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Associations of Perceived Information Adequacy and Knowledge with Pursuit of Live Donor Kidney Transplants and Living Donor Inquiries among African American Transplant Candidates

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Abstract

We studied associations between perceived adequacy of live donor kidney transplant (LDKT) information or knowledge with pursuit of LDKT or receipt of live donor inquiries among 300 African American kidney transplant candidates. Participants reported via questionnaire how informed or knowledgeable they felt regarding LDKT. Participants also reported their pursuit of LDKT, categorized as 'low' (no discussion with family or friends about LDKT and no identified

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donor), 'intermediate' (discussed LDKT with family but no identified donor) or 'high' (discussed LDKT with family and identified a potential donor). We reviewed participants' electronic health records to identify potential donors' transplant center inquiries on participants' behalves. A minority of participants reported they felt 'very' or 'extremely' well informed about LDKT (39%) or had 'a great deal' of LDKT knowledge (38%). Participants perceiving themselves as 'very' or 'extremely' (versus 'not' or 'slightly') well informed about LDKT had statistically significantly greater odds of intermediate or high (versus low) pursuit of LDKT (odds ratio [95% confidence interval] 2.71 [1.02-7.17]). Perceived LDKT knowledge was not associated with pursuit of LDKT. Neither perceived information adequacy nor knowledge were associated with living donor inquiries. Efforts to better understand the role of education in the pursuit of LDKT among African American transplant candidates are needed.

Keywords

Education; Kidney Transplantation: living donor; Patient Education; Donors and Donation; Donors and Donation: living

Introduction

African Americans have been persistently less likely to receive live donor kidney transplantation (LDKT), an optimal therapy for kidney failure,^{1,2} compared to those in other racial groups.³⁻⁵ African Americans' suboptimal LDKT rates may be related to a number of factors, including their poor perceived knowledge or information adequacy regarding LDKT. In previous studies, African Americans have been shown to have less knowledge about kidney treatment options compared to non-African Americans.⁶ However, the relationship between African American transplant candidates' perceived information adequacy or perceived LDKT knowledge with key steps to their receipt of LDKT, including candidates' own actions to pursue LDKT or potential living donors' actions to inquire about donating a kidney on candidates' behalves has not been studied.

Potential transplant recipients most frequently receive information about LDKT after they have visited a transplant center and initiated or completed a transplant evaluation. Transplant candidates who have successfully completed the transplant evaluation process may be optimally physically and psychologically prepared to pursue and receive LDKT. African Americans transplant candidates who pursue LDKT while on the deceased donor waiting list could bypass the deceased donor kidney transplant list, helping to overcome longer deceased donor kidney wait-times experienced by African Americans.^{7,8} Thus, ensuring that potential African American transplant candidates feel adequately informed and knowledgeable about LDKT when they have successfully completed their transplant evaluations may represent an important strategy to improve their LDKT rates.

We conducted a cross-sectional study among African American kidney transplant candidates to quantify the association between their perceived LDKT information adequacy and perceived knowledge with their actions to pursue LDKT as well as actions on the part of potential living kidney donors to donate kidneys on their behalves.

Materials and Methods

Study Design

We collected data from 300 African American transplant candidates during their enrollment in the TALKS study, a randomized clinical trial conducted to study educational, behavioral, and financial interventions to improve access to LDKT among African Americans.⁹ TALKS Study participants were enrolled from September 2015 to May 2017 from the Duke University Kidney and Pancreas Transplant Center. To be included in the study, participants had to be actively registered on the kidney transplant waiting list with no prior history of receiving a living donor kidney transplant, a self-report race as African American, be over the age of 18 years, and speak English. At enrollment, all 300 trial participants answered a standard questionnaire administered via telephone by trained research staff. Participants also provided consent to have their medical records reviewed, including the occurrence of live donor inquiries on their behalves, as recorded by the transplant center. All study protocols were approved by the Duke Health Institutional Review Board.

Assessment of Sociodemographic Characteristics

We assessed participants' sociodemographic characteristics via questionnaire including their sex, age, education (high school or less versus greater than high school), income (less than \$20,000 versus greater), employment (working, retired, retired due to disability, unemployed/looking for work) and medical insurance coverage (private, Medicare, medical assistance or Medicaid, CHAMPUS/CHAMPVA (military veterans, or no insurance). We assessed participants' numeracy using the General Numeracy Scale¹⁰, a validated instrument designed to measure basic adult numeracy skills. We also assessed participants' health literacy, using the validated, shortened version of the Rapid Estimate of Adult Literacy in Medicine (REALM).¹¹

Assessment of Medical Characteristics

We asked participants whether they had already initiated renal replacement therapy at the time they completed the questionnaire, and we confirmed their provided responses via a review of their medical records. We assessed the number of years participants were on dialysis (never started dialysis, less than 3 years or ≥ 3 years). We also reviewed participants' medical records to obtain information about the number of days they had been listed on the deceased donor kidney transplant waiting list at the time of their completion of the enrollment questionnaire.

