

*DISCLOSING PATIENTS' PROTECTED HEALTH
INFORMATION TO SURROGATES*

*A Report by the National Ethics Committee
of the Veterans Health Administration*

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*National Center for Ethics in Health Care
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Founded in 1986, the National Ethics Committee (NEC) of the Veterans Health Administration (VHA) is an interdisciplinary group authorized by the Under Secretary for Health through the National Center for Ethics in Health Care. The NEC produces reports on timely topics that are of significant concern to practicing health care professionals. Each report describes an ethical issue, summarizes its historical context, discusses its relevance to VHA, reviews current controversies, and outlines practical recommendations. Previous reports have been useful to VHA professionals as resources for educational programs, guides for patient care practices, and catalysts for health policy reform. Scholarly yet practical, these reports are intended to heighten awareness of ethical issues and to improve the quality of health care, both within and beyond VHA.

Committee Members: Arthur Derse, MD, JD (Chair); Linda Belton, RN, CNAA, CHE; Michael D. Cantor, MD, JD; Jeannette Chirico-Post, MD; Jeni Cook, DMin; Sharon P. Douglas, MD; Ginny Miller Hamm, JD; Kathleen A. Heaphy, JD; Judy Ozuna, ARNP, MN, CNRN; Peter Nim Kwok Poon, JD, MA; Cathy Rick, RN, CNAA, CHE; Randy Taylor, PhD, MBA

Ex Officio: Ellen Fox, MD

Consultant to the Committee: Michael J. O'Rourke

Staff to the Committee: Bette-Jane Crigger, PhD; Leland Saunders, MA

Director, National Center for Ethics in Health Care: Ellen Fox, MD

The National Ethics Committee thanks the following colleagues for serving as key advisors in the preparation of this report: Arthur Derse, MD, JD; Michael D. Cantor, MD, JD; Randy Taylor, PhD, MBA.

The National Ethics Committee is also grateful to the following individuals, who contributed their expertise in reviewing drafts of this report:

Lawrence Deyton, MD, MSPH Chief Consultant, Public Health Strategic Healthcare Group (VACO 13B)
Michael Rigsby, MD, Director, HIV/Hepatitis C Program (VACO 13B)
Richard Suchinsky, MD, Associate Chief for Addictive Disorders (VACO 116B)
Jonathan Gurland, JD, Office of the General Counsel, Professional Staff Group III (VACO)

Executive Summary

Surrogate decision making often creates ethical tension for health care professionals. On one hand, they have obligations to uphold patient confidentiality, and on the other, equally clear obligations to engage a patient's surrogate in an informed decision-making process on the patient's behalf. Clinicians in VHA face an even greater ethical tension because of the unique environment created by statutes governing VA. Notably, 38 U.S.C. 7332 prohibits VA clinicians from disclosing patient information related to drug or alcohol abuse, sickle cell anemia, or HIV, with few exceptions.

This report by VHA's National Ethics Committee focuses on the professional ethical dilemmas these specific legal constraints create for VA clinicians. It examines the untenable situations clinicians can find themselves facing when they must try to balance this legal duty and their professional ethical duty to respect the responsibility of patients' surrogates to participate fully in health care decisions, and recommends that the Under Secretary for Health request an opinion from VA General Counsel to determine:

- (1) Can 38 U.S.C. 7332 be interpreted to allow disclosures to authorized surrogates?**
- (2) If so, would the regulations implementing the statute need to be amended?**
- (3) If not, what other legal options are available to resolve the conflict of duties for clinicians in VA?**

Introduction

Surrogate decision making often creates ethical tension for health care professionals. On one hand, they have obligations to uphold patient confidentiality, and on the other, equally clear obligations to engage a patient's surrogate in an informed decision-making process on the patient's behalf. Clinicians in VHA face an even greater ethical tension because of the unique environment created by statutes governing VA. Notably, 38 U.S.C. 7332 prohibits VA clinicians from disclosing patient information related to drug or alcohol abuse, sickle cell anemia, or HIV, with few exceptions. This report by VHA's National Ethics Committee focuses on the professional ethical dilemmas these specific legal constraints create for VA clinicians. It examines the untenable situations clinicians can find themselves facing when they must try to balance this legal duty and their professional ethical duty to respect the responsibility of patients' surrogates to participate fully in health care decisions.*

