2001

Grave Secrets: Ethical and Legal Analysis of Postmortem Confidentiality

Jessica Wilen Berg

Follow this and additional works at: http://scholarlycommons.law.case.edu/faculty_publications

Part of the Constitutional Law Commons

Repository Citation


This Article is brought to you for free and open access by Scholarly Commons. It has been accepted for inclusion in Faculty Publications by an authorized administrator of Scholarly Commons.
Grave Secrets: Legal and Ethical Analysis of Postmortem Confidentiality

JESSICA BERG*

I. INTRODUCTION

A young man finds a letter from his recently deceased mother's therapist and calls the psychologist to get information about whether his mother sought counseling because of difficulties in their relationship. The therapist reassures the son that his mother came for help in dealing with her terminal illness.¹

A now-adult child sues her deceased father's physician for failing to warn her that her father's death, which occurred when she was 10 years old, was due to colon cancer, a potentially inheritable disease.²

Following the death of Linda McCartney, a number of newspaper reporters, suspecting physician-assisted suicide, tried to gain access to her death certificate or other medical records.³

The newspaper headlines that reported Dale Earnhardt's deadly race car crash in February, 2001 resulted in more than an outpouring of grief—there has also been outrage. In particular, controversy surrounds whether his autopsy records should be re-

* Assistant Professor of Law and Bioethics, Case Western Reserve University Schools of Law and Medicine. B.A., 1990 and J.D., 1994 Cornell University. I would like to thank Richard Bonnie, Melvyn Durchslag, Paul Giannelli, Peter Gerhart, Sharon Hoffman, Eric Juengst, Juliet Kostrinsky, Max Mehlman, Andrew Morriss, and Stuart Youngner for providing valuable comments on earlier drafts. In addition, John Neal provided excellent research assistance. I would also like to acknowledge the members and staff of the American Medical Association's Council on Ethical and Judicial Affairs for their role in the development of early concepts.

¹ Confidential interview.
leased to the public against his wife’s express plea for privacy.\(^4\)

The legal and ethical protections regarding confidentiality of medical information have undergone significant scrutiny in the past few years and a variety of new legislation, as well as changes to current legislation, have recently been promulgated at both the federal and state levels.\(^5\) Developments in electronic media, as well as advances in genetic medicine, have challenged our traditional understanding of personal information. As a result, there have been a variety of attempts to craft privacy protections in different settings. However, despite all the attention directed at this topic, there is one area that has been largely ignored—protections of confidentiality after death. There are many reasons why confidential health information\(^6\) may be sought after a patient’s death. Requests may be made by family members either because of curiosity or because of its implications for their own health status. Requests may be made by researchers who are seeking to understand or develop treatments for the cause of the patient’s death or to study other issues related to patient care. Requests are even made by the media as well as biographers who are seeking to inform the public. Each of these individuals or groups may express an interest in obtaining the information. Yet few statutes, cases, or even ethical guidelines provide an answer to how the physician should weigh these competing interests against the now-deceased patient’s interest in confidentiality.\(^7\) There is no reason to think that confidentiality protections automatically cease upon a patient’s death, yet keeping information perpetually secret may be similarly untenable. Moreover, the issue of postmortem confidentiality is not limited to physicians; similar concerns affect anyone who gathers confidential information, including mental health professionals, lawyers,\(^8\) and others.


\(^5\) See infra notes 88-96.

\(^6\) For the purposes of this article, this includes information gathered during the patient’s lifetime that would be considered confidential while the patient was alive, as well as information gathered after the patient’s death, such as an autopsy report.

\(^7\) See discussion infra notes 14-28 and accompanying text.

\(^8\) For example, when I spoke with one of my colleagues about this topic he conveyed to me his recent dilemma regarding what to do with the criminal case files that he had acquired during his consulting practice. He had recently made a decision to bequeath them to his university law library, but was uncertain when he should allow them to be opened. In the absence of any guidelines in this area, he settled on a time period of eighty years. Confidential Interview. At least one state explicitly authorizes a lawyer to disclose confidential information regarding a deceased client to the personal representative of the client’s estate, but not to the heirs. N.C. State Bar Ethics Comm., RPC 206 (Apr. 14, 1995), available at http://www.ncbar.com (on file with the Connecticut Law Review) (stating that disclosure of confidential information of a deceased client is prohibited by N.C. REV. R. PROF’L CONDUCT 1.6 (2001) except that a lawyer may disclose such information to the personal representative of the client’s estate but not to the heirs of the estate).

II. LEGAL

Despite the general medical community’s efforts to promulgate a protective code of ethics, there has been little in the way of a mechanism for enforcing these codes.\(^9\) See discussion infra notes 14-28 and accompanying text.

In the 1998 decision of In re C.R., the Court held that the attorney-client privilege is waivable. In re C.R., 62 N.C. App. 536, 363 S.E.2d 352 (1988). In the present case, the Court held that the client’s privilege was waivable. In re C.R., 62 N.C. App. 536, 363 S.E.2d 352 (1988). The Court further held that the privilege was waivable because the client had no interest in the confidentiality of the communication. In re C.R., 62 N.C. App. 536, 363 S.E.2d 352 (1988). In the present case, the Court held that the privilege was waivable because the client had no interest in the confidentiality of the communication. In re C.R., 62 N.C. App. 536, 363 S.E.2d 352 (1988). The Court further held that the privilege was waivable because the client had no interest in the confidentiality of the communication. In re C.R., 62 N.C. App. 536, 363 S.E.2d 352 (1988). The Court further held that the privilege was waivable because the client had no interest in the confidentiality of the communication. In re C.R., 62 N.C. App. 536, 363 S.E.2d 352 (1988).
There has been a great deal of attention focused on the issue of confidentiality of personal information generally, and in particular of personal medical information. Some recent proposals have focused on facilitating individual control over the information via creation of a new property right in personal information. This article takes a different approach, focusing instead on the nature of the interests in both confidentiality and disclosure. Privacy interests are not homogenous; they vary in different contexts. By focusing on the postmortem context, where guidelines are generally absent, there is additional freedom to challenge traditional conceptions of privacy and rights of individual control. Rather than assume the primacy of individual privacy interests, this article engages in a detailed analysis of confidentiality and disclosure interests. Although existing confidentiality protections in the pre-mortem context should have been based on such evaluation, I believe additional scrutiny is warranted before accepting the framework of current confidentiality protections into the postmortem context. Such ethical evaluation will yield better answers to legal and policy questions regarding privacy protections in different settings.

This Article begins by briefly highlighting the current legal and ethical protections of confidentiality for people currently living. Against this backdrop, this Article considers the scope of confidentiality protections and exceptions for people who have died. In doing so, this Article analyzes the type and extent of interests in maintaining confidentiality postmortem. Finally, this Article proposes a framework for determining the circumstances under which disclosure of confidential information postmortem is appropriate. Although the framework is developed in the context of postmortem disclosures, its guidance may prove useful in evaluating confidentiality protections in the pre-mortem context as well.

II. LEGAL AND ETHICAL BACKGROUND ON CONFIDENTIALITY

Despite the general and overt acceptance of confidentiality rules within the medical community, these rules have never functioned as an absolute bar to disclosure.\(^9\) As the United States Supreme Court stated in Whalen v. United States, 524 U.S. 399, 401 (1998), the Supreme Court held that the attorney-client privilege survives the client’s death. At issue in the case was the discoverability of handwritten notes taken during a meeting between White House counsel Vince Foster and his attorney nine days before Foster’s suicide. Id. at 401-02. In holding that the privilege continued to apply, the Court stressed the need to assure confidentiality in communications between clients and attorneys, thus facilitating full disclosure from the client. Id. at 407.

\(^9\) See discussion infra note 129 and accompanying text.

\(^{10}\) Robert M. Gellman, Prescribing Privacy: The Uncertain Role of the Physician in the Protection of Patient Privacy, 62 N.C. L. Rev. 255, 267-68 (1984). First, the legal and ethical protections may be waived. No breach occurs when a patient has authorized disclosure. See, e.g., discussion infra note 129. Second, when the patient is incompetent, certain individuals may be legally authorized to receive information that would otherwise be confidential. Thus surrogates or health care guardians have a right...
Roe, disclosure of confidential medical information is often necessary, and not meaningfully distinguishable from a host of other unpleasant invasions of privacy that are associated with many facets of health care. Unquestionably, some individuals' concern for their own privacy may lead them to avoid or to postpone needed medical attention. Nevertheless, disclosures of private medical information to doctors, to hospital personnel, to insurance companies, and to public health agencies are often an essential part of modern medical practice.\textsuperscript{11}

While existent legal and ethical protections for confidentiality evidence the value our society places on privacy,\textsuperscript{12} they may be outweighed in cases where other societal values, such as public health and safety, take precedence.

to their ward's medical information, and parents generally have a right to their children's medical information. See \textsc{William H. Roach, Jr., Medical Records and the Law} \textsc{108-10} (1998). Third, although there are a number of different bases for confidentiality, no theory provides complete protection from disclosure, and each allows for exceptions based on a balancing of the interests promoted by confidentiality versus the interests promoted by disclosure. See, e.g., \textit{AM. MED. ASS'N, CODE OF MED. ETHICS}, Opinion 5.05, 105 (2000) (stating that "[t]he information disclosed to a physician during the course of the relationship between physician and patient is confidential to the greatest possible degree").

\textsuperscript{11} \textsc{Whalen v. Roe, 429 U.S. 589, 602 (1977)} (considering the constitutionality of a New York statute that required the reporting of the names of patients receiving certain prescription drugs).

\textsuperscript{12} Privacy protections focus on the patient's ability to keep information from being known (sometimes even by the patient himself, such as what happens when the patient refuses genetic testing regarding the presence of a particular gene). Confidentiality protections, on the other hand, deal with information that is known by someone else besides the patient and focus on the patient's ability to keep other individual(s) from disclosing the information to third parties. See \textsc{Lawrence O. Gostin, Public Health Law: Power, Duty, Restraint} \textsc{127-29} (2000).

At the outset it is important to distinguish between legal protections for confidentiality and legal privileges. Privileges are evidentiary protections that function in the context of litigation. In other words, they prevent certain information from being used as evidence in a legal case. See \textit{generally} Swindler & Berlin v. United States, 524 U.S. 399 (1998). Historically, information disclosed by a patient to a physician could not be disclosed by the physician in the course of legal proceedings without the patient's permission, with few exceptions. See \textit{generally} Steven Smith, \textit{Medical and Psychotherapy Privileges and Confidentiality: On Giving with One Hand and Removing with the Other}, \textsc{75 KY. L.J.} \textsc{473} (1986). Thus, a physician could not be forced to reveal patient confidences in the courtroom. See \textit{id}. Today, most states have dispensed with the patient-physician privilege. The one exception to this is the psychotherapist-patient privilege, which remains viable. \textit{id}. at \textsc{487 n.35}. 
A. Legal Protections

There are both state and federal protections of confidentiality. State confidentiality protections vary considerably. Few states have comprehensive confidentiality laws; many states control disclosure of health information through an amalgam of statutes that address everything from particular disease information to autopsy records. In fact, some states eschew the notion of a general confidentiality statute and simply legislate specific exceptions with the assumption that common law or constitutional protections for health information will suffice. Most problematic about the current confidentiality protections are the lack of sanctions for breaches and undesirability of the legal remedy. That is, the solution for a patient who has discovered a breach of confidentiality is to go to court and disclose the information they did not want anyone to know in the first place! Thus, it becomes extremely important to craft front-end safeguards that prevent unauthorized breaches from occurring, while at the same time

---

13 Privacy is often thought of as a "fundamental" right and there are a variety of legal protections that may fall into this category. These include protections of an individual's home, body, and personal information. Olmstead v. United States, 277 U.S. 438, 478-79 (1928). Most issues of informational privacy (and thus confidentiality) are addressed by, or remedied under, tort law. There are several types of lawsuits for invasion of privacy including unreasonable: a) intrusions upon seclusion; b) appropriation of name/likeness; c) publicity of private life; and d) placing someone in a false light. Restatement (Second) of Torts § 652A (2000). However, personal information (what is at issue in medical confidentiality) is not protected at law in the same way one's home or bodily integrity is protected. In fact, quite a bit of personal information is not protected at all. For example, it is fairly simple to obtain a person's credit history (even legally) in contrast to his/her medical history despite the fact that both may be considered highly personal, and thus private, information. One author argues that privacy protections are basically a means to protect other interests such as reputation, avoidance of embarrassment or shame, or discrimination and do not necessarily support the notion that certain information is inherently private. See generally Richard S. Murphy, Property Rights in Personal Information: An Economic Defense of Property, 84 Geo. L.J. 2381 (1996).

14 See discussion infra notes 16, 21, 24 and accompanying text.

15 See discussion infra notes 16, 21, 24 and accompanying text.

16 State laws either address the type of information (usually based on disease or illness) or the entity holding the information (such as government agencies), or both. Joy Prits ET AL., HEALTH PRIVACY PROJECT, GEO. U. INST. FOR HEALTH CARE RES. AND POL'Y, THE STATE OF HEALTH PRIVACY: AN UNEVEN TERRAIN 22, available at http://www.georgetown.edu/research/ihcrp/privacy ,statereport.pdf. (last visited Sep. 19, 2001) (on file with the Connecticut Law Review). Thirty-five states place some restrictions on the use of information contained in medical records that are held by state agencies. Id. at 32. Twenty states have legislation restricting disclosure of medical information from hospitals and health care facilities. Id. Thirty-seven states also have statutes governing how managed care organizations may use patient information and eighteen specifically regulate the use of such information by insurance companies. Id.

17 See, e.g., King v. State, 535 S.E.2d 492, 495-96 (Ga. 2000) (quoting Pavesich v. New England Life Ins. Co. 50 S.E. 68, 70 (Ga. 1905)) ("A right of privacy in matters purely private is therefore derived from natural law.") Applying this definition, a patient's medical information, as reflected in the records maintained by his or her medical providers, is certainly a matter which a reasonable person would consider to be private.")

18 But see HAW. REV. STAT. § 323C-51 (2000) (stating that persons intentionally obtaining or disclosing protected health information are guilty of a class C felony).
accommodating needs for information (for example, to treat patients, assure quality health care, and conduct research to achieve health advances).

