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Patients' Experiences With HIV-positive to HIV-positive Organ Transplantation

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Background. HIV⁺ donor (HIV D⁺) to HIV⁺ recipient (HIV R⁺) transplantation involves ethical considerations related to safety, consent, stigma, and privacy, which could be better understood through studying patients' actual experiences. **Methods.** We interviewed kidney and liver transplant recipients enrolled in clinical trials evaluating HIV D⁺/R⁺ transplantation at 4 centers regarding their decision-making process, the informed consent process, and post-transplant experiences. Participants were interviewed at-transplant (≤ 3 wk after transplant), posttransplant (≥ 3 mo after transplant), or both time points. Interviews were analyzed thematically using constant comparison of inductive and deductive coding. **Results.** We conducted 35 interviews with 22 recipients (15 at-transplant; 20 posttransplant; 13 both time points; 85% participation). Participants accepted HIV D⁺ organs because of perceived benefits and situational factors that increased their confidence in the trials and outweighed perceived clinical and social risks. Participants reported positive experiences with the consent process and the trial. Some described HIV-related stigma and emphasized the need for privacy; others believed HIV D⁺/R⁺ transplantation could help combat such stigma. There were some indications of possible therapeutic misestimation (overestimation of benefits or underestimation of risks of a study). Some participants believed that HIV⁺ transplant candidates were unable to receive HIV-noninfected donor organs. **Conclusions.** Despite overall positive experiences, some ethical concerns remain that should be mitigated going forward. For instance, based on our findings, targeted education for HIV⁺ transplant candidates regarding available treatment options and for transplant teams regarding privacy and stigma concerns would be beneficial.

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INTRODUCTION

In the United States, transplantation from donors with HIV (HIV D⁺) to recipients with HIV (HIV R⁺) is allowed by the HIV Organ Policy Equity (HOPE) Act and is currently permissible only within approved research studies conducted in accordance with federal guidelines.^{1,2} While still experimental, HIV D⁺/R⁺ transplantation has the potential to improve access to transplantation for transplant candidates living with HIV, who are at higher risk of end-stage organ failure and have decreased access to transplantation compared with those without HIV.³⁻⁸ In addition, providing HIV D⁺/R⁺ transplants may help attenuate the problem of organ shortages more generally.⁹⁻¹¹

Nevertheless, the implementation of HIV D⁺/R⁺ transplantation presented involves ethical and psychosocial considerations. First, while there are concerns about donor HIV status disclosure during the donation authorization process,¹² potential and enrolled recipients may also have concerns regarding stigma and disclosure. Likewise, it is important to understand the potential psychosocial toll of concerns regarding the low but theoretical risks of superinfection, graft dysfunction due to HIV-associated organ diseases, and increased rejection.^{11,13-15} Finally, these ethical concerns should be balanced against the potential benefit of decreased wait times for HIV D⁺ organs compared with HIV-negative donor (HIV D⁻) organs. Analogously, a prior study by our group of hepatitis C virus–positive donor to HCV-negative recipient transplants found that recipients understood the risks of the experimental transplants, but they perceived these risks to be minimal compared with the risks of not receiving a transplant.¹⁶

To examine these ethical and psychosocial factors, we conducted a qualitative study assessing the experiences and perspectives of HIV D⁺/R⁺ transplant recipients at 4 transplant centers.

MATERIALS AND METHODS

Study Population

All kidney and liver transplant recipients enrolled in a clinical trial (HOPE trial) evaluating HIV D⁺/R⁺ transplantation at 4 participating centers were eligible for participation (NCT03734393, NCT03500315, NCT02602262). Participating centers were: Johns Hopkins University, Ochsner Clinic Foundation, University of Alabama at Birmingham, and University of Minnesota (representing 3 UNOS regions and 4/28 total HOPE centers). The study team attempted to contact all eligible recipients. Participants were recruited for interviews following their HIV D⁺ transplant. Recruitment occurred by phone or in-person during hospitalization following their transplant. Those who were recruited within 3 wk of their transplant were asked to complete 2 interviews; one within 3 wk of transplant (at-transplant) and the other 3–9 mo after their transplant (posttransplant). Those who were recruited >3 wk after their transplant (because of delayed notification by the study team or opting out of the first interview) were only interviewed once posttransplant. At-transplant interviews occurred an average of 2.6 wk after transplantation, and posttransplant interviews occurred an average of 4.6 mo after transplantation. It was determined a priori that at least 15 at-transplant and 15 posttransplant interviews would be conducted and that additional interviews would be conducted as necessary until thematic saturation was reached.

