

Disclosing Recipient Information to Potential Living Donors: Preferences of Donors and Recipients, Before and After Surgery

J. R. Rodrigue^{a,*}, K. Ladin^{a,b}, M. Pavlakis^a
and D. A. Mandelbrot^a

^aCenter for Transplant Outcomes and Quality Improvement, The Transplant Institute, Beth Israel Deaconess Medical Center, Boston, MA and the Harvard Medical School, Boston, MA

^bHarvard University, Interfaculty Initiative on Health Policy, Cambridge, MA

*Corresponding author: James R. Rodrigue, PhD,
jrrodrig@bidmc.harvard.edu

Consensus guidelines, while recommending that potential living donors should be given information that could impact their donation decision, are nonspecific about the types of information that should be disclosed. We surveyed potential (n = 36) and past (n = 45) living donors and transplant candidates (n = 45) and recipients (n = 45) about their preferences for sharing or knowing specific information about the recipient, how this information would impact decision-making, and who should be responsible for disclosing information. Potential donors were less likely than all others to feel that recipient information should be disclosed to potential donors. Donors and recipients felt most strongly about disclosing if the recipient lost a previously transplanted kidney due to medication nonadherence as well as the likelihood of 1- and 5-year graft survival. Most donors would be less likely to pursue donation if the recipient lost a previously transplanted kidney due to medication nonadherence or generally had problems with taking medications as prescribed. Transplant programs should consider how to best balance the potential donor's right to receive information that could reasonably be expected to affect their decision-making process with the recipient's right to privacy and confidentiality.

Key words: Attitudes, ethics, informed consent, kidney donor, kidney transplantation, living donation

Abbreviations: ANOVA, analysis of variance; BIDMC, Beth Israel Deaconess Medical Center; HIV, human immunodeficiency virus; KPD, kidney paired donation.

Received 28 January 2011, revised 07 March 2011 and accepted for publication 21 March 2011

Introduction

Informed consent is a critical component of the living kidney donation process. Key elements of informed consent for living kidney donation have been described, (1–8) although there is considerable variability in how they are implemented in practice (9,10). It is unclear what specific transplant candidate information, if any, should be disclosed to potential living donors, and when and who should make the disclosure. Most consensus guidelines are nonspecific, stating only that potential living donors should be informed of risks to the recipient (1,3–8), and other discussions are limited to cases of misattributed paternity, HIV and medication nonadherence (11–16). Transplant programs must balance the recipient's privacy and confidentiality rights with the potential donor's right to information that potentially impacts the decision to pursue donation.

Hizo-Abes et al. (17) examined recipient, donor and provider preferences about sharing personal health information in the context of living kidney donation. In response to a single question, most (80%) transplant candidates were willing to share health information and most (86%) potential donors wanted information about the recipient's health. Fewer health professionals (73%) felt recipient health information should be shared with potential donors. Despite the important insights from this study, many important questions remain unanswered. We surveyed potential and past living donors and transplant candidates and recipients about their preferences for sharing or knowing specific information about the transplant candidate, how this information would impact (or would have impacted) their decision-making about living donation, and who should be responsible for sharing recipient information.

Materials and Methods

Study design, setting and participants

This was a cross-sectional study conducted at a single transplant center over 5 months in 2010. A convenience sample of potential and past living kidney donors and kidney transplant candidates and recipients was recruited from The Transplant Institute at Beth Israel Deaconess Medical Center in Boston, Massachusetts. This center evaluates about 230 potential donors and performs 30 to 40 live donor kidney transplants per year. We

enrolled (1) patients who were medically approved for kidney transplantation and had a potential donor being evaluated (transplant candidates); (2) live donor kidney transplant recipients who were 3 to 36 months post-transplant (transplant recipients) (3); living donor candidates who initiated evaluation during the study period and who met donation eligibility criteria (potential donors) and (4) living donors who were 3 to 36 months post-donation (past donors). Additional inclusion criteria were age >18 years, able to read English and verbal assent. We excluded nondirected anonymous donors and donors/recipients in the paired kidney donation (KPD) program because we anticipated that too few would enroll to allow sufficient power to examine preference differences based on KPD participation.

