

# Health-Related and Psychosocial Concerns about Transplantation among Patients Initiating Dialysis

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## Abstract

**Background and objectives** Disparities in kidney transplantation remain; one mechanism for disparities in access to transplantation (ATT) may be patient-perceived concerns about pursuing transplantation. This study sought to characterize prevalence of patient-perceived concerns, explore interrelationships between concerns, determine patient characteristics associated with concerns, and assess the effect of concerns on ATT.

**Design, setting, participants, & measurements** Prevalences of 12 patient-perceived concerns about pursuing transplantation were determined among 348 adults who recently initiated dialysis, recruited from 26 free-standing dialysis centers around Baltimore, Maryland (January 2009–March 2012). Using variable reduction techniques, concerns were clustered into two categories (health-related and psychosocial) and quantified with scale scores. Associations between patient characteristics and concerns were estimated using modified Poisson regression. Associations between concerns and ATT were estimated using Cox models.

**Results** The most frequently cited patient-perceived concerns were that participants felt they were doing fine on dialysis (68.4%) and felt uncomfortable asking someone to donate a kidney (29.9%). Older age was independently associated with having high health-related (adjusted relative risk, 1.35 [95% confidence interval, 1.20 to 1.51], for every 5 years older for those  $\geq 60$  years) or psychosocial (1.15 [1.00 to 1.31], for every 5 years older for those aged  $\geq 60$  years) concerns, as was being a woman (1.72 [1.21 to 2.43] and 1.55 [1.09 to 2.20]), having less education (1.59 [1.08 to 2.35] and 1.77 [1.17 to 2.68], comparing postsecondary education to grade school or less), and having more comorbidities (1.18 [1.08 to 1.30] and 1.18 [1.07 to 1.29], per one comorbidity increase). Having never seen a nephrologist before dialysis initiation was associated with high psychosocial concerns (1.48 [1.01 to 2.18]). Those with high health-related (0.37 [0.16 to 0.87]) or psychosocial (0.47 [0.23 to 0.95]) concerns were less likely to achieve ATT (median follow-up time 2.2 years; interquartile range, 1.6–3.2).

**Conclusions** Patient-perceived concerns about pursuing kidney transplantation are highly prevalent, particularly among older adults and women. Reducing these concerns may help decrease disparities in ATT.

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## Introduction

Disparities in kidney transplantation (KT) are well documented; older adults, women, African Americans, those with less education, and those with less income are less likely to be waitlisted for a kidney or to receive a live or deceased donor transplant (1–5). Nevertheless, the mechanisms by which disparities in access to transplantation (ATT) occur are poorly understood. Unlike age, sex, and race, patient-perceived concerns about pursuing KT, such as inhibitions about asking a living donor to donate or fear of surgery, are potentially modifiable. Thus, understanding the relationships between patient characteristics, patient-perceived concerns, and ATT is important for potentially addressing disparities.

Unfortunately, most studies of the relationship between patient perceptions and clinical decision-making in transplantation involve patients who are already waitlisted (*i.e.*, patients who have already achieved ATT).

For example, studies have examined potential transplant candidates' concerns specific to pursuing and accepting live donor organs (6–8). The more commonly cited concerns from these studies include candidates not wanting to harm donors, to accept a kidney that a donor might need later, or to disappoint the donor if the kidney fails (9). Additional work has investigated barriers to accepting deceased donor organs of certain high-risk phenotypes (10,11). Concerns from these studies included fear of undetected HIV among deceased donors with high infectious risk. However, barriers to accepting live and high-risk deceased donor organs are concerns only for those who have already achieved ATT. Most information about patient-perceived concerns about ATT has arisen only through qualitative methods (9), leaving a gap in knowledge about the quantifiable relationships between patient characteristics, patient-perceived concerns, and ATT.

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Quantifying the more common patient-perceived concerns to pursuing KT would inform potential educational or logistical interventions. However, these concerns are likely to be interrelated. Therefore, when investigating the role of these concerns in ATT, understanding their interrelationships is necessary for appropriate quantitative inference. Exploratory factor analysis (EFA) frequently is used to identify a set of latent constructs underlying interrelated measured variables (12) and to reduce data for further analysis (13). In this study, we applied EFA to patient-perceived concerns about pursuing KT. The aims of this study were to characterize the prevalence of specific patient-perceived concerns, explore whether concerns cluster together into more general categories, determine whether certain patient characteristics were associated with concerns, and assess the effect of concerns on ATT.