Semistructured Interviews

A semistructured interview guide was developed with input from a qualitative researcher, a transplant infectious diseases physician, and an ethicist (Appendix 1). The guide consisted of 20 open-ended questions and several probing questions regarding their overall experiences in the HOPE trial, the decision-making process to enroll in a HOPE trial, the informed consent process, perceived risks and benefits of HIV D⁺/R⁺ transplantation, decisional regret, communication with others regarding the HIV status of their donor organ, and experiences with stigma after transplantation. Participants were also asked about their experiences with the HOPE independent recipient advocate (a role required by the HOPE Act Safeguards and Research Criteria, intended to protect the recipients' interests).¹⁷ Interviews were conducted in-person or over the phone, lasted a median of 21 min, and were audio recorded. Participants provided oral or written informed consent before the interview and were given a \$25 gift card as compensation for their time. Interviews took place between December 2017 and October 2020. This study was approved by the Institutional Review Boards of Johns Hopkins Medicine (IRB00103150) and the University of Minnesota (STUDY00003323); Institutional Review Boards at other sites did not require local review or approval. Interviews were conducted by a single member of the research team (S.E.V.P.R.) with training in qualitative interviewing who had no other involvement in the HOPE clinical trials or prior relationship with the study participants.

Qualitative Analysis

Audio recordings of interviews were transcribed verbatim and checked for accuracy. Three coders (S.E.V.P.R., S.S., and M.A.J.) undertook thematic analysis of the transcripts using NVivo (Version 12, QSR International).¹⁸ An initial codebook was developed by 2 independent coders who each inductively identified codes from the first 6 interview transcripts. Subsequently, each transcript was independently coded by 2 coders and differences in applications of codes were discussed until consensus was reached. Using the constant comparison method, the codebook was refined throughout the coding process, allowing new codes to be added and for codes to be redefined and reapplied.¹⁹ Codes were then clustered into themes that were reviewed, discussed, and revised by study team members. All discussions related to the informed consent process were coded deductively by 2 independent coders (S.E.V.P.R. and K.V.) to capture specific themes predetermined by the study team to be important to assessing informed consent. These themes covered participants' understanding during the consent process, perceived pressure to enroll in a HOPE trial, voluntariness and opportunities to decline enrollment, and information preferences before enrolling. Differences in responses between subgroups (at-transplant versus post-transplant interviews, kidney versus liver recipients, and interviews completed in 2017–2018 versus 2019–2020) were compared qualitatively. The sample size was insufficient to allow meaningful comparisons between study sites. The Standards for Reporting Qualitative Research were followed in reporting this research study.²⁰ Representative quotes presented in the results were chosen on the basis of their clear illustration of the theme and to represent as many participants as possible.

RESULTS

Study Population

We conducted a total of 35 interviews with 22 recipients (15 at-transplant interviews, 20 posttransplant interviews); 13 participants completed interviews at both time points. The participation rate was 85% (26 eligible recipients at participating centers, unable to contact 3, 1 declined to participate). Nonparticipants (opt-out or unable to contact) were qualitatively similar demographically and clinically to enrolled participants (age, sex, race, length of transplant hospitalization, delayed graft function, and graft loss). Most participants were male (77%), Black race (82%), and received a kidney transplant (59%) (Table 1). These demographic characteristics are similar to those of recipients of HIV D⁺ organs nationally.²¹ Of 98 codes identified, 95% were identified in the first 20 interviews, and 100% were identified after the first 30 interviews, suggesting that thematic saturation was reached.

Overall Impressions of HOPE and HIV D⁺/R⁺ Transplantation

Participants reported positive experiences in the HOPE study and expressed excitement for the future of HIV D⁺/R⁺ transplantation.

“I thought [the HOPE Act] was awesome. I was like ‘Oh God, there is a way out... there is a way that you could continue to have life if you chose the way of the HOPE Act.’... It gave me hope, and that’s so funny, because it’s called the HOPE Act. That is exactly what it did. It gave me hope to the situation” (Participant 8 [P8] posttransplant).

Most participants felt positive about HIV D⁺/R⁺ transplantation, explaining that they were “comfortable” (P13 posttransplant), “optimistic” (P5 posttransplant), and “proud” to be a part of the clinical trial (P20 at-transplant). Many understood research participation as integral to scientific advancement and were grateful to be a part of that process: “I’m one of the first ones ... I’m one of the examples, so that’s cool” (P16 posttransplant). Participants’ optimism often related to their good outcomes thus far: “I’m trusting that as it is

now will be the way that it goes” (P12 at-transplant). Others expressed more caution; for instance, some preferred not to think about the experimental nature of HIV D⁺/R⁺ transplantation: “We’re not going to speak that into existence ... I don’t speak on negative stuff” (P17 at-transplant).

