occur,^{15,16} if the at-risk individual(s) is identifiable,^{17,18} and if
2 disclosure is likely to be of benefit to the at-risk individual(s).¹⁹ When there is a threat to the
3 public health, or when legally required to do so, physicians should disclose only necessary
4 information to the appropriate authorities.

5
6 The basis for disclosing information postmortem is to protect at-risk third parties from conditions
7 of which they may not be aware and to offer them the opportunity to be treated. However, it is
8 important to recognize that in nearly all instances, a deceased patient's medical information
9 cannot lead to the diagnosis of a living individual, only to a probability of developing a specific
10 health problem. The physician therefore should explain the nature of the information, leaving the
11 decision for further testing up to the individual.²⁰ Finally, in the rare instances when prior to the
12 death a patient has stated explicitly that certain information should not be disclosed, the above
13 three criteria should determine whether information may be disclosed. In all instances, physicians
14 should disclose only the information that is necessary to warn interested individuals.

15 16 B. Disclosure of Information for Research, Educational or Other Purposes

17
18 There are many reasons why medical information may be sought after a patient's death besides
19 providing medical benefit to particular individuals. These range from research to education to
20 such things as public interest in biographical data. When applicable, confidentiality should be
21 maintained to the greatest possible degree. Thus, for many research and educational purposes
22 individual identifiers can be removed from the information and it may be used as necessary
23 postmortem.

24
25 In other cases, such as biographical studies, identifiers are crucial and disclosure is public. In
26 these instances, physicians should consider any statement regarding postmortem disclosure that
27 was made prior to the patient's death. In the absence of such guidance, the impact disclosure may
28 have on the reputation of the deceased patient is an important consideration. Accordingly, those
29 who hold an interest in preserving a certain memory of the deceased (e.g.-family members)
30 should be involved in these decisions to disclose information. In all cases physicians should be
31 sure that personal gain for himself or herself is not the primary motivation for disclosure.

32
33 Finally, where consent is required to disclose information concerning a deceased patient (e.g.-
34 autopsy results), what is to be disclosed is the decision of the individual(s) granting consent to
35 disclose. Otherwise, only limited information should be disclosed.

36 37 Conclusion

38
39 There are a number of concerns that arise when assessing the appropriateness of disclosure of
40 medical information postmortem. In all cases physicians should consider whether harm is likely
41 to occur in the absence of disclosure, whether an at-risk individual is identifiable, and whether the
42 disclosure is likely to be of benefit to the at-risk third-party. Furthermore, any statement
43 regarding postmortem disclosure of information made by the patient prior to death, the impact
44 disclosure may have on the patient's lasting reputation, and whether personal gain is a motivating
45 factor for disclosure should also be taken into account. Actual disclosure of medical information
46 should be responsive to both the needs of surviving individuals and the deceased, reflecting the
47 nature of the information being provided. Only the information that is necessary to adequately
48 inform or warn third parties or public health authorities should be disclosed to those persons. In
49 order to facilitate the advancement of medicine, a deceased patient's de-identified health
50 information may be used for educational and research purposes.

51

1 Recommendations

2
3 For the foregoing reasons, the Council recommends the following be adopted and that the
4 remainder of the report be filed:

5
6 All information contained within a deceased patient’s medical record, including
7 information entered postmortem, should be kept confidential to the greatest possible
8 degree. However, the obligation to safeguard patient confidences is subject to certain
9 exceptions that are ethically and legally justifiable because of overriding societal
10 considerations (Opinion 5.05: Confidentiality). At their strongest, confidentiality
11 protections after death would be equal to those in force during a patient’s life. Thus, if
12 information about a patient may be ethically disclosed during life, it likewise may be
13 disclosed after the patient has died.

14
15 Disclosure of medical information postmortem for research and educational purposes is
16 appropriate as long as confidentiality is maintained to the greatest possible degree by
17 removing any individual identifiers.