Assessment of LDKT Perceived Adequacy of LDKT Information and LDKT Knowledge

To assess participants' perceived adequacy of LDKT information we asked them, '*How well informed do you feel you are about live donor kidney transplant?*' Response options included, 'not well informed,' 'slightly well informed,' 'moderately well informed,' 'very well informed,' 'extremely well informed,' 'refused,' or 'don't know.' To participants' perceived knowledge about LDKT, we asked them, '*How much knowledge do you feel you have now about live donor kidney transplant?*' Response options included, 'no knowledge,' 'some knowledge,' 'a great deal of knowledge,' 'refused,' or 'don't know.' During

transplant candidates' initial evaluation and annual follow-up appointments, the transplant center documents that patients received education about transplant; however, documentation does not specifically indicate whether or how LDKT education occurred.

Assessment of Pursuit of LDKT or Live Donor Inquiries

To evaluate participants' pursuit of LDKT, we asked them to indicate whether they had (1) discussed LDKT with family members (i.e., asking for a dichotomous response to the question, 'Have you talked with family and/or friends about the possibility of someone giving you a kidney?' [yes/no]), or (2) identified a potential donor (i.e., by asking them 'Has a family member or friend ever told you that that would give you a kidney?' [yes/no]). To quantify participants' pursuit of LDKT, we created an ordinal variable, which we termed 'stage' of LDKT pursuit. We created this variable to reflect increasing intensity of LDKT pursuit behaviors in three stages. We considered participants who reported having completed the fewest pursuit behaviors (i.e., neither discussed LDKT nor identified a potential donor) to have 'low' pursuit. We considered participants who reported completing some (i.e., discussed LDKT with family members but had not identified a potential donor) but not all behaviors to have 'intermediate' pursuit. We considered participants who reported completing all behaviors (i.e., discussed LDKT and identified a potential donor) to have 'high' pursuit.

We reviewed study participants' medical records to identify live donor inquiries on participants' behalves. We considered a live donor inquiry to occur when there was documentation in participants' medical records that individuals (e.g., participants' family members or friends) contacted the Duke Kidney and Pancreas Transplant Center (via telephone) expressing interest in donating a live kidney on participants' behalves.

Statistical Analysis

We described participant sociodemographic characteristics, medical characteristics, receipt of LDKT information, and their LDKT knowledge both overall and by LDKT pursuit and donor inquiry status. We additionally described patient education, income, health literacy and numeracy by perceived information and knowledge. Distribution and frequencies for categorical variables are presented as counts and percentages, and continuous variables are presented as means and standard deviations or medians interquartile ranges. Differences across LDKT pursuit category, donor inquiry status, and perceived information and knowledge were measured using the ANOVA F test or Kruskal-Wallis test (for non-normal data) for continuous variables and the Chi-square test for categorical variables. In separate multivariable logistic regression models, we estimated the odds ratio of greater LDKT pursuit, defined as greater LDKT pursuit ('intermediate and 'high') versus 'low' LDKT pursuit, and the odds ratio of previous live donor inquiry, defined as any prior live donor inquiry to the transplant center versus none, comparing participants with more LDKT information and knowledge to participants with less LDKT information and knowledge. We fit models with and without adjustment for participants' sociodemographic and medical characteristics. In post-hoc analyses, we stratified multivariable models by the median age (less than 52 years versus greater than or equal to 52 years), and tested for potential effect modification by age by incorporating interaction terms between age category and either

receipt of LDKT information or LDKT knowledge. All p-values were two sided at a 0.05 significance level. SAS 9.4 (SAS Institute, Cary, NC) was used for all analyses.

Results

Sociodemographic characteristics

The 300 African American study participants had been waiting on the deceased donor kidney transplant waiting list for a median (Interquartile Range, IQR) 292 (81, 700) days. Most participants had received dialysis less than 3 years (43%), while 34% were on dialysis 3 years and 17% of participants had never started dialysis. A majority of participants were male (56%), 19% had an annual income less than \$20,000, and more than one third had attained high school or less education (39%). Over half of participants were retired or retired due to disability (61%), while 31% were working and 7% were unemployed/looking for work. Of participants with medical insurance coverage, the majority (53%) only had Medicare coverage. Although most (82%) were receiving dialysis, several (18%) had not yet initiated renal replacement therapy. A majority of participants (62 %) had less than maximum numeracy, while more than half (59%) had 9th grade health literacy or higher. (Table 1)

Pursuit of LDKT and LDKT donor inquires

A majority of participants (72%) reported 'high' pursuit of LDKT, while fewer reported 'intermediate' (18%) or 'low' (10%) pursuit of LDKT. Despite these high levels of self-reported pursuit, only approximately one third (35%) previously had potential live donor inquiries to the transplant center on their behalves. Participants with low pursuit were statistically significantly older (mean (Standard Deviation, SD) age 55.2 (8.8) years among those with low pursuit, 54.9 (11) years among those with intermediate pursuit, and 50.8 (11.2) years among 'those with high pursuit, respectively, p=0.01). Similarly, participants with fewer donor inquiries were statistically significantly older (mean (SD) age 53.1 (10.7) years among those with no donor inquiries versus 49.9 (11.4) years among those with donor inquires, p=0.02). Participants with greater education were more likely to have had donor inquiries compared to participants with less education (39% among those with greater than high school versus 27% among those with high school or less, p=0.03). Potential recipients who reported working (48%) and less than half of those who reported being retired (33%) and retired due to disability (28%) had a previous donor inquiry, whereas fewer inquiries were reported among potential recipients who were unemployed/looking for work, p=0.02. Participants who were on dialysis 3 years, were less likely to have had a donor inquiry compared to participants who had never started dialysis or were on dialysis less than 3 years (28%, 31%, and 44%, respectively, p=0.02). (Table 1)