Like the state laws, the federal framework includes specific protections for types of confidential information, as well as protections aimed at particular federal agencies that gather and store health information. Because of the variability of these laws, as well as the proliferation of new forms of the electronic retention and transfer of medical information, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) required Congress to pass comprehensive confidentiality protections by 1999. Since Congress failed to meet this deadline, the Department of Health and Human Services issued proposed regulations on November 3, 1999 and final regulations on December 28, 2000. The proposed regulations speak briefly about postmortem confidentiality. They state that all protections expire two years after the patient’s death, however, like the amalgam of state and other federal laws, the proposed regulations provide little specific guidance in this context.

B. Ethical Basis for Confidentiality

Confidentiality is both a legal and an ethical doctrine. A physician’s duty to keep information confidential dates back to the earliest codes of medical ethics. For example, the Hippocratic Oath requires a physician to promise that: “[w]hat I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself holding such things

19 ROACH, supra note 10, at 231-32 (discussing Center for Disease Control guidelines regarding patient notification of HIV-positive healthcare workers).


21 Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. 82,462 (Dec. 28, 2000) (to be codified at 45 C.F.R. §§ 160, 164). Health and Human Services (“HHS”) issued proposed regulations on November 3, 1999. Id. The comment period for these regulations recently ended and final regulations were issued on December 28, 2000. Id. They will take effect two years from this date. Id. It is still possible that, within the intervening time period, Congress will enact legislation that supercedes the rules.

22 Id.

23 Standards for Privacy of Individually Identifiable Health Information 64 Fed. Reg. 59,950 (Nov. 3, 1999) (the proposed rule issued by HHS). However, this time period was not included in the final rule. See 65 Fed. Reg. 82 (2000).

24 But see HAW. REV. STAT. § 323C-43 (2000) (stating comprehensive protections under the Privacy of Health Care Information Act will continue to apply following the death of an individual); MONT. CODE ANN. § 50-16-504(10) (2000); WASH. REV. CODE ANN. § 70.02.010(10) (2000); WYO. STAT. ANN. § 35-2-605(a)(xiii) (Michie 2001). Iowa implies that the duty of employees of a Health Maintenance Organization (“HMO”) to keep information confidential extends beyond death. See IOWA CODE ANN. § 514B.30 (West 2000) (HMO employee “shall not testify as to such confidential communication or make other public disclosure thereof without the express consent of the person or the person’s legal representative, if the person is deceased . . . .”).

25 See discussion supra note 23.
shameful to be spoken about. . ." 26 This is an absolute prohibition if taken literally. Both the World Medical Organization's Declaration of Geneva and the International Code of Medical Ethics admonish the physician to maintain confidentiality, even after the patient's death. However, they do not identify any basis for evaluating requests for disclosure. 27 The American Medical Association's ("AMA") Council on Ethical and Judicial Affairs recently stated that "all information within a deceased patient's medical record, including information entered postmortem, should be kept confidential to the greatest possible degree," and provides specific guidelines for evaluating exceptions. 28

However, drawing from ethical codes, especially those without specific guidelines, is no more helpful than drawing from laws that state simple rules without providing reasons. Neither provides the additional guidance necessary to apply the general doctrine of confidentiality in the postmortem context. Instead, we might look to ethical theory to explain the purpose of confidentiality protections and thus provide an indication as to how they should function in different circumstances. In general, maintaining confidentiality has been justified in terms of the personal and social consequences of the practice, the necessary role of trust in fiduciary relationships, the intrinsic value of privacy as a human good, and the interpersonal demands of human dignity and autonomy. Although different philosophers and philosophical traditions emphasize some of these justifications over others, in practice, scholars of professional medical ethics combine them as mutually supporting, complementary reasons to endorse the medical profession's tradition of secret-keeping. 29 Importantly, each of the

28 It recommends that physicians consider the following factors in determining whether to disclose information:
the imminence of harm to identifiable individuals or the public health;
the potential benefit to at-risk individuals or the public health . . .;
any statement or directive made by the patient regarding postmortem disclosure;
the impact disclosure may have on the reputation of the deceased patient; and
the personal gain for the physician that may unduly influence professional obligations of confidentiality.

AM. MED. ASS'N COUNCIL ON ETHICAL AND JUD. AFFS., CONFIDENTIALITY OF HEALTH INFORMATION POSTMORTEM REPORT 5-A-00 (June 2000). I served as both the Secretary of the Council, and subsequently a consultant to the Council, during the time period in which this report was developed.

29 For example, according to Tom Beauchamp and James Childress, confidentiality protections can be justified using three types of arguments: consequentialist, rights-based autonomy and fidelity-based. TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 422 (4th ed. 1994). Principle-based theories are deontological in the sense that they focus on promoting certain values, rather than weighing outcomes. But unlike the general deontological theories, principlists acknowledge from the start that there are likely to be a number of principles that should guide our actions and that a balance must be achieved. Confidentiality is sometimes listed as a prima facie principle and other times subsumed under discussions of autonomy with exceptions based on physician
philosophical arguments allow for exceptions in particular circumstances, based on the balance between the goals achieved by confidentiality and the goals achieved by disclosure.\textsuperscript{30}

The rationales reduce to two primary values—privacy and health. Both of these map onto two of the main classes of ethical theory: deontology and consequentialism. Despite the different goals, neither justifies absolute confidentiality protection. First, deontological theories evaluate the ethics of alternative courses of action based on the importance of particular values, without regard to the consequences of promoting those values.\textsuperscript{31} One basic form of deontological reasoning is to test the justice of a particular action or practice by universalizing it: if a practice cannot be sustained when everyone does it, it violates our sense that moral rules ought to apply equally to all autonomous moral agents.\textsuperscript{32} Another variation on this mode of reasoning is to posit a hypothetical group of social contractors charged with writing universal rules of conduct in ignorance of their own individual interests.\textsuperscript{33} Privacy or confidentiality is valuable under this system for its own sake, apart from the consequences of the practice. Although absolute confidentiality protections would be compatible with universal adherence, so too is a system of limited confidentiality protections, if the exceptions are specified in advance as part of the rule. Because universalizable duties must be compatible with, or balanced against, the existing system of other universalized duties\textsuperscript{34} (for example, professional duties to prevent harm), more variegated rules involving specified exceptions would likely be approved. In fact, deontological theories promote a number of values, privacy would just be one of many. In the medical confiden-

\textsuperscript{30} Id. at 423.

\textsuperscript{31} One of the most famous deontologists is Immanuel Kant who argued that determining the moral or right action in a particular circumstance depends on one’s ability to universalize the rule governing the act, otherwise known as the “categorical imperative.” \textit{Immanuel Kant, Grounding for the Metaphysics of Morals} 26, 30 (James W. Ellington trans., Hackett Publ’g, 1981). With respect to confidentiality, a maxim would look something like “physicians should keep all information obtained from patients confidential.” However, there may be competing obligations that cause us to want to modify this rule, such as a physician’s obligation to safeguard the public’s health. \textit{See discussion infra} note 91. One of the major failings of Kantian ethics (and many other deontological theories) is its lack of guidance for dealing with conflicting maxims.

\textsuperscript{32} \textit{See Beauchamp & Childress, supra} note 29, at 423.

\textsuperscript{33} John Rawls’ adaptation of Kantian ethics attempts to demonstrate how a deontological theory can be applied to understand the social contract existing in a just society. \textit{See generally John Rawls, A Theory of Justice} (1973). He argues that valid ethical principles governing action are those to which rational agents would all agree if situated behind a hypothetical “veil of ignorance” (i.e., blind as to individual interests). \textit{Id.} at 136-37, 139. In this state, we might agree that a rule favoring confidentiality of medical information is ideal (since we would not then know our individual information needs), but we might also agree at the outset to certain exceptions to confidentiality based on competing values.

\textsuperscript{34} \textit{See id.} at 136-37, 139 (pointing out that general information would be possessed by decision makers in arriving at solutions that would be universalized).
tiality context, the value of privacy would have to be considered alongside the value of health.

Although deontological theories provide a basis for justifying confidentiality, the more likely basis for the current protections is essentially consequentialist or practical. "The patient should feel free to make a full disclosure of information to the physician in order that the physician may most effectively provide needed services." Consequentialist theories, such as utilitarianism determine the ethical or correct course of action by looking at the consequences of different alternatives. The alternative that leads to the best result, however defined (for example, most happiness, greatest good, etc.), is the ethical one. Confidentiality is thought to be a necessary requirement of the patient-physician relationship. Without assurances of privacy, patients may be less likely to disclose information pertinent to their medical care. As a result, physicians will be unable to provide appropriate treatment. In other words, confidentiality protections are thought to promote health. Thus, a general requirement of confidentiality is applied to medical practice. However, exceptions to this general

35 While Kantian ethics is not new, arguments for legal (and some ethical) protections based on patient rights of autonomy in the medical context are. Take, for example, the law of informed consent. One legal scholar tracing the evolution of informed consent questioned whether "autonomy . . . was put forward as the genuine rationale for the . . . doctrine of informed consent, or whether it was merely a convenient notion—an attractive philosophical and ethical symbol or benchmark at which to nod in passing." Nicholas P. Terry, Apologetic Tort Think: Autonomy and Information Torts, 38 ST. LOUIS U. L.J. 189-91 (1993). Likewise, arguments that confidentiality protections are based on patient autonomy are also probably post hoc rationalizations. This does not mean that the arguments are not valid reasons to maintain confidentiality protections, but they are not the likely basis for the development of the protections in the first place. Significantly, confidentiality protections originated in most medical codes and only later were picked up by law. Friedland, supra note 27, at 256-57. Patient autonomy was an almost nonexistent concept in medicine until fairly recently, although there has been some support for general notions of privacy (a concept related to autonomy). See COMM. ON ENERGY AND COM. DEMOCRATS, PATIENT'S BILL OF RIGHTS, at http://www.house.gov/commerce_democrats/pbor/pborhome.shtml (last visited Sep. 27, 2001) (on file with the Connecticut Law Review) (setting forth a discussion and text of a proposed Patient's Bill of Rights addressing patient autonomy). But here, again, there is little evidence of a freestanding notion of patient privacy, but rather concern appears to be focused on practical constraints that would encourage physicians to maintain confidences.

36 AM. MED. ASS'N, supra note 10, at 105.

37 See BLTC RES., UTILITARIANISM RESOURCES, at http://www.utilitarianism.com (last visited Sep. 27, 2001) (on file with the Connecticut Law Review) (listing a utilitarian glossary and a discussion of the several types of utilitarianism). "Rule-utilitarianism" seeks to effectuate rules that will generally result in the greatest good (e.g., a rule that physicians should keep patient confidences). Id. "Act-utilitarianism," on the other hand, focuses on individual acts and in each cases evaluates what action will lead to the greatest good (which may or may not result in the physician maintaining confidentiality). Id.

38 See AM. MED. ASS'N, supra note 10, at 105.

39 For example, because of the high risk of discrimination, patients may be unwilling to disclose HIV status to their physician if they fear disclosure. See FLA. STAT. ANN. § 381.004(1) (West 2001 Supp.) ("The Legislature finds that despite . . . confidential use of tests designed to reveal human immunodeficiency virus infection, many members of the public are deterred from seeking such testing because they misunderstand the nature of the test or fear that test results will be disclosed without their consent.").
rule apply when the cost of maintaining confidences is outweighed by the harm to others. In other words, when the value served by protecting confidentiality, such as promoting overall health is better served by disclosure, an exception should exist.40

III. POSTMORTEM CONFIDENTIALITY

To what extent should confidentiality protections or exceptions apply after a patient has died? I argue that—given the lack of legal guidance, as well as the theoretical and ethical framework that values both health and privacy—the extent of postmortem confidentiality protections should depend on an analysis of the interests served by confidentiality and the interests served by disclosure. However, before we can evaluate the interests involved, we must identify them. There are three groups of interests in maintaining confidentiality protections postmortem that I will address. First, deceased patients may have interests, including an interest in confidentiality, that survives death. In addition, patients, or potential patients, who are now living, may have an interest in assuring that information they disclose remains confidential postmortem. These two issues are addressed first and second respectively. At the end of this Part, I will consider the interests of third parties in maintaining confidentiality of medical information pertaining to the deceased. In the final Part of this Article, I evaluate the types of interests in disclosure, extrapolating from the range of exceptions in the premortem context, and propose guidelines for postmortem confidentiality protections.

A. Interests of the Deceased

It is an interesting philosophical exercise to consider whether dead people have interests that survive their death, and, if so, whether they can be “harmed” or “wronged” by actions taken after their death.41 According to Joel Feinberg, the question of whether certain entities have rights can be answered, in part, by examining their interests.42 Bonnie Steinbock further

40 One of the biggest problems with assumptions about the effect of new rules or exceptions on patient behavior is that we do not necessarily have an idea about how the current system impacts patient’s willingness to share confidential information with their physicians. See BEAUCHAMP & CHILDRESS, supra note 29, at 423. In fact, it may be that patients and physicians may have differing conceptions of confidentiality, and that the legal protections do not match either of these conceptions. If so, it is not clear what role the law plays (or should play) in this context.

41 See BEAUCHAMP & CHILDRESS, supra note 29, at 423. I do not address the various theological arguments that there is some kind of “afterlife.” This would, I believe, provide one of the strongest arguments for postmortem interests. A full analysis of such arguments are best left to those trained in religious doctrine (or perhaps those who have experienced the phenomenon).

42 See 1 JOEL FEINBERG, MORAL LIMITS OF THE CRIMINAL LAW: HARM TO OTHERS 33-34 (1984) (proposing only entities with interests are owed obligations, such as confidentiality).
explains Feinberg’s position, noting that interests are premised on desires or wants, and thus require consciousness. This does not mean that an individual must be aware of a particular desire, or even that he must be aware someone thwarts the desire: people can be harmed by acts about which they are unaware. But an entity that can form no desires has no interests.

Corpses do not have interests because they do not meet the minimal condition of conscious awareness. Although it seems obvious that a dead body does not have interests, it is not so clear that a previously living person has no interests that survive death. George Pitcher differentiates two ways one might describe someone who is now dead: (a) the antemortem person (for example, the person as he was during his life), and (b) the postmortem person (for example, the person as he is now, a molding corpse). This latter entity cannot be harmed or wronged. However, Pitcher argues, the antemortem person (or the person who once lived) can be harmed. Feinberg uses Pitcher’s distinction and argues that some of a person’s interests survive his death and “in virtue of the defeat of these interests, either by death itself or by subsequent events, we can think of the person who was, as harmed.” In other words, the surviving interests are those of the once-living person (antemortem person), not the now-dead person (postmortem person). Thus, Feinberg would argue that the antemortem person can be harmed by all sorts of things, such as a broken promise to keep medical information confidential, or defamatory statements which result in reputational harms.

