



Published in final edited form as:

Transplantation. 2012 February 27; 93(4): 423–429. doi:10.1097/TP.0b013e318241d0cd.

Perceived Discrimination Predicts Longer Time to be Accepted for Kidney Transplant

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Abstract

Background—Although end-stage kidney disease (ESKD) in African Americans (AAs) is four times greater than in Whites, AAs are less than half as likely to undergo kidney transplantation (KT). This racial disparity has been found even after controlling for clinical factors such as co-

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The contents do not represent the views of the Department of Veterans Affairs or the United States Government.

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No conflict of interest to report.

morbid conditions, dialysis vintage and type, and availability of potential living donors. Therefore, studying non-medical factors is critical to understanding disparities in KT.

Design, Setting, and Participants—We conducted a longitudinal cohort study with 127 AA and White patients with ESKD undergoing evaluation for KT (12/06 – 7/07) to determine whether, after controlling for medical factors, differences in time to acceptance for transplant is explained by patients' cultural factors (e.g., perceived racism and discrimination, medical mistrust, religious objections to living donor KT), psychosocial characteristics (e.g., social support, anxiety, depression), or transplant knowledge. Participants completed 2 telephone interviews (shortly after initiation of transplant evaluation and after being accepted or found ineligible for transplant).

Results—Results indicated that AA patients reported higher levels of the cultural factors than did Whites. We found no differences in co-morbidity or availability of potential living donors. AAs took significantly longer to get accepted for transplant than did Whites (HR=1.49, p=0.005). After adjustment for demographic, psychosocial, and cultural factors, the association of race with longer time for listing was no longer significant.

Conclusions—We suggest that interventions to address racial disparities in KT incorporate key non-medical risk factors in patients.

Keywords

kidney transplantation; disparities; discrimination

Introduction

Although end stage kidney disease (ESKD) in African Americans (AAs) is four times greater than in Whites, AAs are less than half as likely to undergo kidney transplantation (KT), the optimal treatment for ESKD.¹⁻⁴ AA race is associated with a longer time to completion of the medical evaluation for KT,⁵ lower rates of preemptive listing for transplant,⁶ and longer waiting times for KT.^{2-3, 7-8} Differences persist despite the 2002 altered allocation system.⁹ These disparities have been found in KT even after controlling for clinical factors such as co-morbid conditions, dialysis vintage and type, and availability of potential living donors.^{5-6, 10-12} Therefore, studying non-medical factors is critical to understanding disparities in KT.

Health care attitudes and perceived racism in the health care system play important roles in AAs' health behaviors and outcomes for other diseases.¹³⁻¹⁸ Evidence indicates that cultural factors including medical mistrust, perceived racism and discrimination, religious beliefs, and family influence, play a key role in decision making about medical interventions and that these issues are critical to understanding disparities in KT. In the context of evaluation for a kidney transplant, perceived discrimination in healthcare settings, medical mistrust, and perceived racism may affect patients' health behavior by causing them to disengage from the healthcare system and fail to proceed with necessary testing. Alternately, patients' religious beliefs and their beliefs about family responsibility may influence whether patients seek assistance -- including asking for a living donor volunteer -- from their family or friends. However, these factors have received little attention in patients with ESKD. In fact, our recent review¹⁹ found that few studies have directly examined cultural factors that might explain race differences in receiving a transplant. The majority of these studies either examined cultural factors and transplant outcomes retrospectively or cross-sectionally, and could not determine whether such variables are predictive of outcomes.^{11, 20-21}

The influence of patients' psychosocial characteristics (i.e., social support, anxiety/depression levels, locus of control, and self-image) and transplant-related knowledge have

been found to influence decisions about transplantation and donation in a number of previous studies,^{10, 21–29} are included in our study as well. Finally, in addition to basic demographic characteristics (e.g., gender, age, income) that have been found to be associated with receipt of transplant,^{30–31} we controlled for medical factors including, whether patients were on dialysis pre-transplant, medical comorbidities, and whether patients had any potential living donors when they were being evaluated for transplant.^{30–32}