Association of Perceived LDKT Information Adequacy and Knowledge with Pursuit of LDKT or Live Donor Inquiries

Fewer than half (39%) of participants reported they felt 'very well' or 'extremely well' informed about LDKT. In bivariate analyses, participants' education, income, numeracy and literacy were not associated with their perceived LDKT information adequacy. Similarly, fewer than half (38%) reported they had a 'great deal of knowledge' about LDKT. In

bivariate analyses, participants with greater than high school education were statistically significantly more likely to report having a great deal of knowledge than participants with an educational attainment of high school or less (45% versus 28%, respectively, $p < 0.01$). Participants with greater than or equal to a 9th grade health literacy level were also more likely than those with lower health literacy to report they had a great deal of LDKT knowledge (44% among those with 9th grade, 37% among 7th-8th grade, 23% among 4th-6th grade, $p = 0.02$). (Table 2)

In multivariable analyses adjusting for participants' sociodemographic characteristics, participants who perceived themselves as being 'very' or 'extremely' well informed (versus less than very well informed) about LDKT had statistically significantly higher odds of 'intermediate' or 'high' (versus 'low') pursuit of LDKT (odds ratio (OR) 95% confidence interval [CI] 2.83 [1.06-7.57]). In contrast, participants' perceived LDKT knowledge was not statistically significantly associated with their pursuit of LDKT or with the presence of live donor inquires. Neither participants' perceived adequacy of LDKT information nor their perceived knowledge about LDKT were associated with live donor inquiries in primary models. (Table 3)

In age-stratified multivariable models, participants aged less than 52 years of age who reported having 'a great deal of knowledge' were statistically significantly more likely to have had a donor inquiry made on their behalfs compared to those with 'no or some knowledge' (OR [95% CI] 2.14 (1.02-4.50)). Also, Participants aged less than 52 years who reported feeling 'very well' or 'extremely' well informed were statistically significantly more likely to have had a donor inquiry than those who reported being 'not well informed or slightly well informed' or 'moderately well informed' (OR [95% CI] 4.70 (1.46-15.1)). (Table 4)

Discussion

In this cross-sectional study, a majority of African American kidney transplant candidates reported they felt sub-optimally informed or sub-optimally knowledgeable about LDKT. Among all participants, those who felt more informed about LDKT had greater odds of having pursued LDKT when compared to those who felt less informed. Greater perceived adequacy of LDKT information and greater perceived knowledge were both associated with live donor inquiries among younger but not older potential recipients. Findings shed light on the potential influence perceived LDKT information adequacy and knowledge may have on African American transplant candidates' receipt of LDKT.

To our knowledge, this is one of the first studies examining transplant candidates' perceived LDKT information adequacy or knowledge solely among African Americans. This is also one of the few studies to investigate the relation of perceived information adequacy and knowledge with African American transplant candidates' pursuit of LDKT or living donor inquiries. Given persistently lower rates of LDKT among African Americans compared to other racial and ethnic groups,¹² our study helps to elucidate factors that could be targeted in future efforts to improve African Americans' LDKT rates. Findings suggest that enhanced and tailored education to inform African American patients who are already on the deceased

donor waiting list about LDKT could enhance their pursuit and ultimate receipt of LDKT. A previous observational study of potential transplant candidates undergoing evaluation for LDKT, in which African Americans demonstrating higher transplant knowledge were more likely to receive living kidney donor transplants compared to those with less knowledge, supports our findings.¹³ Our study focused on African American transplant candidates who had already completed the transplant evaluation process and were waiting for a deceased donor kidney—persons who may be most ready and eligible receive LDKT yet may need support to overcome LDKT barriers such as talking to potential donors.

Perceived information adequacy may be an important pre-requisite for self-efficacy.¹⁴ Thus, transplant candidates who feel better informed about LDKT may feel better able to pursue LDKT. All of our study participants were established transplant candidates who had been provided with extensive information about LDKT during their routine intake and evaluation processes at the transplant center. Despite this, over half of study participants perceived themselves as being moderately or less well informed about LDKT during our study. This may reflect a need for additional approaches to deliver and reinforce LDKT information to transplant candidates. For instance, our study participants had been waiting on the deceased donor waiting list for a median of over 9 months and may not have received substantial information about LDKT after their initial contacts with the transplant center. Education delivered in-person¹⁵⁻¹⁷, at-home¹⁸⁻²¹, and by peers²²⁻²⁴ has been found to help patients feel informed about their therapies in other areas of medicine, and these approaches may also help to improve African American transplant candidates' information adequacy. We also found study participants with lower health literacy and lower education were more likely to report they felt less knowledgeable about LDKT. Previous studies have demonstrated decreased likelihood of referral for transplant evaluation²⁵ and lower odds of wait listing²⁶ among patients with limited health literacy. Poor health literacy may also limit patients' understanding and knowledge of LDKT. Thus, efforts to ensure LDKT information is tailored to patients' literacy and education levels may have significant value.

