

# Patients' willingness to talk to others about living kidney donation

**Background**—Living donor kidney transplantation has several advantages for patients with end-stage renal disease. However, many patients are reluctant to pursue this treatment option, preferring instead to wait for a deceased donor organ.

**Objective**—To examine predictors of patients' willingness to talk to others about living kidney donation.

**Methods**—One hundred thirty-two adult patients awaiting kidney transplantation who were enrolled in a randomized trial examining the effectiveness of education on rates of live donor kidney transplantation completed a baseline rating of their willingness to talk to others about living kidney donation. Also, patients completed measures of knowledge and concerns about living donation and a rating of perceived health.

**Results**—Slightly more than half the patients (56.1%) had low willingness to talk to others about living donation. The following variables were associated with higher willingness to talk to others: white race (odds ratio, 3.31; confidence interval, 1.7-7.4), college education (odds ratio, 3.43, confidence interval, 2.0-5.6), fewer concerns about living donor kidney transplantation (odds ratio, 0.31; confidence interval, 0.2-0.6), and less favorable perceptions of their current health status (odds ratio, 4.31; confidence interval, 2.6-7.6).

**Conclusion**—White race, more education, less concern about living donor kidney transplantation, and poorer perceived health are associated with greater willingness to talk to others about living kidney donation. These findings have important implications for educating patients about living donor kidney transplantation.

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**James R. Rodrigue, PhD,  
Danielle L. Cornell, RN, BSN,  
Bruce Kaplan, MD, Richard  
J. Howard, MD, PhD**

Beth Israel Deaconess Medical Center,  
Boston, Massachusetts (JRR),  
LifeQuest Organ Recovery Services,  
Gainesville, Florida (DLC), University  
of Illinois at Chicago (BK), University  
of Florida, Gainesville (RJH)

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For patients with end-stage renal disease, kidney transplantation provides the opportunity for improved quality of life and long-term survival.<sup>1-4</sup> Moreover, kidney transplantation may confer benefits to society as well, because transplantation leads to less healthcare expenditure than dialysis, with the cross-over cost benefits occurring at about 3 years.<sup>5-8</sup> Although the initial costs are high in the first few years after kidney transplantation, the aggregate long-term costs are lower than those for dialysis. Unfortunately, the number of organs available for transplantation far exceeds the number of persons in need of and awaiting kidney transplantation.<sup>9</sup> Consequently, living donor kidney transplantation (LDKT) has emerged as an important treatment option. LDKT preempts the need for or shortens the length of dialysis, minimizes the impact of chronic kidney disease on quality of life, reduces waiting time and mortality on the transplant list, ensures receipt of a high-quality kidney graft, lowers the risk of acute graft rejection, increases the likelihood of long-term survival,

and optimizes the timing of transplantation.<sup>10</sup> For these reasons and others (eg, laparoscopic donor surgery, excellent donor outcomes, expansion of donor eligibility criteria), the number of kidney transplants done with living donors has increased 168% in the past 15 years.<sup>9</sup>

Despite the potential benefits and growth of LDKT, many patients decide not to pursue LDKT and will not discuss the possibility of living donation with family members, friends, or other close associates. Many patients are concerned about harming or inconveniencing potential donors, feeling guilty if the graft failed or their health did not improve, feeling indebted to the donor, and causing financial problems for the donor and the donor's family.<sup>11-15</sup> These concerns can be prohibitive for some patients and, if left unaddressed, can lead to years of waiting for a deceased donor kidney even when family members or friends have expressed active interest in being living donors.<sup>16-18</sup> Other factors (eg, age, race, perceived health status, dialysis status, and whether the patient had a previous kidney transplant)

might also play a role in whether patients are willing to talk to others about living kidney donation, although this has not been the focus of much study.

A better understanding of which variables influence patients' willingness to talk to others about living donation would guide the development and implementation of LDKT educational interventions for patients. Therefore, the purpose of this study was to examine patients' willingness to pursue discussions with others about living kidney donation and to determine whether willingness varies with sociodemographic or medical characteristics. Based on previous research and our own clinical experiences, we hypothesized that the following variables would be predictors of greater willingness to discuss living donation with others: younger age, white race, being female, lower perceived health rating, more knowledge and fewer concerns about living donation, and being on dialysis.

