Modifiable Patient Characteristics and Racial Disparities in Evaluation Completion and Living Donor Transplant

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Summary
Background and objectives To reduce racial disparities in transplant, modifiable patient characteristics associated with completion of transplant evaluation and receipt of living donor kidney transplant must be identified.

Design, setting, participants, & measurements From 2004 to 2007, 695 black and white patients were surveyed about 15 less-modifiable and 10 more-modifiable characteristics at evaluation onset; whether they had completed evaluation within 1 year and received living donor kidney transplants by 2010 was determined. Logistic regression and competing risks time-to-event analysis were conducted to determine the variables that predicted evaluation completion and living donor kidney transplant receipt.

Results Not adjusting for covariates, blacks were less likely than whites to complete evaluation (26.2% versus 51.8%, \( P<0.001 \)) and receive living donor kidney transplants (8.7% versus 21.9%, \( P<0.001 \)). More-modifiable variables associated with completing evaluation included more willing to be on the waiting list (odds ratio=3.4, 95% confidence interval=2.1, 5.7), more willing to pursue living donor kidney transplant (odds ratio=2.7, 95% confidence interval=1.8, 4.0), having access to more transplant education resources (odds ratio=2.2, 95% confidence interval=1.5, 3.2), and having greater transplant knowledge (odds ratio=1.8, 95% confidence interval=1.2, 2.7). Patients who started evaluation more willing to pursue living donor kidney transplant (hazard ratio=4.3, 95% confidence interval=2.7, 6.8) and having greater transplant knowledge (hazard ratio=1.2, 95% confidence interval=1.1, 1.3) were more likely to receive living donor kidney transplants.

Conclusions Because patients who began transplant evaluation with greater transplant knowledge and motivation were ultimately more successful at receiving transplants years later, behavioral and educational interventions may be very successful strategies to reduce or overcome racial disparities in transplant.

Introduction
Despite the higher prevalence of CKD among blacks (1,2), they are less likely than whites to receive deceased donor transplants (DDKTs) and living donor transplants (LDKTs) (3,4), even after adjusting for clinical and sociodemographic characteristics (5). In 2009, blacks received just 14% of LDKTs, despite being 28% of ESRD incident patients in that year (6,7). These racial disparities in transplant emerge long before the day of actual transplantation (8); black patients are also less likely than white patients to complete evaluation (3,9–11).

In addition to a patient’s ethnicity, there is a continuum of less- to more-modifiable patient characteristics that could influence transplant outcomes (Figure 1). For example, less-modifiable patient characteristics, including being a man (10,12), being younger (9,10,12–14), having higher levels of formal education (14,15), having better health insurance (11,13–15), being employed (15), having a higher income (4,13), and having a primary care physician (11,16), have all been shown to be associated with completion of transplant evaluation and receipt of transplant. The majority of studies assessing patient characteristics associated with successful transplant outcomes rely on publicly available national databases like those databases from the Scientific Registry of Transplant Recipients (SRTR) or United States Renal Data System, which have limited measurement of more-modifiable patient characteristics.

Research clarifying the influence of more-modifiable factors, like patient transplant knowledge and motivation to receive a DDKT or LDKT, on successful transplant outcomes is still underdeveloped (Figure 1). Limited individual studies have found that obtaining information about transplant from a source other than a nurse or doctor (11), having greater health literacy (17), having greater transplant knowledge (18), and having asked potential living donors to donate (11) all predict completion of transplant evaluation. Similarly, having conversations in dialysis centers about transplant (19) has also been shown to be predictive of
receipt of LDKT. However, few studies (11) have simultaneously examined a large number of less- and more-modifiable patient factors on ultimate completion of evaluation or receipt of DDKTs or LDKTs over time.

To plan and execute effective interventions to reduce racial disparities, we must understand on which modifiable patient characteristics to intervene. Thus, we conducted a 6-year prospective cohort study of 695 patients presenting for transplant evaluation to examine how blacks and whites differ in their less- and more-modifiable characteristics at evaluation onset and determine which of these patient characteristics are associated with evaluation completion and receipt of LDKTs.