Although perceived LDKT information adequacy and knowledge were not associated with donor inquiries among older participants, younger participants who reported having greater LDKT knowledge had statistically significantly greater odds of having had a donor inquire about donating on their behalves, relative to younger participants who reported having less LDKT knowledge. Younger participants who reported feeling more informed about LDKT also had statistically significantly greater odds of having had a donor inquiry compared to younger participants who reported feeling less informed about LDKT. It is possible younger transplant candidates who feel knowledgeable or more informed about LDKT may be more proactive with regard to speaking to potential donors about LDKT. This could, in turn, prompt more donor inquiries on their behalves. In a previous study, older potential LDKT transplant candidates were hesitant to put potential donors at risk and were therefore less willing to discuss LDKT with family members or friends.²⁷ Efforts may be needed to better understand whether certain types of information (e.g., on donor risks) could be provided to transplant older candidates in order to address these or other potential concerns.

Our study has limitations. First, while our study focused on perceived knowledge about LDKT rather than *actual* knowledge, patients' self-efficacy regarding their transplant

knowledge may also influence their pursuit of LDKT. However, in a cross-sectional study of transplant candidates at a single center, perceived knowledge about kidney transplantation better predicted participants' likelihood of asking someone to donate than *actual* kidney transplant knowledge.²⁸ Second, we conducted our study among participants from a single transplant center in central North Carolina, and our findings may not generalize to patients awaiting transplantation from other regions of the U.S. Practices on LDKT education may vary across transplant centers. Nonetheless, studies conducted in centers across other areas of the U.S. have demonstrated a need to improve transplant education among transplant recipients, supporting the validity of our findings.^{13,28-31} Third, many African Americans participating in our study had already pursued LDKT, suggesting high rates of interest in LDKT. Rates of LDKT interest might be greater among study participants compared to those not participating in our study. Fourth, while all patients at Duke receive education about live donor transplantation during their evaluation processes which is documented in their medical records, we did not review study participants' medical records to identify any potential concerns regarding the quality of completeness of education efforts. Also, while study findings suggest participants who were less than 52 years of age who perceived themselves as having 'a great deal' of knowledge were statistically significantly more likely to have a donor inquiry than participants who reported having no or some knowledge, this finding was only present in an age-stratified post-hoc analysis. Future studies specifically exploring these relationships among potential recipients of younger or older age are needed.

Reasons for a lack of an observed association between perceived information and knowledge with donor inquiries could be related to our cross-sectional study design. Specifically, we did not assess identification of live donor inquiries after we assessed participants perceived information or knowledge. It is therefore possible that donor inquiries could have occurred after our assessments, and it is also possible associations we observed could be due to reverse causality. Longitudinal observation would be needed to better quantify the potential causal link between transplant candidates' perceived information or knowledge and donor inquiries. Longitudinal assessments might also be needed to capture influences on donor inquiries that our study did not measure. For example, we did not assess participants' experiences with kidney disease while on the waiting list or potential donor attitudes about participants' treatment experiences. Participants who were recently listed on the waiting list at the time of our study, may have had fewer donor inquiries than participants who had been on the waiting list for a longer time period at the time of our study. While the median time on the list was 292 days for our participants, the potential donor inquiries could increase as potential donors witness the difficulties experienced by transplant candidates in terms of managing their dialysis treatments over time. Other factors that could influence potential donors' willingness to step forward also deserve consideration, including. A number of factors could influence potential donors' willingness to step forward for evaluation, including their potential donors' concerns about their own poor health or eligibility to donate over time (e.g., the need for weight loss), uncertainty about the evaluation process, or their disinterest in donation could also influence donor inquiries. Further, recipients themselves may not speak with potential donors about donating if they are concerned about donors' health. Some study participants might also have had potential donors already be 'ruled out' (e.g., due to ABO-incompatibly) at the time of our questionnaire. Longitudinal studies

capturing these potential influences on donor inquiries, in addition to transplant candidates' perceived information or knowledge, are needed.

In conclusion, a majority of African American transplant candidates felt sub optimally informed or knowledgeable about LDKT. Greater perceived information adequacy was associated with greater LDKT pursuit, particularly among younger transplant candidates. The role of improving candidates' perceived information adequacy and LDKT knowledge should be considered in future efforts to improve LDKT rates among African Americans.