The most troubling aspect of this argument is the appearance of retroactive causation—that an action taken after a person has died (and thus is no longer in existence) can harm the previously living person. Steinbock argues that Feinberg reconciles this problem by thinking about “timelessly true” propositions. In other words, we can agree that an individual now living can be harmed by something after her death, and this harm is something that is timelessly true. Steinbock gives the example of breaking her ankle in six weeks time—she is not harmed now, nor retroactively harmed, nor harmed all along, but all along she had the property of being harmed at

---

43 BONNIE STEINBOCK, LIFE BEFORE BIRTH: THE MORAL AND LEGAL STATUS OF EMBRYOS AND FETUSES 10 (1992). Entities that lack interests lack moral status, and thus have no moral claims upon us (e.g., to maintain confidentiality). Id. Of course this does not mean that you can do anything you want to the being—there might be other interests that control. See also discussion infra pp. 95-96.


47 FEINBERG, supra note 42, at 83. See also Anthony Serafini, Callahan on Harming the Dead, 15 J. PHIL. RES. 329 (1989-1990) (arguing that there are “properties,” rather than “interests” which survive death and can be harmed).

that particular time. Joan Callahan considers this argument and concludes that it actually should be taken for the proposition that the dead cannot be harmed, only the living. The retroactive, or all along property, of being harmed is designed to show that it is not the postmortem person who is harmed, but the antemortem person, in our case the previously living patient.

Callahan makes a strong argument that only the living can sustain harm, however, even if one were to accept that there are interests that survive death, there is still the issue of what harm is done to the deceased by breaching confidentiality. Feinberg describes the harm to interests in terms of blocking of goals or thwarting of desires. He notes that although dead people cannot get what W.D. Ross calls "want-satisfaction," or the feeling of satisfaction that one's desires have been fulfilled, they can get "want-fulfillment" even though they are unaware of this fulfillment. Thus, a person may be harmed after he has died, if his wants or desires are not fulfilled. In the confidentiality context, this translates into the thwarting of the individual's desire to maintain confidentiality. To some extent, this appears to depend on whether the individual did actually desire to maintain confidentiality postmortem. But unlike thwarting a person’s desires as written in her will, in most cases there will not be a specific indication about the patient’s wishes regarding disclosure of information after death.

Another possibility is that the individual is wronged because the physician breaches the “promise” to maintain confidentiality. Few physicians explicitly promise to maintain confidentiality and even fewer extend that promise to the postmortem context. Implied promises provide a shaky basis for confidentiality protections since they must be proved in each case. A third possibility is that the harm is to identity, via memory, as

---

49 Id. at 26.
51 Id. For example, Barbara Levenbook argues that the dead can be harmed or wronged, but that Feinberg's reliance on "interests" as the basis for such harm is incorrect. Rather, she posits that the dead can sustain losses and it is these losses that form the basis of the harm. Barbara Baum Levenbook, Harming Someone After His Death, 94 ETHICS 407, 401-19 (1984). For a critique of her position, see Don Marquis, Harming the Dead, 96 ETHICS 159, 159-61 (1985) and Levenbook's rebuttal, Barbara Baum Levenbook, Harming the Dead, Once Again, 96 ETHICS 162, 162-64 (1985).
52 FEINBERG, supra note 42, at 85.
53 Id. at 84.
Almost every member of the public is aware of the promise of discretion contained in the
constructed by the person when alive. Feinberg states: "the desire to maintain a good reputation . . . can be the basis of interests that survive their owner's death . . . and can be promoted or harmed by events subsequent to that death." 56 This idea of harm to identity is tempting since it sounds very much like what confidentiality rules protect for living patients. We each play a role in constructing our own identity and thus our memory. 57 Adopting this idea, Dorothy Grover argues for a theory of posthumous harm based on the potential that events may have an adverse effect on the interpretation of a person's life. 58 She gives the example of a person who tries to be caring during his life, but, because of information disclosed after his death, causes everyone close to him to think he was faking compassion. 59

Are the interests of the dead in controlling identity via confidentiality weaker or stronger than those of living patients? It may be necessary to have stronger confidentiality protections in the postmortem context because the individual in question is no longer available either to consent to the disclosure or to "defend" his or her reputation or identity. Individual control over identity rests upon two related factors: the individual's ability

---

Hippocratic Oath, and every patient has a right to rely upon this warranty of silence. The promise of secrecy is as much an express warranty as the advertisement of a commercial entrepreneur. Consequently, when a doctor breaches his duty of secrecy, he is in violation of part of his obligations under the contract.

Id. However, breach of contract cases for disclosure of confidential information are rare. Alan B. Vickery, Breach of Confidence: An Emerging Tort, 82 COLUM. L. REV. 1426, 1444-48 (1982).

56 FEINBERG, supra note 42, at 86. It is not clear that the interest in maintaining memory should include an interest in preventing the disclosure of true information; defamation or other legally protected harms to reputation deal with false statements.

57 RONALD DWORKIN, LIFE'S DOMINION 224 (1993). Ronald Dworkin alludes to this in his description of autonomy as "the capacity to express one's own character—values, commitments, convictions, and critical as well as experiential interests—in the life one leads." He further states that "[r]ecognizing an individual right of autonomy makes self-creation possible. It allows each of us to be responsible for shaping our lives according to our own coherent or incoherent—but, in any case, distinctive—personality." Id.

There is a great deal of psychological literature examining the development and control over personal identity. Evaluation of this literature is beyond the scope of this article. For works which undertake this evaluation, see JOHN KOTRE, WHITE GLOVES: HOW WE CREATE OURSELVES THROUGH MEMORY (1995) (discussing the role both real and false memories play in our lives), ELIZABETH A. WAITES, MEMORY QUEST: TRAUMA AND THE SEARCH FOR PERSONAL HISTORY 85-105 (1997) (discussing representation and the self), and Joseph M. Fitzgerald, Autobiographical Memory and Social Cognition: Development of the Remembered Self in Adulthood, in SOCIAL COGNITION AND AGING 143-71 (Thomas M. Hess and Fredda Blanchard-Fields eds., 1999) (discussing the role of autobiographical memory for identity).

58 Dorothy Grover defines harm as something that occurs "when circumstances either seriously impair the present quality of a person's life, or undermine the possibility that a given person could be in a position to choose (or reject) a life of good quality." Dorothy Grover, Posthumous Harm, 39 PHIL. Q. 334, 347 (1989). Under this construction of harm, posthumous harm would be possible since posthumous events can have adverse effects on a person's life (or the interpretation of the person's life).

59 Id. at 338.
to control what information other people know (confidentiality), as well as that individual’s ability to shape his or her own personality and public image (which includes controlling what private information is disclosed in the first place). Because dead people can no longer shape their public image by changing aspects of themselves, sharing private information, or defending, explaining or justifying their actions, the interest in maintaining identity is protected only to the extent that the deceased can “control” the dissemination of confidential information postmortem. Thus, one might argue that confidentiality protections should be absolute in this context, or at least that the deceased’s wishes regarding disclosure should be given great deference.

However, even if deceased patients have fewer avenues to control identity, they are also subject to less harm. As noted previously, although the dead can have their premortem wants fulfilled (or hindered) they cannot experience want satisfaction (or dissatisfaction). Moreover, the dead cannot be hurt, or feel pain, sadness, happiness, or any other physical or emotional sufferance. Thus, one might argue that confidentiality protections should be absolute in this context, or at least that the deceased’s wishes regarding disclosure should be given great deference.

60 Consider the following example: a woman shoots her husband, but claims he is shot by an intruder. She is never charged with the crime. Sometime after her death her statements made to her psychotherapist about her role in the shooting are disclosed, ruining her reputation. As it turns out, however, she had been subject to spousal-abuse and had shot her husband during a particularly violent encounter. This information is not known by anyone currently living (she kept the abuse private). The woman’s reputation would be significantly altered by this knowledge, but with her death (and the loss of the information) it is impossible to repair the damage done.

61 As noted previously, I do not address the possibility of an afterlife. See supra note 41. There are some tort actions that survive the death of the harmed individual. EDWARD J. KIONKA, TORTS IN A NUTSHELL 413 (3rd ed. 1999) (stating, “[a]bout one-third of the states provide for the survival of (1) all tort actions or (2) all tort actions except defamation . . . . In general, actions for harm to tangible property (real or personal) survive . . . .”). Although many suits for damages brought by surviving family members seek to protect their interests (such as an action for wrongful death), RESTATEMENT (SECOND) OF TORTS § 6521 (1977), others focus more specifically on the interests of the deceased. For example, traditional privacy law states that reputational harms do not survive death. Id. It is a well-established principle that: “Actio personalis moritur cum persona.” BLACK’S LAW DICTIONARY 29 (5th ed. 1979) (personal actions die with the person). However, a minority of states allow suits for such things as defamation to be brought by a decedent’s estate or surviving family. Francis M. Dougherty, Annotation, Defamation Action as Surviving Plaintiff’s Death, Under Statute Not Specifically Covering Action, 42 A.L.R.4th 272 (2001) (analyzing state cases in which the courts determined whether a defamation action survives upon the death of a plaintiff under survival statutes not specifically covering defamation actions). Most suits alleging lack of confidentiality would not rest of grounds of defamation since the information disclosed is usually true. RESTATEMENT (SECOND) OF TORTS § 581A (1977). See also Janet Kobrin, Confidentiality of Genetic Information, 30 UCLA L. REV. 1283, 1300 (1983) (stating that “no court has held a physician liable for disclosure solely on the basis of defamation”). See generally 50 AM. JUR. 2D Libel and Slander § 356 (1993) (discussing libel and slander for deceased persons and their representatives); Lisa Brown, Dead But Not Forgotten: Proposals for Imposing Liability for Defamation of the Dead, 67 TEX. L. REV. 1525 (1989) (discussing the interests and issues that judges and legislatures must consider with proposals for relief from the effects of defamation of the dead); Raymond Iryami, Give the Dead Their Day in Court: Imposing a Private Cause of Action for Defamation of the Dead from Criminal Libel Statutes, 9 FORDHAM INT’L. REV. 1083 (1999) (arguing that courts should imply a private cause of action for defamation of the dead to that decedent’s representative and survivors).

emotional state. The potential harm to the living due to a breach of confidentiality is two-fold. One aspect is the harm of having information disclosed that they did not want known and thus having to suffer the consequences of having that information known. The second aspect is knowing that their wishes were disregarded. The dead can be harmed only with respect to the first aspect, having information disclosed that they did not want known. And even so, they cannot "suffer" the consequences in any real sense of the word. 63 The notion of harm to identity is an amorphous concept even for living patients. For the dead it is even more difficult to pin down. The result is that, although the dead may have some interests in maintaining confidentiality postmortem, this interest is not as strong as it is when the patient is living. Thus, other interests may take precedence when weighing the appropriateness of confidentiality versus disclosure.

B. Interests of the Living

Whether or not one accepts the argument that there are interests that survive death, there are clearly interests of the living that must be considered. 64 In fact, these interests seem to form a stronger basis for understanding confidentiality protections in the postmortem context. First, there are the interests of current and future patients in assuming that information they disclose to their physicians will remain confidential. Second, there are interests of third parties in maintaining the confidentiality of information related to the deceased.

1. Interests of Current or Future Patients

As stated previously, Joan Callahan argues that it is not the now-dead person who is harmed, but his previously living incarnation (Pitcher's antemortem person). 65 Furthermore, our use of language that implies harm or wrong to the dead, is a psychological manifestation of our regard for the person who was once alive. It should not be taken to imply that we really believe the dead have interests that survive. In particular, Callahan draws from the example of wills and notes that the practice of honoring wills is based largely on the fact that the wishes of the deceased "coincide with other values we hold important (the value of certain objects, the good of individual heirs, etc.)." 66 Although we have a general moral conviction that people may dispose of their property after death, the obligation to

---

63 Aristotle argues that: "it makes a difference whether the various sufferings befall the living or the dead ... if anything whether good or evil penetrates [the dead], it must be something weak and negligible ...." Grover, supra note 58, at 335 (citation omitted). He seems to recognize that the dead cannot be harmed in the same way as the living.
64 And, in fact, my inclination is to agree with Callahan that the dead do not have interests.
65 Callahan, supra note 50, at 341.
66 Id. at 350.
abide by their wishes is a moral obligation to people still living, not to the deceased.\(^{67}\) Likewise, we might argue that preserving confidentiality after death coincides with our value of confidentiality as a general practice. To the extent that preserving confidentiality in a particular case does not coincide with our general societal values, it need not be maintained (regardless of the individual’s wishes). This mirrors the situation for living patients who cannot prevent the disclosure of confidential information in certain circumstances, such as when public health is at issue.\(^{68}\)

Ernest Partridge takes a slightly different stance.\(^{69}\) He argues that there are general practices which people who are now living have an interest in preserving, even after death, including things like making wills, promises, and truth-telling.\(^{70}\) Consider the example of the execution of wills. People make wills with the assumption that the wills will be effectuated after their death. Even if they retain no interests after death, they have an interest now in a system that assures that their wishes will be effectuated after death. Knowing that wills would not be executed, or that the execution would depend on a whim would harm people’s current interests as well as make them less likely to make wills (or amass assets).\(^{71}\)

There are two ways to consider this argument. One way to think about this is from a consequentialist perspective. Consider the analogy to wills—

\(^{67}\) Callahan argues that a moral obligation exists as to the heirs named in the will. \textit{id.} at 351. Moreover, she notes that although we allow great latitude, there are some ethical restrictions on what people can do with their property after death. For example, we do not accommodate a person who asks to have their pet killed, or all their money buried with them. \textit{id.} at 350.

\(^{68}\) See discussion infra note 88.

\(^{69}\) In addressing Feinberg’s reliance on want-satisfaction and want-fulfillment, Partridge notes that “[d]eath cancels not only the possibility of satisfaction but also the very point of fulfillment.” Ernest Partridge, \textit{Posthumous Interests and Posthumous Respect}, 91 ETHICS 243, 246 (1981). In fact, Partridge agrees with Feinberg that there is no difference between an act (libel) that pertains to the living, but which has absolutely no effect, and an act that pertains to the dead. But rather than accept that the dead therefore may be harmed, he rejects the idea of harm to the living when there are no effects. He stresses, however, that this does not mean that libel (or other acts) are not morally wrong. He merely argues that we cannot base the moral wrongness on harm to the individual libeled. \textit{See id.} at 252.