## Methods

### Patients

Eligible study participants were adults on the kidney transplant waiting list who were enrolled in a randomized, single-center clinical trial evaluating the effectiveness of 2 educational programs to increase rates of LDKT.<sup>19</sup> Inclusion criteria were written informed consent, medical approval for transplantation, African American or white race, age at least 21 years, primary residence within 90 miles (144 km) of the transplant center, and telephone service. Medical approval for transplantation was confirmed by the transplant team. Race, age, residence, and telephone service were assessed via medical record review and then confirmed directly with the patient before enrollment by one of the research assistants. The residence and telephone service criteria were necessary to coordinate the home visits that were part of the clinical trial. Patients who were illiterate or did not speak English were excluded. The University of Florida's institutional review board approved all study procedures.

### Data Collection Procedures

At the time of enrollment in the clinical trial, patients completed a baseline written questionnaire that included measures of willingness to talk to others about living donation, knowledge and concerns about living donation, and perceived health status. These measures were developed by our research team on the basis of previous research, clinical experience, and recommendations of our transplant team members (4 nurse coordinators, 2 nephrologists, 3 surgeons, 2 psychologists, 1 social worker) and 4 transplant patients (2 waiting for a transplant, 1 LDKT recipient, 1 recipient of a deceased donor kidney transplant). Willingness to discuss living donation with others was measured with 1 question (How willing are you to talk to family

members and/or friends about donating a kidney to you for transplantation?) by using a scale from 1 (not at all) to 7 (extremely). Concerns about pursuing living donation were assessed by using 21 statements to which patients responded whether it was true for them (Cronbach  $\alpha = .79$ ). Higher total scores reflect more concern. Living donation knowledge was assessed by using 15 true-false items (eg, "Only a blood relative is able to be a living kidney donor." "A living kidney donor must have their own health insurance to cover the costs of surgery."), which yielded a total score ranging from 0 to 15 (Kuder-Richardson formula  $20 = 0.72$ ). Higher scores reflect more knowledge. Finally, a 1-item question was used to assess patients' perceived health status (How would you rate your current health? 1 = poor, 2 = fair, 3 = good, 4 = very good, 5 = excellent).

We also gathered the following information from the patient and his or her medical record: age, sex, race, marital status, years of education, employment status, dialysis status, months on dialysis, and whether the patient had a previous kidney transplant. In addition, because donor registration status may be a proxy measure for attitudes toward organ donation generally, we asked patients whether they had an organ donor designation on their driver's license or otherwise were registered as a donor at the time they knew of their need for a kidney transplant.

### Statistical Analyses

Descriptive statistics were calculated to summarize the medical and sociodemographic characteristics of the entire sample and the 4 measures. Patients were then divided into low versus high willingness to talk to others about living donation. Univariate relationships between the willingness rating (median split: low vs high) and sociodemographic and medical characteristics, living donation knowledge and concerns, and perceived health were examined by using *t* tests for continuous variables, the Fisher exact test for variables with 2 categories, or a 2-tailed  $\chi^2$  test for variables with 3 or more categories. Logistic regression analyses were then conducted to examine the utility of sociodemographic characteristics, medical variables, and knowledge and concerns about living donation in predicting willingness to talk to others. All data were analyzed by using SPSS (Version 14, SPSS Inc, Chicago, Illinois).

## Results

### Characteristics of Patients

The study included 132 adult patients who met the eligibility criteria. The sociodemographic and medical characteristics of the sample are reported in Table 1. The total sample was relatively balanced in terms of race (45.5% African American) and sex (48.5% female). Mean (SD) age was 52 (12) years, and the sample was predominantly married (57.6%), not working (72.7%),

Table 1 Sociodemographic and medical characteristics of patients included in the study, by willingness to discuss living donor kidney transplantation<sup>a</sup>

Characteristic	Total sample (N = 132)	Low willingness (n = 74)	High willingness (n = 58)
Age, mean (SD), y	52.1 (12.1)	52.2 (11.9)	52.0 (12.5)
Sex, female	64 (48.5)	36 (48.6)	28 (48.3)
Race, white	72 (54.5)	33 (44.6) <sup>b</sup>	39 (67.2) <sup>b</sup>
Marital status, married	76 (57.6)	43 (58.1)	33 (56.9)
Education, >12 y	93 (70.5)	44 (59.5) <sup>b</sup>	49 (84.5) <sup>b</sup>
Employed, yes	36 (27.3)	19 (25.7)	17 (29.3)
Registered donor, yes	35 (26.5)	12 (16.2) <sup>b</sup>	23 (39.7) <sup>b</sup>
Dialysis, yes	95 (72.0)	54 (73.0)	41 (70.7)
Dialysis time, mean (SD), mo	22.5 (18.3)	25.0 (18.9)	19.1 (17.0)
Previous kidney transplant, yes	17 (12.9)	11 (14.9)	6 (10.3)

<sup>a</sup> Values are expressed as No. (%) unless otherwise indicated.

