

Willingness to Pursue Live-Donor Kidney Transplantation Among Waitlisted Patients Infected With Human Immunodeficiency Virus (HIV): A Preliminary Investigation

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We show that HIV-infected waitlisted patients (n=33) had significantly lower knowledge ($P<0.001$), more concerns ($P=0.01$), and lower willingness to pursue live-donor kidney transplantation (LDKT; $P=0.02$) than matched noninfected patients. The majority (78%) of patients felt that their HIV status reduced their chance of LDKT. Although limited to a single center and a small sample, our data suggest that HIV-infected patients who are waitlisted for kidney transplantation may need more education about the potential benefits of LDKT and may benefit from patient-centered decision support to facilitate a risk-benefit assessment consistent with their preferences and values.

Keywords: Kidney transplantation, Living donation, Live-donor kidney transplantation, Human immunodeficiency virus.

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For those infected with HIV, longer survival has been accompanied by a higher rate of kidney disease (1, 2). During the pre–highly active antiretroviral therapy era, HIV-infected patients with renal failure were not considered kidney transplant candidates due to concerns about more rapid progression to AIDS and poor outcomes (3, 4).

Although there is evidence of higher rates of acute rejection (5), graft and patient survival outcomes following kidney transplantation for carefully selected patients who are HIV infected are similar to those of noninfected patients (6–8).

Although live-donor kidney transplantation (LDKT) yields superior outcomes relative to deceased-donor transplantation (9), HIV-infected patients may encounter unique LDKT barriers. For instance, some patients and their nontransplantation providers may not recognize the favorable transplant outcomes for those with HIV and may not feel it is appropriate to ask others to consider living donation. Some transplant programs may require disclosure of HIV to potential living donors, which cause reluctance in some patients because of social stigma concerns. Therefore, we examined the LDKT willingness, readiness, knowledge, and concerns of waitlisted HIV-infected patients in comparison with noninfected patients.

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RESULTS

Thirty-three HIV-infected patients completed study questionnaires (85% participation rate). HIV-infected and noninfected (n=33) patients did not differ significantly on matched variables (age: 47.2 vs. 47.4 years; $P=0.96$; female gender: 30% vs. 30%; $P=1.00$; non-white race: 48% vs. 48%; $P=1.00$; waiting time: 13.7 vs. 12.8 months; $P=0.82$) and nonmatched variables (college education: 27% vs. 18%; $P=0.38$; married: 39% vs. 45%; $P=0.62$; employed: 24% vs. 27%; $P=0.78$; dialysis: 85% vs. 76%; $P=0.35$; dialysis duration: 43.0 vs. 32.9; $P=0.44$). None of the primary outcomes varied

significantly by gender, age, education, marital status, employment, waiting list time, or dialysis status (P values > 0.05). Non-white patients had lower LDKT knowledge ($P=0.02$) and lower willingness to pursue LDKT ($P=0.03$) than white patients, although the HIV status by race interaction effect was not statistically significant.

Compared with noninfected patients, HIV-infected patients reported lower willingness to talk to family members and friends about living donation ($P=0.02$), less LDKT knowledge ($P<0.001$), and more LDKT concerns ($P=0.01$; Table 1). HIV-infected patients were less likely than noninfected patients to know that a person with hypertension could potentially be a living donor at our center (24% vs. 48%; $P=0.04$), most donors can return to work in less than 6 weeks (55% vs. 78%; $P=0.04$), kidney donation does not typically increase the risk of future renal failure (39% vs. 64%; $P=0.05$), and incompatible donors can still benefit the intended recipient through kidney or list exchange (27% vs. 58%; $P=0.01$).

HIV-infected patients reported more concern that nobody would volunteer to be a living donor (3.3 vs. 2.6; $P=0.04$), transplant providers would pressure someone to be a donor (1.7 vs. 1.2; $P=0.05$), transplant providers would be angry if no family members agree to be a donor (1.6 vs. 1.1; $P=0.04$), they would feel guilty if testing showed someone to be a donor match (3.0 vs. 1.4; $P=0.01$), and they might do something to “waste” the donated kidney (2.0 vs. 1.4; $P=0.03$). Noninfected patients were more concerned that they would die if a living donor were not found (2.9 vs. 2.1; $P=0.05$).