Decision Making Regarding HIV D⁺/R⁺ Transplantation

Participants were motivated to enroll in a HOPE study considering several situational factors (Table 2). Many explained that because they were living with HIV themselves, it was “common sense” that they should be able to accept an HIV D⁺ organ. They also believed that because their HIV was undetectable pretransplant, they would be able to manage an HIV D⁺ organ. Many trusted their healthcare team’s recommendations; some felt confident about enrolling only after hearing about the success of prior HIV D⁺/R⁺ transplants. Many were also motivated to accept an HIV D⁺ organ because they believed that it was their only option to receive a transplant; these participants reflected on the risk of mortality if they remained on the transplant waitlist; however, some believed that HIV⁺ transplant candidates were unable to receive HIV D⁻ transplants.

Participants were also motivated by several perceived benefits of accepting an HIV D⁺ organ (Table 2). They described wanting to avoid the potentially long wait for an HIV D⁻ organ, the possibility of receiving a transplant at an earlier stage in their disease progression, and a desire to contribute to scientific advancement through research participation. Some also acknowledged that their acceptance of an HIV D⁺ organ would help all transplant candidates on the waitlist by decreasing demand for HIV D⁻ organs.

These motivations were balanced against several questions and concerns about perceived clinical and social risks of HIV D⁺/R⁺ transplantation (Table 2). Perceived clinical risks included concerns about donor-derived superinfection, changing HIV medications posttransplant, the impact of immunosuppression on HIV, the effect of HIV and HIV therapies on organ function, the quality of an organ from an HIV⁺ donor, and increased risk of coinfection (eg, hepatitis C). Perceived social risks included concerns about anonymity and stigma if their HIV D⁺/R⁺ transplant were disclosed publicly. Despite these concerns, no participants expressed decisional regret posttransplant regarding their acceptance of an HIV D⁺ organ.

Most participants decided to enroll in the HOPE trial within 1 d of receiving information about the trial; some described the decision as a “no brainer” (P13 at-transplant, P2 at-transplant). However, some participants took more time to decide, often consulting with other physicians or doing their own independent information seeking: “I spoke to the doctor about it and I just continued to read more. But, mostly speaking to the doctor. Talking to my nephrologist as well as my [infectious disease] doctor” (P15 posttransplant).

Informed Consent

All participants said that they remembered giving consent to receive an HIV D⁺ organ. Participants felt that they understood the consent form: “they really really made sure that I understood what they was telling me” (P9 posttransplant) and reported having ample opportunities to decline to enroll in the HOPE trial: “She still left it up to me ... she still gave me that option. You can take it, or you can just leave it” (P6 posttransplant). While some participants wished they had been

TABLE 1.

Characteristics of the study population

Characteristic	Frequency or median
Male, n (%)	17 (77)
Race: Black, n (%)	18 (82)
Ethnicity: Hispanic/Latino, n (%)	1 (5)
Age at transplant, median (IQR), y	51 (33–69)
Graft loss, n (%)	3 (14)
Organ, n (%)	
Kidney	13 (59)
Liver	7 (32)
Liver and kidney (SLK)	2 (9)
Transplant center, n (%)	
Johns Hopkins	18 (82)
Other centers	4 (18)
Of kidney recipients	
Dialysis before transplant, n (%)	12 (80)
Time on dialysis, median (IQR), mo	60 (22–98)
Delayed graft function, n (%)	1 (8)
Of liver recipients	
MELD at transplant, median (IQR)	15 (12–19)

IQR, interquartile range; MELD, model for end-stage liver disease; SLK, simultaneous liver kidney.