\(^{70}\) \textit{id.} at 258 (“I have an interest in affecting events beyond my death because I can imagine, anticipate, and evaluate such events now, I can now perceive their impact upon things and persons I care for now.”).

\(^{71}\) Although I have only anecdotal evidence, I suspect this might be one problem with encouraging people to create advance health care documents, such as living wills and advance instruction directives. There is evidence that these documents may not be effectuated after the patient has become incompetent, especially in situations requiring decisions about life-sustaining treatment (presumably the type of situation about which the patient was most concerned about while directing his future care). \textit{See generally} JESSICA W. BERG ET AL., \textit{INFORMED CONSENT: LEGAL THEORY AND CLINICAL PRACTICE} (2d ed. 2001) (suggesting that conflicts with hospital staff members and the patient’s family and friends interfere in the overall decision-making process, especially because cases involving life-sustaining treatment are emotionally charged and accompanied by fear of legal liability). Thus, patients may be reluctant to go through the trouble of creating a legal document that will not be effectuated. Another likely explanation is that patients are satisfied with what they believe (correctly or incorrectly) to be the default rule of family decision-making.
people may be less likely to execute a will if they know it may be ignored. The practical concern in the context of confidentiality is whether people will be less likely to confide sensitive information to their physician (lawyer, mental health professional, etc.) knowing the possibility of disclosure postmortem. The ethical rule to maintain confidentiality, even postmortem, is premised, at least in part, on the notion that such rule will result in the best consequences. But consequentialist (here utilitarian) arguments suffer from empirical difficulties both in predicting behavior and in determining what constitutes the greatest good. On the one hand, up until now we have been functioning largely in the absence of specific confidentiality protections postmortem and this has not seemed to alter patients’ willingness to talk with their physicians. On the other hand, the same point may be made with respect to confidentiality protections for living patients—many states enacted explicit legislation only recently and we still lack a comprehensive federal framework for confidentiality. Most patients have no idea about the legal rules for confidentiality; they rely on (sometimes erroneous) assumptions about disclosure. This is also likely to be true for patients thinking about postmortem disclosure. Moreover, these arguments are premised on the notion that patients will think about postmortem confidentiality in making decisions about talking to their physicians, when in reality the issue is not likely to be foremost on a patient’s mind during a clinical encounter. The bottom line is that it is difficult to identify the practical consequences of specific confidentiality protections in the premortem context, let alone the postmortem one. Thus, decisions about which rules to enact must depend on theoretical suppositions regarding patient behavior.

Alternatively, we might construct postmortem confidentiality protections and exceptions so as to achieve a balance between individual and societal interests that we all would agree is appropriate (using, for example, Rawls’ social contract theory). Importantly, this does not suppose

---

72 See Swidler & Berlin v. United States, 524 U.S. 399 (1998). While the arguments against the survival of the [attorney-client] privilege are by no means frivolous, they are based in large part on speculation—thoughtful speculation, but speculation nonetheless—as to whether posthumous termination of the privilege would diminish a client’s willingness to confide in an attorney. In an area where empirical information would be useful, it is scant and inconclusive. Id. at 410.

73 Most laws and ethical codes are silent on the issue. See discussion supra Part II.

74 As a colleague of mine noted after reading this article, she now will be forced to consider postmortem disclosure when she seeks medical care! This brings up an important point—if a patient knows with certainty that there will not be any protections, that is more likely to have an effect on behavior (resulting in less disclosure) than if the patient is simply unclear as to the extent of the possible exceptions.

75 Partridge, supra note 69, at 259. Rawls’ social contract theory could be useful in this context.
that there are no exceptions to confidentiality, but that exceptions must fit within this balance and should reflect the initial framework that people assume operates. Therefore, if people generally value confidentiality protections that extend beyond death (or the values which confidentiality seeks to protect are generally understood to extend beyond death), disclosure of information postmortem would harm people now in the same way they would be harmed by knowing that their will would be disregarded. This issue is not dependent on empirical evidence because the concern is not with what the majority of people now believe about confidentiality protections, but with what people in some neutral state would have agreed regarding confidentiality protections. Disclosing information about people upon their death may harm people's current interests in confidentiality not because those interests survive death but because the present interest in confidentiality extends indefinitely, or at least does not extinguish immediately upon death. In other words, when someone considers whether to disclose sensitive information to a health care professional he or she assumes that the information will remain confidential and does not put any timeframe or limitation on that assumption.

Both theories provide a basis for postmortem confidentiality protections based on the interests of current and future patients, and both allow for exceptions based on the goals sought to be achieved. Moreover, there is yet another group of interests that must be considered in this context—those of people now living and their interests in preserving the confidentiality of the specific person who has died.

76 This does not mean that there cannot be new exceptions, merely that the exceptions must be understood within the initial framework of values.

77 See Michael H. Kottow, Medical Confidentiality: An Intransigent and Absolute Obligation, 12 J. MED. ETHICS 117 (1986).

If the death of a famous politician should prompt a physician to uncover his knowledge about the deceased's homosexual inclination, still living patients of the same physician might register with distaste and fear the possibility that private information about them could eventually be disclosed after they died. This suspicion may well be unsettling and therefore harmful to them...

Id. at 119.

Following the disclosure of tapes of the poet Anne Sexton's sessions with her psychiatrist, an editorial in the New York Times stressed the public's right to a system of confidentiality. Editorial, Betrayed: The Poet and the Public, N.Y. TIMES, July 20, 1991, at 18. A follow-up letter noted that "even if Anne Sexton wanted the tapes revealed, I still say: Lock them up! Why should Sexton have the right to undermine trust for millions of living patients in a pitch for immortality from the grave?" M.G. Lord, Editorial, Woman Talk to a Psychiatrist While an Ear on the Wall is Listening, NEWSDAY, July 28, 1991, at 32. See generally, Sharon Carton, The Poet, the Biographer and the Shrink: Psychiatrist-Patient Confidentiality and the Anne Sexton Biography, 10 U. MIAMI ENT. & SPORTS L. REV. 117 (1993) (arguing that when psychiatrist Dr. Martin Orne revealed intimate details of his professional sessions with Anne Sexton, he not only harmed Sexton, but mental health patients in general who rely on medical confidentiality).

78 See Kottow, supra note 77, at 19.

Also to be considered are the negative effects a disparaging disclosure might have upon surviving family members as well as groups of individuals with whom the deceased had a
2. Interests of Third Parties

First, blood relatives of the deceased have an interest in controlling information that has implications for their own health (and thus identity). Although the interests of blood relatives in maintaining confidentiality may not supercede the individual’s right to control his or her medical information during life,\textsuperscript{79} they may well be given greater weight (or at least be less likely to be outweighed) after that person has died.

Second, there are more nebulous interests of third parties in preventing the disclosure of confidential information. The dead live on in the memories of the living. Harms to the memory of the deceased may entail very real harms to people now living who have an interest in preserving the original memory, such as relatives or close friends of the deceased. In fact, interests in memory or reputation of a loved one are sometimes legally protected.\textsuperscript{80} However, the idea of harm to memory once again raises questions about the extent to which someone can have a legally protected interest in preserving memory—here a person’s memory pertaining to someone else. The notion of harm to the identity interests of either persons previously living or the memory interests of persons now living is difficult to conceptualize, particularly when the issue is true, rather than false, information.\textsuperscript{81}

C. Summary

I have argued that there are a variety of interests in maintaining confidentiality postmortem that must be taken into account: interests of the deceased; interests of current or future patients; and interests of those close to the deceased. The interests of current or future patients in maintaining a system of confidentiality play out the same way in the postmortem context as they do in the premortem one. In both situations, the values underlying confidentiality protections—privacy and health—must be taken into account. This notion is discussed in the context of evaluating the strength of commonality of interests. Death does not cancel the obligation of confidentiality which remains of import to all survivors within the radius of interests of the deceased.

\textit{Id.}

\textsuperscript{79} As a practical matter, relatives of a living patient cannot prevent the patient from sharing information about him or herself, even if that information has personal implications for the relative in question.

\textsuperscript{80} Potentially through a cause of action for infliction of emotional distress due to statements made about a deceased relative. See 50 AM. JUR. 2D \textit{Libel and Slander} § 356 (1995).

\textsuperscript{81} We tend to give less protection to disclosures of true information than disclosure of false information. For example, a defense to a suit for libel or slander is that the information in question is true. But see discussion supra note 60 (discussing the potential harm to identity from information that is true, but requires additional information in order to be understood in context; and that additional information may no longer be available after the person had died).
the interest in disclosure. The identity interests of the deceased and the memory interests of those close to the deceased are linked—memory interests are those interests in identity that remain after the individual has died. These two aspects are considered below as part of the discussion of the sensitivity of the information in question. Finally, the interests of blood relatives in maintaining the confidentiality of information pertaining to their health has implications for family involvement in determinations regarding disclosure. It is to the evaluation of these issues that I now turn.

IV. CONFIDENTIALITY VERSUS DISCLOSURE

Given that there are interests in maintaining confidentiality postmortem, it might seem prudent simply to require strict confidentiality after death. But such a system is as unpalatable as one in which all information is disclosed freely upon a patient’s death. There are clearly interests that weigh in favor of disclosure of information. Even for living patients, confidentiality protections are not absolute. Determining the extent of protections in the postmortem context entails a weighing of the interests in maintaining confidentiality against the interests in disclosure. If disclosure does not harm the values we seek to promote by maintaining confidentiality (such as privacy or health), then it should be permitted. Likewise, if disclosure promotes the values better than confidentiality, it should be permitted.

A. What Factors to Consider?

There are two factors to consider: (1) the strength of the interest(s) in disclosure; and (2) the strength of the interest in confidentiality. The first factor is essentially an inquiry into the reasons why the information is sought. The second factor I break into two parts: (a) the sensitive or personal nature of the information; and (b) the time elapsed since the individual’s death. Each of these will be considered in turn.

82 See discussion supra Part III.A.1.
83 See discussion supra Part III.A.2.
84 See discussion supra Part III.B.2.
85 As stated previously, one difficulty that has always existed in deontological theories is how to balance competing values, principles or maxims. See discussion supra note 31. Thus, if confidentiality is designed to promote both privacy and health (by encouraging disclosure), in the situation where one of these will be better promoted by disclosure (health) and one by confidentiality (privacy) there is no way to reconcile the conflict. Consequentialist theories allow us to weigh the two in light of an external measure (for example, greatest good). So if more good is produced by favoring health over privacy, disclosure would be allowed. But even without resorting to such utilitarian analysis, we might argue that as a general matter our society places value on both privacy and health, and comes out in favor of one or the other depending on the imposition into privacy versus the imposition into health. For example, privacy protections allow people to do as they wish with respect to their own health, but not with respect to the health of others.
1. Why Is the Information Sought?

There are a variety of reasons why confidential medical information may be sought after a patient’s death. These include: inquiries by family members seeking information pertaining to their own health; information sought by public health authorities; biomedical researchers seeking to promote societal health; and information sought for general interest (such as by media or biographers). What weight should we accord these interests? If a primary purpose of confidentiality protections is to promote health—by encouraging patients to convey information to their physicians to help in diagnosis and treatment—then it should be permissible for the health professional to share the information when health needs are better met by disclosure. This is true particularly when the patient in question is deceased. For living patients there is a general presumption that health needs will be better met through confidentiality (because protections will encourage patients to communicate freely with their physicians), even though some third parties may find the information useful for their own medical care. Nonetheless, there are a number of exceptions permitting disclosure of confidential medical information of living patients for public

---

86 At issue here is the use of identifiable information. Confidentiality concerns the individual’s ability to keep information that has been disclosed from being shared with other people. The protection is not with respect to the information itself, but its link to the individual. Thus it does not make sense to talk about the confidentiality of anonymous information, except to the extent that there are security concerns relating to whether or not the information can be linked back to the individuals in question. For example, the federal guidelines governing research specifically exempt from institutional review board evaluation (and thus the federal requirements such as informed consent) “[r]esearch, involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens . . . if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.” 45 C.F.R. § 46.101(b)(4) (2000).

Even if there is no breach of confidentiality, there may be a violation of other rights. For example, consider the case of a patient who refuses to participate in research because he or she does not approve or agree with the goals of the project (as may occur in some cases of gender or race-based research). Using that person’s medical information against their previously expressed wishes would frustrate this desire.

87 There are arguments made that in certain circumstances disclosure of information to close family members may harm the individual seeking the information. I reject this argument, particularly with respect to information sought for health purposes. Studies regarding informed consent disclosures, for example, suggest that sharing health information with patients generally is not harmful. PRESIDENT’S COMM’N FOR THE STUDY OF ETHICAL PROBS. IN MED. AND BIOMED. AND BEHAV. RES., MAKING HEALTH CARE DECISIONS: THE ETHICAL AND LEGAL IMPLICATIONS OF INFORMED CONSENT IN THE PATIENT-PRACTITIONER RELATIONSHIP 75 (1982). In general, informed consent should function as an adequate safeguard in these circumstances. Thus, individuals wishing to discover certain information might receive counseling regarding the potential implications of the information—as is done for most genetic testing nowadays—before disclosure is appropriate.

There is a separate question about whether information that does not pertain to health status can be harmful. Consider the example in the introduction regarding the son seeking information from the therapist—what if the mother had indeed sought counseling due to problems stemming from her relationship with the son? Information sought for these types of purposes will be considered below under the heading of general interest.
or individual health needs. While there have long been reporting statutes for communicable diseases, more recently there has been discussion of a physician’s duty to disclose genetic information to specific at-risk individuals. At least one state recognizes the likelihood that family members will seek genetic information for health reasons after a patient’s death, and

88 For example, the Department of Health and Human Services’ proposed regulations governing confidentiality of medical information explicitly allow disclosure without patient authorization for public health purposes as well as for law enforcement purposes. 65 Fed. Reg. 82,462, 82,538 (Dec. 28, 2000). The most common examples where public health concerns outweigh individual rights of confidentiality are from the contagious disease cases. A number of states have legislation requiring disclosure of specific diseases such as sexually transmitted diseases (STDs), HIV/AIDS, or general communicable diseases such as tuberculosis and syphilis. Disclosure to public health authorities, People ex rel. Barmore v. Robertson, 134 N.E. 815, 819 (Ill. 1922), other medical care providers, Davis v. Rodman, 227 S.W. 612, 614 (Ark. 1921), partners, DiMarco v. Lynch Homes-Chester County, Inc., 583 A.2d 422, 425 (Pa. 1990), family, Skillings v. Allen, 173 N.W. 663, 664 (Minn. 1919), or even needle sharers, HAW. REV. STAT. ANN. § 325-101(A)-(B) (Michie 2000), may be required.