Readiness to pursue LDKT differed significantly by HIV status ($\chi^2=10.1$; $P=0.04$). Relative to noninfected patients, more HIV-infected patients were not considering LDKT (42% vs. 21%) and fewer were in “action” stages of readiness (6% vs. 12%), that is, had already talked to someone who was considering living donation or who had already contacted the transplant program (Fig. 1).

On average, HIV-infected patients identified 2.6 ± 2.8 primary sources of LDKT information compared with 4.1 ± 2.7 for noninfected patients ($t=2.3$; $P=0.024$). HIV-infected patients were less likely than noninfected patients to identify another transplant patient as a primary source of LDKT information (21% vs. 48%; $P=0.04$), and there were trends ($P<0.10$) showing that HIV-infected patients were less likely to identify healthcare providers (64% vs. 85%), family members (30% vs. 55%), and friends (24% vs. 48%) as sources of LDKT information.

Most infected patients considered their HIV status to be a barrier to discussing living donation (82%) and felt uncomfortable sharing their HIV status with others (73%;

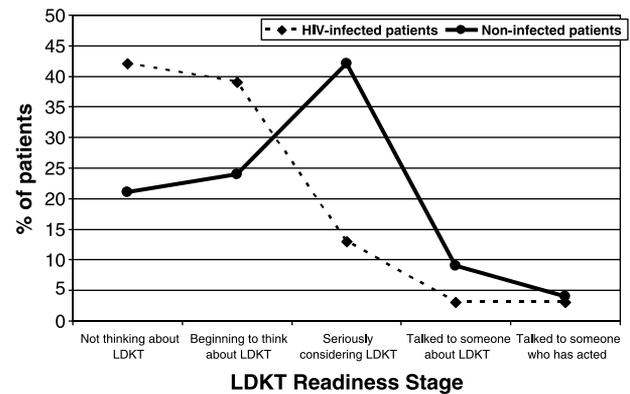


FIGURE 1. Stage of readiness to pursue LDKT by HIV status. LDKT, live-donor kidney transplantation.

Table 2). Only one-third (36%) would share their HIV status with others if it would facilitate getting a LDKT. Willingness to share HIV status with potential donors was not significantly associated with sociodemographic characteristics, medical characteristics, or quality of life scores ($P>0.05$).

DISCUSSION

We found that HIV-infected patients have less knowledge about LDKT, have more concerns about LDKT, and are less willing to pursue LDKT than those without HIV. Moreover, most perceive their HIV status to be a barrier to LDKT. Social stigma persists for those who are HIV infected (10, 11) and concerns about disclosing one's HIV status may partially explain the lower LDKT rate in this population. Although some patients are willing to disclose HIV status with potential donors if it helps facilitate LDKT, most patients in our study felt uncomfortable doing so and felt that being infected represented a barrier to LDKT.

Such perceived barriers also may account for the finding that fewer HIV-infected patients were seriously considering this transplant option or had talked to someone about donation. Although the same number of both HIV-infected and noninfected patients had a potential donor who already had contacted the transplant program, fewer HIV-infected patients were in other “action” stages of thinking about or pursuing LDKT. This may lead to fewer potential donors being evaluated or longer time before a potential donor initiates an evaluation. Less knowledge and more concerns about LDKT may further affect willingness to pursue this transplant option among HIV-infected patients, although

TABLE 1. LDKT willingness, knowledge, and concerns by HIV status

	HIV-infected (n=33)	Noninfected (n=33)	Significance
LDKT willingness ^a	2.7±1.9	3.8±1.8	$t=2.36$; $P=0.02$
LDKT knowledge ^b	7.2±1.7	9.1±2.3	$t=3.89$; $P<0.001$
LDKT concerns ^c	44.9±11.0	38.2±8.0	$t=2.79$; $P=0.01$

^a Willingness to talk to others about LDKT: 1=not at all willingness, 10=extremely willing.

^b LDKT knowledge questionnaire, 16 true-false items, possible scores range from 0 to 16, higher scores reflect more knowledge.