Although previous research has demonstrated that AA patients are not referred to transplant at the same rate as White patients, and that they do not complete the necessary steps in the clinical process leading up to referral at the same rate as White patients,^{7–8, 10, 33–34} this study is one of the first to examine racial disparities once patients have been referred for transplant evaluation.²⁹ This time point, however, is critical to study because patients who have been referred to transplant evaluation have supposedly surmounted the barriers that would have prevented them from being referred to transplant in the first place, but racial disparities in completing evaluation and being accepted for transplant continue.

The goals of our study are to determine whether AA and White patients with ESKD undergoing evaluation for transplantation: (1) differ across cultural factors, transplant knowledge, and psychosocial characteristics; (2) differ in the rate of being accepted for KT; and (3) whether potential differences in time to be accepted for transplant are explained by non-medical factors after controlling for demographics and medical factors.

Results

Race Differences on Predictor Variables

Table 1 displays race comparisons for all predictor variables. We found significant race differences for occupation and family income ($p < 0.05$), but found no significant differences in gender, marital status, age, education, or type of insurance coverage. A significantly larger proportion of AA participants were on dialysis than White participants, i.e. they were less likely to have been referred for preemptive transplantation. All AAs received hemodialysis while 86.7% of Whites received hemodialysis and 13.3% received peritoneal dialysis. There was no significant race difference in Charlson Co-Morbidity, or in participants' report of the availability of potential donors at either their first or second interview. We found significant race differences in perceived discrimination, perceived racism, medical mistrust, and religious objection to LDKT, but not in family loyalty. There were no significant race differences in transplant knowledge or psychosocial characteristics except in external locus of control.

Time to Acceptance

Figure 1 shows the Kaplan-Meier survival analysis curves for comparisons of time to be accepted for a kidney transplant by race. The survival curves indicate that AAs took a significantly longer time than Whites to be accepted for a kidney transplant. The gap between White and AA transplant candidates in time to be accepted for kidney transplant was at least 1.5 years ($p < 0.001$).

Predictors of Time to be Accepted for a Kidney Transplant

Before proceeding with multivariable analyses, variables were examined for multicollinearity. We found that education, occupation, income and insurance level were significantly correlated ($p < 0.02$). Therefore, we excluded educational level and insurance in the final model because they were related to occupation and income, but were not found to be associated with race (Table 1).

Table 2 shows the predictors of time to be accepted for a kidney transplant. Model 1 represents the effect of race without controlling for any of the other variables. It indicates that race was significantly associated with time to be accepted for kidney transplant. Race was found to have a time varying effect on acceptance for transplant. Specifically, we found that there was no difference between Whites and AAs in time to acceptance by the first year of participant tracking, where most of the participants were accepted by this time. After the first year, Whites took significantly less time than AAs to be accepted for a kidney transplant, and that difference continued for the remainder of the time participants were tracked in the study.

Model 2 includes the other key variables and their independent effects on time to be accepted for transplant (while controlling for all other variables in the model). Those results indicated that race, while still having a time varying effect, was no longer significantly associated with time to acceptance. Instead, income, perceived discrimination, transplant knowledge, and religious objection to LDKT were independently and significantly associated with time to be accepted for kidney transplant (all p -values<0.05). Those with a lower income took longer to get accepted for a kidney transplant than those with a higher income. Those who reported previously experiencing any discrimination in health care took significantly longer to be accepted for a transplant than those who reported not experiencing any discrimination. Those with more transplant knowledge took less time to be accepted for a kidney transplant than those with less transplant knowledge. Although there was no overall race difference in transplant knowledge, knowledge did predict race differences in time to be accepted for transplant. Of the 27 knowledge items, 5 showed significant race differences, including where a cadaveric kidney comes from, how long it takes for donors to return to their normal activities, whether dialysis patients live longer than transplant patients, whether donors are more likely to get kidney disease, and whether donors have to pay for testing and hospitalization related to donation. In all 5 items, AA participants had a higher error rate than White participants.