TABLE 2.**Decision making regarding HIV D⁺/R⁺ transplantation****Reasons to accept an HIV D⁺ organ and representative quotations****Situational factors**

Already HIV positive	I wasn't necessarily in the market specifically for an HIV organ, but like I said, because I've been exposed, because I carry the virus, it just kind of made sense to me (P2 at-transplant)
Trust in care team	... my doctor is a really good doctor and even the nurse practitioner and everything, so I trust them enough to know that they wouldn't put me in harm's way (P16 posttransplant)
Belief they would not get a transplant otherwise	I've been waiting for 5 years for a transplant, and none seemed to come my way, so this is like the best opportunity for me to get a new kidney. (P13 posttransplant)
Mortality on waitlist	It wasn't nothing else to say about [deciding to accept an HIV D ⁺ organ] but get it, because I have children ... [without the transplant] I wouldn't be alive. (P19 posttransplant)
Trust that would receive well-matched donor	... as long as the [donor] had their HIV under control, was undetectable and adhering to their medication and ... that the drugs that that [the donor] was on were compatible with whatever I was taking ... [I] felt comfortable with it. (P15 posttransplant)
Prior success of HIV D ⁺ /R ⁺	They've had successes with this type of transplant so why not? (P3 at-transplant)
Own HIV under control	I was doing good, my numbers, my cd4 was high, and being undetectable so I really wasn't worried. (P9 posttransplant)
Perception that HIV ⁺ candidates cannot/ do not receive HIV D ⁻ transplants	Where I'm from, they don't do [transplants] with HIV positive [recipients]. Somehow they put them on the bottom of the list and kill them off. (P11 posttransplant)

Anticipated benefits

Avoid long wait for donor organ	You can jump around [the deceased donor waitlist] if you want to accept hep C or HIV kidneys... you start getting calls around 6 years [on the waitlist] but I could have been on there for 10 years. (P10 at-transplant)
Opportunity to get transplant	I was just not knowing when I was gonna get the transplant or if I ever would, but the HOPE project actually gave me hope, and that's when I actually knew that I was gonna get my kidney transplant. I just knew it after that. (P4 posttransplant)
Contribute to science	[My wife and I] liked [the study] and everything we can be able to assist in further data research, we like to be helpful in this kind of stuff in any way possible. (P18 at-transplant)
Healthier at time of transplant	... you want to be as strong as you can before you go under the knife. I think that was a key element. (P13 at-transplant)
Help others on the waitlist	Why wouldn't the entire world want us to get HIV-positive organs so that we could free up organs for people who aren't. (P20 posttransplant)

Perceived risks and concerns about accepting an HIV D⁺ organ and representative quotations**Anticipated clinical risks**

Donor-derived superinfection (infection with new HIV strain)	I thought that you would get [HIV] worse than what you have already, if [the donor] is affected with it. That was bothering me, kind of. (P17 at-transplant)
Needing to change HIV medications posttransplant	[I would want to ask other HIV D ⁺ /R ⁺ recipients] Did they have to change your medications? Because they didn't for me, but that was something that they were speculating on. So, did they have to change your medications? How did your body take to that? Because you're getting all these other medications. So, how is all that working out for you? (P7 posttransplant)
Impact of immunosuppression on HIV	My main concern was would it go down, and [my infectious disease physician] told me for transplant patients it takes a dip, but that's only because of all the medications. (P6 posttransplant)
Effect of HIV and HIV therapies on organ function	I have been thinking about how HIV meds tend to have an impact on kidney function so [I'm] hoping that I won't experience that and kind of just fly past that and just have a long, productive life with this kidney. (P12 posttransplant)
Quality of HIV donor organ	My main concern was the health of the organ ... if [the donor] take care of himself. Was he an alcoholic? You don't know. (P16 posttransplant)
Coinfection	I was concerned about a hep positive organ because I wasn't too educated on the hep, you know, hep positive organs and how that works with the body. I didn't want anything that would affect my immune system even more. (P8 at-transplant)

Anticipated social risks

Anonymity	As long as I could remain anonymous and nothing was disclosed about me personally, I was fine with it. (P12 at-transplant)
Stigma if D ⁺ /R ⁺ transplant were discussed publicly	I know people would [treat me differently if they heard about my HIV D ⁺ organ]. There's still that fear and prejudice in people's minds and actions. (P5 posttransplant)

D⁻, negative donor; D⁺/R⁺, HIV⁺ donor to HIV⁺ recipient; HIV⁺, HIV positive; P, participant.

told more about the posttransplant recovery process, none reported any unaddressed information needs regarding the HIV aspect of their transplant before enrolling.

While all participants remembered giving consent, some (in both at-transplant and posttransplant interviews) did not remember the details of the consent process. Of those who did remember details, participants described it as “comfortable” (P6 posttransplant), “routine” (P5 posttransplant), “helpful” (P14 posttransplant), and as a continuous process rather than a single event (P11 posttransplant, P17 posttransplant, P8 at-transplant).

