



Predicting Kidney Transplant Evaluation Non-attendance

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Abstract

Non-attendance to kidney transplant evaluation (KTE) appointments is a barrier to optimal care for those with kidney failure. We examined the medical and socio-cultural factors that predict KTE non-attendance to identify opportunities for integrated medical teams to intervene. Patients scheduled for KTE between May, 2015 and June, 2018 completed an interview before their initial KTE appointment. The interview assessed various social determinants of health, including demographic (e.g., income), medical (e.g. co-morbidities), transplant knowledge, cultural (e.g., medical mistrust), and psychosocial (e.g., social support) factors. We used multiple logistic regression analysis to determine the strongest predictor of KTE non-attendance. Our sample ($N = 1119$) was 37% female, 76% non-Hispanic White, median age 59.4 years (IQR 49.2–67.5). Of note, 142 (13%) never attended an initial KTE clinic appointment. Being on dialysis predicted higher odds of KTE non-attendance (OR 1.76; $p = .02$; 64% of KTE attendees on dialysis vs. 77% of non-attendees on dialysis). Transplant and nephrology teams should consider working collaboratively with dialysis units to better coordinate care, (e.g., resources to attend appointment or outreach to emphasize the importance of transplant) adjusting the KTE referral and evaluation process to address access issues (e.g., using tele-health) and encouraging partnership with clinical psychologists to promote quality of life for those on dialysis.

Keywords Kidney transplantation · Transplant evaluation · Non-attendance

Introduction

Although kidney transplantation (KT) is the optimal treatment for patients with kidney failure, there are well-documented barriers that prevent otherwise eligible patients from obtaining KT (Alexander & Sehgal, 2001; Schold et al., 2021). These barriers occur throughout the KT process including access to referral, completion of pre-transplant evaluation, being wait-listed, and receipt of KT. These multiple steps, and potential associated barriers, contribute to long-standing racial/ethnic and socioeconomic disparities in KT receipt (Navaneethan & Singh, 2006; Patzer et al., 2012; Wesselman et al., 2021). The first step following referral is initiating a kidney transplant evaluation (KTE), which traditionally requires many tests conducted by multiple specialists and several follow-up visits. (Crenesse-Cozien et al., 2019) A majority of patients referred for KT who begin the evaluation process do not make it through to receipt of transplant, suggesting significant barriers navigating the KT process following a referral (Kucirka et al., 2015; Patzer et al., 2015). Several

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cross-sectional and retrospective studies identified factors associated with those never attending a KTE appointment; these include perceived medical disqualifications, fear about transplant, logistical barriers (e.g., lack of transportation), and financial concerns (Dageforde et al., 2015; Kazley et al., 2012; Kucirka et al., 2015).

Interventions addressing clinic non-attendance in medical settings often focus on clinic led efforts including over-booking and appointment reminders (LaGanga & Lawrence, 2007; Parikh et al., 2010). For patients seeking KT, efforts to streamline the KTE process into a single initial visit with multiple providers instead of individual appointments are designed, in part, to address non-attendance (Bornemann et al., 2017). Even with these interventions, there could be multiple medical and non-medical factors, including social determinants of health, that make it difficult for patients to begin the KT evaluation process (Crenesse-Cozien et al., 2019). Given that existing studies have relied on obtaining retrospective patient reports about KTE attendance (Dageforde et al., 2015), it is important to collect prospective data to be able to determine which factors predict KTE non-attendance. A better understanding of the bio-psycho-social factors that prospectively predict which patients do not initiate KTE could better inform healthcare delivery interventions that increase access to care. In this study, we aim to identify the frequency of KTE clinic non-attendance (e.g. never presenting to KTE) and characterize the demographic, medical, and socio-cultural factors that predict KTE clinic non-attendance.