<sup>b</sup> Significant differences,  $P < .01$ .

on dialysis (72.0%), and had at least a high school education (70.5%). The length of time that patients had been receiving dialysis varied considerably, with a mean of about 2 years (37% < 1 year). Interestingly, only one-quarter of the patients had agreed to be an organ donor before learning of their need for a kidney transplant. Patients who were white, more highly educated, and registered donors were significantly more willing to talk to others about living kidney donation (all  $P$  values < .05). Age, sex, marital status, employment status, dialysis status or duration, and whether the patient had a previous kidney transplant were not significantly associated with willingness.

### Willingness to Talk to Others

The mean (SD) willingness score was 3.9 (1.8), which is the midpoint on the 7-point rating scale. The Figure illustrates the proportion of patients who selected each of the 7 choices on the willingness rating scale. Eighteen patients (13.6%) provided the lowest willingness rating, whereas 22 (16.7%) stated an extremely high willingness (rating of 6 or 7) to discuss living donation with others. To examine the relationship between willingness and patients' knowledge and concerns about living donation, a median split was performed of the willingness data. This resulted in classifying patients with ratings of 1 through 4 as "low willingness" ( $n=74$ , 56.1%) and classifying those with ratings of 5 through 7 as "high willingness" ( $n=58$ , 43.9%).

### Knowledge About Living Donation

The mean score for knowledge about living donation was 8.8 (1.9). Table 2 shows the proportion of patients who correctly answered each of the 15 items, broken down by willingness level. Half or fewer than

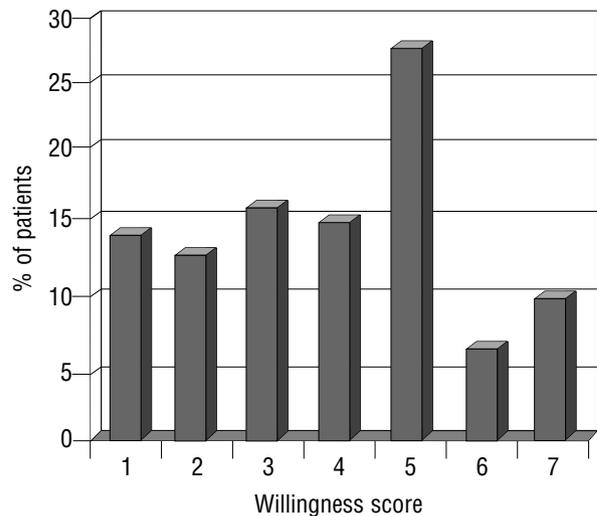


Figure Patients' willingness to discuss living kidney donation with others. Score is based on a rating scale from 1 (not at all willing) to 7 (extremely willing).

half the patients knew that a kidney from a living donor generally lasts longer than one from a deceased donor (47.7%), insurance companies typically do not pay for the living donor's indirect costs (43.2%), and most living donors spend only 1 to 3 days in the hospital (50.0%).

No significant difference was found in total knowledge score between patients with low (mean [SD], 8.6 [1.8]) vs high (9.0 [2.1]) willingness to talk to others about living donation ( $t=1.2$ ,  $P=.23$ ). However, patients with high willingness were significantly more likely than patients with low willingness to know that living donation does not incur a higher risk for kidney disease (73.0% vs 91.4%,  $P=.007$ ), that living donation

Table 2 Items related to knowledge about living donation and the number (and proportion) of patients answering each question correctly, by willingness level<sup>a</sup>

