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Posthumous HIV Disclosure and Relational Rupture

Laura K. Guidry-Grimes and D. Micah Hester

ABSTRACT

In response to Anne L. Dalle Ave and David M. Shaw, we agree with their general argument but emphasize a moral risk of HIV disclosure in deceased donation cases: the risk of relational rupture. Because of the importance that close relationships have to our sense of self and our life plans, this kind of rupture can have long-ranging implications for surviving loved ones. Moreover, the now-deceased individual cannot participate in any relational mending. Our analysis reveals the hefty moral costs that disclosure can bring, which should influence what information is given to would-be donors and how organ procurement coordinators approach these conversations.

We generally agree with the ethical argument put forward by Anne L. Dalle Ave and David M. Shaw in their article, "Positive HIV Tests from De-

ceased Organ Donors: Should We Disclose to Next of Kin?" concerning HIV disclosure in deceased donation cases.¹ However, because the authors inadequately account for how procurements actually happen in specific cases, we believe that they have not sufficiently acknowledged an important moral risk in these disclosures. Specifically, the authors suggest that such disclosures "will concern only the 'image' of the person after his/her death, but will not negatively affect her/his personal, professional or spiritual relationships." We disagree and argue, instead, that these disclosures can, at least in some cases, cause deep relational ruptures between the now-deceased individual and some of those who survive her or him. This rupture, we will argue, has significant implications for how survivors view the identities and life plans they built around that relationship, especially since the deceased individual is incapable of participating in any relational mending.

In this commentary, we will provide a brief overview of the process of disclosing a positive test for human immunodeficiency virus (HIV) in a deceased potential organ donor and highlight some ethical issues that can arise in carrying out the details of this process. In order to ground our discussion in the reality of how organ procurement actually occurs, we will base our discussion on procurement processes in our home state of Arkansas, although many of these details will be shared by other states as well.

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While the authors focus on disclosure in relation to warning at-risk individuals, we broaden our analysis to include disclosures that routinely occur for the purpose of informing next of kin or an agent why an authorized donation will not proceed.² We will then focus our attention on the moral risk of relational rupture. Our analysis illustrates the hefty moral costs that these disclosures can bring, which should affect what information is given to would-be donors and how organ procurement coordinators approach this task.

THE PRACTICE AND MICRO-ETHICS OF DISCLOSURE

Depending on circumstances, different individuals may be responsible for disclosure of HIV status, and the nature of the disclosure conversation will depend on the role of the one disclosing. Treating physicians do not routinely screen for HIV, and if a patient is screened, physicians (should) only disclose HIV status (absent any specific laws or other duties of disclosure to state agencies or individuals) to another party (1) when the patient is incapacitated, (2) the party is identified as the surrogate decision maker, and (3) the HIV status is pertinent to healthcare decisions that have to be made for the patient. In the context of our state, when a patient dies and has been designated as a potential organ donor, the organ procurement organization (OPO) takes over the primary role in coordinating next steps. The coordinator for the OPO approaches the legally appropriate person (usually the next of kin or agent, who may not be the surrogate for other healthcare decisions) and describes the tests that are run, what would keep the OPO from procuring organs, and mandatory reporting requirements to public health agencies. While the coordinator may not ask for consent to procure, she or he has this conversation with the next of kin/agent (NOK/A), even if the patient designated him- or herself as a donor.

Unless the OPO works with a hospital that accepts HIV-positive organs under the HIV Organ Policy Equity (HOPE) Act,³ if the OPO's initial screening is reactive for HIV, then the OPO will not procure the organs. OPOs vary in how they handle this revelation with the NOK/A, either disclosing at that time or waiting until the OPO has run confirmatory tests, which can take two weeks to complete. In our state, the organ procurement coordinator would work with the OPO's medical director to craft a letter that is sent to the NOK/A, describing the results of the tests in more detail. While the coordinator or the letter can encourage the NOK/A to in-

form any at-risk individuals, the OPO is only permitted to disclose to the NOK/A. In Arkansas, the OPO is required to report positive HIV results to the Arkansas Department of Health, and this agency then takes steps to assess and manage infection risks. It is, therefore, the Arkansas Department of Health that has the legal authority and responsibility to disclose to at-risk individuals.