The interviews revealed some uncertainty regarding independent recipient advocates (IAs); many participants did not remember interacting with an IA or did not remember

which member of the care team was the IA. Among those who recalled interacting with an IA, participants disagreed regarding the IA's role and usefulness. Some only met with the IA briefly or did not feel they needed the advocate: “I'm pretty much independent, so I really don't like to call on people unless I'm in dire need” (P3 at-transplant). Others found the IA useful to answer questions or ensure voluntary enrollment in the HOPE trial: “The IA was helpful. Like I said, my main concern was to remain anonymous and so she gave me some reassurance in that regard and at any time that I did not feel that I was obligated to do it [accept an HIV D⁺ organ] even up until the day of [the transplant]. So yeah, she was cool” (P12 at-transplant).

Impact of Receiving HIV D⁺/R⁺ Transplant

Participants described many benefits of their transplants, including improvements in overall health, a general return to normalcy, ability to return to work, ability to discontinue or avoid dialysis, level of activity, ability to travel, mental health, cognitive function, and diet (due to cessation of a renal diet or a motivation to eat healthier overall). Participants seemed to understand that while these impacts were not specific to HIV D⁺/R⁺ transplantation, they likely experienced them earlier than they would have if they had waited for an HIV D⁻ organ:

“[If I hadn’t accepted the HIV D⁺ organ] my numbers would continue to go up and eventually I would have needed a transplant and I would be on the list longer if I didn’t do the HIV organs, so the other list would have been longer and I coulda gotten real, real, real sick waitin’ for an organ” (P9 posttransplant).

Participants also explained that receiving a transplant earlier contributed to their posttransplant recovery: “I didn’t want to wait till my MELD [Model for End-Stage Liver Disease] score was so high.... I’ve been working out and eating healthy. I knew I was gonna be prepared for this [transplant], and so I think that’s what helped me get as far as I have so quickly” (P11 at-transplant). Many participants believed that because of longer wait times for HIV D⁻ organs, they would not have received a transplant without accepting an HIV D⁺ organ:

“[If I hadn’t accepted an HIV-positive organ] I would be having to endure with dialysis longer and with the concern of possibly having to wait to the point where when the transplant came along, I may not have been able to actually get one just because, it just seems to me the longer you’re on dialysis the more things may develop” (P15 posttransplant).

Perceptions and Experiences Regarding Privacy and Stigma

Some participants shared how their acceptance of an HIV D⁺ organ would help combat the stigma of HIV: “You know the stigma of HIV is ‘oh you can’t have this, and you can’t do this.’ And I don’t live my life like that” (P8 at-transplant). Another described wanting to play a role in increasing access to transplantation for transplant candidates living with HIV: “Well, I just wanted to make a change. I also wanted to be a part of the change and a part of the stipulations they had on people with diseases [like HIV] that couldn’t get [a] transplant” (P1 at-transplant). Participants acknowledged that allowing people living with HIV to donate organs would also help reduce stigma:

“I believe anyone with HIV should have the option [to donate], I think healthy people who are HIV-positive should be able to donate organs to other people with HIV and that it should be the standard of care and that anything I can do to help, I mean it made the whole transplant process feel more worthwhile to me” (P20 posttransplant).

While most participants reported that they had not been treated differently after others learned of their HIV D⁺ transplant, a few experienced stigma related to their transplant. One participant experienced stigma after a friend accompanied him to a pretransplant appointment where she learned

that the participant was HIV positive: “It’s like she was scared to touch me or give me a hug” (P11 at-transplant). Some participants believed that transplant candidates living with HIV were treated differently than transplant candidates not living with HIV: “People with HIV ... are deprived of the same treatment that someone with other illnesses are able to get and that they’re still ostracized and discriminated against for a virus” (P20 posttransplant).

In general, discussions about their HIV D⁺ organ were limited to participants’ healthcare teams. This was mostly linked to not being public about their HIV status and a general desire for privacy: “I don’t like to spread my business all around. I don’t want everybody in my business ... everybody don’t know I have HIV” (P16 at-transplant). One participant explained that if he discussed his HIV D⁺ transplant with anyone outside his family, it would “pass on like wildfire” (P17 posttransplant). Some worried explicitly about stigma: “[It] woulda been too much for me [to tell others I received an HIV D⁺ organ], you know, sometimes I think people don’t have information about HIV and my worries was how they would take it, how they would look at it, some people are ignorant when it comes to HIV period” (P9 posttransplant). One participant’s comments were suggestive of internalized HIV stigma through his belief that he would “ruin” an HIV D⁻ organ were he to accept one: “it just kind of made sense to me to go ahead and do it, because that way-- how do I put it? I wasn’t ruining a perfectly good organ that wasn’t [HIV] positive, because then it would end up positive” (P7 posttransplant).

