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Perceptions, Motivations, and Concerns about Living Organ Donation among People Living with HIV

Sarah E. Van Pilsum Rasmussen^{#a}, Macey L. Henderson^{#a,b}, Juli Bollinger^c, Shanti Seaman^d, Diane Brown^d, Christine M. Durand^d, Dorry L. Segev^{a,b,e}, and Jeremy Sugarman^{c,d}

^aDepartment of Surgery, Johns Hopkins University, Baltimore, USA;

^bSchool of Nursing, Johns Hopkins University, Baltimore, USA;

^cBerman Institute of Bioethics, Johns Hopkins University, Baltimore, USA;

^dDepartment of Medicine, Johns Hopkins School of Medicine, Baltimore, USA;

^eDepartment of Epidemiology, Johns Hopkins University Bloomberg School of Public Health, Baltimore, USA;

[#] These authors contributed equally to this work.

Abstract

Recent changes to United States law now permit people living with HIV (PLWH) to donate organs to HIV-infected (HIV+) recipients under research protocols. PLWH may have unique motivations for and concerns about living donation and understanding them is critical to ensuring the integrity of this novel approach to organ transplantation.

We interviewed PLWH from an urban HIV clinic who had previously indicated their willingness to be a living donor. In-depth interviews elicited information about their motivations, perceived benefits, and concerns about living donation. Codes were identified inductively and then organized into themes and subthemes. Two coders analysed independently the interviews and reconciled differences in coding by consensus. Thematic saturation was reached after 20 interviews.

Motivations for living donation among PLWH included an altruistic desire to help others as well as HIV-specific motivations including solidarity with potential recipients and a desire to overcome HIV-related stigma. Perceived benefits of living donation included gratification from saving or improving the recipient's life and conferring a sense of normalcy for the HIV+ donor. Concerns about donation included the possibility of a prolonged recovery period, organ failure, and transmission of another strain of the virus to the recipients.

PLWH had unique motivations, perceived benefits, and concerns about living donation in addition to those previously identified in the general population. These unique factors should be addressed in research protocols, informed consent processes, and the education and training of independent living donor advocates so that these endeavors are ethically sound.

Keywords

People Living with HIV; Organ Transplantation; Living Organ Donation; Ethics

Introduction

The HIV Organ Policy Equity (HOPE) Act of 2013 permits the transplantation of organs from HIV-infected (HIV+) donors to HIV+ recipients (HIV D+/R+ transplantation) under specific research criteria published by the United States Department of Health and Human Services (HHS) (B. J. Boyarsky, Durand, Palella, & Segev, 2015; Brian J. Boyarsky & Segev, 2016; Collins, 2015; Doby, Tobian, Segev, & Durand, 2018; Durand, Segev, & Sugarman, 2016). This law permits people living with HIV (PLWH) to be living kidney donors, but this is controversial because of the risk of post-donation end stage renal disease (ESRD), which may be even greater in donors with HIV (Abraham et al., 2015; Grams et al., 2016; Ibrahim et al., 2009; Jotwani, Li, Grunfeld, Choi, & Shlipak, 2012; Mjøen et al., 2014; Muzaale et al., 2014). Nevertheless, living donation (LD) may result in better transplant outcomes, increased autonomy of donors, and reduced stigma among PLWH. Furthermore, a previous survey of PLWH found that 61.7% were willing to be living organ donors (Halpern, 2017).

Independent donor advocates, who are required by the HHS, must understand the motivations and concerns of potential HIV+ living donors to ensure the integrity of the informed consent process. However, given the unique experiences and challenges facing PLWH, their motivations, concerns, and perceived benefits regarding LD may also be unique. As initial efforts to assess the safety and efficacy of LD among PLWH are underway (Muzaale et al., 2017), it is important to understand these perspectives.

