

Kidney Transplantation and HIV: Does Recipient Privacy Outweigh the Donor's Right to Information?

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Background and objectives: There exists an inherent conflict between a kidney donor's right to know key aspects of a recipient's medical history and specific disease, such as HIV, where federal and state statutes protect this information. The authors of the live organ donor consensus group expressly stated the principal of a donor's right to recipient information. This information includes the risks and benefits of not only the donation procedure, but also the risks, benefits, and alternative treatment options of the recipient. In this paper, a case will be presented highlighting this conflict and the ethical and legal reasoning used to resolve it.

Design, setting, participants, & measurements: A 22-year-old woman came forward as a directed kidney donor for an HIV-positive individual. The donor and recipient were medically appropriate for kidney donation and transplantation. During the donor advocacy panel review, there was disagreement regarding whether or not the potential donor had the right to know about the HIV status of the potential recipient.

Results: In living kidney transplantation to HIV-positive individuals, the recipient's right to privacy of information outweighs the donor's right to know.

Conclusions: Although protecting the recipient's right to privacy is paramount, the donor is still entitled to consider factors *a priori* that could alter their decision to donate. This can be accomplished by informing the donor that they are not entitled to protected health information of the recipient and that their decision to donate should be based on knowing the recipient is medically appropriate for kidney transplantation.

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Case vignette: A 22-year-old woman came forward as a directed kidney donor for an individual who she knew through an organization but with whom she had no emotional or familial connection. The recipient was HIV-positive and the donor was not aware. The donor and recipient were deemed to be medically appropriate for kidney donation and transplantation. During the donor advocacy panel review of the donor, the question was raised whether or not the potential donor had the right to know about the HIV status of the potential recipient.

Kidney transplantation is the optimal therapy for ESRD. Its success has resulted in the expansion of its indications to include transplantation in the elderly population, in high immunologic risk groups, and in situations such as HIV, where it was previously contraindicated. Moreover, better operative and postoperative care has resulted in offering kidney transplantation to higher risk individuals whose comorbidities could negatively impact allograft survival. Quantifying this recipient risk is not easily done;

nevertheless, current guidelines set forth by the American Society of Transplantation suggest that a kidney transplant candidate should have a reasonable 5-year survival (1).

If living donors are involved, the ability to assess this risk becomes even more important when performing kidney transplantation in patients at higher risk of graft failure, recurrent disease, or death. There is a general principle that living donors should receive any information, including all relevant recipient risks, that could impact the success of the transplant and thereby alter their decision to donate. Although there is substantial consensus on this principal in the transplant community (2), informing the donor of a recipient's HIV status presents a conflict between a donor's full right to know and the legal right to privacy of the HIV-positive recipient.

As is often the case, the improvement in medical technology and its application moves faster than the medical ethics that support the decision-making process. In an era before strong clinical evidence supporting organ transplantation into HIV-positive recipients, Hapler, Ubel, and Caplan (3) first outlined the justification for offering kidney transplantation to them. They concluded that "simultaneous consideration of efficacy, urgency and equity" were resolved to limit the immediate exclusion of this patient population to organ transplantation services. Subsequently, clinical studies conducted with highly active antiretroviral therapy (HAART) have shown that the survival of patients with HIV is greatly improved (4). Because

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the survival of appropriately selected HIV-positive patients meets or exceeds the “5 year rule” applied to non-HIV-positive kidney transplant recipients, denying kidney transplantation to a patient on the basis of HIV status alone is not equitable. However, if the outcomes in the HIV-positive recipient were not equivalent, this could still be considered an experimental procedure reserved for unique circumstances.

The question of equivalent survival between HIV-positive and HIV-negative kidney transplant recipients has not conclusively been answered (5). This is in large part due to controversy caused by unequal donor factors. Regardless, the current literature suggests that 1- and 3-year survival in appropriately selected HIV-positive patients is similar to patients with other kidney diseases (6,7).