Materials and Methods

Participants and Procedure

From October of 2004 to December of 2007, we recruited 750 patients presenting at Barnes-Jewish Transplant Center (BJTC) in St. Louis, Missouri and surveyed them by telephone within 4 months of presenting for evaluation. Inclusion criteria for the study included patients who were of white or black race, had insurance enabling them to receive care at BJTC, and had not yet had a transplant when the survey was conducted. All patients in the study were not on the national transplant waiting list at the time of presenting to BJTC. Excluded from the study sample were 23 patients of other races, 8 patients transplanted before the survey began, 5 patients who had insurance not accepted at BJTC, and 19 patients whose outcomes could not be retrieved from the SRTR database 6 years later, leaving a study sample at evaluation onset of 695 white (n=512) and black (n=183) patients. For the predictive modeling of completion of transplant evaluation and receipt of LDKTs, we also excluded 59 additional patients who were determined to be medically ineligible for transplant during evaluation, because this ineligibility would prevent them from completing evaluation or receiving a transplant, leaving a final sample of 636 patients.

Participants consented to complete a transplant decision-making survey measuring 15 less-modifiable and 10 more-modifiable patient characteristics and then have their progress through transplant evaluation followed and outcomes tracked in the BJTC Organ Transplant Tracking Record (OTTR) and through the SRTR 6 years later. This study protocol was approved by the Washington University in St. Louis Institutional Review Board (Protocol Number 08–1349).

Explanatory Measures

Patient characteristics fall along a range of modifiability from not modifiable at all to less modifiable to more modifiable. For the sake of this study, we chose to define less-modifiable characteristics as factors less commonly intervened on during transplant evaluation or factors that are very difficult or unlikely to change.

Less-Modifiable Characteristics. Less-modifiable characteristics measured included demographic characteristics (age, sex, race, and level of education); comprehensiveness of health insurance coverage (less comprehensive is no insurance, only Medicare, or only Medicaid; more comprehensive is having multiple types of insurance or private insurance); clinical characteristics, including etiology of ESRD (diabetes, hypertension, and polycystic kidney disease [PKD]) and comorbid conditions (cancer), the answer to the first question from the Short Form (12) Health Survey (measure of perceived health) (20), and time on dialysis before presenting for transplant (≤2 or >2 years). Psychosocial characteristics, including psychologic health (anxiety and depression using the Brief Symptom Inventory-18 (BSI-18)) (21), medical mistrust (one item: “I trust hospitals”) (22), and burden of kidney disease using the Kidney Disease Quality of Life-36 (KDQOL-36) (lower scores indicate higher disease burden) (23), were also assessed.

More-Modifiable Characteristics. More-modifiable characteristics measured included patients’ transplant knowledge, perceived benefits to transplant, attitudinal willingness to pursue DDKT and LDKT, and quality and amount of transplant education received before beginning evaluation. We assessed transplant knowledge with a 12-item multiple choice and true/false scale, yielding a summed score ranging from 1 to 12 (24), and then created two categories, wherein higher knowledge indicates 9–12 questions answered correctly and lower knowledge indicates 0–8 questions answered correctly. Items measuring patients’ perceptions of the benefits (seven items) and disadvantages (six questions answered correctly) were also assessed.
items) of transplant were summed to create scales ranging from 7 to 21 and from 6 to 18, respectively (24).

We assessed attitudinal willingness to (1) get on the deceased donor waiting list and (2) allow a living donor to volunteer using the Transtheoretical Model of Behavioral Change (25). Patients reported for each factor whether they were in one of four stages of willingness: (1) not willing to take action (precontemplation); (2) might take action (contemplation); (3) will take action (preparation); or (4) in the process of taking or already taking action (action/maintenance). For the purposes of the analyses, we categorized patient responses into two attitudinal willingness groups consistent with the theory: earlier willingness stages (precontemplation, contemplation, and preparation) and later willingness stages (action and maintenance). Throughout the manuscript, references to more willing describe those patients in the later stages of willingness, and references to less willing describe those patients in earlier stages of willingness, consistent with the theory (26).