To Tell or Not To Tell

Consider the case of Mr. K:

Mr. K, a 48-year-old man, was brought to the Emergency Department by his sister who found him alone and disoriented in his apartment. On initial exam he was observed to be completely disoriented, febrile and hypoxemic. A chest radiograph revealed multiple pulmonary nodules. Mr. K's mental status did not improve with oxygen and hydration, and his breathing became more labored.

On inspecting the medical record, Dr. P, the treating physician, learned that Mr. K had a longstanding diagnosis of HIV infection and multiple prior opportunistic infections. He had never taken antiretrovirals consistently and had stopped all medications 6 months ago. Since then, he had seen his primary provider several times for acute problems but had declined to resume HIV therapy. His most recent CD4 lymphocyte count was less than 50. He had never indicated his wishes about intubation or resuscitation.

Dr. P believes that Mr. K has an opportunistic lung infection and may have a central nervous system infection as well. Before further diagnostic or therapeutic steps can be taken, Mr. K will need to be sedated and intubated. He approaches Mr. K's sister, Mrs. W, to begin a discussion about consent for intubation, and asks her what she knows of her brother's medical condition. She indicates that he has always been an extremely private person and never discussed his health.

Dr. P can find no indication that Mrs. W knows her brother is HIV positive, but feels this has significant bearing on whether he should be intubated, because Mr. K's immune compromised state significantly affects his prognosis. How should Dr. P proceed?

* This legal duty itself rests on underlying ethical obligations to preserve confidentiality and respect patients' decision-making authority; hence the concern at stake could ultimately be framed as a tension between ethical duties. The present analysis is intentionally restricted to the narrow question of conflict between a derived legal duty and a primary ethical obligation in order to address the unique dilemma created for VA clinicians with regard to specifically defined categories of patient information. The National Ethics Committee hopes to address broader questions of clinicians' obligations in regard to surrogate decision making in a future report.

The Duty to Protect Confidentiality

Confidentiality of patients' health information is a core value in health care, rooted in professionals' obligation to respect patient autonomy.¹ This core value has been affirmed in many professional codes of ethics,²⁻⁵ and variously codified in court decisions and state law.⁵ Federal privacy statutes, such as the Health Insurance Portability and Accountability Act (HIPAA), also safeguard the confidentiality of patients' records, and normally carry criminal and civil penalties for professionals who violate patient confidentiality through willful or inadvertent disclosures of patients' personal health information.⁶

Privacy Law in VHA

Within VHA there is a unique and complex interplay of six separate privacy-related statutes,⁷ two of which pertain directly to patient health information: HIPAA and 38 U.S.C. 7332. These two statutes differ in application and in the ways in which they protect patient information. Briefly, HIPAA generally prevents clinicians from disclosing any portion of patients' medical records to unauthorized third parties, whereas 38 U.S.C. 7332 prohibits disclosure of only a very limited class of patient information, i.e., information related to HIV infection, sickle cell anemia, and drug and/or alcohol abuse—known as “7332-protected information.” Overlap of these two requirements is all but inevitable, and when that occurs VHA policy specifies that the more stringent provision be followed.⁷

Adhering to the more stringent of the applicable statutory provisions in a given situation ensures both that patients' information is afforded the most rigorous protection possible, and that VHA complies at all times with applicable laws. With regard to surrogate decision making, the HIPAA Privacy Rule specifically provides for disclosure to surrogates who are duly authorized as personal representatives to make health care decisions on behalf of patients (at 45 CFR 164.502(g)). The Office of Civil Rights of the Department of Health and Human Services, the office responsible for interpreting and implementing HIPAA, offers this clarification:

Except as otherwise provided in 45 CFR 164.502(g), the Privacy Rule requires covered entities to treat an individual's personal representative as the individual with respect to uses and disclosures of the individual's protected health information, as well as the individual's rights under the Rule. The personal representative stands in the shoes of the individual and has the ability to act for the individual and exercise the individual's rights. For instance, covered entities must provide the patient's personal representative with an accounting of disclosures in accordance with 45 CFR 164.528, as well as provide the personal representative access to the individual's protected health information in accordance with 45 CFR 164.524 to the extent such information is relevant to such representation.⁸

VHA policy also grants surrogates “the same authority and responsibilities as the patient in the informed consent process.”⁹ The policy further mandates that disclosures otherwise required to be made to the patient also be made to the patient's surrogate—but only “*to the extent permitted by law.*” [8.b.(2), emphasis added] This limitation on disclosures to surrogates is important, in light of special restrictions imposed by 38 U.S.C. 7332. When the patient lacks decision-making capacity, 7332 prohibits disclosure to surrogates except in a few situations—i.e., with prior written authorization in the form of a signed release of medical information form; if the surrogate is the patient's legally appointed guardian for health care; or, in the case of HIV, to the patient's sexual partner. In other words, clinicians are prohibited from disclosing 7332-protected information even

when they believe professional ethical standards require disclosure to the surrogate for the purpose of obtaining informed consent.

The Evolution of Privacy Protections in VHA

This situation is an artifact of the complicated evolution of privacy protections for personal health information within VHA. In the early 1970s, in response to Congressional mandates to protect the confidentiality of records pertaining to substance abuse, VA adopted regulations promulgated by the then Department of Health, Education, and Welfare (HEW). These regulations did not translate well into the clinical setting, however, because they were designed for protecting research subjects; they required both that substance abuse records be kept separately and that information regarding substance abuse be disclosed to those outside of the research team only with the signed consent of the subject. For VA clinicians treating patients for substance abuse, it was impractical to maintain separate records and to seek signed consent to share this information among the treatment team. Moreover, at that time HEW regulations did not recognize a signed power of attorney as granting access to protected records. The lack of VA-specific confidentiality policy regarding substance abuse records was felt by Congress to leave veterans vulnerable to social stigma and prejudice.

The Veterans Omnibus Health Care Act of 1976 clarified protections for substance abuse records and expanded protection to include information relating to sickle cell anemia (codified at 38 U.S.C. 4132, now 38 U.S.C. 7332). Privacy protections were extended to sickle cell because of the similar potential for discrimination against veterans with sickle cell trait. The provision ultimately has its origin in the fact that the military began widespread mandatory testing of recruits for sickle cell trait in 1973—information that would (at least in principle) become available to VA clinicians when a veteran sought care from VA.

The statute was amended in 1988 to extend protection to personal health information about HIV. At that time there were no federal (and few state) laws to protect patients from having their HIV status disclosed, and discrimination against people infected with HIV was widespread. In the years leading up to this legislation, the public's response to HIV/AIDS had been highly emotional. People were denied health insurance, or dropped from coverage, because they were HIV positive.¹⁰ And HIV positive employees were at risk for losing their jobs, especially after some companies began secret testing as part of routine yearly physicals.¹¹

At the same time, there were no effective treatments for HIV, and the only way to control further spread of the virus was to counsel HIV-positive patients about behaviors that would minimize transmission. From a public health perspective, testing was crucial to help stem the growing tide of HIV infections, but from the perspective of patients, the negative social consequences of testing positive could potentially outweigh any benefits. State policymakers realized that one way to bridge this gap between the need for a public health response and patients' concerns was to extend anti-discrimination statutes to cover infection with HIV. A study conducted in 1988 showed that about half of all states had done just that, either by writing new laws or by relying on judicial interpretations of existing laws.¹² Another tactic, taken by Vermont, for example, was to encourage HIV testing by passing a law limiting disclosures of HIV test results.¹³

At the federal level there was vigorous debate about whether to pass a national HIV anti-discrimination statute. Ultimately that measure failed, but policymakers recognized that VA did not have adequate privacy protections for HIV, and so in 1988 amended 38 U.S.C. 4132 to include protections for HIV. In 1991 the content of the code was reorganized and the privacy protections were renumbered as Section 7332.