^c LDKT concerns questionnaire, 21 Likert-type items (1=not at all, 2=slightly, 3=somewhat, 4=quite a bit, 5=extremely), possible scores range from 21 to 105, higher scores reflect more concerns.

LDKT, live-donor kidney transplantation.

TABLE 2. HIV-specific issues related to pursuit of LDKT

	HIV-infected patients only (n=33)
Informed someone about HIV status	16 (48%)
Consider HIV status to be barrier in talking about living donation with potential living donors	27 (82%)
Having HIV reduces or lessens chance of receiving LDKT	26 (79%)
Feel uncomfortable sharing HIV status with potential living donors	24 (73%)
Would share HIV status with potential living donors if it might facilitate LDKT	12 (36%)
Willingness to share HIV status with potential living donors	
Very willing	4 (12%)
Willing	8 (24%)
Unwilling	11 (33%)
Very unwilling	10 (30%)

LDKT, live-donor kidney transplantation.

these differences were unexpected because our educational processes do not vary by HIV status. Indeed, HIV-infected patients had less overall exposure to LDKT information, which likely reflects their precontemplation stage of LDKT readiness and perceived barriers attributed to their HIV status.

There is some debate about whether a recipient's HIV infection status should be disclosed to potential living donors

(12, 13). Consensus guidelines, however, are nonspecific on this issue, stating only that potential donors be informed of factors that increase risk of recipient morbidity or mortality. Recently, we reported that most potential donors would not alter their donation decision if they learned that the intended recipient was HIV infected (14). However, 58% of these same adults and 71% of former donors felt that the HIV status of intended recipients should be disclosed to potential donors. Our program does not require recipients to disclose their HIV status to potential donors. We believe that potential donors should be informed of medical, surgical, and psychosocial factors that heighten the recipient's morbidity and mortality risk, and we work collaboratively with potential donors and recipients under these circumstances to ensure an informed risk-benefit assessment.

Whether or not a transplant program requires HIV disclosure to potential donors, there may be a need to tailor LDKT education to address the unique circumstances of this subgroup of patients. We did not assess this directly in the study, but anecdotally it was our observation that some patients were not aware of current transplant outcomes for HIV-infected patients and, therefore, may not have been as proactive as noninfected patients in seeking more information about the benefits of LDKT. It is also possible that nontransplant providers are similarly unaware of the potential benefits of kidney transplantation in patients with HIV and do not educate their patients about LDKT. Moreover, some may not know that our program does not require the disclosure of their HIV status to potential living donors, which may contribute to their lower willingness to pursue this particular treatment option. HIV-infected patients may need assistance

TABLE 3. Description of study questionnaires

Variable	Description
LDKT willingness	One question asking patients to rate their willingness to talk to family members and friends about living kidney donation (1="not at all willing" to 7="extremely willing").
LDKT readiness	One question asking patients to identify their stage of readiness to pursue LDKT: precontemplation ("I am not thinking about or considering LDKT."), contemplation ("I am now beginning to think about or consider LDKT."), preparation ("I have thought about LDKT and I am seriously considering this possibility."), action ("I have thought about LDKT, and I have talked to someone who is willing to be evaluated as a possible living donor."), or maintenance ("I have thought about LDKT and I have someone who has contacted the transplant center to be evaluated as a potential live donor.").
LDKT knowledge	Sixteen true-false questions assessing what patients know about LDKT and living kidney donation (e.g., "Only a blood relative is able to be a living kidney donor." "A living kidney donor must have his/her own health insurance to cover the costs of surgery."). Scores range from 0 to 16, with higher scores reflective of more LDKT knowledge.
LDKT concerns	Twenty-one questions measuring patients' concerns about pursuing LDKT (e.g., "I am concerned that the donor would no longer be able to do activities that they enjoy." "I am worried that I might do something to 'waste' the kidney that someone donates to me—for example, by not living healthy or not taking my medications."). Responses to each question are given on a Likert-type scale (1="not at all concerned" to 5="extremely concerned"), with higher scores indicating more concern.
LDKT sources of information	Patients identified (yes, no) primary sources of information about LDKT (e.g., doctor or nurse, brochure, and Web site).
HIV-specific concerns about LDKT	HIV-positive patients only responded to six questions assessing the degree to which their HIV status impacts their decisions and behaviors related to LDKT.
Health-related quality of life	SF-36—a widely used generic health status measure with eight QOL domains: physical functioning, role functioning-physical, role functioning-emotional, vitality, pain, general health, social functioning, and mental health. Higher scores reflect better functioning.