89 L.J. Deftos, Genomic Torts: The Law of the Future—The Duty of Physicians to Disclose the Presence of a Genetic Disease to the Relatives of Their Patients with the Disease, 32 U.S.F.L. REV. 105, 111-32 (1997) (noting the general law of duty and the specific duty of physicians to reveal the presence of a genetic disease to the relatives of their patients with such a disease); Janet A. Kobrin, Confidentiality of Genetic Information, 30 UCLA L. REV. 1283, 1285 (1983) (discussing the issue of disclosure to third parties and “how current legislative schemes and case law suggests that a counselor has an affirmative duty to inform appropriate third parties of certain diagnoses”); Angela Liang, The Argument Against a Physician’s Duty to Warn for Genetic Diseases: The Conflicts Created by Safer v. Estate of Pack, 1 J. HEALTH CARE L. & POL’Y 437, 437 (1998) (arguing that the decision by the Superior Court of New Jersey requiring physicians to warn individuals known to be at risk from a genetically transmissible condition “has created serious implications for a patient’s privacy rights, patient-physician confidentiality, as well as a patient’s health and safety”); Sonia M. Suter, Whose Genes Are These Anyway? Familial Conflicts Over Access to Genetic Information, 91 MICH. L. REV. 1854, 1856 (1994) (arguing that courts and legislatures should not permit disclosure of a person’s genetic information to third parties and that genetic testing for the benefit of a third party cannot be constitutionally mandated).

Some states have specific confidentiality statutes addressing genetic information. CAL. CIV. CODE §§ 56.17(a)-(d) (West Supp. 2001) (prohibiting health care service plans from willfully or negligently disclosing the results of a genetic test without written permission); GA. CODE ANN. § 33-54-3(b) (Harrison 1998) (restricting insurer from seeking information derived from a genetic test); ME. REV. STAT. ANN. tit. 5 § 19302 (West Supp. 2001).

An employer may not fail or refuse to hire, discharge or otherwise discriminate against an employee or applicant for employment with respect to the compensation, terms or conditions of employment on the basis of genetic information concerning that individual or because of the individual’s refusal to submit to a genetic test or make available the results of a genetic test or on the basis that the individual received a genetic test or genetic counseling, except when based on a bona fide occupational qualification.

ME. REV. STAT. ANN. tit. 5 § 19302 (West Supp. 2001); Act of June 21, 2000, ch. 304, 2000 N.H. Laws 141-H:2 (codified as amended at N.H. REV. STAT. ANN. § 141-H:2) (Michie 1955 & Supp. 2000) (stating that no person shall disclose to any other person that an individual has undergone genetic testing or the results of a test). But cf. N.M. STAT. ANN. § 24-21-3D (Michie 1978) (exempting insurers from general confidentiality regulations if the use of genetic analysis or genetic information for underwriting purposes is based on sound actuarial principles or related to actual or reasonably anticipated experience).

Despite the fact that genetic information may be useful to third parties, this is true of many other types of medical information and thus it is not clear that it should be treated differently than medical information in general, which is usually kept confidential during the individual’s lifetime, except to the extent that it has serious health implications for other people (for example, contagious diseases). See Suter, supra, at 1870-88.
authorizes disclosure.90

"Health" is a broad category.91 In the premortem context, the concept is expansive enough to include disclosure for protection of public safety and of vulnerable persons. Health needs are likely to fall along a continuum with some information having direct health implications—such as information that a parent died of a potentially inheritable disease—and other information having less direct impact—such as the information that a parent was a carrier of a particular gene that may or may not have been passed on.92

The strongest argument for disclosure can be made when an individual (or individuals) will potentially obtain direct health benefits from the information. But there are also cases, such as disclosure for biomedical research purposes, which may result in a better understanding of the disease

90 S.C. CODE ANN. § 38-93-30(4) (West Supp. 2000) (permitting a deceased individual's confidential genetic information to be disclosed when it will assist in medical diagnosis of blood relatives of the decedent).

Other states have statutes addressing access to medical information by adoptees regarding their biological parents. D. Marianne Brower Blair, Lifting the Genealogical Veil: A Blueprint for Legislative Reform of the Disclosure of Health-Related Information in Adoption, 70 N.C. L. REV. 681, 735 (1992). Some, like Missouri, allow the adopted child to access information about their deceased biological parent if the parent has left explicit instructions to this effect, or, in the absence of such instructions, if a court finds that the information is "necessary for health-related purposes." MO. ANN. STAT. § 453.121 (West 2000). See also OKLA. STAT. ANN. tit. 10, § 7504-1.2 (West 1981) (noting in the comments that medical information about ancestors may be critical to medical treatment or childbearing decisions); TEX. FAM. CODE ANN. § 162.416(b) (Vernon 1999) (allowing disclosure only in cases where the decedent specifically authorized postmortem release of the information). Other states simply allow identifying information to be released if the biological parent is deceased. MONT. CODE ANN. § 42-6-104(6) (1999) (stating that the court may order disclosure of identifying information to the petitioner if the person being sought is deceased). And still other states allow only information regarding the identity of the deceased biological parent to be disclosed. 23 PA. CONS. STAT. ANN. § 2905(c)(3) (Purdons 1998 & Supp. 2001) (stating that if one biological parent is deceased his or her identity may be disclosed, however, requiring the consent of the living biological parent prior to disclosure).

91 It is less clear whether physicians have the same ethical responsibility to protect public safety as they do public health. As a result, mandatory reporting statutes in this context may be more problematic from an ethical standpoint. On the other hand, because "health" is such an expansive concept, it often is difficult to distinguish between concerns about public health and public safety. Many states have reporting statutes for injuries from criminal behavior, injuries from alcohol, motor vehicle impairments, and burns. Ohio, for example, has a statute mandating the reporting of drug abuse when the individual in question is a public transportation employee. OHIO REV. CODE ANN. § 2305.33 (Anderson 1998). New Jersey requires physicians to report cases of epilepsy to the Department of Motor Vehicles. N.J. STAT. ANN. § 39:3-10.4 (West 1970).

Furthermore, although physicians (along with other professionals) have at least some responsibility to safeguard vulnerable persons, it is not clear whether this duty extends to the general public, or whether it should outweigh individual confidentiality protections. With respect to minors, however, these protections are generally thought to be appropriate. Almost all states have child abuse reporting statutes. Missouri specifically requires physicians to report drug dependent minors to the health department. MO. ANN. STAT. § 191.737 (West 2000). New Jersey expands the requirement to all drug dependent patients. N.J. STAT. ANN. § 24:21-39 (West 1970). In addition, some states have statutes that require reporting of abuse of hospital patients or long-term care patients, elder abuse, spousal abuse, and domestic abuse.

92 In essence some of these questions will reduce to comparisons of risk probabilities.
in question and, thus, development of treatments—potential indirect health benefits. Here the issue is not disclosure to a particular individual, but disclosure to an investigator (or perhaps allowing access to medical records). If confidentiality protections are supposed to promote health, then exceptions should be permitted to the extent that they better promote health. The closer the link between the rationale for disclosure and the promotion of health, the stronger the argument for disclosure. Alternatively, one can think of this in terms of the interests involved. The interest in obtaining direct health benefits (for example, information that pertains to current ameliorative health care) is stronger than the interest in obtaining indirect health benefits (for example, information that will be used in a study to gain knowledge about a hereditary disease). Therefore, the balance may come out differently. As a result, disclosure should be permitted in most cases where the information has the potential to directly affect a person’s health. Disclosure for research purposes, which has the potential indirectly to benefit health, will be somewhat more limited.

A number of state laws explicitly carve out an exception to confidentiality restrictions for living patients allowing access to medical records for research purposes. In addition, the federal regulations restricting the

---

93 I refer here to health-related research (as opposed to social research, although that may also have health implications). I include information sought for quality assurance purposes. Other types of research, such as the research conducted by a biographer, are dealt with under the heading of “general interest.” Not all health-related research may be categorized as beneficial. For example, there could be health-related research purposes that are objectionable (and thought to be potentially harmful), such as showing differences in intellectual capacity between different races. I assume for purposes of this analysis that we are discussing research with potential health benefits (and that the research has met all ethical guidelines). To the extent that particular research is not thought to be beneficial, the balance in favor of confidentiality is likely to be stronger.

As noted previously, the issue here is disclosure of identifiable information. Moreover, disclosure is only to investigators (or, in some cases, investigators gain access to the medical records).

94 See R.I. GEN. LAWS § 5-37.3-4(b)(3) (1999) (permitting qualified personnel, conducting scientific research, access to health care providers’ confidential patient records without patient consent provided that any research report shall not identify, directly or indirectly, the patient’s identity); WASH. REV. CODE ANN. § 42.48.020 (West 1999) (permitting a state agency to disclose confidential patient records to researchers provided that a human research review board determines: (1) the disclosure request has scientific merit; (2) that the research purposes cannot be reasonably accomplished without disclosure of patient records in individually identifiable form; and (3) that the remaining risks are outweighed by anticipated health, safety, or scientific benefits, and the researcher enters into an agreement that: (a) establishes safeguards for the continued confidentiality of the patient identifiable records; (b) restricts the use of patients’ visual representations; and (c) requires the researcher to destroy patient identifying information associated with the research report as soon as the purposes of the research project have been accomplished). See also ROACH, supra note 10, at 123-27. Likewise, the Department of Health and Human Services promulgated confidentiality regulations allowing disclosure without patient authorization for research purposes. 45 C.F.R. § 164.512(i) (2000).

In fact, access to confidential medical records by researchers is often permitted by state statutes—many of which require not that the information be stripped of its identity before access, but that the end results (report or publishable article) not directly or indirectly identify the patient. States vary in the degree to which they require assurances or additional safeguards before permitting access. See CA. CIVIL CODE § 56.10(c)(7) (West 1982) (allowing disclosure for “bona fide research projects”); COLO. REV. STAT. ANN. § 6-18-103 (West 2000) (permitting disclosure for “bona fide research projects,” but
requiring that disclosures be restricted "to the minimum amount of information necessary to accomplish the purpose for which the information is being disclosed"); 2000 Fla. Laws ch. 2000-160 § 79 (codified as amended at FL. STAT. ANN. § 455.667(d)) (allowing disclosure for research "provided the information is abstracted in such a way as to protect the identity or the patient or provided written permission is received from the patient or patient's legal representative); HAW. REV. STAT. 323c-37 (Michie 1993) (stating that research must be approved by IRB and include a "realistic plan for maintaining the confidentiality of protected health information," moreover, a researcher must "remove and destroy, at earliest opportunity consistent with the purposes of the project involved, any information that would enable an individual to be identified"); IND. CODE ANN. § 16-39-5-3 (Michie Supp. 2000) (approving, generally, disclosure for research, but requiring that "each party that receives information from a health record . . . shall protect the confidentiality of the health record and may not disclose the patient's identity . . . "); ME. REV. STAT. ANN. tit. 2 § 1711-C (West 2000) (requiring IRB approval of the research); MD. CODE ANN. HEALTH-GEN. § 4-305 (Michie 2000) (allowing disclosure for educational or research purposes, as long as such purposes are "subject to the applicable requirements of an institutional review board"); N.M. STAT. ANN. § 14-6-1 (Michie 1995) (allowing publication of statistical studies and reports based on medical records provided they do not directly or indirectly identify individual patients); R.I. GEN. LAWS § 5-37.3-4 (1999) (explicitly stating that no patient consent is necessary as long as the researcher does not identify the individual); VA. CODE ANN. § 32.1-127.1:03 (Michie 1997 & Supp. 2000) (stating that no person to whom disclosure of patient records was made shall redisclose or otherwise reveal the records of the patient without first obtaining the patient's consent to such redisclosure); UTAH CODE ANN. § 63-2-202(8)(a)(i)-(iii) (1997) (allowing a governmental entity to disclose or authorize disclosure if "the research cannot reasonably be accomplished without . . . disclosure," "the research is bona fide and . . . the value of the research outweighs the infringement upon personal privacy," the researcher assures the confidentiality of the records and removes/destroys individual identifiers as soon as possible); WASH. REV. CODE ANN. § 70.02.050 (1)(g)(i) (West 1997 & Supp. 2001) (requiring the IRB to evaluate whether the research "is of sufficient importance to outweigh the intrusion into the privacy of the patient," "is impractical without individually identifiable information," "contains reasonable safeguards to prevent redisclosure," and "contains procedures to remove or destroy at the earliest opportunity" identifiable information); WIS. STAT. ANN. § 146.82 (West 1997) (allowing disclosure only if the researcher is affiliated with health care provider, and allows private pay patients to sign form denying access, annually); WYO. STAT. ANN. § 35-2-609 (2001) (permitting disclosure without patient's authorization for use in a research project provided that reasonable safeguards are taken to protect against identifying any patient in any report of the research project).

Minnesota is one of the few states that explicitly requires patient notification of potential disclosure. MINN. STAT. ANN. § 144.335(d)(2)(i) (West 1998 & Supp. 2001) ("[T]he provider must disclose in writing to patients currently being treated by the provider that health records, regardless of when generated, may be released and that the patient may object, in which case the records will not be released."). See also WIS. STAT. ANN. § 146.82 (West 2001 & Supp. 2001). Some states even allow research disclosure of particularly sensitive medical information. ALASKA STAT. § 47.30.845 (2000) (mental health records if "bona fide" research); COLO. REV. STAT. § 10-3-1104.7 (Bradford 2000) (information from genetic testing); CONN. GEN. STAT. § 52-146g(a) (2001) (psychiatric records and communications); FLA. STAT. ANN. § 381.004 (West Supp. 2001); LA. REV. STAT. ANN. § 22.213.7 (West Supp. 2001) (genetic information if anonymous research); ME. REV. STAT. ANN. tit. 5 § 19203 (West 1999) (HIV, if stripped of its identity before disclosing to the researcher); ME. REV. STAT. ANN. tit. 34-B § 1207 (West 1999) (mental health records); MD. CODE ANN., Ins. § 27-909 (Michie Supp. 2000) (genetic information if research approved by IRB); MICH. STAT. ANN. § 330.1748 (Michie 1999) (mental health records, but only if "identification is essential in order to achieve the purpose for which the information is sought or if preventing the identification would clearly be impractical, but not if the subject of the information is likely to be harmed by the identification"); MONT. CODE ANN. § 53-21-166 (1999); MO. ANN. STAT. § 375-1309 (West Supp. 2001); (HIV disclosure); MO. ANN. STAT. § 630.140 (West 2001) (mental health records); N.J. STAT. ANN. § 26:5C-8 (West 2000) (HIV record if research approved by IRB); OR. REV. STAT. § 179.505 4(b) (1999) (mental health records, except requires the information to be de-identified unless "disclosure is essential to the research . . . or when the disclosure benefits the provider or patient"); R.I. GEN. LAWS § 40.1-5-26 (Michie 1997) (mental health records). Other states have generic authorizations for disclosure by public health or other governmental agencies. See IND. CODE ANN. § 16-38-4-11 (Michie 1993) (but requires additional safeguards); MASS. GEN. LAWS ANN. ch. 111, § 111B (West 2000) (requiring that research studies not
conduct of research do not apply to research involving dead people, or the use of information from dead people. Nevertheless, it may be appropriate to require an Institutional Review Board (IRB) review and approval of research in this context, particularly since informed consent will not function as a safeguard for individual interests. When the potential harm is minimal (considering both the potential link of information back to the deceased and the possible implications of that link), the interests in promoting general societal health through research may prevail.