Differences in Responses Among Subgroups

Responses were largely consistent across the various subgroups (at-transplant versus posttransplant interviews, kidney versus liver recipients, and interviews completed in 2017–2018 versus 2019–2020), although some themes were only raised by 1 group (Table 3). Of note, only liver recipients reported that mortality on the waitlist was a motivation to accept an HIV D⁺ organ.

DISCUSSION

In this qualitative interview study, recipients of HIV D⁺/R⁺ transplants reported positive experiences. Participants were motivated to accept an HIV D⁺ organ by perceived benefits and situational factors that contributed to their confidence in the clinical trial in which they were enrolled. They balanced these motivating factors against perceived clinical and social risks. Participants also reported positive experiences with the informed consent process. Benefits of receiving an HIV D⁺/R⁺ transplant were largely related to the likely decreased wait time for a transplant compared with waiting for an HIV D⁻ organ. Participants raised some concerns regarding privacy and stigma; however, some participants also believed that the HIV D⁺/R⁺ transplants could help combat the stigma of HIV. In general, responses from at-transplant and posttransplant interviews were similar.

Participants’ optimism and motivations were consistent with studies suggesting that kidney and liver transplantation confer a survival benefit and that transplant candidates living with HIV have lower access to transplantation than candidates without HIV.^{3,4,6,7,22} Our findings are also consistent with early clinical data supporting the safety of HIV D⁺/

TABLE 3.**Differences in responses between subgroups****At-transplant interviews (n = 15) vs posttransplant interviews (n = 20)**

Only raised in at-transplant interviews	None
Only raised in posttransplant interviews	
Reasons to accept an HIV D ⁺ organ	Helping others on waitlist by accepting HIV D ⁺ organ
Impact of transplant	Improved cognitive function posttransplant

Kidney recipients (n = 13) vs liver and SLK recipients (n = 9)**Only raised by kidney recipients**

Reasons to accept an HIV D ⁺ organ	Discontinue or avoid dialysis
Impact of transplant (general)	Discontinue or avoid dialysis
	Ability to travel
	Improved level of activity
Anticipated risks and concerns about HIV D ⁺ organ	Effect of HIV and HIV therapies on organ function
	Coinfection
	Quality of HIV ⁺ donor organ

Only raised by liver recipients

Reasons to accept an HIV D ⁺ organ	Mortality on waitlist
Experienced stigma	Help others on the waitlist

Interviews in 2017–2018 (n = 14) vs 2019–2020 (n = 21)**Only raised by interviews in 2017–2018**

Reasons to accept an HIV D ⁺ organ	Healthier at transplant than if waited for HIV D ⁻ organ
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Only raised by interviews in 2019–2020

Perceptions regarding stigma	Combat stigma
Anticipated risks and concerns about HIV D ⁺ organ	Anonymity
	Needing to change HIV medications posttransplant
	Coinfection
	Impact of immunosuppression on HIV
Reasons to accept an HIV D ⁺ organ	Help others on the waitlist

D⁻, negative donor; D⁺, positive donor; HIV⁺, HIV positive; SLK, simultaneous liver kidney.

R⁺ transplantation.^{14,21,23–25} However, at the time that most of these interviews were conducted (86%), results of experimental HIV D⁺/R⁺ transplantation in the United States had not been published; the only published reports at the time were case reports or relatively small observational studies from South Africa.^{21,23,26–28} Several factors may limit the generalizability of experiences in South Africa to patients in the United States (eg, because of increased prevalence of antiretroviral resistance and HCV coinfection).²¹ This suggests that participants might have experienced therapeutic misestimation, or the overestimation benefits or the underestimation of risks of a study.²⁹ While it is difficult to distinguish personal optimism from therapeutic misestimation,²⁹ it is important to ensure that HIV⁺ transplant candidates are educated about the available evidence regarding HIV D⁺/R⁺ transplantation during the informed consent process.