When initially conceived, transplantation into HIV-positive patients was done with deceased donor kidneys, but this has evolved to offering living donor kidneys to these individuals. However, there exists a conflict between a donor’s right to know aspects of a recipient’s medical history that could alter their decision to donate and conditions (*e.g.*, HIV) where federal and state statutes prohibit disclosure of the information. Bright and Nut (8) recently highlighted this tension between equal yet mutually exclusionary rights in an article discussing the current practice in Great Britain. In 2005, the British HIV Association provided guidance on HIV and renal transplantation: “live donors must always be informed that this [donation to an HIV-positive recipients] is an ‘experimental’ or ‘new’ procedure and that the prognosis for the graft and the patient survival may be significantly less than average” (9). In the same year, the British Transplant Society and the Renal Association provided similar guidance stating that the donor was entitled to know of any information that would increase the risk of morbidity or mortality in the recipient (10). These guidelines have not been modified in light of new data showing good results for kidney transplantation in medically appropriate recipients with HIV. In the United States, there are currently guidelines to help direct the donor evaluation and to ensure that the donor is fully informed and their autonomy is protected (2). However, this article did not address the issue that arises when the recipient had a federally protected right to privacy.

The Donor Argument

There is precedent to discuss recipient factors that may alter transplant outcome with the donor after obtaining informed consent from the recipient; however, these are medical conditions that do not carry the stigma of HIV disease. The reason for this disclosure is based on the tenet that a person dictates what happens to their body. Because the donor is undergoing a procedure they do not need to give up an organ they may need, the practice has been to make the donor aware of any information that could influence their decision. Although no formal practice guideline mandates this approach, the sentiment is clearly articulated in the Consensus Statement on the Live Organ Donor (2): “The person who gives consent to be a live donor should be competent, willing to donate, free from coercion, medically and psychosocially suitable, fully informed of

the risks and benefits as a donor, and fully informed of the risks, benefits, and alternative treatment available to the recipient. ... Nevertheless, donors become special ‘patients’ beginning with the testing to determine whether they can donate. It is incumbent on the transplant center to provide full and accurate disclosure to potential donors of all pertinent information regarding risk and benefit to the donor and recipient.” Exemplary of this is focal segmental glomerular sclerosis because it may recur in the transplanted kidney and result in a transplant outcome that is inferior to what would be expected.

In keeping with the consensus statement, the current practice is to obtain consent from the recipient to disclose pertinent information to the donor and ask the donor to consider whether or not this would alter their decision to donate. However, at the time of the donor consensus conference, transplantation into HIV-positive individuals had only been done in the occasional deceased donor transplants, and the trials to prove safety and efficacy had not yet begun (11). It is fair to say that other diseases that may decrease allograft survival do not carry the same stigma as HIV disease. Moreover the diseases envisioned by the consensus conference were not ones that have federal regulations prohibiting their disclosure. This is the conflict that arises in living donor kidney transplantation to HIV-positive individuals.

The first question is whether or not kidney transplantation into an appropriately selected HIV-positive individual results in shorter-than-expected allograft survival. If this procedure were experimental or resulted in an inferior outcome, the right of the donor to be made aware of the HIV status of the recipient is justified. Acknowledging that long-term outcomes are not available, the current data regarding 1- and 3-year graft survivals support equivalency to non-HIV-positive recipients. If it is accepted that outcomes are equivalent, the premise that the donor is entitled to information about the recipient because of the potential for worse-than-expected outcome of the transplant procedure is not supported in the medical literature.