In addition to information sought for direct and indirect health purposes, information about a deceased patient may also be sought for general interest, either because the individual in question is a public figure (for example, the example of Linda McCartney from the introduction), or because the information is of particular interest to the public (for example, a story about a series of deaths from a particular disease) or to a particular individual (for example, the psychotherapist example described in the intro).}

identify the subjects of the reports or records); OKLA. STAT. tit. 63, § 1-551.1-1 (West 1981) (requiring additional safeguards).

Allowing access to confidential information does not mean that there is no ethical obligation to obtain informed consent (a separate question), but that there is no breach of confidentiality based on disclosure for research. As a practical matter, the two issues (confidentiality and informed consent for research participation) reduce into one—when access to records is authorized by statute it is unlikely that a researcher will seek informed consent from each patient.

45 C.F.R. § 46.101(a) (2000) (stating that the regulations apply to “research involving human subjects”); id. § 46.102(f) (defining a human subject as a “living individual”).

For example, the proposed Health and Human Services medical privacy regulations authorize the disclosure of information regarding living patients to researchers without consent, as long as authorization is obtained from an IRB or privacy board. The IRB or board would have to determine that:

The use or disclosure . . . involves no more than minimal risk to the subjects;

The waiver . . . will not adversely affect the rights and welfare of the subjects;

The research could not practically be carried out without the waiver . . . ;

Whenever appropriate, the subjects will be provided with additional . . . inform[ation] after participation;

The research would be impracticable to conduct without the [waiver];

The research project is of sufficient importance to outweigh the intrusion into the privacy of the individual whose information would be disclosed;

There is an adequate plan to protect the identifiers . . . ; and

There is an adequate plan to destroy the identifiers at the earliest opportunity consistent with conduct of the research, unless there is a health or research justification for retaining the identifiers.


Jonas B. Robertscher, Doctors’ Privileged Communications, Public Life, and History’s Rights, 17 CLEV-MAR. L. REV. 199 (1968) (arguing that physicians should be allowed to write about dead celebrities).

98 Consider the argument of Anne Sexton’s biographer regarding access to her psychiatric transcripts:

Those of us responsible for deciding what should go into the book—heirs, doctor, publisher, author—were acutely aware of the moral complexities. Yet it seemed to us that the tapes provided a historical record of the processes by which a human being had survived a mental illness by turning her treatment into an education in the service of art.

The arguments in favor of disclosure are weakest in this context. Allowing disclosure in cases of health needs fits well within the ethical rationales described earlier. First, under a Rawlsian (or other deontological) perspective, it is likely that society, in general, would favor a system in which health values are promoted by permitting disclosure under these circumstances. Second, under a utilitarian (consequentialist) analysis the greatest good is served by allowing disclosure (in light of the fewer harms to the deceased from disclosure, the potential benefit to health, and the improbability that such limited disclosures would seriously undermine the system of confidentiality). Although there is still a question about empirical impact, there is no evidence thus far that the exceptions allowing disclosure of health-related information which function with respect to living patients (most of which are based on a public health or safety rationale) have altered patients’ overall willingness to communicate with their physicians.

It is more difficult to justify exceptions in cases of disclosure for general interest. The consequences of allowing access to personal medical information merely because of individual or public interest would very likely undermine the goals of confidentiality protections, and it is not clear that the potential benefits of such knowledge would outweigh the potential harms to health. Moreover, the societal value in question is knowledge generally, a value that often loses out to the value our society places on personal privacy. For example, many jurisdictions recognize a tort law cause of action for “public disclosure of private facts,” but all explicitly limit the cause of action based on the “newsworthiness” of the information. Yet disclosure of a person’s medical history, regardless of newsworthiness, is often restricted. The rationale is that medical information is particularly sensitive, and thus private, information.

In fact, disclosure of identifiable personal medical information for purposes of general interest should be rare. Cases in which disclosure is appropriate should be limited to those in which the interests in maintaining

99 In this category, I include information sought for non-health related research (for example, demographic data). To the extent that the information in question is de-identified, the analysis will look similar to that for de-identified information sought for health-related research purposes. For identifiable information, the physician must balance the elements identified below.
100 See discussion supra Part II.B.
101 See discussion supra note 33 and accompanying text.
102 See discussion supra note 37 and accompanying text.
confidentiality are extremely weak. The following section discusses how to evaluate the interests in maintaining confidentiality.

2. How Strong an Interest in Confidentiality?

Although the strength of the interest in disclosure is an important factor, one must also consider the strength of the interest in confidentiality. Part II of this Article discusses three types of interests in maintaining confidentiality postmortem. In the previous section, I considered the balance between the interests of current and future patients in maintaining general confidentiality protections postmortem, and the interests served by disclosure. In this section, I address the notion of a harm to identity or memory in more detail, focusing on two factors—the sensitivity of the information sought and the time elapsed since death. Each of these will be discussed in turn.

a. Sensitivity

Sensitivity is defined here as the extent to which the information is linked to the identity of the individual. For example, one part of the evaluation for the “public disclosure of private facts” tort noted above entails consideration of the extent to which the information is embarrassing. 105 Many courts state that, in order to make out a claim, the plaintiff must show from the outset that the fact in question “concern[s] a matter that would be embarrassing or demeaning to a reasonable person.” 106

The idea of embarrassment, although stated in the law in terms of a hypothetical reasonable person, is a very subjective notion. Someone may be embarrassed by facts about private life based on a number of factors, which include personal beliefs about the meaning of those facts, as well as a current job or position in the community, and the individuals to whom the information is disclosed. 107 For example, blood type may not be

106 DeLaTorre, supra note 104, at 1177. Although some facts in the patient’s medical record will meet this standard, many will not.

It is interesting to note that the two aspects may be linked. Thus the more “newsworthy” disclosures may concern more intimate details of a person’s life. But newsworthiness in this sense (otherwise known as titillation factor) is not truly the issue with respect to disclosure of confidential medical information. Rather the concern is with the importance to the public (or individual) in knowing the information as it pertains to their ability to make choices about their lives.

107 For example, while working in a video store one summer during high school, I rented an adult film to my allergist before he recognized me and hastily left the store. His embarrassment may have stemmed from the type of film he was renting, or perhaps simply the fact that he was a physician, and in particular, my physician (or maybe just known to me). In general, public disclosure will be the most problematic and the more limited the disclosures, the easier they are to justify. But in other situations, even individual disclosure may be inappropriate, especially where the individual in question is exactly the person with whom the deceased did not want to share the information. For example, a patient may not object to disclosing information about her general frustrations as a parent in a biography, but object to sharing information about her negative feelings toward one of her children with that child.
thought to be particularly personal information in most cases, but may become so if paternity is in question. Although the subjective nature of judging sensitivity might seem to argue in favor of applying a subjective standard to determine disclosure (for example, would the deceased have considered this bit of information more or less personal), there are a number of difficulties in applying a so-called "substituted judgment standard" to deceased individuals. The notion of embarrassment is likewise difficult to apply to deceased individuals, and thus the issue is reduced to the relationship between the information and the memory of the deceased. The closer the link between the information and the individual’s memory or identity, the more concern we should have about disclosure. Where an individual has specifically instructed the physician to keep certain information confidential after death (or specifically instructed the physician to not disclose to family members during his lifetime), one might presume that the patient considers the information to be an integral part of his identity.

In situations where there is no guidance from the patient, the physician might look for guidance in determining sensitivity to general societal standards drawn from some of the laws that exist in this area. Although most state laws are silent on the issue of confidentiality protections for deceased individuals, the statutes that do exist often focus on information that might be considered particularly sensitive. Thus some states have statutes asserting that HIV or AIDS information should remain confidential after death. Others address such issues as child abuse, elder abuse, men-

108 See discussion infra note 135-36 and accompanying text.
109 Ga. CODE ANN. § 31-21-3 (Harrison 1998) (requiring HIV information contained in dead body disposition notification to be confidential and privileged); Ind. CODE ANN. § 16-41-13-3 (Michie 1993) (requiring HIV information contained in dead body disposition notification to be confidential); KAN. STAT. ANN. § 65-2438 (1992) (requiring HIV information contained in dead body disposition notification to be confidential); R.I. GEN. LAWS § 23-5-9 (Michie 1996) (requiring HIV information contained in dead body disposition notification to be confidential and privileged); Va. CODE ANN. § 54.1-2807.1 (Michie 1998) (restricting any person practicing funeral services from disclosing information concerning the deceased’s infectious disease). Some statutes extend the duty of confidentiality to funeral home personnel. See also N.J. STAT. ANN. § 26:5C-12 (West 1996) (permitting an executor, administrator of the estate, authorized representative, the deceased’s spouse, family members, and the health commissioner to consent for release of a deceased person’s HIV record under the state’s AIDS program).
110 ALASKA STAT. § 12.65.140 (Michie 2000) (requiring state child fatality review team to maintain the confidentiality of accessed state medical examiner records unless disclosure is necessary to enable the team to carry out its duties); MD. CODE ANN. HEALTH-GEN. I § 5-708(c) (Michie 2000) (restricting disclosure of information regarding a deceased child, family members, or suspected perpetrator of abuse at a public meeting); NEV. REV. STAT. ANN. § 432B.280 (Michie 2000) (stating reports and information concerning a suspected child’s death from abuse are confidential); WASH. REV. CODE ANN. § 74.13.515 (West 2001) (allowing secretary of social and health services to remove personally identifying information from public reports if disclosure of the name of a deceased child is contrary to the best interests of the child’s siblings or other children in the household).
111 OHIO REV. CODE ANN. § 173.20(B)-(C) (Anderson 1999) (granting a state ombudsman access to the records of deceased long-term care patient if there is no estate administrator or the ombudsman has reason to believe that the patient’s attorney or guardian is not acting in the best interests of the
tal health, and sexual assaults. For some particularly sensitive information, only the strongest needs for disclosure (for example, potentially life-threatening health needs) will suffice to override confidentiality, absent an indication that the patient would have wanted the information disclosed.

b. Timing

The importance of the information and its link to identity (or personal nature) are two crucial factors in determining whether to disclose. There is a third factor, however, that is linked to the other two, and that is time. Both identity and memory interests attenuate over time. Memory exists in the minds of survivors; it fades and alters over time. Memories in the minds of people who actually knew the deceased are more relevant than those that remain over subsequent generations. Thus, although the notion of confidentiality itself does not have a built-in time limit, the interests it protects in this context (that of memory or identity) may well change over time. In particular, the interests of family members in maintaining the memory of the deceased attenuate over time. Thus while disclosures about Thomas Jefferson’s relationship with Sally Hemings may have been scandalous soon after his death, their “privacy” was less of an issue when disclosed recently. Likewise, the currently living descendants of Jefferson (or Hemings) had few grounds to argue that their memory of their ancestor was harmed. In considering whether disclosure is appropriate, the time elapsed since the individual’s death is particularly relevant.

Confidentiality protections should decrease over time, eventually disappearing. One possibility is simply to end all protections for confidentiality within a set time frame—perhaps one or two generations past the individual’s life or death. To make things easy, we might simply pick a set

---

112 2000 Fla. Laws ch. 00-163 § 394.4615(1) (codified as amended at FLA. STAT. ANN. § 394.4615(1)) (permitting personal representative or family member to consent to release of decedent’s state held mental health records); Act of June 2, 2000, No. 91-726, § 110/10 (codified as amended at 740 ILL. COMP. STAT. ANN. 110/10(10)) (requiring records and communications of a deceased mental health patient must be limited to the factual circumstances of the incident being investigated when they are disclosed to a coroner); R.I. GEN. LAWS § 40.1-24.5-11(d) (Michie 1997) (requiring personal representative, surviving spouse, or kindred of the closest degree to consent to release of a deceased’s confidential mental health information from mental health community residences).

113 TEX. HEALTH & SAFETY CODE ANN. § 44.073 (Vernon 2001) (requiring personal representative to consent to release of confidential information held by state sexual assault prevention and crisis services).

114 This may not always be true—in some cases an individual might become a legend in family folklore and unexpected revelations may be particularly devastating to this memory. Even so, the harm to people who did not know the deceased personally (or perhaps even know other people who knew the deceased personally) is less relevant.

115 We could borrow from the Rule Against Perpetuities and allow confidentiality protections to remain for a life in being at the time of the patient’s death, plus a certain number of years to ensure we
number of years, that would assure the information would only be disclosed after all people who actually knew the deceased had themselves died. Given increased life spans, perhaps a number like eighty or 100 years after death would be attractive. For example, copyright law protects original works of authorship for the author's life plus seventy years after his or her death.\footnote{116} The seventy-year time span is thought to represent two generations (the author's children and grandchildren).\footnote{117} In Alabama, vital records become unrestricted public information after 125 years from the birth of the individual or twenty-five years after death.\footnote{118} Access is permissible before this time period has elapsed for family members, the legal representative(s), and "[o]thers . . . if they can demonstrate that the information . . . is needed for the determination or protection of his or her personal or property right."\footnote{119} Alaska continues the protection for 100 years after birth or fifty years after death, as do Florida and Idaho.\footnote{120} Arizona extends the protection for seventy-five years after birth or ten years after death.\footnote{121}

Time limitations for confidentiality protections are supported by other laws that protect postmortem interests. The most obvious general body of law involving the legal interests of the dead is estate law. Estate law varies, but generally stands for the proposition that an individual may control the disposition of property accumulated during life after his or her death. Although individuals may determine the disposition of their worldly goods after their death, the ability to maintain control is limited. In particular, the Rule Against Perpetuities (and the related Rules Against Accumulations, limiting duration of trusts, etc.) restrict an individual's ability to control the disposition of property beyond a certain time period—commonly understood as a life in being plus twenty-one years.\footnote{122} The Rule itself is fairly beyond the relevant lifespan of one or two subsequent generations. \textit{See} discussion \textit{infra} note 122 and accompanying text.