## Materials and Methods

### Study Population

This study (an ancillary study to R01-DK072367, Predictors in Arrhythmic Cardiovascular Events) was an in-person, staff-administered survey of 348 patients who had initiated hemodialysis within the prior 6 months at 26 free-standing dialysis centers in Baltimore, Maryland, and six surrounding counties (14). Participants were enrolled between January 2009 and March 2012. The parent study was designed to investigate sudden unexpected cardiac death in an incident dialysis population with eligibility criteria including age  $\geq 18$  years and English speaking and strict exclusion criteria including living in a hospice, nursing facility, or prison; having a pacemaker or automatic implantable cardioverter defibrillator; or having cancer other than nonmelanoma skin cancer within the prior year. The parent study visits included exposure to ionizing radiation, so those who were pregnant or breastfeeding were also excluded. Individuals who were unable to complete consent or follow through on a study visit and those with a diagnosis of dementia, Alzheimer's, or schizophrenia were also excluded. Additionally excluded from the ancillary study were those who were HIV infected and those who had a diagnosis of cancer other than nonmelanoma skin cancer within the prior 5 years, because these are relative contraindications to transplantation. Those individuals who were preemptively listed for KT (*i.e.*, listed before initiation of dialysis) were excluded when assessing ATT, because they had already achieved the outcome of listing for transplantation. All study procedures were approved by the Johns Hopkins University Institutional Review Board. All participants provided informed consent.

### Participant Characteristics

Demographics (age, sex, race, employment, education, income, and household size), health behavior (smoking and alcohol use), and dialysis-related factors (time on dialysis and time between the first nephrologist visit and dialysis initiation) were obtained by participant self-report and augmented with data from the US Centers for Medicare and Medicaid Services (CMS) Form 2728. Body mass index (BMI) was calculated from self-reported height and weight. Comorbidities were assessed based on participant-reported medical history, augmented with data from CMS

Form 2728, and included hypertension, diabetes, heart failure, atherosclerotic disease, cardiovascular disease, cerebrovascular disease, peripheral vascular disease, asthma/chronic obstructive pulmonary disease, hepatitis C or hepatitis B infections, and history of cancer excluding nonmelanoma skin cancers  $\geq 5$  years before study entry.

### Concerns about Pursuing KT

Potential patient-perceived concerns about pursuing KT were identified from a literature review (9,15); opinions from an advisory panel of physicians experienced in counseling, consenting, and caring for patients considering transplants; and results from focus group discussions and pilot testing. Participants were asked whether they agreed with, felt neutral about, or disagreed with 12 potential individual concerns as a reason they would not pursue KT (Figure 1). Differences in reported concerns between age, sex, and racial groups were quantified using unadjusted ordered logistic regression.

### Exploratory Factor and Principal Components Analyses of Concerns

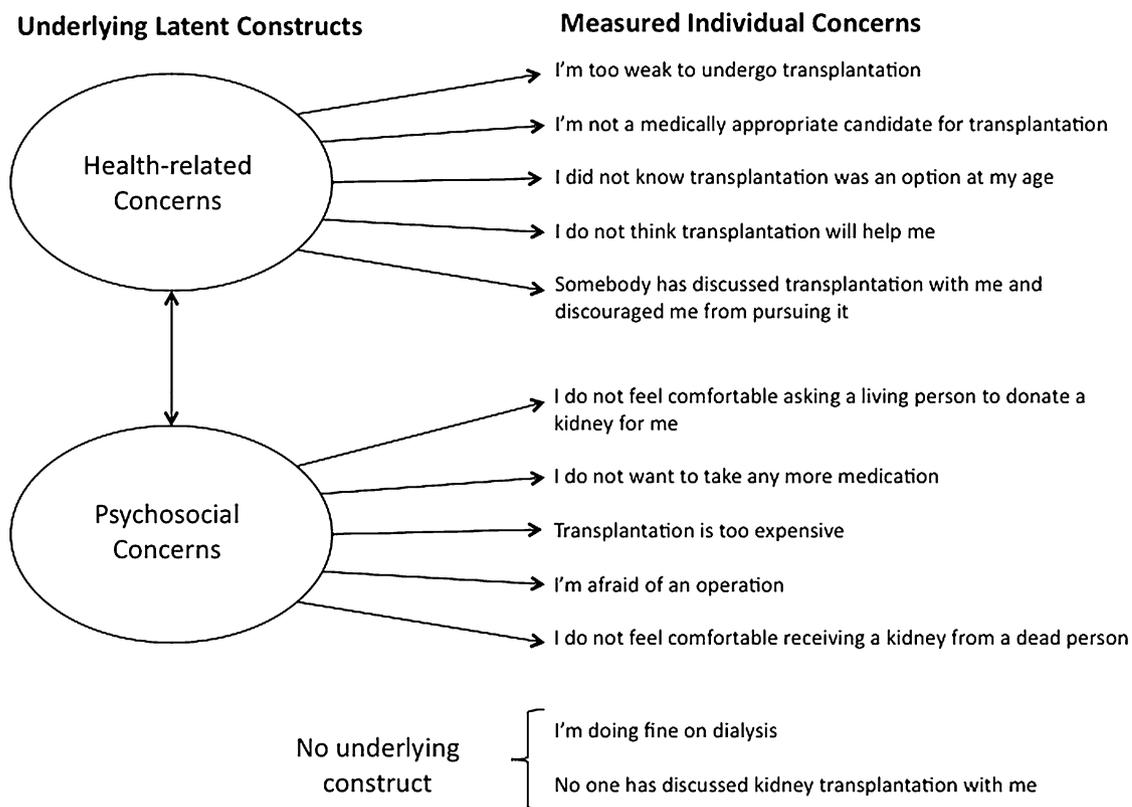
We then used EFA (13,16) to assign the individual concerns to categories (*i.e.*, underlying latent constructs) for further analysis. Two underlying latent constructs emerged that gave rise to two categories, which we named health-related and psychosocial concerns. Two individual concerns remained independent from underlying constructs, "I'm doing fine on dialysis" and "No one has discussed KT with me" (Figure 1). Health-related or psychosocial concerns were quantified using standardized scale scores (for statistical methods for this approach, see the Supplemental Appendix) and were dichotomized as high (highest quartile) and low (lower three quartiles) levels (17–21).