Methods and Measures

Study Design and Procedures

We recruited patients who were scheduled for KTE at the Starzl Transplant Institute at the University of Pittsburgh Medical Center (UPMC) between May, 2015 and June, 2018. Since 2015, UPMC has performed the fifth largest number of KT procedures of the 42 transplant centers in UNOS Region Two. (OPTN Organ Procurement and Transplantation Network, n.d.) We conducted a research study interview with these patients to assess the relationship of demographic, medical, and sociocultural facts with subsequent KTE non-attendance. Participants completed their KTE appointment an average of 33 days after the study interview. However, the time between the study interview and the KTE appointment varied based on clinic wait times, cancelations and rescheduling. The majority of the 45-min structured interviews were conducted by telephone ($n = 1073$; 96%). Another 44 interviews (4%) were collected with paper versions with respect for participant preference.

This interview was part of a larger longitudinal study that included a quasi-experimental design to determine the efficacy of a fast-track KTE process (Bornemann et al., 2017).

Study Sample

Patient inclusion criteria were: (1) scheduled for a KT appointment; (2) English speaking; (3) 18 or older; (4) no history of KT and; (5) not accepted for KT at another transplant center. During the recruitment timeframe, 1472 people were eligible for the study, 1315 consented to participate (89% consent rate), and 1288 completed the pre-transplant interview. This study includes data from 1119 of the total 1288 sample; those who completed the study interview after their KTE ($n = 67$) were excluded as were those who reported race as other than Black or White ($n = 102$) due to small numbers (7.9%) and significant heterogeneity within the “other” group. Assessment of worry about post-KT outcomes (see Predictors section) was added to the study interview after the start of data collection.

Predictors

Potential predictors included demographic (e.g., income, education), medical (e.g., dialysis, co-morbidities), transplant knowledge, cultural (e.g., medical mistrust), and psychosocial factors (e.g., social support, depression), as well as worry about post-KT outcomes. See Table 1 for a full description of potential predictors of KTE clinic non-attendance. We included all the factors assessed in the interview from the parent study as potential predictors of clinic non-attendance (Fig. 1).

Outcome Variables

The primary outcome variable in this study was KTE clinic non-attendance, defined as a patient referred to and scheduled for initial KTE who never attended the initial appointment or any re-scheduled appointments during the study period. This includes patients who were no-shows, canceled, and/or re-scheduled appointments in any combination but ultimately never attended a clinic appointment by the end of the study period in August 2019.

Statistical Analyses

We performed descriptive analyses of baseline characteristics using median and interquartile range for numerical variables, and frequency and percentage for categorical variables. Using Wilcoxon Rank Sum Tests, we compared medians of continuous variables between patients who attended an initial KTE appointment and patients who did not attend an initial KTE appointment. For categorical variables, we

Table 1 Description of study variables

Variable	Description and scoring	Cronbach's α^a
Demographics		
Race	Patient-reported	
Age	Patient-reported; years	
Sex	Patient-reported; male and female	
Education	Patient-reported and dichotomized as "High School or less" versus "Some College or more"	
Occupation (Hollingshead, 2011)	Patient-reported and classified according to the Hollingshead Occupational Scale, ranging on a scale from 1 (e.g., Service Workers) to 9 (e.g., Executives, CEOs) The cutoff between "high" and "low" was a score of 4 (e.g., Smaller Business Owners, Skilled Manual Workers, or Craftsmen)	
Household income (U.S. Department of Health and Human Services, 2015)	Patient-reported and classified as either below or at/above the 2015 Federal poverty line	
Health insurance	Obtained from the electronic medical record and classified as private insurance only, public insurance only, or both private and public	
Married	Patient-reported as never married, separated or divorced, widowed, or domestic partnership/married	
Medical factors		
Body Mass Index (BMI)	Calculated with patient height and weight (obtained from medical record) using NHLBI's calculator: https://www.nhlbi.nih.gov/health/educational/lose_wt/BMI/bmicalc.htm	
Charlson co-morbidity score (Charlson et al., 2008)	The score was obtained using patient data obtained from the medical record reflecting the number and severity of co-morbid health conditions. The score is continuous with a possible range of 0 to 33 with higher scores reflecting a more significant type of comorbidity	
Burden of kidney disease (Waterman et al., 2008)	A three-item measure of perceived burden of kidney disease with item responses ranging from 1 (definitely true) to 5 (definitely false). A sample item is "I feel frustrated dealing with my kidney disease"	$\alpha = 0.75$
Number of potential donors (count of social network)	The network of potential living donors available for evaluation was determined by asking participants to indicate how many living relatives and friends they had aged 18–70 years of age	
Have a living donor at T1	Actual living donors were individuals who were undergoing, had already undergone, or were planning to undergo evaluation for living donation to a specific patient. For our analyses, we summed across these 3 groups for an overall number of potential living donors	
Dialysis	Determined from the either the medical record or self-report (either Hemodialysis or Peritoneal Dialysis)	
ESKD etiology	Abstracted from medical record and divided into two categories: diabetes-related and not diabetes-related. Non-diabetes comprises eight different conditions (listed in Table 2)	
Cultural factors		
Racism in healthcare (Boulware et al., 2002)	A four-item measure of patient beliefs about experiences of racism	$\alpha = 0.76$
Medical mistrust (LaVeist et al., 2009)	Seven items assessing participant belief that their healthcare organizations are trustworthy, competent, and acting in their best interests	$\alpha = 0.78$
Trust in physician (Anderson & Dedrick, 1990)	Eleven items assessing patient trust in their physician	$\alpha = 0.85$
Family loyalty (Bardis, 1959)	Sixteen items assessing participant family loyalty and mutual support	$\alpha = 0.83$

