3.2.2 Confidentiality Postmortem

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 postmortem. However, the obligation to safeguard confidentiality postmortem 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.

(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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(e) Consider the effect disclosure is likely to have on the patient’s reputation.

(f) Restrict disclosure to the minimum necessary information. [adopts terminology consistent with the Health Insurance Portability and Accountability Act]

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. [new content clarifies scope of guidance]

AMA Principles of Medical Ethics: IV
Introduction

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

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

Premise and Scope of Confidentiality

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

\(^*\) 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.
maintain confidentiality of medical information may be superceded by other interests and concerns.

Confidentiality of Medical Information Postmortem

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

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

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

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

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

Although this example is helpful in some cases, a variety of problems arise similar to ones that exist in the context of living patients. These include the difficulty of ascertaining an appropriate decision-maker, if one has not already been designated, as well as elucidating the patient’s preferences. However, there is an important difference in the nature of the decision to be made by the surrogate of a living patient and the surrogate of a deceased one. In the former case,
decisions focus on treatments the patient would have chosen. In the medical context, patient autonomy is an expression of choice among various potential therapeutic benefits. In the latter case, decisions should reflect how the decedent would have wanted to control his or her lasting identity in general, and his or her health information in particular. Although this also constitutes an expression of autonomy, there are no therapeutic benefits that will come to rest with the deceased regardless of a decision made by a surrogate. Simply articulating an individual’s attitudes and values may be adequate to infer treatment decisions but may be inadequate in determining how to protect an individual’s life story or narrative.

Disclosure of Medical Information Postmortem

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

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

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

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

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

The familial nature of genetic information creates the potential of gaining genetic information about blood relatives of the deceased. Similarly, information relating to an infectious disease may be of significant use to at-risk third parties. In the case of living patients, the treating physician could discuss disclosure with the affected patient or encourage the patient to avoid endangering others. Clearly, encouraging disclosure or avoidance is no longer an option postmortem. In this context, physicians considering disclosure should examine whether the
potential for harm is likely to occur, if the at-risk individual(s) is identifiable, and if disclosure is likely to be of benefit to the at-risk individual(s). When there is a threat to the public health, or when legally required to do so, physicians should disclose only necessary information to the appropriate authorities.

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

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

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

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

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

Conclusion

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

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

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

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

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

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

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

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.
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).”
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.)