### Participant Characteristics and Concerns

Relative risks (RRs) for concerns were estimated using modified Poisson regression (22,23). The best functional form of age was determined empirically to be continuous (reported for ease of interpretation as "for every 5 years older") in all final models, and was also found empirically to include a linear spline at age 60 years in the final models for health-related and psychosocial concerns. Final multivariable models were selected based on statistical significance of independent variables, model-fit using the Akaike information criterion, and *a priori* rationale. All final multivariable models included age, sex, race, education level, BMI, number of comorbidities, smoking status, time on dialysis, and whether a participant had seen a nephrologist before initiating dialysis. Modification of the association between age and high levels of concerns by sex was determined using interaction terms in the final multivariable model.

### ATT

ATT was defined as waitlisting or live donor transplant without waitlisting after hemodialysis initiation and was assessed using data from the Scientific Registry for Transplantation (SRTR). The SRTR data system includes data on all donor, waitlisted candidates, and transplant recipients in the United States, submitted by members of the Organ Procurement and Transplantation Network (OPTN). The



**Figure 1. | Relationship between measured individual concerns and underlying latent constructs.** This figure depicts the concept behind using exploratory factor analysis in identifying underlying latent constructs (*i.e.*, factors) that give rise to the measured individual concerns (measured variables). Using this methodologic approach, we identified two underlying latent constructs (health-related and psychosocial concerns), which each comprised five of the measured concerns. Two of the measured individual concerns (“I’m doing fine on dialysis” and “No one has discussed kidney transplantation with me”) were not representative of an underlying latent construct.

US Department of Health and Human Services Health Resources and Services Administration provides oversight to the activities of the OPTN and SRTR contractors.

### Concerns and ATT

Associations between patient-perceived concerns and ATT were estimated using Cox proportional hazards models. Proportional hazards assumptions were assessed by visual inspection of complimentary log-log plots. Participants entered the study at the date of dialysis initiation and were censored at the waitlisting date, live donor transplantation without waitlisting date, date of death, or last available SRTR date for waitlisting or live donor transplantation without waitlisting (June 30, 2013). Two models were fit to ensure that inferences were not sensitive to covariate selection: one based on statistical significance or *a priori* biologic rationale and one empirically reflecting optimal parsimony by minimizing the Akaike information criterion. All fully adjusted models included age, sex, race, education, number of comorbidities, BMI, smoking status, and seeing a nephrologist before dialysis initiation. Parsimonious models included age, race, BMI, and smoking status.

### Statistical Analyses

All analyses were performed using STATA 12.1/SE software (College Station, TX).

## Results

### Participant Characteristics

Of 348 participants, the average age was 56.2 years, 40.2% were aged  $\geq 60$  years, 44.3% were women, 65.8% were African American, 77.3% had seen a nephrologist before initiating dialysis, and the median time on dialysis was 2.1 months at enrollment (Table 1). The median follow-up time was 2.2 years (interquartile range, 1.6–3.2 years). After enrollment, 21.0% were waitlisted for transplantation. No participants received a live donor kidney transplant before waitlisting.