Table 1 (continued)

Variable	Description and scoring	Cronbach's α^a
Any religious objection to LDKT (Rumsey et al., 2003)	Adapted subscale of the 8-item Organ Donation Attitude Survey (ODAS). From these questions, we categorized respondents into either "Any objection" (i.e., "disagree", "strongly disagree", or "not sure" with any religious objection to transplant) vs. none (i.e., "agree", "strongly agree" with all religious objections to transplant)	
Experienced discrimination in healthcare (Williams et al., 1997)	Seven items assessing participant report of discrimination based on their race/ethnicity in any healthcare setting	$\alpha=0.90$
Psychosocial factors		
Social support (Cohen et al., 1985)	12-item Interpersonal Support Evaluation List (ISEL-12)—assessed patient perceived availability of 3 separate functions of social support: "tangible", "appraisal", and "belonging"	$\alpha=0.87$
Anxiety (Derogatis & Melisaratos, 1983)	6-item Brief Symptom Inventory (BSI) Anxiety subscale [e.g., "nervousness or shakiness inside"; original range: 1 (not at all) to 5 (extremely)]	$\alpha=0.84$
Depression (Derogatis & Melisaratos, 1983)	6-item Brief Symptom Inventory (BSI) Depression subscale [e.g., "feeling hopeless about the future"; original range: 1 (not at all) to 5 (extremely)]	$\alpha=0.84$
Transplant factors		
Transplant knowledge (Waterman et al., 2008)	Participants were assessed on their knowledge about transplant using a 19-item KT Knowledge Survey	
Number of learning activities	Participants reported the type and number of KT-related learning activities (e.g., reading brochures, online research)	
Hours engaged in learning activities	Participants reported the amount of time spent in KT-related learning activities (e.g., reading brochures, online research)	
Total transplant concerns (Waterman et al., 2006, 2008)	Patients reported which of list of 24 common transplant-related concerns were most important in influencing their decision to pursue transplant [e.g., "I would not have to be on dialysis"; range: 1 (not important) to 5 (extremely important)]	
Transplant worry (McHorney, 2009; Pringle et al., 2014)	A 3-Item measure of patient worry about transplant in areas of harm, importance, and economic impact. Items were considered individually. Adapted from Pringle et al	

^aCronbach's alpha values calculated for the current study sample

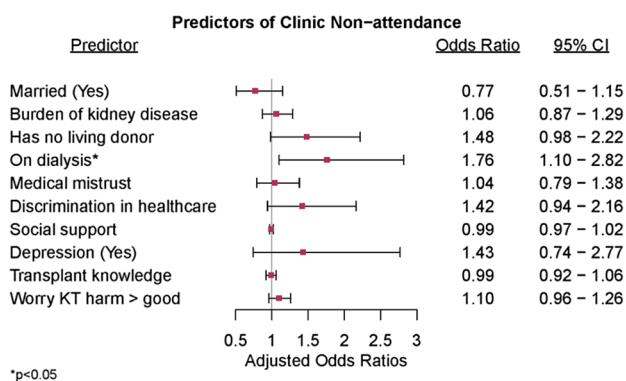


Fig. 1 Forest plot of predictors of clinic non-attendance in adjusted model

used Chi-Square Tests (or Fisher's Exact Test when expected cell sizes were very small) to assess the association between KTE non-attendance and each categorical variable.