Finally, religious objection to LDKT was found to have a time varying effect on acceptance for transplant. Initially, participants with high religious objections to LDKT were less likely to be accepted for transplant than those with low objections; but, after 7 months, they were more likely to be accepted for kidney transplant. By 1 year, however, religious objection to LDKT no longer influenced being accepted for transplant.

Discussion

This report demonstrated significant race differences on several cultural factors in patients as they begin the process of KT evaluation. AA patients reported experiencing more discrimination in healthcare, more perceptions of racism in healthcare, higher medical mistrust, and more religious objections to LDKT than did White patients. These results confirm previous research examining racial differences in experience with health care in other medical conditions.^{13–18}

A critical finding of our work was that co-morbidity, dialysis status, and availability of potential living donors were not associated with days to be accepted for transplant. This confirmed our hypothesis that medical factors alone could not explain the racial disparities. Also confirming national findings regarding racial disparities in KT,^{3–6, 34–35} we found that AA ESKD patients took significantly longer to complete their medical work up before being presented to the transplant team and to be accepted for kidney transplants, than did White kidney disease patients. We believe that these disparities could be partially explained by the non-medical predictors we examined.

It is of note that race ceased to be a significant predictor of being accepted for KT after controlling for cultural and psychosocial characteristics. We found that perceived discrimination in healthcare, less transplant knowledge, more religious objection to transplantation, and lower income explained the racial disparities observed in the time it took to be accepted for transplant. These results add to the existing research about racial disparities in transplantation which previously found significant effects of perceived discrimination,²⁰ religious objection to transplantation,^{11, 21} and knowledge about transplantation^{10, 25} in retrospective analyses of reasons for such disparities. Our prospective study validated these findings, and found that these factors can account for the racial disparities. Thus, as in other healthcare domains, non-medical factors may prove to be important considerations in efforts to reduce racial disparities in KT.

These findings may help transplant teams identify patients who may be at risk for longer evaluation times. Once patients are identified as at risk, one of several approaches may be chosen. For example, transplant teams may target at-risk patients for interventions that would ensure timely completion of the evaluation process (e.g., fast-track transplant evaluation that would involve the coordination of all of their evaluation testing in one place over a period of a few days, rather having to coordinate and complete all of the testing on their own). Another clinical approach would include increasing contact with patients who are identified as at risk by transplant staff to ensure that patients follow-through on necessary testing to complete the evaluation. Transplant staff may have to facilitate scheduling of appointments or contacting third party clinicians to ensure patients' timely completion of necessary testing. Yet another approach would entail the use of transplant recipients as trained peer mentors or navigators, who would help current transplant candidates navigate the system in order to complete the required testing and be available to answer questions and lend culturally appropriate support.³⁶⁻³⁷ Finally, transplant teams could enhance their own cultural competency to become better educated about the reasons that patients may take longer to complete evaluation. For instance, some patients may purposely choose to take longer to complete the process because they may need more time to decide whether to go through with transplantation. In this case, the team's goals would be to respect the needs of the patient and their culture, providing extra help with coordination of appointments and follow-up, and answering patients' questions to address their transplant concerns. To this end, transplant teams need to be trained to be more aware of patients' cultural differences and to approach patients with respect and care when it comes to helping them complete the evaluation process. Cultural competency training is available online via *The Provider's Guide to Quality and Culture*.³⁸ This online interactive tutorial provides training, assesses skills, and provides profiles of major US ethnic groups, and is a joint project of Management Sciences for Health, the U.S. Department of Health and Human Services, the Health Resources and Services Administration, and the Bureau of Primary Health Care.