### Concerns about Pursuing KT

The most frequently reported patient-perceived concern about pursuing KT was “I’m doing fine on dialysis” (68.4%). Older adults (aged  $\geq 60$  years) were more likely to report this than their younger (aged  $< 60$  years) counterparts (75.7% versus 63.5%;  $P=0.01$ ). Older adults also were more likely to report “No one has discussed KT with me” (32.9% versus 22.6%;  $P=0.02$ ), “I do not feel comfortable asking a living person to donate a kidney” (32.9% versus 27.9%;  $P=0.05$ ), and all individual health-related concerns (all  $P$  values  $< 0.01$ ). Women were more likely to report “I’m afraid of an operation” (26.0% versus 7.7%;  $P<0.001$ ), “I’m too weak to undergo transplantation” (18.8% versus 7.7%;  $P=0.01$ ), “I don’t think a transplantation would help me” (16.2% versus

**Table 1. Characteristics of study population at dialysis initiation**

Participant Characteristic <sup>a</sup>	
Age (yr)	56.2 (13.7)
Women	44.3
African-American race <sup>b</sup>	65.8
<b>Marital status</b>	
Married/domestic partner	33.7
Single	26.7
Separated/divorced	27.3
Widowed	12.1
Household size	2 (2, 4)
<b>Highest education level</b>	
Grade school or less	34.4
High school	22.0
Postsecondary	43.6
Working	16.1
Smoke cigarettes, ever	21.0
Alcohol use, current	17.2
BMI (kg/m <sup>2</sup> )	28.3 (24.4, 34.3)
<b>Comorbidities (n)</b>	3 (2, 4)
Diabetes	58.1
Hypertension	98.6
Heart failure	30.8
Atherosclerotic disease	24.4
Cardiovascular disease, other	24.1
Cerebrovascular disease	20.1
Peripheral vascular disease	7.5
Asthma/COPD	22.7
HCV/HBV	14.4
Cancer history (prior 5–10 yr) <sup>c</sup>	2.3
Time on dialysis (mo)	2.1 (1.4, 3.1)
Never saw nephrologist before dialysis initiation	22.7

Data are presented as the percentage, mean (SD), or median (interquartile range). BMI, body mass index; COPD, chronic obstructive pulmonary disease; HCV, hepatitis C viral infection; HBV, hepatitis B viral infection.

<sup>a</sup>N=348. Values are given as the percentage of the total study sample unless otherwise specified.

<sup>b</sup>African-American race is compared with non-African-American race, which is 92.4% Caucasian, 3.4% Asian/Asian American, 1.7% American Indian/Alaskan Native, and 2.5% other.

<sup>c</sup>Excludes those with a history within the prior 5 years and those with a history of only nonmelanoma skin cancer.

emerged from the EFA: health-related and psychosocial concerns. Health-related concerns incorporated the following specific concerns: “I’m not a medically appropriate candidate for transplantation,” “Somebody has discussed transplantation with me and discouraged me from pursuing it,” “I don’t think a transplant will help me,” “I’m too weak to undergo a kidney transplant,” and “I didn’t know a transplantation was an option at my age.” Psychosocial concerns incorporated the following specific concerns: “I don’t feel comfortable receiving a kidney from a dead person,” “I don’t feel comfortable asking a living person to donate a kidney for me,” “It’s too expensive,” “I don’t want to take any more medications,” and “I’m afraid of an operation.” Two concerns (“I’m doing fine on dialysis” and “No one has discussed KT with me”) did not cluster onto either the health-related or psychosocial categories (Figure 1). Of participants, 31.0% had at least one health-related concern and 54.0% had at least one psychosocial concern.

### Participant Characteristics and Concerns

In multivariable models, for every 5 years older, participants were more likely to report “I’m doing fine on dialysis” (adjusted RR [aRR], 1.04; 95% confidence interval [95% CI], 1.02 to 1.07;  $P=0.002$ ) and “No one has discussed KT with me” (aRR, 1.10; 95% CI, 1.03 to 1.18;  $P=0.01$ ) as concerns about pursuing KT. Similarly, for every 5 years older after age 60 years, participants were 1.35-fold (95% CI, 1.20 to 1.51;  $P<0.001$ ) and 1.15-fold (95% CI, 1.00 to 1.31;  $P=0.05$ ) more likely to have high levels of health-related and psychosocial concerns. Women were more likely to have high levels of health-related (aRR, 1.72; 95% CI, 1.21 to 2.43;  $P=0.002$ ) and psychosocial (aRR, 1.55; 95% CI, 1.09 to 2.20;  $P=0.02$ ) concerns. Those with grade school-level education or less were more likely to report “I’m doing fine on dialysis” as a concern (aRR, 1.27; 95% CI, 1.08 to 1.49;  $P<0.003$ ). Likewise, they were more likely to have high levels of health-related (aRR, 1.59; 95% CI, 1.08 to 2.35;  $P=0.02$ ) and psychosocial (aRR, 1.77; 95% CI, 1.17 to 2.68;  $P=0.01$ ) concerns. For each additional comorbidity, participants were 1.16-fold (95% CI, 1.06 to 1.28;  $P=0.002$ ), 1.18-fold (95% CI, 1.08 to 1.30;  $P<0.001$ ), and 1.18-fold (95% CI, 1.07 to 1.29;  $P=0.001$ ) more likely to report “No one has discussed KT with me” as a concern, to have high levels of health-related concerns, and to have high levels of psychosocial concerns. Participants who had not seen a nephrologist before dialysis initiation were more likely to report “No one has discussed KT with me” as a concern (aRR, 1.92-fold; 95% CI, 1.38 to 2.68;  $P<0.001$ ) and to have high levels of psychosocial concerns (aRR, 1.48; 95% CI, 1.01 to 2.18;  $P=0.05$ ) (Table 3).