Methods

We conducted semi-structured, in-depth interviews with PLWH who indicated their willingness to be a living organ donor in a prior survey conducted between August-October 2016 (Halpern, 2017). Interviewees were contacted for participation if, in the previous survey, they had agreed to be contacted for future research studies and stated they were “definitely” willing to be a living donor (other response options were “probably yes,” “not sure,” “probably no,” and “definitely no”).

Interviews were conducted from September 2016 to February 2017. All those contacted agreed to participate and provided written consent. Interviewees were asked about their motivations, concerns, and perceived benefits regarding living organ donation and were given a \$25 gift card. Interviews were conducted over the phone, audio recorded, transcribed, and verified for accuracy by members of the study team. Two coders (SR & SS) analyzed independently the interviews using NVivo (QSR International). Codes were inductively identified. Differences in the application of codes were reconciled by consensus. An analysis revealed that thematic saturation had been reached after 20 interview (Patrick et al., 2011). This study, as well as the survey from which this study population was recruited, were approved by the Johns Hopkins Medicine Institutional Review Board (IRB00056369).

Results

Study Population

20 PLWH were interviewed (Table 1). Of the interviewees, 50% reported knowing someone receiving dialysis, 45% reported knowing someone on the organ transplant waitlist, and 30% reported knowing a transplant recipient (Table 1).

Motivations for Living Donation

General (Table 2a).—Interviewees expressed many common motivations for LD such as a desire to help others or save the life of the recipient, particularly a relative or loved one. Other motivations included long wait-times for a transplant and religious convictions.

HIV-specific (Table 3a).—Many motivations for donation were specific to HIV. A frequent motivation was a sense of solidarity with HIV+ transplant candidates. One interviewee expressed empathy for someone else living with HIV, saying they wanted to donate “because bein’ [sic] HIV positive myself I know how it is.” Interviewees were also motivated by a desire to help overcome the stigma associated with HIV. Further, they articulated a sense of having lived on borrowed time, explaining that they wanted to “give back” after having survived with HIV for many years. One was motivated by a sense of obligation, as a person living with, to participate in research.

Perceived Benefits of Living Donation

General (Table 2b).—Many of the potential benefits of LD identified by interviewees were not specific to PLWH, such as feeling good about helping someone and religious benefits. Some believed there would be no benefits to being a living organ donor.

HIV-specific (Table 3b).—Some potential benefits of LD identified were specific to PLWH: being an organ donor would confer a sense of normalcy for the donor and reduce the stigma around HIV. One interviewee explained that being a living donor would give PLWH a sense of purpose despite the challenges of their disease.

“When I found out about my disease and everything I was at the point where I didn’t care... [the] first thing [someone diagnosed with HIV] look[s] at is, I’m gone, I’m dead, it’s over with. But if you feel that you can help somebody you don’t think of it like that because you can help somebody while you’re still living”

Another believed that contributing to research about HIV+ organ transplants would be a benefit of LD.

Concerns about Living Donation

General (Table 2c).—Many interviewees said they had no concerns about LD, or that they were not informed enough to know about the risks. Others expressed concerns about surgical risk and survival after the surgery, the subsequent failure of their remaining kidney or liver, health problems not related to HIV-infection, and the wellbeing of the recipient if the donation were unsuccessful. Some expressed concern that the recipient would engage in behavior making the donation “useless”.

HIV-specific (Table 3c,d).—Other concerns raised were specific to HIV, relating to both the donor and the recipient. Donor concerns included the possibility that their HIV might complicate recovery and that PLWH are more likely to “have other health problems to deal with” that would make LD especially risky. In particular, the risk of kidney failure due to HIV. Recipient concerns focused on the possibility of transmitting a different strain of virus through transplantation, worrying that this would lead to a more difficult course of HIV treatment for the recipient. One interviewee believed that recipients would have concerns about accepting organs from HIV+ donors, and that the HIV+ living donor might be refused based on recipient’s doubts.