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References

1. Mange KC, Joffe MM, Feldman HI. Effect of the use or nonuse of long-term dialysis on the subsequent survival of renal transplants from living donors. *N Engl J Med*. 2001;344(10):726–731. [PubMed: 11236776]
2. Terasaki PI, Cecka JM, Gjertson DW, Takemoto S. High survival rates of kidney transplants from spousal and living unrelated donors. *N Engl J Med*. 1995;333(6):333–336. [PubMed: 7609748]
3. Gore JL, Danovitch GM, Litwin MS, Pham PT, Singer JS. Disparities in the utilization of live donor renal transplantation. *Am J Transplant*. 2009;9(5):1124–1133. [PubMed: 19422338]
4. United States Renal Data System. Annual Renal Data Report, 2018, Chapter 6: Transplantation 2018; https://www.usrds.org/2018/view/v2_06.aspx. Accessed December 7, 2018.
5. Purnell TS, Luo X, Cooper LA, et al. Association of race and ethnicity with live donor kidney transplantation in the united states from 1995 to 2014. *JAMA*. 2018;319(1):49–61. [PubMed: 29297077]
6. Finkelstein FO, Story K, Firaneck C, et al. Perceived knowledge among patients cared for by nephrologists about chronic kidney disease and end-stage renal disease therapies. *Kidney Int*. 2008;74(9):1178–1184. [PubMed: 18668024]
7. Eggers PW. Racial differences in access to kidney transplantation. *Health Care Financ Rev*. 1995;17(2):89–103. [PubMed: 10157383]
8. Sanfilippo FP, Vaughn WK, Peters TG, et al. Factors affecting the waiting time of cadaveric kidney transplant candidates in the United States. *JAMA*. 1992;267(2):247–252. [PubMed: 1727521]
9. Strigo TS, Ephraim PL, Pounds I, et al. The TALKS study to improve communication, logistical, and financial barriers to live donor kidney transplantation in African Americans: protocol of a randomized clinical trial. *BMC Nephrol*. 2015;16:160. [PubMed: 26452366]
10. Lipkus IM, Samsa G, Rimer BK. General performance on a numeracy scale among highly educated samples. *Med Decis Making*. 2001;21(1):37–44. [PubMed: 11206945]
11. Davis TC, Long SW, Jackson RH, et al. Rapid estimate of adult literacy in medicine: a shortened screening instrument. *Fam Med*. 1993;25(6):391–395. [PubMed: 8349060]
12. Purnell TS, Luo X, Cooper LA, et al. Association of Race and Ethnicity With Live Donor Kidney Transplantation in the United States From 1995 to 2014. *JAMA*. 2018;319(1):49–61. [PubMed: 29297077]
13. Waterman AD, Peipert JD, Hyland SS, McCabe MS, Schenk EA, Liu J. Modifiable patient characteristics and racial disparities in evaluation completion and living donor transplant. *Clin J Am Soc Nephrol*. 2013;8(6):995–1002. [PubMed: 23520044]
14. Bandura A Self-efficacy mechanism in human agency *Am Psychol*. 1982;37(2):122–147.

15. Boulware LE, Hill-Briggs F, Kraus ES, et al. Effectiveness of educational and social worker interventions to activate patients' discussion and pursuit of preemptive living donor kidney transplantation: a randomized controlled trial. *Am J Kidney Dis.* 2013;61(3):476–486. [PubMed: 23089512]
16. Patzer RE, McPherson L, Basu M, et al. Effect of the iChoose Kidney decision aid in improving knowledge about treatment options among transplant candidates: A randomized controlled trial. *Am J Transplant.* 2018;18(8):1954–1965. [PubMed: 29446209]
17. Weng FL, Peipert JD, Holland BK, Brown DR, Waterman AD. A Clustered Randomized Trial of an Educational Intervention During Transplant Evaluation to Increase Knowledge of Living Donor Kidney Transplant. *Prog Transplant.* 2017;27(4):377–385. [PubMed: 29187135]
18. Ismail SY, Luchtenburg AE, Timman R, et al. Home-based family intervention increases knowledge, communication and living donation rates: a randomized controlled trial. *Am J Transplant.* 2014;14(8):1862–1869. [PubMed: 24935081]
19. Rodrigue JR, Cornell DL, Kaplan B, Howard RJ. A randomized trial of a home-based educational approach to increase live donor kidney transplantation: effects in blacks and whites. *Am J Kidney Dis.* 2008;51(4):663–670. [PubMed: 18371542]
20. Rodrigue JR, Cornell DL, Lin JK, Kaplan B, Howard RJ. Increasing live donor kidney transplantation: a randomized controlled trial of a home-based educational intervention. *Am J Transplant.* 2007;7(2):394–401. [PubMed: 17173659]
21. Rodrigue JR, Paek MJ, Egbuna O, et al. Making house calls increases living donor inquiries and evaluations for blacks on the kidney transplant waiting list. *Transplantation.* 2014;98(9):979–986. [PubMed: 24825528]
22. Garonzik-Wang JM, Berger JC, Ros RL, et al. Live donor champion: finding live kidney donors by separating the advocate from the patient. *Transplantation.* 2012;93(11):1147–1150. [PubMed: 22461037]
23. Tan JC, Gordon EJ, Dew MA, et al. Living Donor Kidney Transplantation: Facilitating Education about Live Kidney Donation—Recommendations from a Consensus Conference. *Clin J Am Soc Nephrol.* 2015;10(9):1670–1677. [PubMed: 25908792]
24. Clark CR, Hicks LS, Keogh JH, Epstein AM, Ayanian JZ. Promoting access to renal transplantation: the role of social support networks in completing pre-transplant evaluations. *J Gen Intern Med.* 2008;23(8):1187–1193. [PubMed: 18478302]
25. Grubbs V, Gregorich SE, Perez-Stable EJ, Hsu CY. Health literacy and access to kidney transplantation. *Clin J Am Soc Nephrol.* 2009;4(1):195–200. [PubMed: 19056617]
26. Warsame F, Haugen CE, Ying H, et al. Limited health literacy and adverse outcomes among kidney transplant candidates. *Am J Transplant.* 2019;19(2):457–465. [PubMed: 29962069]
27. Boulware LE, Hill-Briggs F, Kraus ES, et al. Identifying and addressing barriers to African American and non-African American families' discussions about preemptive living related kidney transplantation. *Prog Transplant.* 2011;21(2):97–104; quiz 105. [PubMed: 21736237]
28. Gupta N, Salter ML, Garonzik-Wang JM, et al. Actual and perceived knowledge of kidney transplantation and the pursuit of a live donor. *Transplantation.* 2014;98(9):969–973. [PubMed: 24837542]
29. Patzer RE, Perryman JP, Pastan S, et al. Impact of a patient education program on disparities in kidney transplant evaluation. *Clin J Am Soc Nephrol.* 2012;7(4):648–655. [PubMed: 22344515]
30. Waterman AD, Barrett AC, Stanley SL. Optimal transplant education for recipients to increase pursuit of living donation. *Prog Transplant.* 2008;18(1):55–62. [PubMed: 18429583]
31. Rodrigue JR, Paek MJ, Egbuna O, et al. Readiness of wait-listed black patients to pursue live donor kidney transplant. *Prog Transplant.* 2014;24(4):355–361. [PubMed: 25488559]