Procedure and survey

Participants were recruited in person in the clinic waiting room or by mail. We designed separate surveys for donors and transplant patients. Items were generated by two nephrologists, a psychologist, a nurse and a health policy expert with experience in transplantation and living donation. Items then were reviewed for completeness and clarity by four transplant providers (nephrologist, surgeon, social worker, nurse), two research assistants, and two patients (recipient, donor) who were not involved in the study. Surveys included 17 statements reflecting different types of recipient information. Using a 4-point rating scale (1, strongly disagree; 2, disagree; 3, agree; 4, strongly agree), participants indicated whether such recipient health information should be disclosed to potential living donors. Next, they indicated when the disclosure should be made and by whom. The donor survey included 21 additional questions, which asked whether knowing specific recipient information would have had any effect on their decision to be evaluated (potential donors) or to be a donor (past donors). Finally, we recorded age, sex, race, ethnicity, education level, donor-recipient relationship, perceived closeness with the recipient/donor and time since transplant/donation (past donors and transplant recipients only). Study procedures were approved by the BIDMC Institutional Review Board.

Statistical analysis

Data were expressed as means and standard deviations, or the percentage of participants with specific responses. One-way ANOVA and Fisher's exact test assessed for baseline differences between the four groups on sociodemographic information. Fisher's exact test examined for group differences on disclosure preference items, preferred disclosure timing, and disclosure responsibility. Proportions were calculated to assess whether knowing recipient information would have affected willingness to be evaluated (potential donors) or the decision to donate (past donors). We examined whether disclosure preferences were associated with sociodemographic variables and perceived donor-recipient emotional closeness, using t tests or one-way ANOVAs. Pairwise comparisons following a significant ANOVA result were done using the Scheffe method. A level of P < 0.05 was used to denote statistical significance.

Results

Recruitment and sample characteristics

We screened 375 adults for study inclusion, 284 met eligibility criteria, and 171 completed the survey (36 potential donors, 45 transplant candidates, 45 past donors and 45 transplant recipients) (Figure 1). Response rates were 72% for potential donors, 55% for transplant candidates, 57% for past donors and 60% for transplant recipients (P = 0.29). Most nonrespondents either did not return a mailed questionnaire or did not complete the questionnaire in clinic after consenting to participate. Nonrespondents were generally older (mean age 53.6 years) and non-White

(34%), relative to respondents (mean age 50.7 years, t = 2.1, P = 0.04, 18% non-White, $\chi^2 = 13.1$, P = 0.005).

Table 1 summarizes sample characteristics. Groups did not differ on age, sex, and education (P's > 0.05). However, there was a higher proportion of non-Whites in the transplant candidate group compared to the three other groups ($\chi^2 = 13.1$, P = 0.005), and there were proportionally more siblings as past donors and transplant recipients ($\chi^2 = 26.9$, P = 0.03).

Disclosure preferences

There were significant differences in disclosure preferences by group (Table 2). Potential donors were less likely than transplant recipients to feel that potential donors should be told how long the recipient has been on the deceased donor waiting list (50% vs. 78%) and how much longer they would likely have to wait for a deceased donor transplant (61% vs. 85%), in addition to the recipient's history of diabetes (50% vs. 71%), cancer (47% vs. 73%) and previously failed kidney transplant due to medication nonadherence (75% vs. 91%). Potential donors were less likely than past donors to want information about all of the recipient's physical health problems that could affect how long the kidney would last (53% vs. 76%), the recipient's history of medication nonadherence (58% vs. 82%), whether the recipient previously lost a transplanted kidney due to nonadherence (75% vs. 91%) and history of drug abuse (58% vs. 80%). Additionally, 17% of potential donors felt that none of the information in Table 2 should be disclosed to potential donors, compared to only 7% of transplant candidates, 2% of past donors and none of the transplant recipients.

All groups felt most strongly about disclosing whether the potential recipient lost a transplanted kidney due to medication nonadherence (potential donors, 75%; past donors, 91%; transplant candidates, 84%; transplant recipients, 91%) and the likelihood of the kidney still working after 1 year (potential donors, 75%; past donors, 89%; transplant candidates, 80%; transplant recipients, 82%) and 5 years (potential donors, 72%; past donors, 84%; transplant candidates, 76%; transplant recipients, 78%). There were strong preferences for disclosing history of alcohol abuse or dependence (transplant candidates, 78%), diabetes (transplant candidates, 78%), and medication nonadherence (past donors, 82%), as well as waiting time for a deceased donor transplant (transplant recipients, 85%) and length of time on the deceased donor waiting list (transplant recipients, 78%). The only item on which the majority of participants in all groups agreed should not be disclosed is recipient psychiatric history.

