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Positive HIV Test Results from Deceased Organ Donors: Should We Disclose to Next of Kin?

Anne L. Dalle Ave and David M. Shaw

ABSTRACT

In the context of deceased organ donation, donors are routinely tested for HIV, to check for suitability for organ donation. This article examines whether a donor's HIV status should be disclosed to the donor's next of kin.

On the one hand, confidentiality requires that sensitive information not be disclosed, and a duty to respect confidentiality may persist after death. On the other hand, breaching confidentiality may benefit third parties at risk of having been infected by the organ donor, as it may permit them to be tested for HIV and seek treatment in case of positive results.

We conclude that the duty to warn third parties surpasses the duty to respect confidentiality. However, in order to minimize risks linked to the breach of confidentiality, information should be restrained to only concerned third parties, that is, those susceptible to having been infected by the donor.

INTRODUCTION

A test for HIV (human immunodeficiency virus) is one of the routine blood tests that are conducted on organ donors, in order to avoid the transmission of diseases to seronegative recipients. If the result of an HIV test is positive, organs from the donor are usually not transplanted. However, organ donation may be considered[1] when compatible HIV-positive recipients are available. In the United States, organ donation from HIV-positive organ donors recently became permitted, but initially only under a research protocol.[2]

But what else should be done in case of a positive HIV result? Do health professionals have a duty to disclose positive HIV results to relatives or partners who were at risk of infection when doing so would be a breach of medical confidentiality?

There is no consensus answer to this question in the literature. In the United Kingdom, for instance, the next of kin is informed about "the need for virology testing and that results may be discussed with them if a test result were found to be positive."[3]

In the U.S., according to Slam and colleagues, the Public Health Service Guideline for Reducing Transmission of Human Immunodeficiency Virus (HIV), Hepatitis B Virus (HBV), and Hepatitis C Virus (HCV) through Solid Organ Transplantation "does not address the ethical question of whether next of kin should be notified of a positive test if they were previously unaware and the 'donor' never consented to that testing, nor to disclosure to family members."[4]

Here, we analyze the ethics of disclosing a positive HIV result from a deceased organ donor to third parties who might have been infected by the donor.

Anne L. Dalle Ave, MD, MS, is an Ethicist in the Ethics Unit of the University Hospital of Lausanne, Switzerland, and at the Institute for Biomedical Ethics, University Medical Center of Geneva, Switzerland. *Anne.Dalle-Ave@chuv.ch*

David M. Shaw, PhD, is a Senior Researcher at the Institute for Biomedical Ethics, University of Basel, Basel, Switzerland, and at the Care and Public Health Research Institute, Maastricht University, the Netherlands. *david.shaw@unibas.ch*

ETHICAL ANALYSIS

Professional Confidentiality for the Living

Professional confidentiality is the obligation to keep silent "a secret of which he [the physician] has knowledge or of which he becomes aware within his professional role."[5] However, as stated by Ketels and colleagues, professional confidentiality is not absolute, and "other values, such as the health of others, may indeed take precedence in certain circumstances."[6] Such exceptions to professional confidentiality have different justifications; these include a state of necessity,[7] a duty to warn,[8] a "duty to protect imperiled third parties,"[9] and a "duty to breach patient confidentiality to protect others."[10] All of these refer to the same concept, that is, the idea that duties to protect others sometimes trump confidentiality concerns.

Since the emergence of HIV in the 1980s, discussions about whether to breach professional confidentiality in order to protect third parties have generated animated debates, and legislation and recommendations vary among countries.

In the U.K., the General Medical Council (the organization that helps to protect patients and improve medical practice across the U.K.) has stated that "Personal information may, therefore, be disclosed in the public interest, without patient's consent, and in exceptional cases where patients have withheld consent, if the benefits to an individual or to society of the disclosure outweigh both the public and the patient's interest in keeping the information confidential,"[11] and that "you may disclose information to a known sexual contact of a patient with a sexually transmitted serious communicable disease if you have reason to think that they are at risk of infection and that the patient has not informed them and cannot be persuaded to do so."[12]

Nonetheless, there is no legal *duty* to warn those possibly infected in the U.K., because of the common law rule that there is no legal duty to rescue.[13]