in making an assessment of both the benefits (e.g., reduced dialysis exposure and good transplant outcomes for HIV-infected patients) and the risks (e.g., social stigma if others learn of HIV status) of LDKT so they can make a treatment decision that is consistent with their preferences and values.

In conclusion, data from several studies show that carefully selected HIV-infected patients with renal failure benefit from transplantation. The current study shows, however, that HIV-infected patients have many concerns about pursuing LDKT and are less willing or ready to consider this treatment option compared with a matched group of noninfected patients. A patient-centered decision support approach that considers the unique circumstances of HIV-infected patients may be beneficial for this patient population. Importantly, this was a single-center study and it is limited by its small sample size, which did not permit us to conduct multivariate analyses to isolate the independent effects of HIV status on the study outcomes. Also, we developed a questionnaire to assess the specific HIV-related concerns of patients and this instrument has not been validated. More research with a larger cohort of HIV-infected patients is needed to better understand the lower LDKT willingness in this unique population and barriers that may adversely affect access to this superior treatment option.

MATERIALS AND METHODS

HIV-infected patients approved for kidney transplantation were matched sequentially 1:1 with noninfected patients on year of evaluation, age (± 5 years), sex, race (white, non-white), and waiting time (± 1 year). All patients were participating in a larger study on strategies to increase LDKT rates but had not been randomized to receive the assigned intervention at the time of the questionnaire assessment described herein. Patients were excluded if they were awaiting combined kidney-liver transplantation or did not speak or comprehend English or Spanish.

All patients were identified in our electronic transplant database and then approached privately by our study coordinator during a transplant clinic appointment. The coordinator was not involved in the clinical care of patients. Patients were informed of the study procedures, time commitment, and that none of their individual responses would be shared with their transplant providers. Written informed consent was then obtained and study questionnaires were completed. Patients were compensated \$20. Research procedures were approved by the institutional review board.

At our center, HIV-infected patients must meet standard medical, surgical, and psychosocial criteria for placement on the transplant waiting list, be on a stable antiretroviral regimen for at least 3 months before listing or be able to maintain a persistently undetectable HIV-1 RNA level, have a CD4 T-cell count ≥ 200 /mL for the past 6 months, and have or be willing to start seeing a primary medical care provider with expertise in HIV management. Also, patients with opportunistic complications are considered on a case-by-case basis if they have received appropriate acute and maintenance therapy and have no evidence of active disease. However, patients are not eligible for transplantation if they have a history of diseases caused by *Aspergillus* or *Aspergillus* colonization, a history of documented resistant fungal infections, or a history of neoplasm (excluding cutaneous Kaposi's sarcoma, in situ anogenital carcinoma, adequately treated basal or squamous cell carcinoma of the skin, or solid tumors treated with curative therapy and disease-free for > 5 years). Our center participated in the multisite observational cohort study on kidney and liver transplantation in HIV-infected adults (8); however, we did not recruit patients who were participating in the multisite cohort study.

Patients completed several validated questionnaires that have been used in prior studies (Table 3) (15–18). Additionally, we gathered the following

information from the patient's medical record: age, sex, race/ethnicity, education, marital status, primary renal disease etiology, dialysis status and duration, year of evaluation and listing, and months on the waiting list.

Descriptive statistics were calculated to summarize the sociodemographic and medical characteristics of patients as well as the questionnaire responses. Differences between HIV-infected and noninfected patients were examined using *t* tests for continuous variables and Fisher's exact test or chi-square test for categorical variables. Findings of $P < 0.05$ were considered statistically significant. PASW 17.0 (Chicago, IL) was used for all statistical analyses.

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