This raises the question of whether or not a potential donor would make a different decision about donating a kidney on the basis of the recipient’s HIV status. The line of reasoning to support disclosure to the donor in this situation proceeds as such. Currently a donor may withdraw from the kidney donation process at any time and for any reason. During the donor evaluation process, the donor is told that this decision need not be justified to anyone but himself or herself. Although medical professionals cannot allow a recipient’s HIV status to affect their decisions other than to insure medical appropriateness for kidney transplantation, this does not apply to a private citizen who is not under any fiduciary obligation to the recipient. Moreover, from the perspective of the donor, the decision to donate is emotional and not medical. The very argument that disclosing a recipient’s HIV status would result in harm because of social stigmatization by its very nature acknowledges that within the population there are different opinions and emotions about this topic. Although the medical community should never foster perceptions regarding medical conditions, the donor is an individual who is free to make the decision to donate a kidney on the basis of their own belief

system. It is not for the medical community to judge the reasons why they may choose not to donate. Although medical professionals are required to avoid making medical decisions on the basis of social stigma, it is not the profession's right to impose a belief system on the general public.

Finally, a guiding principle of the medical profession is to first do no harm. If the donor were to discover *post facto* the recipient's HIV positivity and this information would have caused them to decide differently about kidney donation, might this constitute harm. It is standard practice to inform potential donors about the risk of depression after donation. It is also standard practice to take into consideration the emotional health of the donor before donation. Given the importance of the psychosocial component of the kidney donor evaluation, it is contradictory to hide information from the donor that could result in them having a feeling of betrayal or of being "tricked" or deceived.

In summary, donors are not a commodity or "owned" by the recipient. The recipient is entitled to have access to kidney transplantation; however, this access does not specify live kidney donation. Because of this, in situations in which the donor and recipient rights are mutually exclusive, the rights of the donor should prevail.

The Recipient Argument

A discussion of the recipient's rights must begin by acknowledging the history of discrimination against persons with HIV and the resulting federal and state legislation to protect against it. Unlike other medical information that is protected by the Health Insurance Portability and Accountability Act (HIPAA), HIV confidentiality has more stringent standards and is protected by name in federal and state statutes (12,13). Historically, these protections were placed because of the stigma and discrimination associated with HIV disease and concern that without these protections persons at risk for HIV would not seek medical therapy and thus harm society as a whole. HIV confidentiality falls under four board provisions: HIPAA, fiduciary duty of confidentiality, constitutional right to privacy, and the federal privacy act. Additionally, although not intended to include confidentiality issues, the Americans with Disabilities Act (ADA) of 1990 protects persons with HIV. The act protects an individual who is considered to have a "disability" if there are physical or mental impairments that substantially limit one or more major life activities. Moreover, the law protects persons regardless of their true HIV status and in circumstances in which a discriminatory act was conducted on persons who simply associated with an HIV-positive individual. The ADA's stringent protections were necessary and underscore the significant stigma associated with HIV.

Most states have specific laws to protect HIV medical information. Article 27-F, NY State Public Health Law, sees.2780 *et seq.*, provides specific provisions for HIV confidentiality, including confidentiality of testing regardless of result, written authorization requirements for distribution of HIV-related information, and protections regarding the disclosure of persons exposed to HIV infection. Again, these guidelines are more stringent than HIPAA and are designed to limit the discrimi-

natory practices based on HIV status or even the perception of having an HIV status.

The guidance provided by the consensus statement on living donors that donors be made aware of recipient factors was premised on the principle that donation is completely voluntary and is not associated with any tangible medical benefits. Thus, a donor should be afforded any and all information, including medical information of the recipient, that could alter their decision to donate. In practice, typical information that is shared about the risks and benefits of the recipient could include graft survival, patient survival, allograft rejection, recurrent disease, and history of noncompliance. This information is provided to the donor because of the potential adverse recipient outcomes that could result and the potential psychologic harm this may cause the donor. For example, a donor should be provided information regarding the risk of disease recurrence in a recipient with membranoproliferative GN or the fact that a recipient may have a hypercoagulable state, which are both associated with graft loss. Requiring disclosure of recipient HIV status that does not appear to impact transplant outcome is therefore based on the premise that someone would not donate a kidney they otherwise would solely on the basis of HIV positivity.