### Concerns and ATT

Of participants who reported “I’m doing fine on dialysis” as a concern about pursuing KT, only 7.9% and 15.5% achieved ATT within 1 and 2 years of dialysis initiation. By contrast, of those who did not report this, 15.0% and 26.3% achieved ATT within 1 and 2 years of dialysis initiation ( $P=0.002$ ). Of participants who reported “No one has discussed KT with me” as a concern, only 2.2% and 9.3% achieved ATT within 1 and 2 years of dialysis initiation versus 13.1% and 22.4% for those who did not report this ( $P=0.01$ ). Of participants with high levels of health-related

5.7%;  $P=0.05$ ), and “I’m not a medically appropriate candidate for transplantation” (14.9% versus 9.3%;  $P=0.05$ ). African Americans were less likely to report “I’m not comfortable asking a living person to donate a kidney” (24.0% versus 41.2%;  $P=0.001$ ) and “I’m not a medically appropriate candidate for transplantation” (9.6% versus 16.0%;  $P=0.01$ ) (Table 2).

### EFA of Concerns

Two constructs (*i.e.*, interrelated categories of concerns also commonly referred to as “underlying latent constructs”)

**Table 2. Prevalence of patient-perceived concerns about pursuing KT, stratified by patient characteristics (N=348)**

Concern about KT	Age (yr)		Sex		Race		P <sup>a</sup>		
	<60	≥60	Men	Women	African American	Non-African American			
I'm doing fine on dialysis	68.4	63.5	75.7	0.02	65.0	72.7	0.12	68.1	0.94
No one has discussed KT with me	26.7	22.6	32.9	0.01	26.8	26.6	0.88	23.6	0.07
Health-related concerns									
I'm too weak to undergo a transplantation	12.6	8.2	19.3	<0.001	7.7	18.8	0.01	12.2	0.30
I'm not a medically appropriate candidate for transplant	11.8	6.3	20.0	<0.001	9.3	14.9	0.05	9.6	0.01
I did not know transplantation was an option at my age	10.6	4.8	19.3	<0.001	11.3	9.7	0.82	7.9	0.06
I do not think transplantation will help me	10.3	6.7	15.7	0.01	5.7	16.2	0.05	9.2	0.18
Somebody has discussed KT with me and discouraged me from pursuing it	5.8	3.9	8.6	0.01	4.1	7.8	0.10	3.9	0.29
Any of the above	31.0	19.7	47.9	<0.001	26.3	37.0	0.04	28.0	0.09
Psychosocial concerns									
I do not feel comfortable asking a living person to donate a kidney for me	29.9	27.9	32.9	0.05	28.9	31.2	0.46	24.0	0.001
I do not want to take any more medication	27.9	31.3	22.9	0.12	24.7	31.8	0.16	28.0	0.57
Transplantation is too expensive	21.0	23.1	17.9	0.44	19.6	22.7	0.21	24.0	0.42
I'm afraid of an operation	15.8	14.4	17.9	0.19	7.73	26.0	<0.001	14.9	0.21
I do not feel comfortable receiving a kidney from a dead person	10.6	10.6	10.7	0.16	10.3	11.0	0.08	11.4	0.61
Any of the above	54.0	54.3	53.6	0.91	51.6	57.1	0.33	52.0	0.31

Each cell indicates the prevalence of participants in the given subgroup who reported the given concern. Columns do not sum to 100% because patients could indicate more than one concern. Concerns were categorized empirically into health-related or psychosocial categories. "I'm doing fine on dialysis" and "No one has discussed KT with me" did not fall into either health-related or psychosocial concerns categories. See the Materials and Methods and the Supplemental Appendix for a description of the exploratory factor analysis used to categorize concerns. Non-African-American race is 92.4% Caucasian, 3.4% Asian/Asian American, 1.7% American Indian/Alaskan Native, and 2.5% other. P values were estimated using ordered logistic regression except for "Any of the above" in which case they were estimated using Fisher's exact test. KT, kidney transplantation.