We created a measure to assess the quality and amount of transplant education patients received before beginning evaluation, where patients were counted as having received adequate prior transplant education if they talked to a doctor/other medical staff for at least 1 hour about transplant and read brochures/browsed internet websites about transplant for at least 1 hour (yes/no). In addition to this measure and to further assess patients’ exposure to information and communication with others about transplant, we also asked patients whether physicians had recommended that they call a transplant center to be evaluated (yes/no), whether they talked to a prior kidney recipient for any length of time (yes/no), and whether they talked to family and friends about transplant for any length of time (yes/no).

We also used OTTR to determine the number of living donors who called the transplant center between evaluation onset and the end of patient follow-up (August of 2010).

Outcome Measures

Completion of Transplant Evaluation. Similar to previous studies (27), completing transplant evaluation was defined as the patient being activated on the deceased donor waiting list or receiving an LDKT within 1 year of starting evaluation, which was indicated in either OTTR or SRTR. We chose 1 year as the cutoff for successful evaluation, because 80% of patients who were listed or received LDKT did so within this timeframe and re-evaluation must occur after a patient has been on the waitlist for 1 year. In August of 2010, we pulled BJTC patients’ medical records from OTTR and also requested SRTR data to determine whether patients had been listed for a DDKT or received an LDKT within 1 year of presenting for evaluation at either BJTC or another transplant center.

Final Outcomes Including Receipt of LDKT. Also, in August of 2010, using OTTR and the SRTR, patients’ final transplant outcomes were determined to be one of the following: received (1) an LDKT or (2) a DDKT, (3) assessed to be medically ineligible for transplant, (4) died, (5) dropped out of transplant pursuit at BJTC, or (6) listed and still actively pursuing transplant at any transplant center.

Data Analysis

Data were analyzed using SAS version 9.3 and R version 2.14.2. The two-sided statistical significance level was set at 0.05, and confidence intervals (CIs) used a 95% threshold. To assess differences at onset of evaluation for blacks and whites, we conducted t tests, chi-squared/Fisher’s tests, or unadjusted logistic regressions. To predict successful completion of transplant evaluation within 1 year (yes/no) among medically eligible patients, we fitted a multivariable logistic regression model using the less- and more-modifiable patient characteristics described in Explanatory Measures. Collinearity among the predictors was examined, and because depression and anxiety were significantly correlated, anxiety was not included in the model. Also, the number of living donors coming forward for a patient was not included in this model, because it was not possible to determine if the donors presented within 1 year of the patient beginning transplant evaluation. After removing these two variables, we used a stepwise selection process with the 23 remaining less- and more-modifiable patient characteristics described above, with race forced into the model.

For medically eligible patients, we examined the time (in months) from onset of evaluation to receipt of an LDKT using cumulative incidence curves in a competing risks setting and a multivariable proportional subdistribution hazards model using the Fine and Gray approach (28), treating DDKT as a competing event. In the multivariable competing risks model, we omitted anxiety because of collinearity with depression and entered the remaining 24 less- and more-modifiable patient characteristics described above using a stepwise selection process. Patients were followed from onset of evaluation (first patient started on July 12, 2004) and censored at the time of death, date of dropout, or end of follow-up (indicating that the patient was still listed as of August 24, 2010.) The cmpsk package in R was used for this analysis.

Results

Racial Differences at Onset of Evaluation

The complete set of less- and more-modifiable characteristics examined for whites and blacks when presenting for transplant evaluation is presented in Table 1. When examining more-modifiable characteristics only, at onset of evaluation, black patients were less likely to have talked to family and friends about transplant for any length of time (72.7% versus 80.1%, P=0.04), were less likely to have received adequate transplant education (38.8% versus 54.3%, P<0.001), had lower transplant knowledge (20.8% versus 50.2%, P<0.001), and perceived fewer benefits to transplant (13.4 versus 14.4, P=0.004) compared with whites. They also were less willing to get on the deceased donor waiting list (66.5% versus 79.3%, P<0.001) and allow a living donor to volunteer (21.0% versus 39.5%, P<0.001).