To examine the relationship between baseline characteristics and clinic non-attendance, we performed bivariate logistic regression analyses, modeling each baseline characteristic with clinic non-attendance. We then assessed variables with *p* values less than .10 [or significant odds ratios (OR < .5 or OR > 2)] for multicollinearity. After verifying that none of the statistically significant predictors exhibited multicollinearity, we entered these variables into a final multiple logistic regression model to account for potential demographic, medical, psychosocial, cultural, and transplant-specific predictors of KTE non-attendance. The multiple regression analysis used case-wise deletion for missing data to ensure that all factors were equally weighted. We also conducted a sensitivity analysis using a multiple regression model that excluded the variable that caused a majority of the case-wise missingness, and found the results to be virtually identical (results listed in Supplementary Table). We performed all data analyses in SAS.

Results

In Table 2, we detail the baseline characteristics and outcomes of study participants who completed the initial interview ($n = 1119$). Because we found virtually no difference between mode of interview completion (phone vs paper), we present all results across the complete cohort.¹ The window for attendance for patients enrolled at the end of the data collection period (August 2019) was between one and four years. The overwhelming majority (95%) of those who attended clinic did so within four months of survey completion. The cohort included those who subsequently attended an initial KTE appointment ($n = 977$), and those who never attended an initial KTE ($n = 142$). Patients who attended KTE were more likely to be married, had a higher number of potential donors in their social network, and a higher frequency of having identified potential living donor (all p values $\leq .05$) compared to the group of patients who did not attend KTE. Among patients who did not attend KTE, there was a higher frequency of being on dialysis, higher levels of perceived racism and medical mistrust, higher frequency of experienced discrimination, lower social support, higher frequency of moderate or greater depression, and a higher likelihood of reporting worry that KT could be harmful.

The univariable logistic regression, summarized in Supplementary Table 1, yielded the ten variables individually associated with KTE non-attendance. Because none of these variables exhibited high variance inflation factors nor high inter-correlations, we used all of them in the final multiple logistic regression model presented in Table 3. The multiple logistic regression model (Table 3) showed that being on dialysis was associated with 76% higher odds of clinic non-attendance [OR (95% CI) 1.76 (1.10–2.82), p value = .02]. Trending variables included not having a living donor [OR (95% CI) 1.48 (.98–2.22), p value = .06] and experiencing discrimination in healthcare settings [OR (95% CI) 1.42 (.94–2.16), p value = .09]. To explore why dialysis may have been the only significant predictor in the multivariable model, we conducted a follow-up analysis of demographic differences between those on dialysis and not (see Supplementary Table S1). We found that patients who were on dialysis were more likely to be Black, unmarried, insured by public insurance only, have income below federal poverty level, and a lower status occupation.

¹ We found no demographic differences between participants who chose to complete the interview via telephone (96%) versus paper (4%) by gender, education, occupation, income, insurance status, or marital status. However, participants who completed a written version were more likely to be older or non-Hispanic white compared to those who completed it by telephone.

Discussion

To our knowledge, this is the first prospective study of patients referred to and scheduled for KTE who never attended an evaluation appointment. More than ten percent of those in our sample never attended their scheduled KTE appointment. After comparing multiple individually significant predictors, dialysis status was the sole statistically significant predictor of KTE non-attendance. These results (other than our finding that race/ethnicity was non-significant in all of our analyses) are broadly consistent with previous cross-sectional pilot studies, and may have important implications for increasing access to KT (Dageforde et al., 2015).