**Table 3. Associations between participant characteristics and patient-perceived concerns about pursuing KT**

Characteristic	Health-Related Concerns	I'm Doing Fine on Dialysis	No One Has Discussed KT with Me	Psychosocial Concerns
Age				
Per 5-yr increase		1.04 (1.02 to 1.07)	1.10 (1.03 to 1.18)	
<b>Spline with knot at 60</b>				
<60 (per 5-yr increase)	1.02 (0.89 to 1.17)			0.96 (0.86 to 1.07)
≥60 (per 5-yr increase)	1.35 (1.20 to 1.51)			1.15 (1.00 to 1.31)
Being a woman	1.72 (1.21 to 2.43)	1.12 (0.97 to 1.29)	1.05 (0.75 to 1.47)	1.55 (1.09 to 2.20)
African-American race <sup>a</sup>	0.90 (0.62 to 1.30)	1.04 (0.89 to 1.22)	0.87 (0.60 to 1.26)	1.00 (0.69 to 1.45)
<b>Highest education level</b>				
Postsecondary	Ref	Ref	Ref	Ref
High school	1.19 (0.73 to 1.94)	1.20 (0.99 to 1.46)	0.94 (0.57 to 1.57)	1.37 (0.83 to 2.26)
Grade school or less	1.59 (1.08 to 2.35)	1.27 (1.08 to 1.49)	1.10 (0.77 to 1.59)	1.77 (1.17 to 2.68)
Comorbidities ( <i>n</i> , per one condition increase) <sup>b</sup>	1.18 (1.08 to 1.30)	0.98 (0.93 to 1.02)	1.16 (1.06 to 1.28)	1.18 (1.07 to 1.29)
Never saw nephrologist before dialysis initiation	1.08 (0.71 to 1.64)	1.13 (0.97 to 1.32)	1.92 (1.38 to 2.68)	1.48 (1.01 to 2.18)

Data are presented as relative risks (95% confidence intervals). Relative risks were estimated using multivariable modified Poisson regression. Concerns were categorized empirically into health-related or psychosocial categories. "I'm doing fine on dialysis" and "No one has discussed KT with me" did not fall into either health-related or psychosocial concerns categories. See the Materials and Methods and the Supplemental Appendix for a description of the exploratory factor analysis used to categorize concerns. See Table 2 for individual concerns.

<sup>a</sup>African-American race is compared with non-African-American race, which is 92.4% Caucasian, 3.4% Asian/Asian American, 1.7% American Indian/Alaskan Native, and 2.5% other.

<sup>b</sup>The number of comorbidities includes diabetes, hypertension, heart failure, atherosclerotic disease, coronary artery disease, cerebrovascular disease/stroke, peripheral vascular disease, asthma/COPD, HCV or HBV, and history of cancer >5 years before enrollment.

concerns, only 3.7% and 8.2% achieved ATT within 1 and 2 years of dialysis initiation versus 12.3% and 22.2% for those who reported low levels ( $P=0.001$ ). Of participants with high levels of psychosocial concerns, only 4.7% and 10.5% achieved ATT within 1 and 2 years of dialysis initiation versus 11.9% and 21.6% for those who reported low levels ( $P=0.02$ ) (Figure 2).

In parsimonious models, reporting "I'm doing fine on dialysis" as a concern (adjusted hazard ratio [aHR], 0.55; 95% CI, 0.34 to 0.89;  $P=0.01$ ), reporting "No one has discussed KT with me" as a concern (aHR, 0.49; 95% CI, 0.24 to 0.99;  $P=0.05$ ), having high levels of health-related concerns (aHR, 0.37; 95% CI, 0.16 to 0.87;  $P=0.02$ ), and having high levels of psychosocial concerns (aHR, 0.47; 95% CI, 0.23 to 0.95;  $P=0.03$ ) were associated with being less likely to achieve ATT. Estimates were consistent in parsimonious and fully adjusted models, except that statistical significance was lost in the fully adjusted models for the effects of reporting "No one has discussed KT with me" as a concern ( $P=0.07$ ) and high levels of psychosocial concerns ( $P=0.05$ ) on achieving ATT (Table 4).