Some study limitations deserve mention. First, because this study was conducted in one region our findings may lack generalizability. However, our sample was comparable to the national OPTN and USRDS databases in basic demographics (i.e., race, gender, and age).³⁹⁻⁴⁰ We also did not include measures of adherence pre-transplant. Future work should assess this factor in order to control for its effect on acceptance for kidney transplant.

Despite these limitations, we found that perceived discrimination in healthcare can be as much of a risk factor as race, income, or low transplant knowledge. Directions for future work include replicating our study with a larger sample and in other geographic regions, tracking the influence of the identified significant factors on long-term graft and patient survival, as well as patient quality of life post-transplant, determining how these factors may predict patient adherence to the post-transplant immunosuppression and health behavior

regimen, and testing the suggested clinical interventions to reduce disparities in kidney transplantation.

Materials and Methods

Study Design

This longitudinal study was approved by the University of Pittsburgh and VA Pittsburgh Healthcare System IRBs and all participants provided written informed consent to a master's level research assistant. Participants completed two semi-structured telephone interviews. The first interview (1 hour) was completed shortly after participants' first transplant clinic appointment. The second interview (20 minutes) was completed shortly after they were accepted or found ineligible for kidney transplant.

Study Sample

Participants for the study were recruited from the University of Pittsburgh Starzl Transplant Institute kidney transplant clinic, and the VA Pittsburgh Healthcare System renal clinic. Inclusion criteria were: (1) referral for kidney transplant; (2) no prior history of KT; (3) English speaking; and, (4) age 18 or older. A total of 168 patients met these criteria and 127 of those agreed to participate and had usable data at both time points in the study, yielding a 76% response rate. Participants were evaluated for transplant between December 2006 and July 2007.

Interview Procedures and Measures

Our study variables were assessed with standard measures administered via semi-structured interview and medical record review. The interviews were conducted by a highly qualified staff of 4 bachelors- or masters-level survey professionals from the Survey Research Program (SRP) at the University of Pittsburgh Center for Social and Urban Research (UCSUR). This group is independent of the transplant team, thereby assuring patient confidentiality and no coercion for interview completion. All interview data was entered directly on the computer with the use of a computer-aided telephone interview system, therefore no recordings of the interviews were made. The measures described below describe the full content of the interview. For a copy of the interview, please contact the first author.

Demographics (e.g., race, gender, age, etc.) were obtained via self-report during the interview.

Medical factors including, receipt of dialysis, dialysis type, and Charlson co-morbidity index³² were abstracted from medical records. The number of potential living donors available for evaluation at participants' first and second interviews was determined by asking participants to indicate how many living relatives and friends they had between the ages of 18 and 70, the age range of adult living kidney donors.⁴¹

Cultural factors: We measured participants' *perceived discrimination* with an adapted version of the perceived discrimination in health care measure (7 items; Cronbach's $\alpha=.90$).^{13-14,42} We measured *perceived racism in health care* with 4 items based on the work of LaVeist,⁴³⁻⁴⁴ which assess the belief that racism is common in healthcare in general (Cronbach's $\alpha=.76$). We assessed *medical mistrust* with 18 items adapted from LaVeist's Medical Mistrust Index (MMI).⁴³⁻⁴⁵ This index assesses the degree to which participants believe their hospital to be trustworthy, competent, and acting in the best interest of the patient (Cronbach's $\alpha=.87$). We assessed *religious objection to LDKT* with a revised subscale of the Organ Donation Attitude Survey (ODAS),⁴⁶ a measure to assess religious

beliefs related to LDKT (e.g., I have religious objections to living donor KT; Cronbach's $\alpha=.71$). Finally, we assessed *family influence* with the 16-item Bardis Familism scale, a measure of kinship rights and obligations.⁴⁷ (Cronbach's $\alpha=.81$).

Transplant knowledge was assessed with items adapted from the KT Knowledge Survey (KTKS)⁴⁸ and the Kidney Transplant Questionnaire^{25, 49}. This measure included 27 multiple choice and true-false items (Cronbach's $\alpha=.71$) that assessed participants understanding about kidney disease and transplantation (e.g., "A person can live with only one working kidney").