The regulatory landscape has changed significantly since the 7332 protections were enacted, however. Two federal statutes now protect all Americans from both employment discrimination

connected with personal health status or medical information and unauthorized disclosure of their personal health information. First, the Americans with Disabilities Act (ADA), passed in 1990, prohibits employers from unfairly discriminating against employees with “physical or mental impairment that substantially limits one or more life activities.”¹⁴ This definition is intentionally broad, and can be construed to cover individuals with HIV-related illnesses, sickle cell anemia, and drug or alcohol abuse.⁺ Second, the HIPAA Privacy Rule, enacted in 2001, generally prohibits “covered entities” (which includes all health plans and most other health care providers) from disclosing any patient’s protected health information to unauthorized third parties. With laws like the ADA and HIPAA now in place, the value of 38 U.S.C. 7332 is no longer obvious.

Not only has the legal environment changed in the years since the 7332 privacy protections were enacted; the living situation for people with AIDS has changed dramatically as well. The development of therapeutic interventions, especially protease inhibitors, has significantly improved the prognosis for HIV-positive patients—for example, one study (of a large, representative patient population) reported that mortality rates decreased from 29.4 per 100 person-years in 1995 to 8.8 per 100 person-years in 1997.¹⁷⁻¹⁸ The same study also reported significant declines in rates of serious opportunistic infection: AIDS defining diagnoses decreased from 50 per 100 person-years in 1994 to 13.3 per 100 person-years by the end of 1996.¹⁷ In the developed world at least, a diagnosis of HIV is no longer seen as a death sentence:

Potent antiretroviral therapies have transformed HIV disease from a rapidly debilitating and fatal illness during the first 15 years of the epidemic to a chronic, treatable illness now. This shift toward chronicity means that HIV patients can hope for and set goals to live long, healthy lives . . .¹⁹

Surrogate Decision Making & Protected Health Information

Surrogate decision making supports important ethical values in health care, notably respect for autonomy and shared decision making, both of which are operationalized through informed consent. Informed consent is the most important means by which health care professionals respect patients’ moral agency and status as autonomous decision makers. When a patient loses decision-making capacity, respect for autonomy is preserved by having an authorized surrogate make decisions on the patient’s behalf, on the basis either of what the patient him- or herself would have wanted in the same or similar circumstances (substituted judgment), or of what is in the patient’s best interests (best interest standard).^{9,20}

Informed consent also embodies the ethical ideal of shared decision making, “[a] process by which patients are educated about likely treatment outcomes, with supporting evidence, and engaging them in deciding which choice is best for them, taking into account their preferences, values, and lifestyles.”²¹ When patients lose decision-making capacity, surrogates “stand in” for the patient in his or her role as a participant in jointly making decisions with health care providers.⁹ Surrogates’ participation assures that the value of shared deliberation and decision making is sustained even when the patient cannot participate, and thus assures that health care providers do not assign unilateral decision-making authority to themselves.

Clearly, surrogates need information about the patient’s situation if they are to make well-considered decisions. But just *what* do surrogates need to know to make informed choices on the patient’s behalf and play an appropriate role in shared decision making?

⁺ There is concern, however, that for HIV this protection is no longer as robust as it was originally. In its 1994 decision in *Bragdon v. Abbott*, the U.S. Supreme Court held that the act protected individuals with HIV from discrimination, but subsequent decisions have effectively eroded that protection, by “narrowing the definition of disability, limiting the scope of protection, and removing the right to sue states for disability discrimination.”¹⁵⁻¹⁶

The Relevance of Protected Information for Surrogate Decision Making

Certain information is generally considered essential to the informed consent process and therefore must always be shared with the decision maker (whether patient or surrogate), although how much detail should be provided will depend on the specific circumstances. Thus clinicians should disclose at least: the condition for which the treatment or procedure is being recommended, the nature of the proposed intervention, the risks and benefits of the intervention, and alternative treatments or procedures.^{9,22}