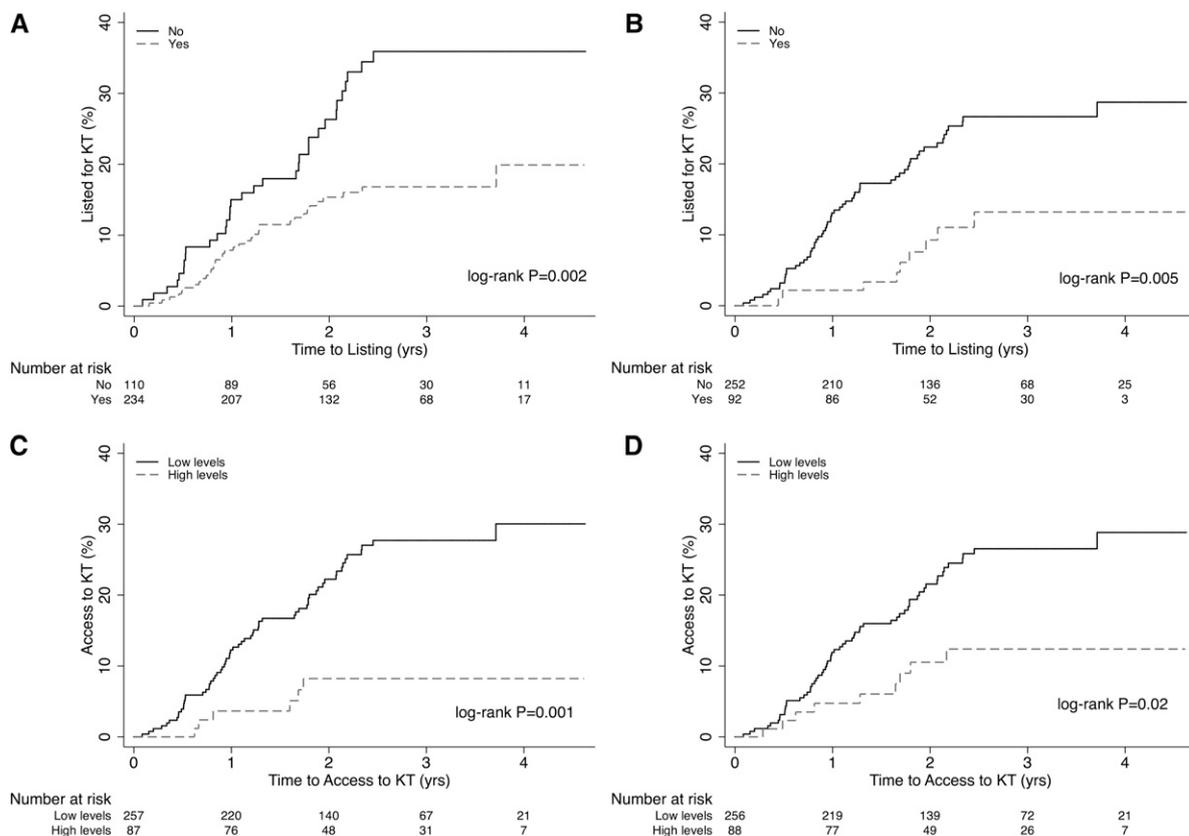
## Discussion

In this multicenter study of patients who had recently initiated dialysis, the prevalence of patient-perceived concerns about pursuing KT was high. Of participants, 68.4% reported that they were not interested in pursuing KT because they felt that they were doing fine on dialysis. Older age, being a woman, and less education were associated with

high levels of health-related and psychosocial concerns. Furthermore, high levels of health-related and psychosocial concerns were independently predictive of not achieving ATT.

Our finding that older adults and women are more likely to report concerns about pursuing KT is consistent with the documented age and sex disparities in access to KT (24–32), as well as with studies demonstrating that older adults and women report less interest in KT compared with younger adults and men (3,33). Similar to study participants reporting that their "doing fine on dialysis" was a concern about pursuing KT, patients undergoing dialysis have previously reported that the social and emotional support from the dialysis community is an advantage to remaining on dialysis (9). Furthermore, with 29.9% of participants reporting that they did not feel comfortable asking a living person to donate a kidney, our results are consistent with studies of prevalent dialysis patients and waitlisted patients reporting reluctance to talk to others about live donation (8,34,35). In addition, the association between less education and high levels of concerns observed among our study population is consistent with documented decreased access to KT among those with less education (36,37). Educational interventions to reduce concerns about KT targeting older adults and women, more detailed discussions between providers and patients about the risks and benefits of RRTs, and programs to improve comfort in initiating conversations about live donor kidney transplantation may help reduce concerns about pursuing KT.

Interestingly, of participants who agreed with the statement "No one has discussed KT with me" as a reason they



**Figure 2. | Access to transplantation by patient-perceived concerns about pursuing KT.** (A) "I'm doing fine on dialysis" (as a reason not to pursue KT). (B) "No one has discussed KT with me" (as a reason not to pursue KT). (C) Levels of health-related concerns. (D) Levels of psychosocial concerns. Concerns were categorized empirically into health-related or psychosocial categories. "I'm doing fine on dialysis" and "No one has discussed KT with me" did not fall into either health-related or psychosocial concerns categories. High and low levels of health-related and psychosocial concerns are based on comparing the highest quartile to the lower three quartiles of scale scores. See the Materials and Methods and the Supplemental Appendix for a description of the exploratory factor analysis used to categorize concerns and for creation of scale scores. See Table 2 for individual concerns. KT, kidney transplantation.