18
19 Otherwise, in determining whether to disclose identified information after the death of a
20 patient, physicians should consider the following factors:

- 21
22 (1) the imminence of harm to identifiable individuals or the public health;
23
24 (2) the potential benefit to at-risk individuals or the public health (e.g.- if a
25 communicable or inherited disease is preventable or treatable);
26
27 (3) any statement or directive made by the patient regarding postmortem disclosure;
28
29 (4) the impact disclosure may have on the reputation of the deceased patient; and
30
31 (5) personal gain for the physician that may unduly influence professional obligations of
32 confidentiality.

33
34 When a family or other decision-maker has given consent to an autopsy, physicians may
35 disclose the results of the autopsy to the individual(s) that granted consent to the
36 procedure.

REFERENCES

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- ² Pellegrino, Edmund D. “From the Couch to the Grave: The Anne Sexton Case.” *Cambridge Quarterly of Healthcare Ethics* 1996; 5: 189-203.
- ³ The American Society of Human Genetics Social Issues Subcommittee on Familial Disclosure. “ASHG Statement: Professional Disclosure of Familial Genetic Information.” *Am. J. Hum. Genet.* 1998; 62:474-483.
- ⁴ Council on Ethical and Judicial Affairs, American Medical Association. “Opinion 5.05: Confidentiality.” *Code of Medical Ethics: Current Opinions and Annotations*. Chicago, IL, 1998.
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- ⁹ Council on Ethical and Judicial Affairs, American Medical Association. “Confidentiality of HIV Status on Autopsy Reports.” *Arch Pathol Lab Med.* 1992; 116:1120-1123.
- ¹⁰ Bierig, Jack R. “A Potpourri of Legal Issues Relating to the Autopsy.” *Arch Pathol lab Med* 1996; 120: 759-762.
- ¹¹ House of Delegates, American Medical Association. “H-140.989: Informed Consent and Decision-Making in Health Care.”
- ¹² Council on Ethical and Judicial Affairs, American Medical Association. “Opinion 5.057: Confidentiality of HIV Status on Autopsy Reports.” *Code of Medical Ethics: Current Opinions and Annotations*. Chicago, IL, 1998.
- ¹³ Pellegrino, Edmund D. “From the Couch to the Grave: The Anne Sexton Case.” *Cambridge Quarterly of Healthcare Ethics* 1996; 5: 189-203.
- ¹⁴ Such action is also recommended by Opinion 2.23, “HIV Testing,” in the Council on Ethical and Judicial Affairs’ of the American Medical Association *Code of Medical Ethics: Current Opinions and Annotations* 1998-99 edition.
- ¹⁵ This is reflective of CEJA Opinion 5.05, “Confidentiality” encouraging physicians to assess the “reasonable probability” that a threat will be carried out before breaching confidentiality.
- ¹⁶ TL Beauchamp and JF Childress. *Principles of Biomedical Ethics*. Fourth Edition , Oxford University Press, New York 1994: 418-429.
- ¹⁷ This is in line with CEJA Opinion 5.057: Confidentiality of HIV Status on Autopsy Reports which calls for physicians to “fulfill ethical obligations to notify endangered third parties (e.g., identifiable sexual and needle-sharing partners).”
- ¹⁸ TL Beauchamp and JF Childress. *Principles of Biomedical Ethics*. Fourth Edition , Oxford University Press, New York 1994: 418-429.
- ¹⁹ These criteria are in line with the statement by the American Society of Human Genetics Social Issues Subcommittee on Familial Disclosure entitled “Professional Disclosure of Familial Genetic Information.” *Am. J. Hum. Genet.* 1998; 62: 474-483.
- ²⁰ If an at-risk individual is informed that a deceased relative had a certain genetic disorder, the living relative may only be able to infer a probability of inheriting or developing the mutation. In cases where disclosure is appropriate, physicians should be careful to convey the results of such tests in terms of shifting ranges of probabilities, influenced both by genes and environmental factors, and avoid sounding overly deterministic. (Juengst, Eric T. “Ethics of prediction: genetic risk and the physician-patient relationship” *Genome Science and Technology*. 1995; 1(1): 21-36.)