Table 1. Baseline Characteristics of all Randomized Patients in TALKS Study by Pursuit of LDKT (N=300)

Characteristic	All Subjects	Pursuit of LDKT Stage [†]			Donor Inquiry		P
		1 (least activated)	2 (moderately Activated)	3 (most activated)	Yes	No	
Sociodemographics							
Age, mean (sd)	52.0 (11.0)	55.2 (8.8)	54.9 (11.0)	50.8 (11.2)	49.9 (11.4)	53.1 (10.7)	0.02
Sex, N (%)							
Female	133 (44%)	13 (10%)	24 (18%)	96 (72%)	49 (37%)	84 (63%)	0.48
Male	167 (56%)	18 (11%)	30 (18%)	119 (71%)	55 (33%)	112 (67%)	
Education, N (%)							
High school or less	117 (39%)	12 (10%)	26 (22%)	79 (68%)	32 (27%)	85 (73%)	0.03
More than high school	183 (61%)	19 (10%)	28 (15%)	136 (74%)	72 (39%)	111 (61%)	
Income, N (%)							
Refused/Don't Know	45 (15%)	8 (18%)	8 (18%)	29 (64%)	11 (24%)	34 (76%)	
Under \$20,000	58 (19%)	4 (7%)	16 (28%)	38 (66%)	15 (26%)	43 (74%)	
\$20,000 - \$39,999	70 (23%)	5 (7%)	14 (20%)	51 (73%)	25 (36%)	45 (64%)	0.14
\$40,000 - \$59,999	60 (20%)	6 (10%)	11 (18%)	43 (72%)	25 (42%)	35 (58%)	
\$60,000 or More	67 (22%)	8 (12%)	5 (7%)	54 (81%)	28 (42%)	39 (58%)	
Employment, N (%)							
Full-time employee	59 (20%)	9 (15%)	6 (10%)	44 (75%)	30 (51%)	29 (49%)	
Part-time employee	21 (7%)	3 (14%)	3 (14%)	15 (71%)	6 (29%)	15 (71%)	
Student	5 (2%)	1 (20%)	0 (0%)	4 (80%)	5 (100%)	0 (0%)	
Retired	33 (11%)	4 (12%)	7 (21%)	22 (67%)	11 (33%)	22 (67%)	<0.01
Homemaker	8 (2.7%)	1 (13%)	3 (38%)	4 (50%)	4 (50%)	4 (50%)	
Retired due to disability	151 (50%)	11 (7%)	31 (21%)	109 (72%)	43 (28%)	108 (72%)	
Unemployed/looking for work	22 (7%)	2 (9%)	4 (18%)	16 (73%)	5 (23%)	17 (77%)	
<i>Refused</i>	1 (<1%)	0 (0%)	0 (0%)	1 (100%)	0 (0%)	1 (100%)	
Employment, N (%)							
Missing/Refused/Don't Know	1 (0%)	0 (0%)	0 (0%)	1 (100%)	0 (0%)	1 (100%)	0.64
							0.02