The micro-ethics of the conversations between the OPO and NOK/A include considerations of transparency, trust, role delineation, empathic communication, showing respect for the deceased individual and surviving loved ones, and providing on-the-spot education in a sensitive and helpful manner. Thoughtful judgment calls must be made to determine how best to separate the NOK/A from others at the bedside and how to emphasize the implications of serology testing. For instance, the family might not have read or understood the part of the authorization form that describes testing, so they might not have grasped the full implications of having the deceased tested for certain infectious diseases, some of which are stigmatized. Given this, OPOs should decide how its staff should respond to a preliminary positive HIV result while evaluating a deceased patient; it is not morally neutral whether to disclose the preliminary results immediately to the NOK/A or to wait for confirmatory tests. If the OPO chooses to disclose in the moment, then staff must be prepared to give useful information about risk factors and allay misinformed fears, which can be especially challenging given common misunderstandings about this disease. If the OPO chooses to wait, the coordinators need a way of responding to the family's questions respectfully and honestly. The letter that the OPO medical director writes to the NOK/A could perhaps allow for individualized recommendations, information about risk factors, and suggestions for whom to contact. This letter could be one of the last documents that a loved one receives about the recently deceased, and the care exhibited in the letter could make a significant difference for how the individual processes those final hours in the hospital. Having these details in the form of a letter has its own drawbacks, since person-to-person contact might be preferable for many loved ones in this situation, so they can ask additional questions, talk through available resources, and have the human connection from the beginning to the end of this process.

These micro-ethical concerns can be further enumerated; however, we choose to devote the balance of our comment to an aspect of the HIV disclosure process that should not be overlooked: the poten-

tial for relational rupture with long-ranging consequences for surviving loved ones.

RELATIONAL RUPTURES, POSTHUMOUSLY

Intimate relationships substantially influence how we develop our sense of self over time. David DeGrazia nicely makes this point:

A large part of who you are is a function of your interpersonal relationships, some of which are central to your identity. . . . So, to some extent, their interests are your interests. That is why if my wife or daughter flourishes, I am *ipso facto* better off. It is not simply that their flourishing makes them better company, or easier to live with or care for. To the extent that they are part of my identity, our interests overlap and their well-being constitutes part of my well-being.⁴

We are relational creatures, relying on others to develop and maintain our sense of self over time. Our relationships also transform how we structure our ends—that is, how we make plans and set personal aims. Connection with another person could make us more likely to take certain risks or embrace new endeavors. An individual's interests—be it Indian cooking, reading historical biographies, or wakeboarding—could all trace back to sharing time with another person and having the affection they share and those experiences shape who they are.

Imagine that Jane had been married to George for 20 years before he died suddenly, and after authorizing his organs for donation, Jane learns from the OPO that George was HIV positive. Before this revelation, Jane thought of herself as, among other things, a partner to an honest man who shared every major aspect of their lives together. She took a certain amount of pride from knowing George better than anyone. Upon hearing that he had HIV, she might start to doubt the closeness of their relationship and how she has built her sense of self over the last 20 years. She allowed herself to be changed by the relationship, but now there is potential evidence that George was not equally vulnerable with her. She might never know whether he knowingly put her risk. Processing her grief over his death has just become all the more confounding and difficult. Their shared interests will continue to guide Jane's life after his death, at least initially, because of the pull that our close relationships have on our identity. In this way, their relationship continues in some form for Jane, but Jane does not have the benefit of critically reflecting on any of this *with* George. As such, the relationship might always feel ruptured to her, even

if she copes with the revelation and its uncertainties at some point. Jane might wonder whether she made a mistake in authorizing the organ donation, given how it led to new tests and disclosures. Especially if her own tests happen to be negative, she might think that she would have been better off, in the end, if she had decided against donation. At minimum, she might wish that she had been more informed of this particular risk of world-altering disclosure.

Roles such as “spouse” or “sibling,” “friend” or “colleague” are not simply accidental attributes in our lives. They make up a substantive part of who we *are*. Information, actions, choices, and events have the power to undermine, fundamentally, the status of those relationships and, in turn, our very sense of self. As such, disclosure of something as nontrivial as HIV can impact relationships, and thereby, make us question who we are. It would seem, then, that limiting disclosure is good practice. However, the distribution of disclosure is not under the control of healthcare professionals alone. In fact, the NOK/A is entrusted with much of the information and decision making in the procurement process. The NOK/A could inform others, and any at-risk individuals could be contacted by a public health agency. Additionally, if anyone learns that the organ procurement was planned but then suddenly canceled, they might end up inferring the patient's HIV status. Given that disclosure is difficult to delimit, we must acknowledge that there is a reasonable chance that many people can come to know the HIV status of the deceased, and such a discovery could affect how survivors view their relationship to the deceased, which has further implications for how survivors view the parts of themselves and their lives that were structured around that relationship.

Dalle Ave and Shaw mention that HIV is shrouded in stigma and unfair bias, and this is not unimportant, but the authors focus too narrowly on these concerns. We contend, more broadly, that the revelation of HIV could impact relationships for other reasons as well. At-risk individuals are left with a number of upsetting questions: What is the level of risk they now have? Did the deceased knowingly put them at risk? Have they now unknowingly put others at risk as well?