Disclosure responsibility and timing

There were no group differences on who should be responsible for disclosing recipient information to potential donors (P's > 0.05). Most (63%) felt that the disclosure

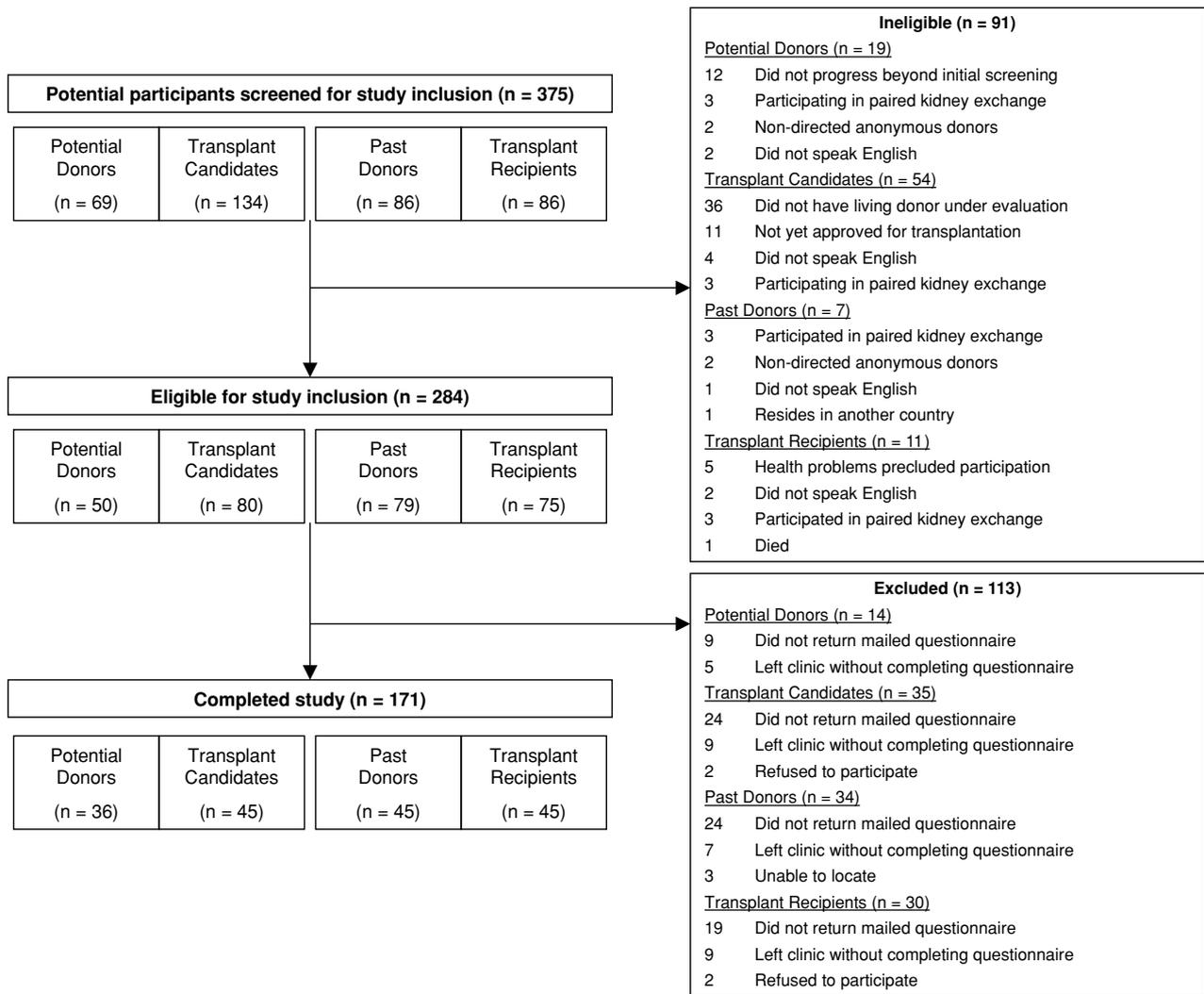


Figure 1: Diagram showing recruitment and participation rates.

responsibility should be shared and 76% felt at least one donor team member (i.e. physician, nurse coordinator or advocate) should be responsible. One-third (33%) felt that the recipient should share the information with the potential donor.