A strength of this study is the prospective collection of predictors that are richer than could be obtained with medical record review alone. By having the research team call patients ahead of their appointment to conduct the baseline interview, patients received at least one and sometimes several additional reminders of their initial KTE appointment. Although this approach may be perceived as a limitation with the unintended consequence of reducing non-attendance, we believe this approach only served to underestimate non-attendance. We hypothesize that without this approach, non-attendance rates would be even higher in our sample, matching results from other studies of clinic non-attendance (Parikh et al., 2010).

Even when much of the KTE process is streamlined into a single visit as was the case in this sample, there are unique challenges for dialysis patients scheduled to attend KTE. For those with kidney failure, there are well-documented deleterious physical and psychological side effects associated with being on dialysis (Unruh et al., 2008). Furthermore, the experience of traditional thrice-weekly hemodialysis is logistically burdensome, making it difficult for patients to attend additional medical appointments on days between dialysis sessions (Tong et al., 2017). The combination of these medical, psychological, and logistical burdens would likely lead to greater difficulty in attending a scheduled KTE. Importantly, the effect of being on dialysis is so strong, that it even eclipsed the effect of race/ethnicity, a factor often found significant in research on non-attendance (Alexander & Sehgal, 2001; Navaneethan & Singh, 2006; Schold et al., 2021). We believe this finding supports previous work arguing that race/ethnicity is a proxy of other social determinants of health (Patzner et al., 2012, 2015; Wesselman et al., 2021).

Early referral to KTE prior to initiating dialysis (i.e., preemptive listing) may be an important intervention in increasing KT access. As with other transplant outcomes, racial and ethnic disparities persist for those who are referred to and approved for listing prior to initiating dialysis (King et al., 2019). Despite changes to the Kidney Allocation

Table 2 Baseline and comparison of characteristics and outcomes of complete KTFT cohort and subgroups