The experiences of HIV D⁺/R⁺ recipients reported here are also consistent with the experiences and perspectives of transplant recipients and candidates regarding infectious risk donor organs (organs from donors whose characteristics may increase the risk of disease transmission). In 2 single-center studies of recipients of HCV D⁺/R⁻ transplants, participants believed that the risks of receiving the HCV D⁺ organ were acceptable compared with the risks of not receiving a transplant and acknowledged that they were motivated to accept an HCV D⁺ organ by shorter wait times.^{16,30} Likewise, a national survey of HIV⁺ transplant candidates found that 84% would be willing to accept an HIV⁺ deceased donor organ, 88%

believed that they would receive an HIV D⁺ organ faster than a D⁻ organ, and 69% believed that HIV D⁺/R⁺ transplantation was safe for the recipient.³¹

Participants also reported good experiences with the informed consent process, feeling that they understood what was discussed, they had ample opportunities to decline, and that no information specific to receiving an HIV D⁺ transplant was neglected. Despite this, many participants believed that because of organ shortages and their clinical circumstances, accepting an HIV D⁺ organ was their only viable pathway to transplantation, raising concerns about reasonable alternatives to enrolling in the trial. This belief, that the study was the only opportunity to receive a transplant, may reflect pessimism due to the organ shortage, a misunderstanding of the available options, or another instance of potential therapeutic misestimation. Consequently, future work should focus on ensuring that HIV⁺ transplant candidates are educated about all of their options, and efforts should be taken to ensure that they understand this information. This may be done through education of primary care physicians, HIV care providers, and medical specialists referring patients for transplantation. Furthermore, transplant evaluation teams should consider taking additional steps to ensure that HIV⁺ transplant candidates understand all options available for them, as well as the data supporting each option. For instance, during the consent process, transplant candidates could be asked explicitly to explain what HIV D⁺/R⁺ involves and its alternatives and a short quiz of key points could be administered immediately

before obtaining formal consent. These steps could be used as an opportunity to correct any misunderstandings.

Participants were ambivalent about the role of the IA. This finding is consistent with the results of an interview study with HOPE IAs, which found that their role was not clearly defined or understood.³² These emerging data may challenge prior conceptual scholarship asserting the importance of independent advocates in the protection of HIV D⁺/R⁺ transplant recipients.^{13,17} Consequently, additional data would likely be useful in informing future conceptual and policy deliberations regarding IAs in this setting. In particular, future work should aim to more clearly define their roles and responsibilities and their potential benefit to patients.

Interview participants often discussed stigma, both in terms of the possibility of combating stigma through HIV⁺ donation and transplantation and in terms of fears regarding being treated differently because of their HIV status and HIV status of their donors. Many participants had only disclosed their donor's HIV status with few trusted relatives or friends and many others had not discussed it with anyone. This is consistent with a synthesis of 55 prior qualitative studies, which found that people living with HIV are at risk for social isolation because of fear of stigma.³³ Like the participants in our study who believed that HIV D⁺/R⁺ transplantation could reduce stigma, the same synthesis found that people living with HIV also sought out ways to actively reduce stigma in their communities.³³ Finally, 1 interviewee described an incident resulting in the unintended disclosure of the patient's HIV status to a friend accompanying the patient during a transplant evaluation appointment. While not directly related to HIV D⁺/R⁺ transplantation, this instance highlights the need to ensure that transplant teams are sensitive to concerns related to privacy and take measures to maintain HIV confidentiality.

Despite the value of the data we collected, they should be interpreted in light of several limitations. First, these interviews are subject to recall bias, as participants were interviewed after a successful transplant. However, we conducted interviews both proximate to the time of transplant (within 3 wk post-transplant) once they were clinically stable and at least 3 mo after transplant to capture changes in perspectives over time and found no major differences. Likewise, participant responses in these interviews were consistent with surveys conducted with candidates before transplantation.³¹ Second, these interviews are also subject to participation bias, as recipients with better clinical experiences may have been more likely to participate than those recipients with more posttransplant complications. Nevertheless, the response rate was good and there were no qualitatively different demographic or posttransplant clinical characteristics among participants and nonparticipants (ie, age, sex, race, length of transplant hospitalization, delayed graft function, and graft loss). Third, this study only interviewed recipients who chose to accept an HIV D⁺/R⁺ transplant; while there was an insufficient sample of candidates who opted-out of the HOPE trials at the time these interviews were conducted, future work should assess the perspectives and experiences of transplant candidates and recipients living with HIV who chose not to accept an HIV D⁺/R⁺ transplant.