Groups did not differ significantly on the timing of information sharing with potential donors (P = 0.40). About half (47%) of the participants indicated that information should be shared before the donor evaluation starts, 27% felt it should occur after ABO compatibility testing, 11% thought that information sharing should be done after the potential donor was cleared medically and 15% reported that the disclosure timing was not important.

Perceived impact of disclosure on donation decision

As shown in Table 3, most potential and past donors indicated they would be less likely to pursue donation if

the recipient lost a transplanted kidney due to medication nonadherence (75% and 78%, respectively) or generally had difficulties taking medications (56% and 64%, respectively). Otherwise, most potential donors felt that knowing other types of recipient information would not have any effect on their decision to pursue donation. Most past donors would have been less likely to donate if the recipient had a drug (58%) or alcohol (53%) abuse history.

Secondary analyses

There were no differences in disclosure preferences based on sex, age (≤ 50 vs. ≥ 51 years), education (less than college degree vs. college degree), race (White vs. non-White), donor–recipient relationship (related vs. unrelated vs. spouse) or level of emotional closeness (P’s > 0.05). Whites (50%) were more likely than non-Whites (29%) to feel that recipient information should be disclosed before the potential donor starts the evaluation process, while

Table 1: Sociodemographic characteristics of study participants

Characteristic	Potential donors (n = 36)	Transplant candidates (n = 45)	Past donors (n = 45)	Transplant recipients (n = 45)
Age	46.3 ± 14	52.5 ± 13	50.4 ± 11	52.8 ± 12
Sex				
Female	20 (56%)	14 (31%)	25 (56%)	18 (40%)
Male	16 (44%)	31 (69%)	20 (44%)	27 (60%)
Race				
White	30 (83%)	29 (64%)	42 (93%)	39 (86%)
Black	4 (11%)	10 (22%)	2 (4%)	3 (7%)
Hispanic	2 (6%)	3 (7%)	1 (2%)	2 (5%)
Other	0 (0%)	3 (7%)	0 (0%)	1 (2%)
Education				
High school or less	7 (19%)	12 (27%)	7 (16%)	9 (20%)
Some college	6 (17%)	12 (27%)	9 (20%)	13 (29%)
College degree	16 (44%)	12 (27%)	19 (42%)	15 (33%)
Professional degree	7 (19%)	9 (20%)	10 (22%)	8 (18%)
Donor–recipient relationship				
Parent/child	9 (25%)	9 (20%)	10 (22%)	11 (24%)
Sibling	4 (11%)	7 (16%)	19 (42%)	19 (42%)
Relative	4 (11%)	3 (7%)	2 (4%)	4 (9%)
Spouse	7 (19%)	6 (13%)	4 (9%)	4 (9%)
Friend	7 (19%)	10 (22%)	8 (18%)	5 (11%)
Other	5 (14%)	10 (22%)	2 (4%)	2 (4%)

Data expressed as N (%) or mean ± standard deviation.

non-Whites preferred that the disclosure occur after the donor was medically approved (29% vs. 8%) ($\chi^2 = 9.9$, $P = 0.02$). Nonspouses (51% vs. 21% for spouses) similarly preferred that recipient information be disclosed prior to evaluation, while spouses preferred disclosure after ABO compatibility testing (53% vs. 24%) ($\chi^2 = 9.2$, $P = 0.01$).

Discussion

Most donors and recipients felt strongly that certain types of recipient information should be shared with potential donors. Hizo-Abes et al. (17) also found that most potential transplant recipients and living donors supported sharing information about the recipient’s health that could affect the transplant. Our study provides a more detailed assessment of donor and recipient preferences, both before and after surgery. It also illuminates the complexity of sharing information, given that for some potential and past living donors, the sharing of specific information about the recipient may have made them less likely to consider living donation.

We hypothesized that potential donors would have the strongest preferences for information disclosure because they were undergoing evaluation at the time of study participation. Surprisingly, they were less likely than past donors and transplant patients to feel that recipient information should be disclosed. Young et al. (18) found that potential donors have high tolerance for health risk when future outcomes are unknown. Our findings may further reflect such tolerance in this population. Alternatively, many po-

tential donors spontaneously decide to pursue evaluation (19) to improve the recipient’s health and quality of life, and may not consider how recipient issues (e.g. nonadherence, substance use) might affect their own experience of donation. Transplant candidates, on the other hand, may think about these more sensitive issues as they contemplate approaching others about living donation, and past donors and transplant recipients have had time to reflect on their experiences.