	Full Cohort (<i>n</i> = 1119)	Attended KTE (<i>n</i> = 977)	Never Attended KTE (<i>n</i> = 142)	<i>p</i> value
Demographic characteristics				
Race— <i>n</i> (%) ^a				.188
Non-Hispanic White	853 (76.2)	751 (76.9)	102 (71.8)	
Non-Hispanic Black	266 (23.8)	226 (23.1)	40 (28.2)	
Age—median (Q1–Q3)	59.4 (49.2–67.5)	59.4 (49.2–67.4)	59.0 (49.0–67.7)	.729
Female— <i>n</i> (%)	417 (37.3)	366 (37.5)	51 (35.9)	.722
Education (High school or less)— <i>n</i> (%)	530 (47.4)	445 (46.8)	73 (51.4)	.302
Occupation (\leq lower status)— <i>n</i> (%)	598 (54.6)	531 (54.4)	67 (55.8)	.767
Income (below Federal poverty line)— <i>n</i> (%)	284 (26.5)	241 (25.8)	43 (31.6)	.147
Insurance (public only)— <i>n</i> (%)	483 (43.22)	414 (42.4)	69 (48.9)	.187
Married— <i>n</i> (%)	533 (47.6)	479 (49.0)	54 (38.0)	.014
Medical factors				
Body Mass Index at evaluation—median (Q1–Q3)	29.5 (25.3–34.9)	29.5 (25.4–34.8)	28.9 (24–35.2)	.422
Charlson co-morbidity score—median (Q1–Q3)	4 (3–5)	4 (3–5)	4 (3–6)	.183
Burden of kidney disease—median (Q1–Q3)	4 (3–4.7)	4 (3–4.7)	4.0 (3.3–4.7)	.074
Number of potential donors—median (Q1–Q3)	19 (11–33)	19 (11–33)	16 (8–31)	.046
Have a living donor at T1— <i>n</i> (%)	472 (42.3)	423 (43.4)	49 (34.5)	.046
Dialysis ^b (yes)— <i>n</i> (%)	731 (65.3)	622 (63.7)	109 (76.8)	.002
ESKD etiology ^c				.191
Diabetes Mellitus	257 (26.6)	251 (26.5)	6 (30.0)	
Hypertension	117 (12.1)	112 (11.8)	5 (25.0)	
Diabetes and hypertension	179 (18.5)	177 (18.7)	2 (10.0)	
Glomerulonephritis	87 (9.0)	87 (9.2)	0 (0)	
Polycystic kidney disease	59 (6.1)	58 (6.1)	1 (5.0)	
Structural kidney disease	37 (3.8)	37 (3.9)	0 (0)	
CNI nephrotoxicity	65 (6.7)	65 (6.9)	0 (0)	
Acute kidney injury/Acute tubular necrosis	39 (4.0)	39 (4.1)	0 (0)	
Others	127 (13.1)	121 (12.8)	6 (30.0)	
ESKD etiology (binary)				.644
Diabetes-related	436 (45.1)	428 (45.2)	8 (40.0)	
Not diabetes-related	531 (54.9)	519 (54.8)	12 (60.0)	
Cultural factors				
Racism in healthcare—median (Q1–Q3)	2.3 (2–2.8)	2.0 (2.0–2.8)	2.5 (2.0–3.0)	.057
Medical mistrust—median (Q1–Q3)	3.0 (2.6–3.6)	3.0 (2.6–3.6)	3.1 (2.6–3.7)	.039
Trust in physician—median (Q1–Q3)	4.0 (3.6–4.5)	4.0 (3.6–4.5)	4.0 (3.6–4.4)	.250
Family loyalty—median (Q1–Q3)	3.2 (2.8–3.6)	3.2 (2.8–3.6)	3.1 (2.7–3.6)	.175
Any religious objection to LDKT— <i>n</i> (%)	797 (72.1)	691 (71.7)	106 (74.7)	.462
Experienced discrimination in healthcare— <i>n</i> (%)	329 (29.4)	273 (27.9)	56 (39.4)	.005
Psychosocial factors				
Social support (Total)—median (Q1–Q3)	43 (37–47)	43 (38–47)	42 (35–47)	.054
Anxiety (\geq moderate)— <i>n</i> (%)	53 (4.7)	45 (4.6)	8 (5.7)	.577
Depression (\geq moderate)— <i>n</i> (%)	76 (6.8)	59 (6.0)	17 (12.1)	.008
Transplant knowledge				
Transplant knowledge—median (Q1–Q3)	11 (9–13)	11 (9–13)	11 (9–12)	.104
Number of learning activities—median (Q1–Q3)	2 (1–3)	2 (1–3)	2 (1–3)	.701
Hours engaged in learning activities—median (Q1–Q3)	4 (2–9)	4 (2–9)	4 (1.5–9)	.843
Total transplant concerns—median (Q1–Q3)	87 (78–97)	87 (78–97)	87 (76–97)	.836
Transplant worry measure				

Table 2 (continued)

	Full Cohort (<i>n</i> = 1119)	Attended KTE (<i>n</i> = 977)	Never Attended KTE (<i>n</i> = 142)	<i>p</i> value
Item 1: I worry that transplant will do more harm than good ^d —median (Q1–Q3)	2 (1–3)	2 (1–3)	3 (1–4)	.056
Item 2: I am convinced that the kidney transplant is important ^e —median (Q1–Q3)	1 (1–2)	1 (1–2)	1 (1–2)	.337
Item 3: I will have trouble with affording the costs associated with kidney transplant ^f —median (Q1–Q3)	4 (2–5)	4 (2–5)	4 (2–6)	.562

Missing values: Etiological reason for transplant (152), Transplant worry measures (n.b., 103 patients were not administered this measure) Item 1 (131), Item 2 (118), Item 3 (218); BMI (71); Charlson co-morbidity score (70); Poverty level (47); Occupation (23); Any religious objection (13); Racism in healthcare (8); Medical mistrust (5); Family loyalty (2); Have a living donor at T1 (2); Insurance (1); Burden of KD (1); Trust in physician (1); Social support (1); Anxiety (1); Depression (1); Hours engaged in learning activities (1)

Q1–Q3 Interquartile range (between 25 and 75th percentiles)

p value represents Wilcoxon Rank Sum Tests for continuous variables and Chi-square Tests (*or Fisher's Exact test when Chi-square not valid) for categorical variables

^aPatients who reported race as other than Black or White or declined to answer (*n* = 102), excluded due to heterogeneity of the group