Requesting permission from the recipient to disclose their HIV status to the donor under the veneer of fairness to the donor in reality is coercive to the recipient. Although it is accurate to assert this does not limit their access to kidney transplantation, it is also true that transplant outcomes with a living donor kidney are superior to those with a deceased donor kidney. This requires the recipient to choose between protecting their privacy and receiving a superior form of therapy. Additionally, depending on the social circle of the recipient, they may have valid concerns that disclosing their HIV status would result in their being ostracized. Although physicians are bound to confidentiality, there is no such duty placed on a donor. Even having the donor sign a contract to keep this information confidential provides no guarantees.

The recipient could rightly question what about HIV with its good survival in patients on HAART makes it different from other medical conditions such as diabetes mellitus. A diabetic who was on dialysis and then receives a kidney transplant could arguably have a shorter life expectancy than a similar individual with HIV. The current 3-year graft survival rate for diabetic recipients of standard criteria donor kidneys is 78.1% (14). The comparable graft survival for HIV-positive recipients, without censoring death with function, is 83% (6). However, no effort is made to inform the donor of the recipient's "diabetic status." This reflects a pervasive public bias against individuals with HIV at a time when the literature supports that patients who comply with HIV therapy and participate in their health care have excellent survival. HIV has become a chronic disease similar to diabetes. Already the threshold that an HIV-positive patient must surpass to be referred for kidney transplantation with regards to medical compliance and stability of disease is much higher than a diabetic.

In summary, requiring an HIV-positive kidney transplant candidate to disclose their HIV status to a kidney donor is not

based on medical literature demonstrating that this is an experimental procedure or yields inferior results. In fact, it is due to a still present social bias and stigmatization against persons with HIV, and this is the very reason that federal and state privacy laws were enacted.

Discussion

At this time, given the good results of kidney transplantation into the HIV-positive population, our assessment is that the recipient's right to privacy exceeds the donor's right to information. However, we feel the donor should still be allowed to consider whether or not there are conditions that would alter their decision to donate. To reconcile these positions, we have added the following text to the end of our consent form for medical evaluation for kidney donation.

“As the donor you are entitled to know that the recipient has undergone an extensive medical and psychosocial evaluation and was found to be an appropriate candidate for renal transplantation. However, the recipient may have medical or social information about which you are unaware. In choosing to donate your organ, you acknowledged that you do not have access to information about the recipient that is not deemed relevant to the outcome of kidney transplantation.”

Specific medical conditions were not included in this paragraph because we wanted to avoid telegraphing recipient information to the donor. After reviewing the paragraph with the donor, the evaluating physician asks them whether or not there are any medical conditions that would cause them to change their decision to donate. Once all questions are answered, the patient is asked to initial the paragraph.

If after reviewing this consent, the donor decides to withdraw from the donation process, they are given an option on how to proceed. They can tell the recipient directly and provide an explanation of their choosing or they can default to the Donor Advocacy Panel and report to the recipient that they were medically disqualified. This option is currently offered to all donors who decide to withdraw from the donation process. Psychosocial indications, including ambivalence about donation, are medical reasons not to proceed. However, we acknowledge that these reasons do not resonate with the general public in the same way as traditional medical contraindications. Although the donor is being evaluated at a transplant center, the evaluating physician and the Donor Advocacy Panel are bound to keep all donor information confidential. Therefore, the donor merely reports to the recipient they were medically disqualified, their information is kept confidential, and in this manner the relationship between the donor and recipient that existed before this evaluation is preserved.

Although this tool was developed to address the specific question of informing the donor of the recipient's HIV status, we believe it is a more appropriate approach than the current practice of asking the recipient for permission to disclose other medical conditions. As the disparity between the number of recipients active on the deceased donor waiting list and the number of donors continues to increase (15), living donor kidney donation will become increasingly more prevalent and more transplants will occur between individuals with more

distant emotional ties. This will increase the likelihood that the donor will not know the specifics of the recipient's medical history. This approach removes the subjectivity as to which conditions rise to the level of requiring donor notification. It provides the donor with another opportunity to consider whether or not they wish to proceed with kidney donation and removes the burden of guessing which issues will be important to which donors.

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