Psychosocial characteristics: *Social support* was measured with the Interpersonal Support Evaluation List (ISEL-12)⁵⁰ (Cronbach's $\alpha=.85$). *Emotional distress* was assessed with the anxiety and depression subscales of the Brief Symptom Inventory (BSI)⁵¹ (Cronbach's α was .87 and .88, respectively). *Self-image* was assessed with the Rosenberg Self-Esteem Scale⁵² and the Sense of Mastery scale.⁵³ The Self-Esteem Scale assesses patients' feelings of self-worth and self-respect (Cronbach's $\alpha=.85$), and the Sense of Mastery Scale assesses the degree to which participants feel they have personal control over the things that happened to them (Cronbach's $\alpha=.76$). *Locus of control* was assessed with the Multidimensional Health Locus of Control (MHLC) scale, Form C.⁵⁴ We grouped locus of control into internal (Cronbach's $\alpha=.68$) versus external locus of control (Cronbach's $\alpha=.79$).

Outcome Variables: We conducted medical record review to determine the total number of days from first presenting to transplant clinic to being accepted or found ineligible for transplant.

Statistical analysis

All data were examined for statistical assumptions. Due to non-normal distributions, age, education, occupation, income, cultural factors, transplant knowledge, and psychosocial characteristics were dichotomized as high or low using a median cutoff (except perceived discrimination was categorized as any/none). Locus of control was normally distributed.

Race differences were examined using chi-square tests or Fisher's exact test for categorical variables, and t-tests or Wilcoxon rank sum tests for continuous variables. Kaplan-Meier survival curves were constructed to depict race differences in time to be accepted for transplant. Log rank or Peto-Peto tests were used to assess the difference between these survival functions.

To determine which variables would be in the final model predicting time to be accepted for transplant, univariate analyses of each variable of interest and the outcome were examined. Any variable associated with the outcome at a $p<0.10$ significance level was included in the multivariable model. This procedure ensured that only the variables that had the strongest association with time to be accepted for transplant would be included in the final model, and would limit Type 1 error. The proportionality assumption was evaluated before fitting the models. We considered 9 predictors. Given our total sample size, we maintained an appropriate respondent-to-variable ratio within the recommended range of 10:1 to 15:1.⁵⁵

To identify a model predicting time to be accepted for kidney transplant, the proportional hazards (PH) assumption was first assessed at $p<0.05$ significance level using Gray's test for each potential predictor.⁵⁶ Because some of the predictor variables violated the PH assumption, we used Gray's time-varying coefficients survival regression model for the multivariable analyses.⁵⁷ Two models were run for each outcome. Model 1 examined the between group differences in time to be accepted for transplant. Model 2 examined racial

differences after controlling for demographics, cultural factors, transplant knowledge, and psychosocial characteristics.

Acknowledgments

Work on this project was funded by support from the Veterans Administration (VA) Health Services Research and Development Department (HSR&D) Merit Review Entry Program #04-409, VA HSR&D Merit Award #IIR 06-220, VA Center for Health Equity Research and Promotion (CHERP) Pilot Fund # LIP 72-023, VA Veterans Integrated Service Network (VISN) 4 Competitive Pilot Project Funds # XVA 72-034, National Institutes of Diabetes, Digestive, and Kidney Diseases (NIDDK) R01DK081325, and the University of Pittsburgh Center for Social and Urban Research Manners Faculty Development Award # XNV 72-085.

Abbreviations

AA	African Americans
DDKT	deceased donor kidney transplantation
ESKD	end-stage kidney disease
KT	kidney transplantation
LDKT	living donor kidney transplantation

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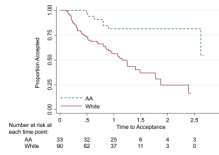


Figure 1. Kaplan-Meier survival curves for proportion of sample to be accepted for a kidney transplant over 3 years by race.