^bCombination of dialysis duration (when not missing; *n* = 1049) abstracted from medical record and self-reported dialysis yes/no (when dialysis duration not available; *n* = 70)

^cWe present this for reader's convenience, but we use binary version in subsequent analyses

^dHigher score = more worry

^eHigher score = less important

^fHigher score = more trouble

Table 3 Adjusted odds ratios for predictors of clinic non-attendance

	Adjusted OR	95% CI	<i>p</i> value
Demographic characteristics			
Married	0.77	0.51–1.15	.199
Medical factors			
Burden of kidney disease	1.06	0.87–1.29	.565
Have a living donor (no)	1.48	0.98–2.22	.060
Dialysis (yes)	1.76	1.10–2.82	.020*
Cultural factors			
Medical mistrust	1.04	0.79–1.38	.770
Health care discrimination (yes)	1.42	0.94–2.16	.099
Psychosocial factors			
Social support	0.99	0.97–1.02	.671
Depression (≥ moderate)	1.43	0.74–2.77	.292
Transplant knowledge			
Transplant knowledge	0.99	0.92–1.06	.724
Transplant worry measure			
Item 1: I worry that transplant will do more harm than good	1.10	0.96–1.26	.186

981 observations used in the analysis (853 attended KTE, 128 did not attend KTE)

**p* < 0.05

System (KAS), the proportion of patients who have been on dialysis for years without transplant remains high (Kadatz et al., 2022). A follow-up analysis of demographic differences between those on dialysis versus those not on dialysis

in our study yielded results consistent with well-known disparities between those who are pre-emptively referred for transplant and those referred after initiating dialysis. (King et al., 2019) Patients who were on dialysis were more likely to be Black, unmarried, and have lower SES (public insurance only, income below federal poverty level, lower status occupation). In this way dialysis status, which is strongly influenced by social determinants of health, eclipsed other potential predictors of attendance. Those who are referred for KTE prior to initiating dialysis may have other advantages that help ensure they are moving along the process. Advantages may include a greater likelihood of having a living donor, having a proactive medical team, and having greater access to resources including choice of healthcare facility.

The findings from our study suggest several implications for dialysis and transplant teams, working to improve KT access to increase equity. Clinical psychologists, already established as part of transplant teams in the KTE screening process, could play an important upstream role on dialysis units in improving the quality of life of those on dialysis through addressing barriers to transplant. The use of psychological interventions for those with end-stage kidney disease is an active area of research which has demonstrated feasibility, acceptability and modest improvement in dialysis patient mental health symptoms (Jakubowski et al., 2020; Mehrotra et al., 2019). The work of clinical psychology within dialysis units could be extended to screen for and target patient ambivalence

related to the transplant process. Ambivalence is a well-documented part of medical decision-making and identified as relevant to patient behavior in previous qualitative analyses of those awaiting transplant (Tong et al., 2015; Venkataraman & Kendrick, 2020). Several variables in the current study may be considered proxy measures to ambivalence of initiating the KT process. These included expressing transplant worry (i.e., “I worry that transplant will do more harm than good”), not having a potential living donor, and having an experience of discrimination in health care. Expressing transplant worry may most directly reflect patient’s ambivalence related to possible negative outcomes of a KT. Those who have not initiated discussions with potential living donors, a possible behavioral reflection of ambivalence, may be less ready to initiate the KTE process (Waterman et al., 2006). Finally, having an experience of discrimination in healthcare, a cultural contributor to ambivalence regarding healthcare utilization, may also contribute to reluctance of patients to initiate the KTE process. Although we found that these variables were not significant in our combined multi-variable model, they did matter when evaluated individually, and thus serve as potential factors to explore in subsequent research.