While some recipient risk information (e.g. graft/patient survival) is consistent with published guidelines (1,3), behavioral health patterns (e.g. substance use, nonadherence) have not previously been addressed. Most study participants felt that this type of recipient information should be shared with potential donors, even if these health behaviors do not otherwise exclude patients from transplant eligibility. Many past donors felt that they would have been less likely to donate a kidney had they known that the recipient had a history of substance abuse or were currently smoking. Also, most potential and past donors felt that prior graft loss due to nonadherence should be disclosed and they would be less likely to donate if this was true for their recipient. This is an appropriate concern considering that nonadherence to the immunosuppression regimen is a primary reason for acute rejection, chronic rejection, and graft failure following kidney transplantation (20).

Perhaps living donors feel that they are making a considerable sacrifice for the well-being of the recipient and these behavioral health patterns suggest to them that the recipient may not be committed to a healthier lifestyle. They

Table 2: Number (percent) of study participants who “agree” or ‘strongly agree’ with each of the disclosure items

Potential living donors should be told...	Potential donors (n = 36)	Transplant candidates (n = 45)	Past donors (n = 45)	Transplant recipients (n = 45)
<i>Waiting time</i>				
1. How long the potential transplant recipient has been on the deceased donor transplant waiting list	18 (50%) ^a	27 (60%)	31 (69%)	35 (78%) ^b
2. How long the potential transplant recipient would have to wait for a deceased donor transplant	22 (61%) ^a	33 (73%)	31 (69%)	38 (85%) ^b
<i>Graft survival</i>				
1. What the likelihood is that the donated kidney will still be working in the transplant recipient after 1 year	27 (75%)	36 (80%)	40 (89%)	37 (82%)
2. What the likelihood is that the donated kidney will still be working in the transplant recipient after 5 years	26 (72%)	34 (76%)	38 (84%)	35 (78%)
<i>Medical comorbidity</i>				
1. About all of the potential transplant recipient's physical health problems that could affect how long the kidney is likely to last in the patient	19 (53%) ^a	30 (67%)	34 (76%) ^b	27 (60%)
2. Whether the potential transplant recipient has diabetes	18 (50%) ^a	35 (78%) ^b	28 (62%)	32 (71%) ^b
3. Whether the potential transplant recipient had cancer	17 (47%) ^a	31 (69%) ^b	27 (60%)	33 (73%) ^b
4. Whether the potential transplant recipient has HIV infection	21 (58%)	30 (67%)	32 (71%)	34 (76%)
5. Whether the potential transplant recipient has Hepatitis B virus infection	19 (53%)	30 (67%)	29 (64%)	30 (67%)
6. Whether the potential transplant recipient has Hepatitis C virus infection	20 (56%)	31 (69%)	29 (64%)	30 (67%)
7. Whether the potential transplant recipient has heart disease	19 (53%)	33 (73%)	28 (62%)	32 (71%)
<i>Nonadherence</i>				
1. Whether the potential transplant recipient lost their previous transplanted kidney because they did not take their anti-rejection medications as prescribed	27 (75%) ^a	38 (84%)	41 (91%) ^b	41 (91%) ^b
2. Whether the potential transplant recipient has problems with taking medications as prescribed	21 (58%) ^a	31 (69%)	37 (82%) ^b	35 (78%)
<i>Substance abuse/psychiatric</i>				
1. Whether the potential transplant recipient has a past history (greater than 2 years ago) of drug abuse or dependence	21 (58%) ^a	33 (73%)	36 (80%) ^b	34 (76%)
2. Whether the potential transplant recipient has a past history (greater than 2 years ago) of alcohol abuse or dependence	21 (58%)	35 (78%)	32 (71%)	31 (67%)
3. Whether the potential transplant recipient is a current cigarette smoker	20 (56%)	32 (71%)	29 (64%)	32 (71%)
4. Whether the potential transplant recipient has a past history of depression, anxiety, bipolar disorder, or other psychiatric disturbance	15 (42%)	19 (42%)	15 (33%)	14 (31%)

Different superscripts within rows denote statistically significant differences, $P < 0.05$. For example, for question 1, 50% is statistically different from 78% and none of the other pair-wise comparisons reached statistical significance.