In the U.S., and in many other countries, medical confidentiality is protected under the law.[14] To override such a norm, good reasons are necessary and negative effects must be minimized.[15] In 2001, Wolf and Lo wrote that, concerning HIV, physicians may be allowed to breach medical confidentiality and to disclose a positive HIV test from one of their patients to a third party if it "will help prevent serious harm to an identifiable person," "there is no other effective means of achieving the goal," and "the breach of confidentiality is minimized."[16] Generally, it is required that the physician try to persuade the patient to disclose his or her HIV-positive status to persons whom he or she may have infected or with whom he or she still engages in risky behavior. However, if the patient agrees to disclose her or his positive HIV status, the physician has no way of checking whether the patient has disclosed the information. This means that any such claim must be trusted in the absence of any evidence to the contrary. Depending on the country, if the patient refuses to disclose the information, and, if it is permitted by law, the physician can disclose the positive HIV result to identified third parties who are at risk of infection.[17] If it is not permitted by law, the physician can notify local public health authorities. Furthermore, Lehman and colleagues write, some U.S. states have "legislation that criminalizes potential HIV exposure."[18]

In 2006, the *American Journal of Bioethics* devoted several essays to the question of whether one should breach medical confidentiality to protect third parties.[19] Kipnis, acknowledging "the collision between medical confidentiality and the duty to protect imperiled third parties," advocated in favor of "an unqualified confidentiality rule," that is, a rule that "contemplates no exceptions.[20] Interestingly, he argued that unqualified medical confidentiality "will allow the profession to discharge its collective responsibilities to patients and society," as it will be the responsibility of patients and/or society to balance the need to protect others against the need to protect confidentiality.[21] Other authors pointed out that other values, such as "do not harm"[22] and the duty to protect patients against diseases,[23] may outweigh medical confidentiality.[24]

HIV disclosure is particularly challenging because of the stigma that still surrounds the disease. As Radcliffe states, "As long as people with HIV face stigma and discrimination from those close to them, from healthcare professionals, and from society, many will find it difficult to disclose."[25]

Professional Confidentiality for the Deceased Organ Donor

Professional confidentiality may continue even after death in some countries.[26] For instance, in the U.K., medical records cannot be accessed until 100 years after a patient's death, with some exceptions for research purposes subject to approval by the Public Records Office.[27] In the U.S., however, according to Smolensky, the family has "the ability to obtain sensitive information about a decedent's medical conditions."[28]

While some authors may advocate that the deceased person can have no interests, as they have ceased to exist,[29] many others believe that some in-

terests can survive the death of a person,[30] including confidentiality, wills,[31] and reputation,[32] acknowledging that some interests may persist after death. For instance, most societies will respect the wishes of a person concerning the disposal of their body after death (incineration or burial). Furthermore, most societies spend a lot of time and institutional resources protecting the wishes of a person who is dead by distributing their assets and enforcing wills. Finally, in English law, the notion of "extended best interests" has been acknowledged in the context of organ donation.[33] Traditionally, a patient's best interests (which is the test doctors used for decision making regarding incapacitated patients) only concern what was of medical benefit to them, but consideration of extended best interests enables treatment aimed not at benefiting the patient, but at facilitating organ donation after his or her death—and thus enables the pursuit of interests beyond the point of death.[34] Indeed, organ donation, although presenting no direct medical benefit for patients, may represent indirect benefits for patients, if the well-being of others (through organ donation) is important for organ donors.

The particular question of whether health professionals have a duty to disclose the positive HIV results of a deceased organ donor to relatives or partners who are at risk of infection, when doing so would be a breach of medical confidentiality, is unresolved. To answer this question, one has to determine whether the interests of a living person override those of a decedent,[35] such as the preservation of his or her reputation or legacy.

The U.S. Centers for Disease Control and Prevention (CDC) estimates that "of the 1.2 million people living with HIV in the United States, nearly one in seven (more than 168,000 individuals) do not know they are infected."[36] It is thus very possible that a deceased donor might have been unaware of her or his positive status or had chosen not to disclose it to persons whom he or she might have infected.

To disclose the positive HIV status of a deceased organ donor to third party who is at risk of having been infected would breach medical confidentiality, but, on the other hand, would permit the third party to seek necessary testing, counseling, and treatment in case she or he tests HIV positive, and would permit better public health prevention.

In the case of a deceased organ donor, the risk of harm induced by breaching medical confidentiality is minimal, as the person is dead. Principally, breaching medical confidentiality can harm the reputation and memories of the deceased.[37] It will concern only the "image" of the person after her or his death, but will not negatively affect her or his personal, professional, or spiritual relationships, as would be the case for a living person, as positive HIV status is still unfortunately surrounded by stigma. It can also harm persons who are related to the deceased, by interfering with their memories of the person, particularly as long as HIV has a connotation of stigma.