Table 1

Characteristics of Kidney Transplant Candidates (n=127)

Characteristic	White (n=94)	African American (n=33)	p-value
Demographic - % (N)			
Gender (male)	66.0 (62)	60.6 (20)	0.58
Age (≤ 50)	20.2 (19)	36.4 (12)	0.06
Educational level (≤ High School)	38.3 (36)	48.5 (16)	0.31
Occupation (≤ Semi-skilled workers)	42.6 (40)	63.6 (21)	0.04
Family Income (< \$24,999) ¹	36.3 (33)	60.6 (20)	0.02
Insurance (public/uninsured)	71.3 (67)	72.7 (24)	0.87
Marital Status (married)	58.5 (55)	45.5 (15)	0.20
Medical Factors and Availability of Donors - % (N)			
Received Dialysis (yes) ²	64.5 (60)	87.9 (29)	0.01
Dialysis Type (yes)			0.05
Hemodialysis	86.7 (52)	100.0 (29)	
Peritoneal dialysis	13.3 (8)	0 (0.0)	
Potential Donors at Time 1 (yes)	44.7 (42)	30.3 (10)	0.15
Potential Donors at Time 2 (yes) ³	40.8 (31)	44.0 (11)	0.78
Charlson Co-Morbidity Index, Mean (SE) ⁴	2.83 (0.20)	2.97 (0.32)	0.56
Cultural Factors - % (N)			
Perceived Discrimination (Any)	33.0 (31)	75.8 (25)	<0.001
Perceived Racism (High)	33.0 (31)	84.9 (28)	<0.001
Medical Mistrust (High)	42.6 (40)	72.7 (24)	0.003
Family Loyalty (High)	45.7 (43)	57.6 (19)	0.24
Religious Objection to LDKT (High)	31.9 (30)	57.6 (19)	0.009
Transplant Knowledge – % High (N)	46.8 (44)	33.3 (11)	0.18
Psychosocial Characteristics - % (N)			
Social Support (High)	46.8 (44)	57.6 (19)	0.29
Anxiety and (High)	48.9 (46)	48.5 (16)	0.96
Depression (High)	47.9 (45)	51.5 (17)	0.72
Self-esteem (High)	51.1 (48)	42.4 (14)	0.39
Mastery (High)	38.3 (36)	21.2 (7)	0.07
Locus of Control - Mean (SE)			
Internal	3.94 (0.10)	3.97 (0.19)	0.90
External	3.28 (0.09)	3.89 (0.15)	<0.001

¹ N=124 Participants responded to this question; 3 Whites are missing

² N=126 Participants responded to this question; 1 White is missing

³ N=101 Participants responded to this question; 8 African Americans and 18 Whites are missing

⁴ N=118 Participants responded to this question; 2 African Americans and 7 Whites are missing

Table 2

Predictors of time to be accepted for kidney transplant

Variables	HR	HR Min	HR Max	p-value
Model 1 (Unadjusted)				
Race ^{I***}				0.005
African American	Ref			
White	--	1.49	25.96	
Model 2 (Adjusted)				
Race ^I				0.08
African American	Ref			
White	--	0.70	14.27	
Occupation				0.55
≥ Semi-skilled workers	Ref			
< Semi-skilled workers	0.83			
Income **				0.01
> \$24,999	Ref			
≤ \$24,999	0.41			
Perceived Discrimination *				0.04
None	Ref			
Any	0.50			
Religious Objection to LDKT ^{I*}				0.02
Low	Ref			
High	--	0.33	3.34	
Transplant Knowledge **				0.01
Low	Ref			
High	2.49			
Depression				0.22
Low	Ref			
High	0.66			
Mastery				0.46
Low	Ref			
High	0.78			
External Locus of Control	0.72			0.07

Note:

^ITime-dependent covariates;* $p \leq .05$,** $p \leq .01$,*** $p \leq .001$