Table 3: Number (percent) who felt that the disclosure item would have altered their decision to be evaluated as a living donor (potential donors) or to be a donor (past donors)

	Potential donors (n = 36)			Past donors (n = 45)		
	Less likely to be evaluated as a donor	No effect on my decision to be evaluated as a donor	More likely to be evaluated as a donor	Less likely to donate a kidney	No effect on my decision to donate a kidney	More likely to donate a kidney
Potential donors: would knowing the following information make you less likely to be evaluated as a donor, have no effect at all on your decision to be evaluated as a donor, or more likely to be evaluated as a donor?						
Past donors: would knowing the following information have made you less likely to donate a kidney, have had no effect at all on your decision to donate a kidney, or more likely to donate a kidney?						
<i>Waiting time</i>						
1. The transplant recipient was very likely to get a deceased donor kidney in less than 1 year	13 (36%)	23 (64%)	0 (0%)	15 (33%)	26 (58%)	4 (9%)
2. The transplant recipient was very likely to get a deceased donor kidney in 1 to 2 years	9 (25%)	24 (67%)	3 (8%)	5 (11%)	29 (64%)	11 (24%)
3. The transplant recipient was very likely to get a deceased donor kidney in 3 to 4 years	1 (3%)	26 (72%)	9 (25%)	2 (4%)	26 (58%)	17 (38%)
4. The transplant recipient was very likely to get a deceased donor kidney in 5 or more years	1 (3%)	24 (67%)	11 (31%)	2 (4%)	24 (53%)	19 (42%)
<i>Graft survival</i>						
1. There was a 90% chance that the donated kidney would still be working in the transplant patient after 1 year	0 (0%)	19 (53%)	17 (47%)	0 (0%)	25 (56%)	20 (44%)
2. There was a 80% chance that the donated kidney would still be working in the transplant patient after 1 year	0 (0%)	25 (69%)	11 (31%)	0 (0%)	34 (76%)	11 (24%)
3. There was a 70% chance that the donated kidney would still be working in the transplant patient after 1 year	0 (0%)	28 (78%)	8 (22%)	8 (18%)	29 (64%)	8 (18%)
4. There was a 50% chance that the donated kidney would still be working in the transplant patient after 1 year	12 (33%)	20 (56%)	4 (11%)	13 (29%)	27 (60%)	5 (11%)
<i>Medical comorbidity</i>						
1. The transplant recipient has/had any physical health problem that could affect how long the kidney is/was likely to last in the patient	12 (33%)	22 (61%)	2 (6%)	13 (29%)	31 (69%)	1 (2%)
2. The transplant recipient has diabetes	4 (11%)	31 (86%)	1 (3%)	2 (4%)	37 (82%)	6 (13%)

Continued.

Table 3: Continued.

3. The transplant recipient had cancer	8 (22%)	27 (75%)	1 (3%)	10 (22%)	33 (73%)	2 (4%)
4. The transplant recipient has/had HIV infection	13 (36%)	23 (64%)	0 (0%)	15 (33%)	30 (67%)	0 (0%)
5. The transplant recipient has/had Hepatitis B virus infection	8 (22%)	28 (78%)	0 (0%)	13 (29%)	32 (71%)	0 (0%)
6. The transplant recipient has/had Hepatitis C virus infection	9 (25%)	27 (75%)	0 (0%)	15 (33%)	30 (67%)	0 (0%)
7. The transplant recipient has heart disease	5 (14%)	31 (86%)	0 (0%)	7 (16%)	36 (80%)	2 (4%)
<i>Nonadherence</i>						
1. The transplant recipient had problems with taking medications as prescribed	20 (56%)	16 (44%)	0 (0%)	29 (64%)	16 (36%)	0 (0%)
2. The transplant recipient lost their previous transplanted kidney because they did not take their anti-rejection medications as prescribed	27 (75%)	9 (25%)	0 (0%)	35 (78%)	10 (22%)	0 (0%)
<i>Substance abuse/psychiatric</i>						
1. The transplant recipient had a past history (greater than 2 years ago) of drug abuse or dependence	14 (39%)	22 (61%)	0 (0%)	26 (58%)	19 (42%)	0 (0%)
2. The transplant recipient had a past history (greater than 2 years ago) of alcohol abuse or dependence	14 (39%)	22 (61%)	0 (0%)	24 (53%)	21 (47%)	0 (0%)
3. The transplant recipient was a cigarette smoker	16 (44%)	20 (56%)	0 (0%)	18 (40%)	27 (60%)	0 (0%)
4. The transplant recipient had a past history of depression, anxiety, bipolar disorder or other psychiatric disturbance	6 (17%)	30 (83%)	0 (0%)	5 (11%)	39 (87%)	1 (2%)