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Characteristic	All Subjects	Pursuit of LDKT Stage [†]			Donor Inquiry		P
		1 (Least activated)	2 (moderately Activated)	3 (most activated)	Yes	No	
		31 (10%)	54 (18%)	215 (72%)	104 (35%)	196 (65%)	
Working	93 (31%)	14 (15%)	12 (13%)	67 (72%)	45 (48%)	48 (52%)	
Retired	33 (11%)	4 (12%)	7 (21%)	22 (67%)	11 (33%)	22 (67%)	
Retired due to disability	151 (50%)	11 (7%)	31 (21%)	109 (72%)	43 (28%)	108 (72%)	
Unemployed/looking for work	22 (7%)	2 (9%)	4 (18%)	16 (73%)	5 (23%)	17 (77%)	
Medical Insurance coverage							
Private	68 (23%)	8 (12%)	7 (10%)	53 (78%)	29 (43%)	39 (57%)	
Medicaid Only	13 (4%)	2 (15%)	0 (0%)	11 (85%)	3 (23%)	10 (77%)	
Medicare Only	158 (53%)	16 (10%)	34 (22%)	108 (68%)	52 (33%)	106 (67%)	0.29
Medicare/Medicaid	57 (19%)	4 (7%)	12 (21%)	41 (72%)	20 (35%)	37 (65%)	
Other	4 (1%)	1 (25%)	1 (25%)	2 (50%)	0 (0%)	4 (100%)	
Numeracy Score, mean (SD)	1.9 (1.0)	1.9 (1.0)	1.6 (1.0)	2.0 (1.0)	2.1 (1.0)	1.8 (1.0)	<0.01
Numeracy Score, n (%)							
0 (0% Correct)	34 (11%)	3 (9%)	7 (21%)	24 (71%)	11 (32%)	23 (68%)	
1 (33% Correct)	64 (21%)	7 (11%)	16 (25%)	41 (64%)	16 (25%)	48 (75%)	
2 (67% Correct)	91 (30%)	10 (11%)	18 (20%)	63 (69%)	24 (26%)	67 (74%)	0.008
3 (100% Correct)	103 (34%)	10 (10%)	10 (10%)	83 (81%)	49 (48%)	54 (52%)	
<i>missing</i>	8 (3%)	1 (13%)	3 (38%)	4 (50%)	4 (50%)	4 (50%)	
Health Literacy Score, mean (SD)	6.0 (1.7)	5.5 (2.2)	5.9 (1.5)	6.1 (1.6)	6.3 (1.4)	5.9 (1.8)	0.06
Health Literacy Score, n (%)							
<= 3rd Grade	10 (3%)	2 (20%)	1 (10%)	7 (70%)	3 (30%)	7 (70%)	
4th-6th Grade	13 (4%)	3 (23%)	2 (15%)	8 (62%)	1 (8%)	12 (92%)	
7th-8th Grade	89 (30%)	9 (10%)	20 (22%)	60 (67%)	29 (33%)	60 (67%)	0.26
>= 9th Grade	177 (59%)	15 (8%)	28 (16%)	134 (76%)	67 (38%)	110 (62%)	
<i>missing</i>	11 (4%)	2 (18%)	3 (27%)	6 (55%)	4 (36%)	7 (64%)	
Interest in LDKT, mean (sd)	7.8 (3.4)	7.0 (4.2)	7.1 (3.6)	8.1 (3.1)	8.4 (3.0)	7.4 (3.5)	0.01
Kidney disease treatment							
No kidney replacement treatment yet	53 (18%)	6 (11%)	12 (23%)	35 (66%)	17 (32%)	36 (68%)	0.36
In-center hemodialysis	189 (63%)	20 (11%)	32 (17%)	137 (72%)	65 (34%)	124 (66%)	

Characteristic	All Subjects	Pursuit of LDKT Stage [†]			Donor Inquiry		P
		1 (least activated)	2 (moderately Activated)	3 (most activated)	Yes	No	
		31 (10%)	54 (18%)	215 (72%)	104 (35%)	196 (65%)	
Home hemodialysis	12 (4%)	0 (0%)	3 (25%)	9 (75%)	7 (58%)	5 (42%)	
Peritoneal hemodialysis	46 (15%)	5 (11%)	7 (15%)	34 (74%)	15 (33%)	31 (67%)	
Days since entry on the deceased transplant list, median (IQR)	292 (81, 700)	321 (69, 752)	288 (56, 707)	291 (86, 676)	306 (102, 682)	271 (63, 724)	0.36
Years on Dialysis, n (%)							
Never started dialysis	52 (17%)	6 (12%)	11 (21%)	35 (67%)	16 (31%)	36 (69%)	
Less than 3	130 (43%)	11 (8%)	22 (17%)	97 (75%)	57 (44%)	73 (56%)	0.02
Greater than or equal to 3	101 (34%)	13 (13%)	18 (18%)	70 (69%)	28 (28%)	73 (72%)	
<i>missing</i>	17 (6%)	1 (6%)	3 (18%)	13 (76%)	3 (18%)	14 (82%)	

[†] Stage 1: Discussed with Family and Identified a Potential Donor

Stage 2: Discussed with Family but No Donor Identified

Stage 3: No Family Discussion and No Donor Identified

Table 2. Association of perceived information and knowledge about LDKT with participant sociodemographic characteristics