\footnote{116} 17 U.S.C. § 302(a) (1994). Although there were a variety of reasons why Congress amended initial copyright protections to allow longer protections, H.R. Rep. No. 94-1476, at 134-35 (1976), the primary reason appears to be compliance with the Berne Convention, which determines copyright protection for European Union countries, H.R. Rep. No. 105-452, at 4 (1998).

\footnote{117} Joseph A. Lavigne, \textit{For Limited Times? Making Rich Kids Richer Via the Copyrights Term Extension Act of 1996}, 73 U. DET. MERCY L. REV. 311, 359 (1996) (arguing that the seventy year extension is not justifiable since there is no good basis for according protections to two generations of the author's descendants).

\footnote{118} ALA. CODE § 22-9A-21(f) (1999).

\footnote{119} Id. § 22-9A-21(b)(4).

\footnote{120} ALASKA STAT. § 18.50.310(f) (Michie 2000). \textit{See also} FLA. STAT. ANN. §§ 382.025(1)(a)(4), (2)(a)(3)(b) (West 1998) (birth records are confidential for one hundred years; certificates are confidential for fifty years after death); IDAHO CODE § 39-270(e) (1999) (certificates and records in the custody of the state are confidential for one hundred years after birth; fifty years after death).

\footnote{121} Act of March 29, 2000, ch. 88, § 36-302(B) (codified at ARIZ. REV. STAT. ANN. § 36-302(B)).

\footnote{122} For example, a testator may write a will leaving his estate to $A$ for life and then $A$'s future
specific and potentiality confusing to apply. However, it might be taken to support the general proposition that although people can exert some control over their property after death, they cannot do so for an indefinite period of time into the future.\textsuperscript{123} Thus, an individual may control the disposition of his or her property for at least one and possibly two generations, but no further.\textsuperscript{124}

It is important to stress that ending protections after a set time period does not mean that the information becomes public, merely that the protections cease to operate. As a practical matter, after such time has passed, it may be difficult both to uncover particular information, and to prevent its disclosure. In most cases, the physician or other custodian of the information will no longer be living, and thus the question is really about the disposition of the remaining records. Institutional policies about maintaining records vary and in many cases the documents may no longer be in existence.\textsuperscript{125} In particular, custodians of sensitive information may choose to destroy the records after a set time period, thus avoiding future disclosure

---

children who survive $A$ and live to age thirty. In order to prevent indefinite control over property, the Rule Against Perpetuities limits the grant to interests that vest not later than twenty-one years past the life of a person in being at the time of the creation of the interest. Thus $A$'s interest would vest immediately upon the testator's death (a life in being) and fall within the time frame. Assuming, from the language, that $A$'s children are not in existence at the time of the will, their interest fails—it vest thirty years after the death of $A$ (the life in being). WILLIAM B. STOEBUCK & DALE A. WHITMAN, THE LAW OF PROPERTY 118 (3d ed. 2000).

\textsuperscript{123} The Rule Against Perpetuities is thought to have developed specifically to avoid tying up land. \textit{Id}. at 126 (stating that "[t]he additional twenty-one years included in the perpetuities period seems to have been derived from the period of an actual minority during which a fee tail estate could be made unbarrable at common law").

\textsuperscript{124} It is an interesting question whether current reproductive technologies will alter estate rules such as this. Consider the case of frozen embryos that are kept in storage indefinitely—could they function as the hypothetical "life in being" by which to measure time? ANDREW MORRIS & SHARONA HOFFMAN, BIRTH AFTER DEATH: PERPETUITIES AND THE NEW REPRODUCTIVE TECHNOLOGIES (forthcoming 2002).

\textsuperscript{125} The issue of what to do with medical records has never been entirely clear. Some institutions and associations have developed their own policies and destroy records after a certain time period. ROACH, supra note 10, at 36-43. State statutes that control the retention of records usually do so in light of statutes of limitations for tort actions, or based on concerns about spoliation of evidence. Many states have no specific requirement for retention of medical records. Douglas Rallo, \textit{No Cure Yet For Spoilation of Patient Records}, CHI. B. ASS'N REC, Oct. 1992, at 30. However, Medicare guidelines require hospitals to maintain medical records for at least five years. Condition of Participation: Medical Record Services, 42 C.F.R. § 482.24(b)(1) (2000). And OSHA guidelines also address retention of medical records. Rules of Agency Practice and Procedure Concerning OSHA Access to Employee Medical Records, 29 C.F.R. §1910.10 (2000) (requiring retention by OSHA only for so long as needed to accomplish the purpose of access). The Joint Commission on Accreditation of Hospitals states that the length of time that medical records are to be retained is dependent on the need for their use in continuing patient care and for legal, research, and educational purposes and on law and regulation. \textit{JOINT COMM'N ON ACCREDITATION OF HEALTHCARE ORG., COMPREHENSIVE ACCREDITATION MANUAL FOR HOSP. IM-5} (Jan. 2000). And the American Health Information Management Association delineates specific retention times for different types of records. ROACH, supra note 10, at 40 (reprinting guidelines).
of the information.126

B. Who Controls Information Postmortem?127

Having identified the relevant factors to consider, I now turn to the issue of who has responsibility for evaluating the factors and determining when disclosure is appropriate.128 In the context of living patients, in-

126 A historian, for example, may argue in favor of preservation. The bottom line evaluation entails a weighing between the interests promoted by confidentiality and those promoted by disclosure (or preservation). Eventually, the interests of all people currently living in the confidentiality of the records/information in question would be greatly attenuated (because of the time elapsed). And it may be hard to argue that patients will alter their willingness to communicate with their physicians based on the possibility that the information will be accessible decades after their death. So the final disposition of the records may be merely a matter of administrative convenience.

127 Confidentiality, as I have stated earlier, is usually framed in terms of “control” over information. There are some commentators who argue that privacy rights are miscast as rights of individual control over information, since people are not really able to control all information about themselves. Instead, privacy should be thought of in terms of balancing the interests involved. See Anita M. Allen, Privacy-as-Data Control: Conceptual, Practical and Moral Limits of the Paradigm, 32 CONN. L. REV. 861, 861-62 (2000) (stating that “[t]he popularity of the privacy-control paradigm is problematic because there are a number of conceptual, practical, and moral limits to its plausibility); Paul M. Schwartz, Internet Privacy and the State, 32 CONN. L. REV. 815, 834 (2000) (noting that “access to personal information and limits on it help form the society in which we live and shape our individual identities”).

Other authors accept the “control paradigm” and suggest the creation of an intellectual property right in personal information. Pamela Samuelson, Privacy and Intellectual Property?, 52 STAN. L. REV. 1125, 1130 (2000). But why should an individual be thought to have a property right in information pertaining to herself? This is not to say that there isn’t a privacy interest, but despite the fact that individuals play a role in constructing their identity, they do not “create” it, at least in the sense of a creation that is due intellectual property protection. See id. at 1136-46 (pointing out the problems with creating such a right). See generally Symposium, Cyberspace and Privacy: A New Legal Paradigm?, 52 STAN. L. REV. 987, 987-1461 (2000) (discussing recent changes in cyberspace and the resulting implications on privacy interests). Consider the case of Paul v. Davis, 424 U.S. 693 (1976), in which the U.S. Supreme Court held that a person’s interest in his reputation alone was not cognizable as property within the meaning of the due process clause. Id. at 712. At least one author argues in favor of a control paradigm, but based on personal autonomy, rather than property rights. Julie E. Cohen, Examined Lives: Informational Privacy and the Subject as Object, 52 STAN. L. REV. 1373, 1377 (2000). This would be analogous to my arguments for control over identity and memory. Another author suggests using new technologies to create a trusted system that would allow individuals limited control over access to their private information, including medical records. Jonathan Zittrain, What the Publisher Can Teach the Patient: Intellectual Property and Privacy in the Era of Trusted Privication, 52 STAN. L. REV. 1201, 1240 (2000). Such a model would not be inconsistent with my suggestions.

128 Many state statutes give control of a decedent’s medical records to the executor of the estate. ARIZ. REV. STAT. ANN. §12-2294(B)(8)(a)-(f) (West 2000) (permitting health care provider to disclose a deceased patient’s medical records to patient’s personal representative or estate administrator); VA. CODE ANN. § 32.1-127.1:03(D)(23) (Michie 2001) (permitting health care provider to disclose a deceased patient’s medical records to the patient’s personal representative, executor, or legal guardian).

One possible rationale for granting authority over the records is to allow access to information needed for lawsuits (for example, medical malpractice), but more likely the rule serves to provide a clearly designated individual who can make decisions about the disposition of the records. Giving control to an executor is problematic for a number of reasons, not the least of which is that very few circumstances would warrant disclosure of a complete medical record.

Durable Power’s of Attorney for health care (or other health care statutory proxy documents) give authority to access the medical records of the patient to the designated proxy. This situation makes sense during the patient’s life, but even then it is not clear that the proxy should have access to all the
formed consent functions to protect the individual interests—it is the patient who determines what information should be shared, except in cases where there is a risk of significant harm to another individual. The application of this doctrine to the postmortem context encounters serious limitations. The primary difference in the postmortem context is the obvious one—the deceased patient is no longer in existence. This turns out to have a number of implications for the general framework of disclosure protections. First, the patient clearly is unable to consent to disclosure. Thus although a physician initially might approach a living patient seeking either consent for disclosure or encouraging the patient himself to disclose the information, this route is unavailable after the patient has died. Moreover, even if an individual has explicitly stated that she does not want the information disclosed at any time in the future, there is no way for her to change her mind. Thus, new or different requests for information cannot be brought, as they can be to living patients, for an individual determination.

Although it will certainly be pertinent that the deceased has left specific instructions regarding disclosure, the interests in self-determination in this context are not the same as those for living patients. Self-determination presumes control over the "self." To the extent that the self is no longer in existence, the interests in self-determination are lessened. As a result, in cases where third-party interests in disclosure (or confidentiality) are strong enough, they may be able to overcome even the deceased’s previous explicit statements on the matter. But the interests in

---

129 Patients who explicitly grant permission for postmortem disclosure thereby waive confidentiality protections and the resulting disclosure does not constitute a breach. Acosta v. Richter, 671 So.2d 149, 151 (Fla. 1996) (holding waiver of confidentiality of medical information exists where patient provides written authorization).

130 For example, the individual's specific instructions are taken into account in the evaluation of the sensitivity of the information. See discussion supra Part IV.A.2.a.


132 Buchanan and Brock argue that for currently living incompetent patients, the right to self-determination is a "quasi-property" right and may "justifiably be overridden to secure some very important good or to avoid some important harm." Id. at 166. Specifically, "if faced with a choice between following one person's wishes in an advance directive and saving another person's life we would have to disregard the advance directive." Id. at 168. Whether or not this argument is valid in the case of living patients, it is surely true for deceased patients.

In explaining why it is important to consider advance decisions made by (now) incompetent patients, Ronald Dworkin distinguishes between experiential and critical interests. RONALD DWORKIN, LIFE’S DOMINION 201-08 (1993). Critical interests are an individual's interests in living a good life as she defines it, and are closely linked with the notion of identity, discussed above. The dead clearly have no experiential interests. Although the dead may retain critical interests (at least to the extent that they retain any interests in identity after death), I have already pointed out that these are lessened.
Disclosure must be particularly strong to overcome the deceased's interests, as well as societal interests in maintaining the validity of advance directives and other patient decision-making tools. Most patients, however, are never asked about the use of their previously gathered medical information after their death, and are thus unlikely to have indicated their preferences. The result is that someone other than the patient will control its use.

As a general rule, surrogate consent mechanisms (for example, proxy decision makers), which usually function in situations where the patient cannot make a decision, do not necessarily work in this context. There are two reasons for this—one practical and the other theoretical. First, the individual most likely to be designated as a surrogate is a family member and this is quite often just the person who is seeking the information. Health information about a deceased patient has a personal health impact on a small group of people—generally those who are either blood relations or those who are in close everyday contact (for example, spouse, if contagious disease). These are exactly the next-of-kin who would be identified as appropriate surrogate decision makers in other contexts since they are the people who are best able to determine what the individual would have wanted had he or she been available to make the decision. And yet it seems ludicrous to ask, for example, a wife if she thinks her husband would want her to know certain information that has implications for her health. Moreover, shifting the identity of the surrogate is not likely to be an acceptable solution since as you move further away from close family members you are less likely to find an individual who is able accurately to ascertain the patient's preferences or best interests. Finally, disclosure to these individuals for purposes of evaluating the patient's preferences would result in an initial breech of confidentiality, which may not be appropriate in many circumstances.

The second problem with surrogate decision-making is theoretical—a "best interests" inquiry is almost meaningless with respect to a deceased person, and it is almost impossible for anyone to accurately ascertain the

---

133 Surrogate decision-makers are individuals who make choices about medical care in place of a patient (because the patient lacks capacity). They are designated by statute, courts (for example, guardian), or by the patient in an advance care document (for example, proxy). See Jessica Berg et al., Informed Consent: Legal Theory and Clinical Practice 109 (2001).

134 The preference for family members is based on a number of factors. There is some evidence that relatives are better able to accurately judge patient preferences. Joseph Ouslander et al., Health Care Decision Among Elderly Long-term Care Residents and Their Potential Proxies, 149 Archives of Internal Med. 1367 (1989). This has not held true in all circumstances, especially in the absence of any previous discussion between the family member and patient regarding treatment choices. Jeremiah Suhl et al., Myth of Substituted Judgment: Surrogate Decision Making Regarding Life Support is Unreliable, 154 Archives of Internal Med. 90 (1994). And close family members are also likely in a better position to judge what action would be in the patient's best interests. Buchanan & Brock, supra note 131, at 136.
deceased’s preferences (“substituted judgment”) in this context. For example, drawing from evidence that the patient had not, during his lifetime, disclosed the information, does not necessarily answer the question of what the individual would want done after death. Quite literally, the substituted judgment standard asks the surrogate to place herself in the position of the deceased in order to determine what he would have done had he been able to make the decision. The patient is not merely unavailable or lacking in decision-making capacity, but is no longer in existence! Under the best circumstances the substituted judgment standard is a type of legal fiction. For deceased individuals, it makes even less sense to apply the standard in the absence of the deceased’s previous explicit statements on the matter.