would not pursue transplantation, 78% were informed about kidney transplantation according their provider on CMS Form 2728. By contrast, only 20% of these participants

self-reported any discussion about KT with anyone at the dialysis center (nephrologist or other dialysis staff). This discrepancy between providers and patients (*i.e.*, providers

**Table 4. Associations between patient-perceived concerns about pursuing KT and access to transplantation**

Patient-Perceived Concern	Hazard Ratio of Achieving Access to Transplantation		
	Unadjusted	Adjusted <sup>a</sup>	Parsimonious <sup>b</sup>
I'm doing fine on dialysis	0.48 (0.30 to 0.77)	0.57 (0.34 to 0.94)	0.55 (0.34 to 0.89)
No one has discussed KT with me	0.38 (0.19 to 0.77)	0.51 (0.25 to 1.06)	0.49 (0.24 to 0.99)
High health-related concerns <sup>c</sup>	0.27 (0.12 to 0.63)	0.40 (0.17 to 0.96)	0.37 (0.16 to 0.87)
High psychosocial concerns <sup>c</sup>	0.43 (0.21 to 0.86)	0.49 (0.24 to 1.01)	0.47 (0.23 to 0.95)

Data are presented as hazard ratios (95% confidence intervals). Hazard ratios were estimated using Cox proportional hazards models. Concerns were categorized empirically into health-related or psychosocial categories. "I'm doing fine on dialysis" and "No one has discussed KT with me" did not fall into either health-related or psychosocial concerns categories See the Materials and Methods and the Supplemental Appendix for a description of the exploratory factor analysis used to categorize concerns. See Table 2 for individual concerns.

<sup>a</sup>Adjusted for age, sex, race, education, number of comorbidities, BMI, smoking status, and seeing a nephrologist before dialysis initiation.

<sup>b</sup>Adjusted for age, race, BMI, and smoking status.

<sup>c</sup>Comparing those in the highest quartile of the concerns scaled score with those in the lower three quartiles.

reported discussing KT with the patients, but the patients reported no discussion with the provider and reported that lack of discussion was a reason not to pursue transplantation) motivates further research as to its mechanism and potential ways to bridge this gap.

This study has several limitations. First, because participants had not been specifically evaluated for KT, we could not be certain that all participants were appropriate candidates. However, because of the strict exclusion criteria of the parent study, participants represented a selected and relatively healthy cohort that has a high likelihood of being eligible for transplantation. Moreover, in this ancillary study, we further excluded participants with contraindicated conditions for transplantation as measured in the study, so eligibility was likely. Second, we did not capture referral or evaluation for KT, two intermediate outcomes between patient-perceived concerns at dialysis initiation and ATT. As such, we cannot be certain whether a patient did not achieve ATT because he or she did not pursue evaluation or if the patient failed evaluation. Linkage between our primary data and the national registry of patients who are waitlisted or transplanted, however, enabled us to determine correlation between patient-perceived concerns and a clinically relevant and robustly measured outcome. Third, because patient-perceived concerns were only captured at dialysis initiation, we are unable to evaluate how concerns change over time or differ among those who have been on dialysis long term. For example, the question about whether “I’m doing fine on a dialysis” was a reason not to pursue KT was asked only at initiation of dialysis, so our study cannot address changes in the way patients feel on dialysis as their disease progresses or the effects of these changes on pursuit of transplantation. Nevertheless, by using an incident sampling method, prevalence sampling bias was minimized (38). Thus, our inferences are more likely to be generalizable to the total population of patients with ESRD rather than to a select group of survivors. Finally, African Americans were over-represented in our study population compared with those initiating dialysis in the United States [65.8% versus 28% (39)]. This difference, nevertheless, would only bias our inferences if race modified the relationship between concerns and ATT. Because no interactions with race were identified, we feel confident that the over-representation of African Americans was unlikely to have affected our inferences. In fact, this over-representation might actually be advantageous in terms of statistical power to have detected such interactions.

In conclusion, perceived health-related and psychosocial concerns about pursuing KT are highly prevalent among persons who have recently initiated dialysis, particularly among older adults and women. As such, patient-perceived concerns may be a potentially modifiable mediator of the relationship between older age or being a woman with reduced access to KT. Irrespective of patient characteristics, however, levels of concerns at dialysis initiation have long-term implications for likelihood of accessing transplantation. Interventions to reduce these patient-perceived concerns could help decrease age and sex disparities in KT access. Finally, given that participants who had seen a nephrologist were less likely to report psychosocial concerns, further investigation of a potential role for the nephrologist in reducing these patient-perceived concerns is worthwhile.

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## Disclosures

None.

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