When a surrogate is asked to make decisions on the patient's behalf, a different kind of information may also be material to the informed consent process, that is, information about the patient's health—including past and current medical history. It is this category of information that gives rise to special privacy concerns, because while patients are generally entitled to and receive a great deal of information about their health (and so there is no need to "disclose" this information as part of the informed consent process), the same is not necessarily true of surrogates. Yet for a given clinical decision, past and present medical history may have a significant bearing on a surrogate's decision-making process. For example, the fact that a patient with recurrent endocarditis continues to use dirty needles to inject intravenous drugs could certainly affect decisions about subsequent valve replacement operations. In other circumstances, information about the patient's medical history may be completely extraneous: The fact that a patient was hospitalized many years ago for alcohol intoxication would be unrelated to a decision about emergency surgery for a ruptured appendix.

In general, clinicians should disclose to decision makers "information that a patient [or surrogate] in similar circumstances would reasonably want to know" to make an informed decision.⁹ However, given the special privacy concerns relating to surrogates, clinicians should also apply a "minimum necessary" standard, revealing only the information the surrogate needs to make an informed decision.

To determine whether a particular piece of information about the patient's health should be disclosed to a surrogate, the clinician should carefully weigh two factors: whether the patient would want this information disclosed to this surrogate, and whether the surrogate's decision would be affected by the disclosure.

To assess whether a patient would have wanted specific information disclosed, clinicians should look to the patient's prior statements for guidance. Did he or she ever indicate a preference that the information be withheld from a particular individual?—e.g., "Whatever happens, don't tell my sister about my drug problem!" Or give oral permission for the disclosure?—"If I get sick, I guess you should tell her about my sickle cell anemia." The patient's behavior may also offer clues about his or her preferences, for example, if the patient asked the surrogate to step out of the room when certain matters were discussed, or, by contrast, regularly included the surrogate in discussions with the clinician. More general statements or actions may also be indicative of the patient's preferences regarding disclosure, for example, questions about how the privacy of his or her health information would be protected or willingness to participate in public discussion groups or other activities explicitly related to his or her medical condition. Knowing whether disclosure usually is/is not preferred by other patients facing similar situations may also be helpful, though clinicians should never rely solely on general knowledge about a class of patients in deciding whether to disclose information in a particular instance.

Similarly, to assess whether the surrogate's decision would be affected by the disclosure, clinicians should first consider the patient's prior statements and behaviors. When the patient has previously expressed clear preferences regarding the specific treatment or procedure at issue—i.e., when the surrogate is able to follow the substituted judgment standard—there may be no need to disclose other specific personal health information about the patient. Similarly, when the patient's

behaviors suggest his or her preferences for care sufficiently clearly to guide the surrogate, there may be no compelling reason to disclose the specific information whose relevance is in question.

However, when the patient's preferences regarding treatment are not known and cannot reasonably be inferred and the surrogate must decide based on the best interest standard, the question of disclosure becomes more problematic. It has been suggested that when there is uncertainty about the relevance of personal medical information, respect for the patient's autonomy requires disclosure to the surrogate standing in for him or her.²³ The presumption should be to disclose, it is argued, because only the surrogate, *not* the clinician, has the moral authority to determine whether specific information is relevant to a given decision. This seems to us not to take seriously enough the obligation to protect confidentiality, however, particularly if there is reason to suspect the patient might not want the personal health information disclosed.

In these latter instances, clinicians must make a good faith effort to decide whether having the information could reasonably be expected to lead the surrogate to make a different decision than he or she would make without the information. Among the factors to be considered in making that determination would be the degree to which the as yet undisclosed information might materially affect how the treatment or procedure is carried out, the findings or outcomes of the intervention, and/or the likelihood of achieving the intended overall goal(s) of therapy. In general, the more severely the patient's health is affected and the more closely the treatment or procedure is tied to the specific information, the more likely it is that the surrogate's consent decision would be materially affected by disclosure.

For VA patients who lack decision-making capacity and whose possibly relevant personal health information includes information about HIV, sickle cell, or substance abuse, the ethical ideal of shared decision making and the professional ethical obligation to assure that surrogates have the information they would reasonably need to uphold that ideal run up against 38 U.S.C. 7332's legal restriction on disclosure.