---

135 Some authors have argued that advance directives (and application of the substituted judgment standard) are problematic even for patients who are still living. The concern is that some conditions of severe incapacity, which trigger advance directives and surrogate decision-making, alter personal identity. Or to put it another way, the now incompetent person is not the “same” person as the previous competent individual. This change in identity forces one to reconsider whether the instructions or preferences of the previously competent person should apply to the now incompetent individual. See DEREK PARFIT, REASONS AND PERSONS 119-23 (1984) (arguing that personal identity is based on psychological continuity); Rebecca Dresser, Dworkin on Dementia: Elegant Theory, Questionable Policy, 25 HASTINGS CENTER REP. 32, 33-35 (1995) (pointing out that “people exercising advance planning are denied knowledge of treatments and other relevant information that may emerge during the time between making a directive and giving it effect); Rebecca Dresser, Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law, 28 ARIZ. L. REV. 373, 379 (1986) (arguing that a person’s interests can change radically by the time the life and death situation arises); Rebecca Dresser & John Robertson, Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach, 17 L., MED. & HEALTH CARE 234, 236 (1989) (commenting that “it is wrong to assume that the incompetent patient’s prior competent preferences are the best indicator of the patient’s current interests); Rebecca Dresser & Peter J. Whitehouse, The Incompetent Patient on the Slippery Slope, 24 HASTINGS CENTER REP. 6, 6 (1994) (explaining that the current model for basing decisions on the patient’s former competent concerns overlooks changes in interests that may accompany incompetency).

Other authors rebut this conclusion, arguing that advance directives and substituted judgment mechanisms are correctly applied in this context. See Jeffrey Blustein, Choosing for Others as Continuing a Life Story: The Problem of Personal Identity Revisited, 27 J.L. MED. & ETHICS 20 (1999). Blustein argues that “proxy decision-makers should regard themselves as continuers of the life stories of those who have lost narrative capacity” and that this theory “provides a defense of the moral authority of advance directives that is immune to the loss of personal identity objection.” Id. at 21. See also DWORKIN, supra note 132, at 201-08 (discussing the need to fully understand the “dimension of the interests people have” in determining someone’s best interests). See also BUCHANAN & BROCK, supra note 131, at 162-89 (arguing that there are interests which survive incapacity and thus advance directives should be applied). Buchanan and Brock argue (correctly I think) that if there are interests that survive death, then there are certainly interests that survive incapacity. Id. at 163. But the reverse is not necessarily true—there may be interests that survive incapacity, but not death.

136 Historically, the doctrine of substituted judgment appears to have been borrowed from English common law where it developed as a legal fiction allowing courts to distribute parts of a “lunatic’s” estate to relatives that were not owed any duty of support. Although it initially started out with no constraints, it quickly became dependent upon evidence of what the incompetent person would have wanted (or done) were he competent. Louis Harmon, Falling off the Vine: Legal Fictions and the Doctrine of Substituted Judgment, 100 YALE L. J. 1, 16 (1990).

137 These statements may be oral or written. Note that this does not mean we cannot make general inferences such as “most people would want their medical information to remain confidential.”
As a general rule, physicians (or, more common today, health care organizations—HCOs) own the actual medical records and thus have the obligation to maintain confidentiality of the information contained therein. Likewise, in the postmortem context, it is these information caretakers who should have the responsibility to consider the issues identified above and determine whether disclosure is appropriate. In evaluating the interests in disclosure, the extent of the individual or public health need would be determined by the health professional in whose possession the information is kept. Physicians have the expertise to evaluate health needs. Moreover, they generally have been charged with balancing needs for confidentiality against needs for disclosure and there is no reason why they should not have this responsibility in these cases. Furthermore, physicians should be responsible for determining sensitivity, absent individual or legal guidance. This assures that sensitive information will not be shared with others until is it determined that disclosure is appropriate—thus maintaining confidentiality to the greatest extent.

Although traditional surrogate decision-making tools may not be applicable in many situations, family involvement in confidentiality determinations may still be appropriate, particularly when the issue is disclosure for general interest reasons. An analogy may be made to the organ dona-

---

But this is not an application of a substituted judgment standard. Nor does this mean we might not seek consent from other individuals. But the surrogate’s role in this context is not to promote self-determination, but to make decisions based either on a hypothetical reasonable person standard, or their own preferences.

This reflects the current state of the law regarding medical records and information. Although physicians control the physical records, patients are considered the “owners” of the information contained therein. Striegal v. Tofano, 399 N.Y.S.2d 584, 585-86 (Spec. Term 1977). The AMA Code of Ethics provides that:

notes made in treating a patient are primarily for the physician’s own use and constitute his or her personal property. However, on request of the patient a physician should provide a copy or a summary of the record to the patient or to another physician, an attorney, or other person designated by the patient.


Many states, in fact, explicitly authorize access to particular medical records by relatives. One example is state law allowing family access to autopsy information. N.D. CENT. CODE § 23-02.1-27 (Supp. 2001) (allowing relative or personal representative access to information indicating cause of death which may be based on practical reasoning that in the absence of such disclosure the relatives will withhold consent to the autopsy). AM. MED. ASS’N COUNCIL ON ETHICAL AND JUD. AFFS., CONFIDENTIALITY OF HEALTH INFO POSTMORTEM REPORT 5-A-00 (June 2000). The access to medical information by relatives of a deceased is in line with their general authority to determine what happens to the deceased’s bodily remains. Even so, control over medical information raises privacy concerns not implicated by control over bodily remains. Hawaii explicitly denies that deceased individuals have privacy interests in their autopsy reports, but recognizes interests of living people who are mentioned in an autopsy report and states that “disclosure of that report, under the UIPA, will depend upon a balancing of the privacy interests of that living individual against the public interest in disclosure.” Disclosure of Autopsy Reports, Haw. Op. Att’y Gen. No. 91-32 (Dec. 31, 1991), 1991 WL 474729 (Haw. A.G.). The Hawaii Legislature, however, has just enacted comprehensive confidentiality protections that continue to apply postmortem. See supra note 24. The implications with respect to autopsy reports are unclear. Nevada, by contrast, states that autopsy reports should remain completely confiden-
tion situation where health professionals have recognized that there are other interests involved besides those of the deceased patient, specifically those of close family members. Seeking family consent allows family members to have input into a decision to disclose information that may have implications for their own health, and thus identities. Even for information that does not have implications for the health status (and thus identity or privacy) of family members, family consent is still appropriate in this context. As noted previously, one of the interests in maintaining confidentiality after death is based on the interests of those close to the deceased in maintaining the memory of the deceased. It is worth noting, however, that the idea of family consent—based on the notion that it is most closely linked with the interests of deceased—is not without controversy. In the case of a psychiatrist's disclosures of taped interviews with the famous poet Anne Sexton, the daughter of the poet gave permission, claiming her responsibility to the literary community. Further inquiry into the matter, however, showed that such motivation was questionable.

---

140 See Laura A. Siminoff & Kata Chilag, The Fallacy of the 'Gift of Life', 29 HASTINGS CTR. REP. 34, 36 (1999) (discussing donor families). In fact, consent of family members is often sought even when the patient has explicitly consented to donation. Many authors have challenged this practice, although there are a variety of practical reasons for its existence (for example, fear of lawsuits).

141 The consent would be based on the preferences of the surrogate, rather than an artificial application of surrogate decision-making standards. Where the executor of the estate is not a relative, this individual may be a less appropriate spokesperson for the interests of the family.

142 See, e.g., MO. ANN. STAT. § 610.035 (West 2000) (allowing postmortem disclosure of social security numbers provided the state agency disclosing the information knows of no reason why such disclosure would prove detrimental to the deceased individual's estate or harmful to the deceased individual's living relatives).

143 See discussion infra Part III.B.2.


145 Id. Interestingly, when questioned, the daughter noted that "[a] literary executor is the future eyes and ears of the artist, and her most important duty is to keep the work both visible and alive after the author dies. Sometimes I was able to obey instructions left me, other times I had to override them." Linda Grey Sexton, A Daughter's Story: I Knew Her Best, N.Y. TIMES, Aug. 18, 1991, at 20. It is not clear what role executors (literary or otherwise) are supposed to play in this context. As the discussion
Even so, family control over the information is generally appropriate. It is their memories regarding the deceased, after all, which are most at risk.

Moreover, we can presume, in the absence of specific instructions to the contrary, that most patients would want their family involved in these decisions. Furthermore, physicians are not experts in judging newsworthiness, in contrast with health needs, and thus family involvement in these determinations provides an additional safeguard against improper disclosure. However, when the physician feels that the information should be kept confidential even from family (because of its sensitivity), disclosure for general interest would be inappropriate. Finally, acknowledging the role of family brings up another question: Who should count as "family"? The group of potentially affected individuals may be quite large. As a result, it may be most practical to borrow from the traditional next-of-kin hierarchy of decision makers, perhaps designating a spokesperson for family interests.  

C. Disclosure in Practice

Although physicians have the primary responsibility to evaluate requests for disclosure, they should not be considered to have a duty to reveal information gathered during counseling if the patient's statements indicate that he is likely to seriously injure an identifiable third party. The concept of a duty to warn in this context originated in the California case Tarasoff v. Regents of California, 551 P.2d 334 (Cal. 1976). In Tarasoff, a patient informed his therapist of his intention to kill a young woman. After her murder, the family sued claiming that the physician should have warned the victim. The court held that a therapist might be required to reveal information gathered during counseling if the patient's statements indicate that he is likely to seriously injure an identifiable third party.

A number of states have adopted this doctrine and some have extended it to all physicians or mental health professionals. Christine E. Stenger, Taking Tarasoff Where No One Has Gone Before: Looking at "Duty to Warn" Under the AIDS Crisis, 15 ST. LOUIS U. PUB. L. REV. 471, 476 (1996). Duty to warn cases focus on (1) the seriousness of the threat of harm, and (2) the identifiability of the victim. Tarasoff, 551 P.2d at 347. Thus, a physician is not under an obligation to reveal threats of minor harm, threats that the physician does not believe are serious, or general threats where there is no identifiable third party. Duty to warn cases are not without controversy, and some people believe that posting such a duty places the physician in the undesirable role of law enforcer, rather than healer. John G. Fleming & Bruce Maximov, The Patient or His Victim: The Therapists Dilemma, 62 CAL. L. REV. 1025, 1045-46 (1974). It is unclear whether the conflict between such roles forces physicians into an untenable position with respect to confidentiality, and thus undermines generally the protections of
disclose information in the absence of a specific request.  

Positing a duty in this context is particularly problematic. First, the physician in whose custody the information resides may not have any contact with the potentially affected family members. The physician may be the pathologist who conducts the autopsy, or simply (as is more and more true these days) an internist treating only one family member. Furthermore, the group of potentially affected parties may be large and it would be onerous to require the physician to track down everyone. Moreover, in some cases the individuals in question may want to exercise their right not to know particular information and it would be inappropriate for a physician to force information on unwilling recipients.

Although a duty to warn is inappropriate, there may be situations in which a physician will voluntarily seek to inform, even in the absence of a request for information. For example, a physician who is acquainted with a deceased’s spouse and discovers important information relating to a contagious disease may choose to disclose such information. Like disclosures following a particular request, these breaches of confidentiality should also be allowed. Thus the physician in the colon cancer case described in the introduction should not have been held to have a duty to warn the ten-year old (and from a practical standpoint we might question how this would have been handled), but may permissibly disclose the information to her remaining parent or guardian, explaining the possibility of disease inheritance.

Physicians who receive requests for information should consider carefully the extent to which confidential information should be shared. Disclosures should be limited to the specific need in question; under almost no circumstances should information be disclosed publicly. Rarely, if ever, should entire medical records be shared. Even for living patients, physi-
cians may not have to grant access to a complete medical record, and in most circumstances it will be more appropriate to provide a summary of the information contained therein.

Finally, confidentiality requirements should extend to all individuals who gain access to the information, thus an initial disclosure should not vitiate the protections. In general, confidentiality determinations will be made informally, by these information caretakers, as is done for living patients. Accountability for abiding by the standards may be dealt with through common law or statutory confidentiality protections, many of which may already exist and should be read to be applicable to the postmortem context, as limited by the model identified here. Alternatively, the failure appropriately to consider the factors may be remediable as malpractice.

---


154 Although I recognize that HMOs or other health organizations will often be the owners of the records, physicians should make evaluations regarding disclosure. See discussion supra note 138 and accompanying text (discussing control of medical records and evaluation of health needs).
V. CONCLUSION

We are a society strangely obsessed both with privacy and obtaining information. There are numerous aspects of our lives that are available for anyone to access and yet most people remain either unaware of these possibilities, or unconcerned with the potential trespass. Medical information is one of the most contradictory areas. Most patients are not even aware of the extent to which information about their care is shared within a hospital setting, but are horrified by the potential that an insurer may need access for reimbursement purposes. Confidentiality protections for medical information are currently undergoing scrutiny at both the federal and state level. But amidst all the discussion, one area has seen little attention—the extent of confidentiality protections postmortem. This article attempts to remedy that oversight.

I have argued that to determine the extent of confidentiality protections postmortem, the goals sought to be achieved by confidentiality must be balanced against the goals sought to be achieved by disclosure. Privacy values are important, but may be outweighed by health needs. Moreover, to the extent that disclosure better serves health needs, it should be allowed. I have eschewed bright line rules, arguing that most issues of confidentiality must be considered on a case-by-case basis. The physician has the obligation to determine the appropriateness of disclosure, as is traditionally the case for almost all medical information, and family members should be involved when appropriate. Although states may adopt statutes incorporating my framework, in general, legal institutions such as courts should have little role in these evaluations, except as an ultimate review mechanism in cases of disputes.

As a final note I want to stress that the framework provided here can be used with respect to the premortem context as well as the postmortem one. In fact, the factors identified apply equally well to information sought regarding living patients. Obviously the interests involved may weigh differently—in particular the interests articulated by the currently living patient are due a certain amount of deference, and self-determination plays a greater role. But, although I think that we would do well to reconsider the scope of confidentiality protections overall, since my focus has been on the postmortem context, I do not advocate for wholesale adoption of my framework in the premortem context without further analysis.