Item	Total sample (N = 132)	Low willingness (n = 74)	High willingness (n = 58)
Donating a kidney affects ability to have children (False)	112 (84.8)	64 (86.5)	48 (82.8)
Most living donors return to work in 4 to 6 weeks (True)	107 (81.1)	61 (82.4)	46 (79.3)
Most living donors are at higher risk for kidney disease later in life (False)	107 (81.1)	54 (73.0) <sup>b</sup>	53 (91.4) <sup>b</sup>
A potential living donor can change their mind about donation at any time before the surgery (True)	102 (77.3)	58 (78.4)	44 (75.9)
A living donor who needs a kidney transplant later in life is given special priority for transplantation (True)	97 (73.5)	52 (70.3)	45 (77.6)
Most living donors have problems getting or keeping health insurance after donating (False)	95 (72.0)	54 (73.0)	41 (70.7)
Only blood relatives of the patient can be a living donor (False)	89 (67.4)	50 (67.6)	39 (67.2)
Living donors must have own health insurance to cover costs of donation (False)	85 (64.4)	45 (60.8)	40 (69.0)
Living donors must be < 50 years old (False)	84 (63.6)	39 (52.7) <sup>b</sup>	45 (77.6) <sup>b</sup>
The risks of live donor surgery are generally small and manageable (True)	83 (62.9)	41 (55.4) <sup>b</sup>	42 (72.4) <sup>b</sup>
A living donor's blood and tissue must be a perfect match with the patient (False)	73 (55.3)	37 (50.0)	36 (62.1)
Only healthy adults can be living donors (True)	73 (55.3)	37 (50.0)	36 (62.1)
Most living donors spend only 1 to 3 days in the hospital (True)	66 (50.0)	36 (48.6)	30 (51.7)
Kidney from living donor usually lasts longer than kidney from deceased donor (True)	63 (47.7)	35 (47.3)	28 (48.3)
Most insurance companies will pay for living donor's indirect costs, like travel, parking, lodging, and lost wages (False)	57 (43.2)	29 (39.2)	28 (48.3)

<sup>a</sup> Values are expressed as No. (%) unless otherwise indicated.

<sup>b</sup> Significant differences,  $P < .05$ .

is not restricted to those younger than 50 years of age (52.7% vs 77.6%,  $P = .003$ ), and that the donor nephrectomy risks are generally small and manageable (55.4% vs 72.4%,  $P = .04$ ).

### Concerns About Living Donation

Patients endorsed a mean (SD) of 9.6 (3.8) concerns about living donation. Table 3 shows the proportion of patients who identified each of the 23 items as a concern. Most commonly, patients reported being concerned about the kidney not functioning after surgery and the impact that this would have on the donor ( $n = 97$ , 73.5%), donor pain and discomfort ( $n = 95$ , 72.0%), the financial impact on the donor ( $n = 89$ , 67.4%), the long-term health of the donor ( $n = 84$ , 63.6%), the donor experiencing problems at work ( $n = 80$ , 60.6%), how long it would take for the donor to resume normal activities ( $n = 78$ , 59.1%), not completely understanding the donor evaluation and surgery process ( $n = 78$ , 59.1%), and wasting the donated kidney because of lifestyle factors ( $n = 73$ , 55.3%).

Patients with low willingness to discuss living donation with others reported a mean (SD) of 10.4 (3.7) concerns, 2 concerns more than the 8.5 (3.8) concerns reported by patients with high willingness ( $t = 2.9$ ,

$P = .005$ ). Relative to high-willingness patients, those less willing to talk to others about donation had significantly more concern about donor out-of-pocket costs (56.9% vs 75.7%,  $P = .02$ ), donor long-term health problems (43.1% vs 79.7%,  $P < .001$ ), not fully understanding the donor evaluation, surgery, and recovery (48.3% vs 67.6%,  $P = .03$ ), the experience of the transplant team (22.4% vs 37.8%,  $P = .05$ ), and the negative reaction of family members if someone does not agree to be a donor when asked (22.4% vs 43.2%,  $P = .01$ ).

### Perceived Health Rating

The mean (SD) perceived health status rating was 2.8 (1.0). Fifty-six patients (42.4%) reported their health to be good, 25 (18.9%) reported it to be very good or excellent, and 51 (38.6%) reported it to be fair or poor. Patients who were more willing to discuss living donation with others (2.7 [1.1]) reported significantly worse health than did patients who were less willing (3.1 [1.0];  $t = 2.2$ ,  $P = .03$ ).