Hard Choices

To return to the case of Mr. K, Dr. P is faced with a constellation of difficult decisions regarding Mr. K's care and the inclusion of Mrs. W in the informed consent process. Dr. P must decide, first, whether his patient's HIV status is information the surrogate needs to know in order to give informed consent for an invasive procedure about which the patient's wishes are not known (the intubation). He must also consider VHA informed consent policy, which requires him to "provide information that a patient or surrogate in similar circumstances would reasonably want to know."⁹ If, after careful analysis, Dr. P believes she does need or would reasonably want to know her brother's HIV status, Dr. P is in an ethically untenable position because he lacks the legal authority to disclose this information to Mrs. W.

In such a case, Dr. P will have to choose among three possible courses of action, each of which is problematic: 1) he could seek to have a court appoint Mrs. W as Mr. K's legal guardian for health care decisions, to whom he would then be permitted to disclose 7332-protected information (under federal regulation 38 C.F.R. 1.465); 2) he could obey 38 U.S.C. 7332, withhold the protected information, and violate his professional ethical obligations to his patient and his patient's authorized surrogate; or 3) he could fulfill his ethical duty and disclose the protected information at risk of legal sanction.

Although it would resolve the disclosure question in the end, the guardianship approach is unsatisfactory. There is no plausible way for Dr. P to explain why he would ask a court to appoint Mrs. W as her brother's legal guardian for health care. Dr. P must either tell Mrs. W that although she is Mr. K's authorized surrogate and is empowered to make health care decisions for him, unless

the court formally names her Mr. K's legal guardian, "the law" prohibits Dr. P from disclosing certain specific health information that might be important for her to know in making those decisions. That explanation would be cryptic and confusing, and in the end could defeat the confidentiality protection if Mrs. W finds out just what law Dr. P is talking about, as she reasonably might, and therefore surmises that Mr. K's condition involves HIV disease, sickle cell anemia, or substance abuse. Or Dr. P could be so vague as effectively to provide no explanation at all. Either course of action might have an adverse impact on the surrogate-clinician relationship and the process of shared decision making. Going to court also carries potential risks for the patient in delaying the clinical decision. And the added time, and the formality of a court proceeding, with its aura of an adversarial encounter, risks distracting both clinician and surrogate from their mutual goal of serving the patient's interests.

Obeying the law and withholding protected information would undermine the surrogate's ability to fulfill her responsibilities to the patient and play her intended role in shared decision making. She would be asked to consent to the procedure without knowing critical information about the patient's diagnosis—information that might influence her decision.

Finally, violating federal law in order to honor his professional ethical obligation to assure that Mrs. W is adequately informed for the decisions she must make is hardly an attractive proposition for Dr. P.

Recommendations

The situations in which clinicians truly face a conflict between the legal duty to protect the confidentiality of specific information under 38 U.S.C. 7332 and a professional ethical obligation to disclose protected information in order to support surrogate decision making for an incapacitated patient will be rare. However, the significance of the dilemma for health care professionals does not rest on the frequency with which it arises, but on the fact that compelling but mutually incompatible obligations are at issue. The foregoing analysis has suggested that advance care planning can play a role in forestalling such dilemmas, and has highlighted the importance of using sound judgment in determining whether disclosure is warranted in a particular case. But situations like that faced by Dr. P will arise from time to time—when urgent decisions must be made on behalf of a patient whose preferences are not known and when clinicians will reasonably judge that knowledge of protected information is material to assure that the patient's surrogate is able to fulfill his or her decision-making responsibilities.

Given the ethically untenable position VA clinicians face in such situations when their obligation to share patients' personal health information with authorized surrogates conflicts with the obligation not to disclose information protected under 38 U.S.C. 7332, the National Ethics Committee recommends that the Under Secretary for Health request an opinion from VA General Counsel to determine:

- (1) Can 38 U.S.C. 7332 be interpreted to allow disclosures to authorized surrogates?**
- (2) If so, would the regulations implementing the statute need to be amended?**
- (3) If not, what other legal options are available to resolve the conflict of duties for clinicians in VA?**

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