Discussion

In this study, we identified HIV-specific motivations for LD, including the desire to overcome HIV-related stigma. Furthermore, we found HIV-specific perceived benefits of LD such as conferring a sense of normalcy, reducing stigma, and contributing to HIV research. HIV-specific concerns about LD related to both donors and recipients. These included the risk of a long recovery period due to weakened immune system, organ failure due to HIV, and transmitting a different strain of HIV. Many motivations, concerns and perceived benefits regarding LD raised by PLWH here have been identified among living donors without HIV (Lennerling, Forsberg, & Nyberg, 2003; Papachristou et al., 2004; Tong et al., 2012).

Such concerns are understandable. While recent projections estimate the 9-year risk of ESRD among PLWH vary across subgroups, among those with no comorbidities and well-controlled HIV infections, there is a slight risk increase associated with HIV (Abraham et al., 2015; Jotwani et al., 2012; Ryom et al., 2013). However, carefully selected candidates for LD with well-controlled HIV infection and without diabetes, hypertension, albuminuria, or history of smoking, seem to have an acceptable risk for donation (Muzaale et al., 2017). Regardless, health care professionals and independent living donor advocates need to be prepared to address these potential concerns among HIV+ living donor candidates.

HIV D+/R+ deceased donor transplants are being performed in a number of countries, including the United States (Calmy et al., 2016; Doby et al., 2018; Hathorn et al., 2016; Muller, Barday, Mendelson, & Kahn 2015). However, to the best of our knowledge, HIV+ living organ donation has not yet been performed anywhere in the world. The regulations pertaining to HIV D+/R+ living organ donation vary among countries that currently perform HIV D+/R+ deceased donor transplants; HIV D+/R+ transplants are not permitted in the U.K. and Spain (*BOE #167 of July 14, 1987*; British Transplantation Society, 2015) but are permitted in South Africa and Switzerland (Personal Communications, C. van Delden, April 17, 2018; and E. Muller, April 17, 2018). Given the unique motivations, concerns, and perceived benefits that were identified in this study, other countries pursuing HIV+ D+/R+ LD should also consider assessing the perceptions of LD that are held by local PLWH.

Our findings should be interpreted with some limitations in mind. Although qualitative interviews allowed us to obtain rich insight into the perspectives of PLWH regarding LD,

our interviewees were from an urban clinic with a predominately African American population in Baltimore, Maryland, so the findings may not be generalizable to all PLWH.

In the context of HIV D+/R+ transplantation, patient-reported HIV-specific motivations and concerns about LD should be addressed in screening, evaluation, and informed consent, alongside current evidence on the risk to HIV+ live donors (Muzaale et al., 2017).

Independent living donor advocates should also be aware of the unique motivations and concerns held by HIV+ potential living donors. This is essential to ensuring that endeavors related to assessing the safety and efficacy of HIV D+/R+ transplantation are ethically sound.

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Table 1.

Interviewee Characteristics.

Characteristic	
Age (median (IQR))	54.5 (49.5–56.5)
Male	60%
African American	95%
High school/GED or less	70%
Government insurance	80%
On Disability	70%
Single	60%
Straight/heterosexual	70%
Years known they were HIV + (Median (IQR))	20.5 (12–27.5)
Know HIV viral load	80%
<i>Self-reported HIV viral load undetectable</i>	75%
Know CD4 count	70%
<i>Self-reported CD4 (Median (IQR))</i>	530 (462–716)
Feel knowledgeable about HIV	100%
Know someone on dialysis	50%
Know someone who received a transplant	30%
Know someone on organ waitlist	45%

Table 2:

General (HIV-nonspecific) motivations, perceived benefits, and concerns regarding HIV+ living donation