The benefits of breaching confidentiality are obvious for those who may have been infected with HIV: they can be tested for HIV, and if the results are positive they can seek treatment (to turn a lethal disease into a chronic condition), refrain from risky behaviors, and also inform any recent sexual contacts that they too might be infected. It can be argued that the duty to warn is more important than the duty to respect confidentiality—particularly after death. In countries where healthcare professionals can inform third parties of the risk of HIV transmission despite the fact that the patient wants his or her HIV status to be kept confidential,[38] it would be odd not to also inform people that a now-dead person who can no longer be harmed by the disclosure posed a risk of infection. Furthermore, one of the reasons for not informing sexual partners about the HIV-positive status of a living patient is the possibility that the patient will him- or herself disclose that information. This is obviously not an option for a deceased patient, and given the potential risk to the bereaved partner (and previous sexual partners), disclosure will often be appropriate. In one case in the U.K., the sister of a deceased patient informed staff that he had been HIV positive and his wife—and two young children—remained unaware of this. In this case a decision was made to disclose this information. Ultimately, the right to confidentiality of the deceased person must not be weighed only against the rights of his or her most recent sexual partner, but also against the prospective benefit and prevention of harm to previous sexual partners of the deceased and future (and perhaps also previous) sexual partners of the surviving sexual partner. In more complex cases involving multiple sexual partners who may have been infected, public health authorities tend to work with the police in tracing and contacting those at risk.

Overall, as the benefits of disclosure outweigh the risks of breaching medical confidentiality, health professionals have a duty to inform third parties who are at risk of infection. However, risks linked to the breaching of confidentiality should be minimized to avoid harm induced by such information. Thus, policies and consent procedures should indicate to potential donors how the positive HIV results of de-

ceased organ donors will be given to concerned third parties.

Generally, during the process of obtaining consent for organ donation by surrogates, the organ procurement organization (OPO) team informs donors' next of kin that blood tests, such as HIV test, will be conducted on their relative. The team also usually inquires if the deceased organ donor was known to suffer from particular diseases, such as hypertension, diabetes, and HIV, and if he or she had previous risky behaviors that might have led to infection with HIV. This is the perfect moment to consider not only the organ recipient's future health, but also the well-being of third parties who are at risk of having been infected, and public health more generally. For instance, next of kin can be informed that HIV tests will be performed and that positive results would be returned only to third parties at risk of having been infected, specifying that the goal is to permit the concerned person to be tested and to prevent further spread of the disease, while still minimizing the breach of medical confidentiality. Names and contact information of known third parties who would be at risk of infection could be obtained during the discussion with the family, so that these persons would be easily contacted in case of a positive HIV result. However, it is possible that family members would not have such information, and such discussions would need to be cautious, as questions regarding sexual partners or drug use may be delicate to raise. If the medical team already knows the positive HIV status of the deceased organ donor (because the information is available from the medical chart, for instance), and still considers him or her as a potential organ donor, a similar procedure (see above) can be used, as confirmation of positive HIV status will be necessary, in addition to further laboratory tests such as CD4 count and viral load.

Such a procedure will mean that in case of positive results, only persons who might have been infected by HIV would be directly informed of positive tests. This would protect sensitive information from being spread among persons who could not benefit from it, such as parents or siblings of the deceased person.

Usually, if organ donation cannot go ahead, the reasons are explained to the family (for instance, tests discover an active oncologic disease). In cases when organ donation cannot be pursued because of a positive HIV test result (if, for example, no HIV-positive recipients exist), the reason should be disclosed only to a concerned third party and not to other family members, in order to protect and respect medical confidentiality.

CONCLUSION

Under specific conditions, health professionals working in transplant coordination have a duty to inform concerned third parties about a positive HIV test from a deceased organ donor. However, in order to minimize risks of stigmatization and harm, an adequate procedure that will inform only the concerned third parties has to be in place. Here we have considered the issue of HIV status, but similar parallels could be drawn with hepatitis B and C, or with any other transmissible disease. A detailed analysis of other infectious diseases is outside the scope of this article. Briefly, one may argue that because such diseases carry less stigma than HIV, and one might thus expect less harm to the deceased's reputation and image, it might be argued that the threshold for disclosure should be lower.

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