### Multivariate Predictors

Logistic regression analysis was used to examine the relative contributions of sociodemographic and medical variables, knowledge and concerns about LDKT,

Table 3 Concerns about living donation and the number (and proportion) of patients endorsing each item, by willingness level<sup>a</sup>

I am concerned that...	Total sample (N = 132)	Low willingness (n = 74)	High willingness (n = 58)
The donor will feel badly if my body rejects the donated kidney	97 (73.5)	54 (73.0)	43 (74.1)
The donor surgery and recovery will be too painful for donor	95 (72.0)	55 (74.3)	40 (69.0)
Out-of-pocket expenses for the donor will be too high	89 (67.4)	56 (75.7) <sup>b</sup>	33 (56.9) <sup>b</sup>
The donor might have long-term health problems because of donation	84 (63.6)	59 (79.7) <sup>b</sup>	25 (43.1) <sup>b</sup>
The donor may have problems at work because of his/her decision to be a living donor	80 (60.6)	45 (60.8)	35 (60.3)
It will take too long for the donor to return to normal activities	78 (59.1)	44 (59.5)	34 (58.6)
I don't completely understand what the evaluation, surgery, and recovery are like for the donor	78 (59.1)	50 (67.6) <sup>b</sup>	28 (48.3) <sup>b</sup>
The donor will have problems getting or keeping health, life, or disability insurance	74 (56.1)	42 (56.8)	32 (55.2)
I might waste a new kidney by not taking care of my health	73 (55.3)	38 (51.4)	35 (60.3)
The donor's family will not be taken care of while the donor recovers	71 (53.8)	42 (56.8)	29 (50.0)
After surgery, the donor might not be able to do some of the activities that they enjoy doing	67 (50.8)	40 (54.1)	27 (46.6)
The surgery scars will be unattractive to the donor or his/her partner	56 (42.4)	34 (45.9)	22 (37.9)
No one will volunteer to be a donor	51 (38.6)	31 (41.9)	20 (34.5)
I will feel relieved if someone is a good donor match	45 (34.1)	26 (35.1)	19 (32.8)
My family members will be angry if someone doesn't agree to be a donor	45 (34.1)	32 (43.2) <sup>b</sup>	13 (22.4) <sup>b</sup>
I will feel guilty if someone donates	44 (33.3)	23 (31.1)	21 (36.2)
Transplant team does not have enough experience	41 (31.1)	28 (37.8) <sup>b</sup>	13 (22.4) <sup>b</sup>
My or my donor's religion might not support living donation	38 (28.8)	19 (25.7)	19 (32.8)
I will die if someone does not agree to be a donor	36 (27.3)	18 (24.3)	18 (31.0)
Surgery will affect the donor's ability to have children	29 (22.0)	16 (21.6)	13 (22.4)
Members of the transplant team will pressure someone to be a donor	19 (14.4)	11 (14.9)	8 (13.8)
I will be angry if someone doesn't agree to be a donor	15 (11.4)	10 (13.5)	5 (8.6)
My family members will be angry if someone does agree to be a donor	5 (3.8)	3 (4.1)	2 (3.4)

<sup>a</sup> Values are expressed as No. (%) unless otherwise indicated.

<sup>b</sup> Significant differences,  $P < .05$ .

and perceived health in predicting willingness to talk to others about kidney donation. The following variables were predictive of higher willingness to talk to others: white race (odds ratio, 3.31; confidence interval, 1.7-7.4), college education (odds ratio, 3.43; confidence interval, 2.0-5.6), fewer concerns about LDKT (odds ratio, 0.31; confidence interval, 0.2-0.6), and less favorable perceptions of their current health status (odds ratio, 4.31, confidence interval, 2.6-7.6).

## Discussion

It is now clearly established that LDKT is an effective treatment option for most patients in need of transplantation. Despite the advantages of LDKT,<sup>2-4,20</sup> expanding donor criteria,<sup>21,22</sup> and willingness of others to be living donors,<sup>23,24</sup> many patients are very reluctant to consider LDKT. Indeed, we found that more

than half (56%) of the patients in our study were either not willing to consider discussing living donation with others at all or were ambivalent about doing so. Other researchers similarly have found that many patients are not willing to actively pursue this treatment option.<sup>13-16</sup> Initiating a dialogue with others about living donation can be uncomfortable and, in the absence of guidance from the transplant team, may seem like an insurmountable emotional hurdle for some patients. However, even when approached directly by potential living donors, many patients are likely to reject the offer without adequate consideration of the potential risks and benefits of their decision.<sup>18</sup>