also represent behaviors that are often criticized by society on moral grounds. Potential donors may harbor anxiety about negative changes in the donor–recipient relationship if the recipient is not adhering to lifestyle modifications, which may deter them from pursuing living donation. Many transplant programs have substance abuse and nonadherence policies pertaining to transplant eligibility. Sharing these policies and their rationale with potential donors may provide some reassurance and place these behavioral health issues within their appropriate clinical context.

For most potential donors, the amount of time the patient would have to wait for a deceased donor transplant would likely not affect their decision to be evaluated. However, approximately one-third of potential donors would likely not pursue evaluation if the wait for a deceased donor kidney was less than 1 year and 25% would not pursue it if the wait was 1–2 years. In contrast, 25% and 31% of potential donors indicated a higher likelihood of pursuing evaluation if the patient had to wait 3–4 years or 5 or more years, respectively, for a deceased donor transplant. Live donor kidney transplantation has advantages that extend beyond earlier transplantation, e.g. lower rejection risk, longer graft and patient survival, less immunosuppression. These data suggest that potential donors may be more focused on preempting or reducing dialysis exposure rather than other benefits of live donor kidney transplantation such as longer graft survival.

Transplant programs should consider how to best balance the potential donor's right to receive information that could reasonably be expected to affect their decision-making processes with the recipient's right to privacy. The goal of informed consent stems from patients' desire for the information needed to decide on a course of treatment, and from the ethical duty of clinicians to involve patients in health care decisions. One might ask why recipient information should be considered at all in the informed consent. One consideration may be that, while high risk recipients (e.g. nonadherence, heart disease) may not increase donor risk per se, they may decrease donor benefits, particularly in cases of directed donation where the benefit stems from prolonging the life of a loved one. Reduced benefits may also result from psychological stress associated with regret when a graft is lost due to nonadherence or other avoidable factors. Additionally, in considering these disclosure issues, it may be important for transplant programs to distinguish between recipient-specific information (e.g. past nonadherence) and statistical probabilities about future events that may not be specific to the transplant candidate (e.g. survival probabilities).

Although this study has many strengths (e.g. inclusion of donors and recipients before and after surgery, comprehensive survey), findings should be considered within the context of a few methodological limitations. First, study participants may have differed systematically from those who refused participation (i.e. self-selection bias). Second,

while generally representative of the donor and recipient population at our center, the study sample was predominantly White, thus limiting our ability to carefully examine differential outcomes based on race or ethnicity. This was a single-center study with small sample sizes per subgroup, thus limiting broader generalizability. Third, it is possible that potential donors had higher disclosure needs than they reported on the survey. Although we emphasized during study recruitment that responses would be de-identified and confidential, some potential donors may have felt uncomfortable identifying disclosure preferences for fear that it might adversely affect their donor eligibility. Fourth, we focused exclusively on the disclosure of recipient information and did not assess preferences for the sharing of living donor information with recipients, a topic of clinical, scientific and ethical importance (16). Finally, data collected in close proximity to the event in question are likely to be most reliable and less influenced by memory and decision justification processes over time. For instance, it is difficult to know whether past donors who were far removed from surgery would have altered their decision to be a living donor had they been given more information about their intended recipient prior to surgery.

Future research should examine the impact of recipient health information sharing policies or practices on adults' willingness to pursue living donation or live donor kidney transplantation, as well as overall satisfaction with the donation or transplant process. We encourage further exploration of whether providing potential donors with general transplant candidacy guidelines and evaluation processes alters their attitudes toward or perceived need for recipient information sharing. Additionally, it would be interesting to examine whether the information sharing needs of donors and recipients changes over time. Cultural beliefs, personal values, risk tolerance, dispositional optimism and religiosity may influence disclosure preferences, and warrant consideration in future studies.

Acknowledgments

This study was funded, in part, by support from the Julie Henry Fund, Beth Israel Deaconess Medical Center, Boston, MA. We are thankful for the data collection and entry assistance we received from Jonathan Berkman, Noelle Dimitri, Ariel Hodara, Matthew Paek, Nancy Salompuro and Stacey Senat.