The association of patient ambivalence with several factors related to KTE non-attendance also indicates the potential utility of developing brief screeners for transplant ambivalence. Psychological screening for those on dialysis could include assessment of biopsychosocial factors, including ambivalence, that might affect influence the trajectory of KT outcomes. Identifying ambivalence in other health domains has been useful in improving access to care (e.g., medication adherence, see (Pringle et al., 2014)) and could be used to identify those at risk of non-attendance after referral for KTE. Furthermore, clinical psychologists as well as other medical providers may consider behavioral interventions, especially motivational Interviewing (MI), which have been successfully used to address behavior change in patients with end-stage kidney disease (García-Llana et al., 2014). MI, which can be facilitated by medical and mental health providers, as well as MI-trained peers, may be particularly useful for addressing KT ambivalence (Andersen et al., 2022; Sullivan et al., 2012).

Finally, given that there are multiple reasons for non-attendance at the patient, provider, and system level, there are also several potential interventions to improve patient access to the transplant clinic (Venkataraman & Kendrick, 2020). To address logistical challenges of scheduling dialysis patients for evaluation, working to change where and how kidney transplant evaluations are performed may be an appropriate target (Axelrod et al., 2010). There has been evidence for tele-health access to aid in facilitating initial screening visits ultimately leading to reduced time to complete a full evaluation for transplant (Concepcion & Forbes,

2020; Forbes et al., 2018). The acceleration of telehealth access during the public health crisis of COVID-19 may serve to increase these opportunities (Yadav et al., 2020).

Limitations

Although the current study had a number of strengths including a prospective design, a racially diverse sample, and a very high survey completion rate (1288/1315, 98%), there are also several limitations to consider. There may have been relevant medical data related to calculating medical comorbidity scores that were not included as part of the EMR at the study hospital. There was also a significant minority of patients administered the post-KT worry questions who did not answer a question related to concerns about affording future transplant costs; we note this limitation as it may reflect either true missingness or an inability to answer this question if they did not know what future costs would be. Another important concern was that we found several predictors that were associated with KTE non-attendance, yet none were uniquely predictive in the multiple logistic regression model (although some trended toward significance). This result tells us that each of these variables is important individually, however when considered together they explained factors common to non-attenders. When considering ways to increase attendance, clinics should consider focusing on multiple factors, but this study cannot specifically recommend one predictor more than another, other than being on dialysis. Finally, although there was a racially diverse sample reflective of the transplant center’s location, this was a single-site study that may not be generalizable to all patients with kidney failure.

Conclusion

Increasing access to KT begins with making sure that those referred for KT evaluation, attend their initial evaluation appointment. Our study prospectively identified salient factors in predicting those who did not end up attending an initial evaluation appointment and thus never initiated the KT process. Being on dialysis was the single most important factor after considering multiple potential predictors, all of which predict KTE non-attendance individually. Because many patients on dialysis face medical and logistical challenges in attending appointments, there are novel opportunities to make the existing system better fit the needs of those being served. There may also be utility in developing brief screeners for transplant ambivalence and using behavioral interventions within dialysis clinics to address important factors impacting patient behavior and clinic resources. Ultimately, increasing equity and KT access to care will take

a multilevel approach to address a significant public health need.

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Author Contributions Research idea and study design: CGF, EC, KK, MAD, YHN, CP, LM; data acquisition: EC, KK; data analysis/interpretation: YL, EK, YZ, CP, MAD, YHN, MU, LM; statistical analysis: YL, EK, YZ; supervision or mentorship: MAD, LM. Each author contributed important intellectual content during manuscript drafting or revision and agrees to be personally accountable for the individual's own contributions and to ensure that questions pertaining to the accuracy or integrity of any portion of the work, even one in which the author was not directly involved, are appropriately investigated and resolved, including with documentation in the literature if appropriate.

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Data Availability The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Declarations

Conflict of interest C. Graham Ford, Yuridia Leyva, Eric S. Kruger, Yiliang Zhu, Emilee Crowell, Kellee Kendall, Chethan Puttarajapa, Mary Amanda Dew, Yue Harn Ng, Mark L. Unruh, Larissa Myaskovsky declare that they have no conflict of interest.

Ethical Approval The Institutional Review Boards at the University of Pittsburgh and the University of New Mexico approved this study.

Research Involving Human and Animals Rights All procedures performed in studies involving human participants were in accordance with the ethical standards of the Institutional Review Boards at the University of Pittsburgh and the University of New Mexico and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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