	Perceived Knowledge		p	Perceived Information			p
	No knowledge or some knowledge	A great deal of knowledge		Not well informed or slightly well informed	Moderately well informed	Very well informed or extremely well informed	
Education, n (%)	185 (62%)	115 (38%)		76 (25%)	107 (36%)	117 (39%)	
High school or less	84 (72%)	33 (28%)	<0.01	37 (32%)	41 (35%)	39 (33%)	0.10
More than high school	101 (55%)	82 (45%)		39 (21%)	66 (36%)	78 (43%)	
Income, N (%)							
Refused/Don't Know	35 (%)	10 (%)	0.31	18 (%)	14 (%)	13 (%)	0.46
Under \$20,000	33 (57%)	25 (43%)		13 (22%)	19 (33%)	26 (45%)	
\$20,000 - \$39,999	43 (61%)	27 (39%)		17 (24%)	24 (34%)	29 (41%)	
\$40,000 - \$59,999	40 (67%)	20 (33%)		13 (22%)	29 (48%)	18 (30%)	
\$60,000 or More	34 (51%)	33 (49%)		15 (22%)	21 (31%)	31 (46%)	
Numeracy							
Missing	7 (%)	1 (%)		1 (%)	3 (%)	4 (%)	
0 (0% correct)	23 (68%)	11 (32%)		8 (24%)	14 (41%)	12 (35%)	
1 (33% correct)	47 (73%)	17 (27%)	0.07	21 (33%)	23 (36%)	20 (31%)	0.75
2 (67% correct)	50 (55%)	41 (45%)		22 (24%)	31 (34%)	38 (42%)	
3 (100% correct)	58 (56%)	45 (44%)		24 (23%)	36 (35%)	43 (42%)	
Literacy, n (%)							
Missing	10 (%)	1 (%)		3 (%)	4 (%)	4 (%)	
<= 3 rd grade	10 (100%)	0 (0%)		6 (60%)	2 (20%)	2 (20%)	
4 th -6 th grade	10 (77%)	3 (23%)	0.02	3 (23%)	4 (31%)	6 (46%)	0.18
7 th -8 th grade	56 (63%)	33 (37%)		26 (29%)	29 (33%)	34 (38%)	
>= 9 th grade	99 (56%)	78 (44%)		38 (21%)	68 (38%)	71 (40%)	

Odds Ratio of greater (versus less) LDKT pursuit or receipt of potential living donor inquiries according to participants' perceived LDKT knowledge or perceived LDKT information.

Table 3.

Characteristic	N (%)	OR (95% CI)		
		(Stages 3 or 2) vs Stage 1		Donor Inquiry (Yes vs No)
		Unadjusted	Adjusted [‡]	Adjusted [‡]
Perceived Knowledge				
No knowledge or some knowledge	185 (62%)	ref	ref	ref
A great deal of knowledge	115 (38%)	2.30 (0.96, 5.53)	2.01 (0.80, 5.07)	1.28 (0.75, 2.19)
<i>p-value</i>		0.06	0.14	0.36
Perceived Information				
Not well informed or slightly well informed	76 (25%)	ref	ref	ref
Moderately well informed	107 (36%)	2.46 (1.00, 6.02)	2.31 (0.90, 5.93)	1.61 (0.84, 3.06)
Very well informed or extremely well informed	117 (39%)	3.08 (1.22, 7.74)	2.83 (1.06, 7.57)	1.75 (0.93, 3.29)
<i>p-trend</i>		0.02	0.04	0.29

[‡] Adjusted for potential confounders: age (continuous), sex (binary), education level (binary: less than or equal to a high school education vs. greater than a high school education), income (binary: less than \$20K vs. greater than or equal to \$20K), health literacy (risk numeracy and health literacy scores, continuous), reported interest in LDKT (continuous), time since enrolling on the deceased transplant list (continuous), years on dialysis (categorical)

Post-hoc Analysis: Odds Ratio of greater (versus less) LDKT pursuit or receipt of potential living donor inquiries according to participants' perceived LDKT knowledge or perceived LDKT information, stratified by cohort median age (52 years).

Table 4.

Characteristic	N (%)	OR [†] (95% CI)						p-int*
		(Stages 3 or 2) vs Stage 1			Donor Inquiry (Yes vs No)			
		Age < 52 146 (49%)	Age >= 52 154 (51%)	p-int	Age < 52 146 (49%)	Age >= 52 154 (51%)		
Perceived Knowledge								
No knowledge or some knowledge	185 (62%)	ref	ref		ref	ref		0.04
A great deal of knowledge	115 (38%)	1.08 (0.27, 4.31)	2.71 (0.67, 11.0)	0.54	2.14 (1.02, 4.50)	0.67 (0.28, 1.58)		
<i>p-value</i>		0.91	0.16		0.04	0.36		
Perceived Information								
Not well informed or slightly well informed	76 (25%)	ref	ref		ref	ref		
Moderately well informed	107 (36%)	4.03 (0.73, 22.2)	1.27 (0.35, 4.67)	0.80	3.04 (0.94, 9.80)	1.22 (0.46, 3.29)		0.02
Very well informed or extremely well informed	117 (39%)	2.70 (0.54, 13.5)	2.37 (0.57, 9.78)		4.70 (1.46, 15.1)	0.57 (0.21, 1.55)		
<i>p-trend</i>		0.27	0.23		0.01	0.24		

[†] Adjusted for potential confounders: age (continuous), sex (binary), education level (binary: less than or equal to a high school education vs. greater than a high school education), income (binary: less than \$20K vs. greater than or equal to \$20K), health literacy (risk numeracy and health literacy scores, continuous), reported interest in LDKT (continuous), time since enrolling on the deceased transplant list (continuous), years on dialysis (categorical)

* *p-int* = p-value for interaction term