Overall, recipients of HIV D⁺/R⁺ transplants reported positive experiences with HIV D⁺/R⁺ transplantation, including the informed consent process. Concerns about the clinical and social risks of HIV D⁺/R⁺ transplants were outweighed by the perceived potential benefits. While some participants

were concerned about stigma related to their transplant and described a need for privacy regarding their decision, many expressed hope that the widespread adoption of HIV D⁺/R⁺ transplantation would reduce HIV-related stigma. Transplant teams should be trained to be sensitive to the privacy and stigma concerns held by some HIV⁺ transplant recipients. Furthermore, concerns about understanding all available treatment options and potential therapeutic misestimation highlight the importance of educating HIV⁺ transplant candidates about these issues using the best available data and ensuring that they understand information presented during the informed consent process.

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APPENDIX 1. RECIPIENTS OF HIV+ DONOR ORGANS INTERVIEW GUIDE

Thank you for talking with me today about your transplant. As you know, I will be recording our conversation. During the interview, if you do not want to discuss a particular question or topic, that is fine, just let me know. Are you ready to begin?

1. How has the transplant experience been for you?

DECISION MAKING AND CONSENT PROCESS

2. Tell me about how you decided to accept an HIV+ organ. From the time you first heard about HIV+ transplants until you received the transplant, what was the decision process like?

(If they do not answer these in their response to #2):

- a. When did you decide to accept an HIV+ organ?
- b. How long did it take you to decide to accept an HIV+ organ?
- c. What things did you think about when making your decision?
- d. Did you talk about your decision with anyone? If so, with whom?
- e. Who or what was helpful in making your decision?
 - i. Were any family/friends helpful?
 - ii. Were any healthcare workers helpful?
 - iii. How so?
- f. Who or what was unhelpful in making your decision?
 - i. Were any family/friends unhelpful?
 - ii. Were any healthcare workers unhelpful?
 - iii. How so?
- g. Did you have any questions about accepting an HIV+ organ?
 - i. If so, what were your questions?
 - ii. If so, who did you ask?
 - iii. How did you feel about their responses?
- h. Was the organ you received the first organ you were offered? Had you turned down an organ before accepting the organ you received?

3. Do you remember giving consent to receive an HIV+ organ?
 - a. Can you describe the process of giving consent?
 - b. Was there anything good or bad about giving consent?
4. Is there anything you wish you had been told when making your decision?

OVERALL EXPERIENCE

5. Before being offered an HIV+ transplant, had you heard of this type of transplant before? If so, please tell me about that.
6. What were some reasons you accepted an HIV+ organ?
 - a. Have any of those reasons/expectations come true?
 - b. Have any of those reasons/expectations not come true?
7. What were some of your concerns or fears about accepting an HIV+ organ?
 - a. Have any of those concerns/fears come true?
 - b. Have any of those concerns/fears not come true?
8. Has anything about the experience been different than you expected? If so, how?
9. Has anything surprised you? If so, how?
10. What were some positive things about the experience?
11. What were some negative things about the experience?
12. Is there anything you regret about having a transplant?
 - a. Is there anything you regret about accepting an HIV+ transplant?
13. Does anything about your transplant make you afraid?
 - a. Does anything about accepting an HIV+ transplant make you afraid?
14. As a reminder, HIV+ to HIV+ transplants are new and experimental. We do not yet know if they are safe and effective. How does that make you feel?

EFFECT OF TRANSPLANT ON RELATIONSHIPS AND DAILY LIFE

15. How has the transplant affected your life?
 - a. (If in a relationship) How has the transplant affected your relationship with your partner?

- b. How has the transplant affected your relationships with family?
 - c. How has the transplant affected your relationships with friends?
 - d. (If employed) How has the transplant affected your work life?
 - e. How has the transplant affected your day-to-day life?
 - f. How has the transplant affected your overall health?
16. How do you think your life would be different if you had not accepted an HIV⁺ organ?

COMMUNICATION OF TRANSPLANT

17. Who knows that you received an HIV⁺ organ?
- a. How did [each person listed in #17] learn you received an HIV⁺ organ?
 - b. How did [each person listed in #17] react when they learned you received an HIV⁺ organ?

- c. (If they have told people they received an HIV⁺ organ) How did you tell them? Are there good ways to tell people? Are there bad ways to tell people?

STIGMA

18. Has anyone treated you differently after learning you received an HIV⁺ organ?
19. Is there anything else we could do better with these types of transplants?
- a. Any ways we could improve the experience for other recipients of HIV⁺ organs?
20. Is there anything else you'd like me to know about receiving an HIV⁺ organ?

General Probing Questions

- If concerns: Does that worry you? How does that make you feel?
- If states information, data, etc: Where did you learn that?