	REPRESENTATIVE QUOTE
a. Motivations	
Desire to help others	<i>Because it could help somebody else, you know, that's the main thing, givin' somebody else a chance at life</i>
Help loved one	<i>I love my grandkids, I love the heck outta 'em. And if anything, I could give up, even if I could give my heart out my body for one of 'em. That's what I would do it for.</i>
Organ shortage and organ wait times	<i>Because it's a helping service to help someone out because the organ donor list is kinda short</i>
Religion	<i>I think that's God's way of sharing. You know, he gave his life and now you get a chance to share, give an organ and help somebody with their life.</i>
b. Perceived benefits	
Helping someone / Good feeling	<i>makes you feel good about yourself. And I know that I may be able to help someone before I die... it's a really good feeling to have.</i>
No benefits	<i>There probably would be a benefit to the other person, but not the person that's giving it</i>
c. Concerns	
No concerns / not enough information	<i>[I would] have to read on it a little more... once I get a good insight and reading on it then I could determine, ok that won't harm me, won't harm the next person having the transplant and things of that nature</i>
Surgical risk / Survival	<i>Any operation is a slight risk</i>
Failure of remaining kidney or liver	<i>[Ending up] in the person's situation that you was tryin' to help</i>
Other pre-existing health problems not related to HIV	<i>I don't think I would do a living for the simple fact that I have pancreatitis</i>
Being allowed to donate	<i>You know, to me it's just like not being able to donate because, you know, you're not a match or something.</i>
Want to know who the recipient is	<i>You know, well, like is it possible if they match with somebody, get to meet them, and know what kind of life they lived, and no drug addicts. Nothing that they do damaging to the body because if I'm giving you a second chance and you continue to do the same thing it's useless.</i>
Graft function in recipient	<i>the person's body might reject it. Sure would feel sorry about that but I'd know I tried.</i>

Table 3:

HIV-specific motivations, perceived benefits, and concerns regarding HIV+ living donation

	REPRESENTATIVE QUOTE
a. Motivations	
Solidarity with HIV+ Recipient	<i>...to help somebody else, especially another HIV positive person... because bein' so many things that can take away our lifespan, especially those of us who are long term survivors... we help each other out</i>
Stigma associated with HIV	<i>[Because of] the stigma with HIV still, and a lot of people don't wanna help people with HIV sometimes.</i>
Giving back borrowed time	<i>I've been positive for 30 years or more, so I like to give back and what better way to help because there's not a lot of people who can donate organs.</i>
Obligation to science	<i>I think it's everybody's [with HIV] obligation. You know? For research²⁰²⁶ I'm a 30-plus year survivor, you know, that's a long time... I think it's my duty for them to be able to check my body out and maybe... save some kid down the line.</i>
b. Perceived benefits	
Sense of normalcy and reduced stigma	<i>[Being a living donor would] make you feel more normal</i>
Contribution to science	<i>[Helping doctors learn] what kind of danger and what kind of help [HIV+ living donation could be]</i>
c. Concerns about donor	
Compromised immune system complicating recovery from surgery	<i>the recovery period, our immune system is a little bit weaker, and it may take longer to recover... just to have to worry about infections and stuff</i>
Other pre-existing health problems related to HIV	<i>... [people living with HIV] probably have other health problems to deal with</i>
Increased risk of kidney failure due to HIV	<i>I wanna help somebody if I wasn't positive living. But being that I'm living with it, like I see a lot of people's health decline. Like a girlfriend of mine, she lost one of her, I think a kidney, and then all of a sudden the other kidney started going bad that she had to be on dialysis, so that's why I say living no,</i>
d. Concerns about recipient	
HIV superinfection	<i>You know, like one medication might work for me but don't work for another person, so that probably will be a big challenge right there, as far if I'm on one regimen and somebody on another regimen, we might be a match as a donor but is my medication that's in my system gonna have that other person setback or something like that?</i>
Recipient doubts about accepting HIV+ organ	<i>Yes in the beginning [the recipient would] probably be, you know, why should I take this because, you know, I don't know, not quite sure... That's a fear factor so yeah I think it's gonna be a problem with that, just convincing [the recipient] that they will be alright.</i>