Disclosure

The authors of this manuscript have no conflicts of interest to disclose as described by the *American Journal of Transplantation*. The study was not funded by a commercial organization, nor was any commercial organization involved in the preparation of the manuscript.

References

1. Department of Health and Human Services Medicare Program; Hospital conditions of participation: Requirements for approval and

- re-approval of transplant centers to perform organ transplants; final rule. Fed Reg 72: 2007.
2. Organ Procurement and Transplantation Network. Guidance for the informed consent of living donors. http://optn.transplant.hrsa.gov/ContentDocuments/Guidance_InformedConsentLiving_Donors.pdf. Accessed December 10, 2010.
 3. United States Department of Health and Human Services, Advisory Committee on Transplantation. <http://www.organdonor.gov/research/acot.htm>. Accessed December 10, 2010.
 4. Ethics Committee of the Transplantation Society. The consensus statement of the Amsterdam forum on the care of the live kidney donor. *Transplantation* 2004; 78: 491–492.
 5. Abecassis M, Adams M, Adams P et al. Consensus statement on the live organ donor. *JAMA* 2000; 284: 2919–2926.
 6. Adams PL, Cohen DJ, Danovitch GM et al. The nondirected live-kidney donor: Ethical considerations and practice guidelines. A national conference report. *Transplantation* 2002; 74: 582–589.
 7. Dew MA, Jacobs CL, Jowsey SG et al. Guidelines for the psychosocial evaluation of living unrelated kidney donors in the United States. *Am J Transplant* 2007; 7: 1047–1054.
 8. Joint Working Party of the British Transplantation Society and the Renal Association. *United Kingdom guidelines for living donor kidney transplantation*, 2nd Ed. Cambridge: British Transplantation Society, 2005. <http://www.cambridge-transplant.org.uk/program/renal/Irdgui.pdf>. Accessed December 10, 2010.
 9. Parekh AM, Gordon EJ, Garg AX et al. Living kidney donor informed consent practices vary between US and non-US centers. *Nephrol Dial Transplant* 2008; 23: 3316–3324.
 10. Rodrigue JR, Pavlakis M, Danovitch GM et al. Evaluating living kidney donors: relationship types, psychosocial criteria, and consent processes at US transplant programs. *Am J Transplant* 2007; 7: 2326–2332.
 11. Soderdahl DW, Rabah D, McCune T et al. Misattributed paternity in a living related donor: To disclose or not to disclose? *Urology* 2004; 64: 590.
 12. Young A, Kim SJ, Gibney EM et al. Discovering misattributed paternity in living kidney donation: prevalence, preference, and practice. *Transplantation* 2009; 87: 1429–1435.
 13. Bright PD, Nutt J. The ethics surrounding HIV, kidney donation and patient confidentiality. *J Med Ethics* 2009; 35: 270–271.
 14. Formica RN Jr., Asch WS, Wagner KR, Kulkarni S. Kidney transplantation and HIV: Does recipient privacy outweigh the donor's right to information? *Clin J Am Soc Nephrol* 2010; 5: 924–928.
 15. O'Hara JF Jr., Bramstedt K, Flechner S, Goldfarb D. Ethical issues surrounding high-risk kidney recipients: Implications for the living donor. *Prog Transplant* 2007; 17: 180–182.
 16. Wright L, Daar AS. Ethical aspects of living donor kidney transplantation and recipient adherence to treatment. *Prog Transplant* 2003; 13: 105–109.
 17. Hizo-Abes P, Young A, Reese PP et al. Attitudes to sharing personal health information in living kidney donation. *Clin J Am Soc Nephrol* 2010; 5: 717–722.
 18. Young A, Karpinski M, Treleaven D et al. Differences in tolerance for health risk to the living donor among potential donors, recipients, and transplant professionals. *Kidney Int* 2008; 73: 1159–1166.
 19. Switzer GE, Dew MA, Twillman RK. Psychosocial issues in living organ donation. In: Trzepacz P, DiMartini A, eds. *The transplant patient: biological, psychiatric and ethical issues in organ transplantation*. Cambridge, Cambridge University Press, 2000.
 20. Morrissey PE, Flynn ML, Lin S. Medication noncompliance and its implications in transplant recipients. *Drugs* 2007; 67: 1463–1481.