Additionally, close relationships are built on each person's willingness to be vulnerable and to confide in one another. Although few, if any, relationships demand *total* disclosure of *all* sensitive information and *complete* vulnerability, true intimacy (in the sense described here) involves mutual

trust in being charitable, kind, and supportive of each other, even when those dispositions are normally difficult with other people or in trying circumstances. If one person does not share an important aspect of her or his life, something central to that person's health and relationships and overall well-being, then the other person might reasonably doubt to what extent their relationship is/was close at all. A brother, for example, might feel deeply hurt that his sister did not trust him with her HIV status, and he might feel that they lost out on opportunities for bonding and support. A caring and distraught loved one might think, "I would have been there for her. Why couldn't she trust me with this?" None of these considerations are unique to HIV; there could be similar impacts on relationships if it were discovered that an individual chose not to reveal his or her heart attack history, hepatitis A, or (beyond issues of disease) the existence of an estranged spouse. However, the life-threatening nature of HIV, if unmanaged, and the stigma surrounding it make its disclosure especially sensitive.

Of course, there are numerous factors that could excuse or at least partly justify the withholding of HIV status. The individual might not have known; he or she could have learned recently and wanted to process the news on his or her own first; the individual might have believed he or she should withhold out of consideration for what was happening in the other person's life; or maybe the individual was wary of how the relationship might be transformed by the disclosure, and holding onto normalcy was more valuable at the time. The individual might have also had legitimate concerns that the relationship was *not* as close as the other person believed, for example because the other person revealed harsh judgmental attitudes towards people with HIV in the past. When this revelation occurs while both people in the relationship are alive, there is a *possibility* of discussion, explanation, apology (if called for), and support. They have a chance, at least, to move forward in their relationship and build new closeness around this aspect of the persons' life, particularly since living with HIV, following a medical regimen, and enduring through stigma can be challenging for many individuals. The other person has the opportunity to prove her- or himself, so to speak, as a trustworthy and loving family member or friend. When the disclosure of HIV occurs posthumously, then all of these possibilities end; the now-deceased individual cannot respond to the aftereffects. Even if the individual had the foresight to leave a letter before dying to address some of foreseeable questions, a letter cannot take the place of interpersonal interac-

tions in which both people have the ability to ask questions, listen empathically, ask for apologies (again, if called for), and decide together how to move forward in their relationship.

CONCLUSIONS

The authors offer an ethical analysis that touches on a number of salient concerns in cases of deceased donors with positive HIV status. The authors say that damage to the reputation or image of the deceased is the only harm at stake, but we contend that there is a significant moral risk of what we are calling "relational rupture." One response to this concern is to increase public awareness of the routine tests done as part of the donation process as well as any reporting requirements, so would-be donors can evaluate this risk for themselves and plan accordingly. The authors make a similar suggestion, and we have elaborated on the reasons why this educational effort could help alleviate relational harms. For example, in a hospital participating in the HOPE Act, an informed HIV-positive patient could choose to designate a trusted person as her or his agent for organ donation decisions, and the patient could tell the agent what sort of narrative or context the patient wants to accompany disclosures. An individual who wished to minimize disclosure of his or her HIV status might choose against donation.

Our argument also has implications for how organ procurement coordinators should approach conversations with the NOK/A. Coordinators should take steps to ensure that the information about serology testing and reporting requirements is sufficiently understood. Family members might not have considered that the now-deceased individual was at risk for HIV, so this information could slip by if not accentuated by the coordinator. While assessing family members' level of understanding, the coordinator should also make the point that the information gleaned from these tests can be extremely difficult for loved ones to process, particularly since they do not have the benefit of discussing any positive results with the now-deceased individual. This conversation will require great care and tact, and it should be part of every organ authorization discussion, since these revelations can occur in any family.

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NOTES

1. A.L. Dalle Ave and D.M. Shaw, "Positive HIV Test Results from Deceased Organ Donors: Should We Disclose to Next of Kin?" in this issue of *JCE*, volume 29, number 3 (Fall 2018).

2. The authors do mention that the reason for not pursuing organ donation due to positive HIV status "should be disclosed only to a concerned third party and not to other family members," but it is not clear who they think would qualify as a "concerned third party" for this purpose or how this claim fits in their weighing of duties to warn and to respect confidentiality.

3. UNOS, "At Two Years, HOPE Act Still Offering Hope." 1 December 2017, <https://unos.org/at-two-years-hope-act-still-offering-hope>.

4. D. DeGrazia, *Human Identity and Bioethics* (New York, N.Y.: Cambridge University Press, 2005), 87.