Race, education, and donor designation status were significantly associated with willingness to discuss living donation with others, although donor status dropped out in the multivariate analysis. Consistent

with previous research, African Americans were less willing to talk to others about living donation.<sup>13,25</sup> African Americans cope with the need for transplantation and the possibility of LDKT very differently than do whites, and they are more likely to misunderstand or deny the need for kidney transplantation, to question the benefits of transplantation with respect to survival and quality of life, and to perceive secondary benefits to remaining on dialysis.<sup>11,13,17,25,26</sup> Waterman et al<sup>25</sup> found that African Americans were less likely than whites to pursue LDKT because of less transplant knowledge, more concern about harming the health of potential donors, and fears that the transplant might fail. Other researchers have found African Americans to harbor more mistrust of the transplant system, particularly around allocation policies and decisions, and this may contribute to less favorable attitudes toward organ donation in general.<sup>24,26-30</sup> Perhaps as a result of these personal and cultural beliefs, African Americans are more hesitant to approach potential living donors and less persuasive when they do so.<sup>11,25</sup>

We also found that patients who are more educated are more willing to talk to others about living donation. It is possible that such patients have greater access to information about LDKT and living donation, for instance, online resources. They may have higher health literacy,<sup>31</sup> which may be reflected in our finding that patients with low willingness to talk to others about living donation feel that they do not fully comprehend all aspects of the living donation experience. In addition, it is possible that patients with more formal education read more newspapers, magazines, and other print media, and therefore they may have been exposed to more favorable stories about LDKT and living donation in general.

How much a patient knows about LDKT and living donation was not predictive of their willingness to talk to others about living donation. Our findings here suggest that simply increasing patients' knowledge about living donor transplants will not, by itself, lead to more LDKTs. Indeed, more important than what patients may know about LDKT and living donation is patients' level of concern about pursuing this treatment option. A number of concerns have been implicated in the LDKT decision-making processes of patients, including concerns about long-term guilt, potential health consequences to the donor, the financial impact of living donation, and the impact of donation on the donor-recipient relationship, to name a few.<sup>11-16,18,19</sup> In this study, we also found that patients are less willing to pursue LDKT when they have concerns about the transplant team's experience. Collectively, the emerging research in this area suggests that patient's concerns about living donation are not homogeneous. Therefore, patients are most likely to benefit from information that is both general (eg, benefits of trans-

plantation vs dialysis) and a more detailed discussion that specifically addresses their unique concerns about LDKT and living donation (eg, typical out-of-pocket expenses for a donor). For instance, at one of our transplant centers (Beth Israel Deaconess Medical Center), patients who are ambivalent about pursuing LDKT are provided the opportunity to meet with the transplant psychologist, who identifies the patient's specific concerns, provides general (eg, *The Living Gift*<sup>32</sup> and *Keep an Open Mind: Recipient Education About Living Donation*<sup>33</sup>) and concern-specific information, role-plays several strategies for initiating the living donor conversation with others, and then develops a LDKT action plan collaboratively with the patient. Collecting follow-up data from LDKT recipients and living donors at your center and making these data available to potential recipients may help ease their concerns about the program's experience and outcomes for patients and donors.

In the univariate analyses, patients who are themselves registered organ donors are more willing to talk to others about donating a kidney to them. It is possible that their favorable attitudes toward deceased organ donation generalize to living donation as well. Registered organ donors may have thought more about the benefits of organ donation and have discussed their intentions with others, a major emphasis of public organ donation campaigns. For them, the idea of discussing organ donation (deceased or living) with others may not be so daunting or uncomfortable. In contrast, patients who have chosen not to be organ donors at the time of their death may harbor concerns about donation that may also be present when considering living donation (eg, body integrity, injustice and unfairness in transplant system, medical care of donors).<sup>34,35</sup>

Patients who perceived their health as more favorable, regardless of dialysis status, were less likely to consider talking to others about living donation. They may not have a sense of urgency about transplantation that those with lower health-related quality of life may have. It may seem more intuitive for these patients to be placed on the kidney transplant waiting list and to cross the proverbial bridge to LDKT if their health deteriorates. This relationship between perceived health status and willingness to talk to others about living donation exemplifies the need to talk to patients, especially those who are known to have potential living donors, about LDKT periodically because their attitudes about it may change along with their functional status.

This study is not without limitations. It is a single-center study that included only those patients who agreed to be part of a larger study on LDKT education. These self-selected patients may not be representative of the larger population of patients awaiting kidney transplantation. Also, and importantly, we recognize that a patient's willingness to pursue LDKT may change

throughout the course of the transplant evaluation and waiting periods. In this article, we report on the willingness rating of patients at one point in time. Additional research is needed to characterize how patients' willingness to talk about living donation with others changes over time.

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