Predictors of Successful Completion of Transplant Evaluation

Unadjusted for covariates, blacks were less likely than whites to complete evaluation within 1 year (26.2% versus 51.8%, P<0.001). Excluding medically ineligible patients and after adjusting for covariates, patients who completed
transplant evaluation within 1 year were more likely to be white (odds ratio \( OR = 1.8 \), 95% CI=1.1, 2.9), have PKD (\( OR = 3.7 \), 95% CI=1.9, 7.1), report that they trusted hospitals (OR=3.0, 95% CI=1.7, 5.6), have hypertension (OR=1.9, 95% CI=1.3, 2.9), and have more comprehensive health insurance coverage (OR=1.9, 95% CI=1.1, 3.3) (Table 2). In regards to their more-modifiable characteristics, patients who completed evaluation successfully within 1 year began evaluation in later stages of DDKT attitudinal willingness (OR=3.4, 95% CI=2.1, 5.7), in later stages of LDKT attitudinal willingness (OR=2.7, 95% CI=1.8, 4.0), having had adequate prior transplant education (OR=2.2, 95% CI=1.5, 3.2), and with higher transplant knowledge (OR=1.8, 95% CI=1.2, 2.7).

### Predictors of Successful LDKT

After 6 years, fewer black patients had received an LDKT (8.7% versus 21.9%, \( P<0.001 \)) or a DDKT (19.1% versus 29.5%, \( P=0.006 \)) than white patients (Table 3).

At the conclusion of follow-up, 45% of patients had received transplants (128 LDKTs and 186 DDKTs), with 322 subjects censored (patients who were deceased, dropped out, or were still listed and actively pursuing transplant). In the multivariable analysis, patients who ultimately received an LDKT were more likely to begin evaluation in later stages of attitudinal LDKT willingness (hazard ratio=4.3, 95% CI=2.7, 6.8) and with greater transplant knowledge (hazard ratio=1.2, 95% CI=1.1, 1.3). There were no racial differences in receipt of LDKTs after knowledge, willingness, and other predictor variables were included in the model (Table 4).

### Discussion

Although racial disparities in transplant have been firmly established (3,5), few studies have compared the effect of large sets of less- and more-modifiable patient characteristics to determine where best to intervene to increase patients’ successful completion of evaluation and receipt of LDKTs (11). From the beginning of the transplant-seeking process, our study found that blacks began transplant evaluation less willing to get on the deceased donor waitlist,
less willing for LDKT, and less knowledgeable about the benefits of transplant compared with whites. As patients moved through the transplant process, those patients with less transplant knowledge and motivation to pursue LDKT at transplant onset were ultimately less likely to complete evaluation or receive LDKTs years later. When patients’ initial knowledge and attitudinal differences were controlled in the multivariable modeling, the racial disparity in receipt of LDKTs disappeared. Because previous research indicates that behavioral and educational interventions can improve patients’ transplant knowledge and attitudinal willingness to pursue DDKT and LDKT (29), an important direction for future research is to test if these interventions also lead to more blacks completing evaluation and receiving LDKTs.

Previous studies have indicated that educational interventions in different care settings can increase blacks’ knowledge, willingness to pursue, and actual pursuit of DDKT and LDKT (15,29,30). This study also underscores the importance of educationally intervening early and before patients ever present for transplant, particularly in settings like community nephrologists’ offices and dialysis centers. Black patients presenting for transplant, on average, knew only 21% of 12 basic transplant knowledge questions compared with whites, who knew 50% on average. Although black patients presenting for transplant had been on dialysis for significantly longer than whites, their exposure to information about transplant as a treatment option and discussions with family members and friends about it also were less frequent. Research has shown that dialysis administrators (31) and transplant educators within dialysis centers (32) both report barriers in having sufficient time to educate, previous training in transplant, and transplant educational resources to disseminate to their patients. With dialysis providers mandated to provide unbiased education around transplant (Regulation 494.90) (33), interventions to improve transplant knowledge within dialysis centers, where over 70% of ESRD patients receive regular care, will be critical. Culturally competent and tailored transplant education (34), particularly resources discussing the value of preemptive LDKT (35), available from nephrologists may also help with this effort (36).

Although this study did not assess the efficacy of a specific intervention, the finding that the level of transplant knowledge and readiness to pursue LDKT at evaluation onset were significant predictors of successful transplant outcomes years later indicates that interventions focused on helping kidney patients be as knowledgeable about transplant as possible and willing to receive transplants may increase the numbers of black patients successfully completing evaluation and receiving transplants. Recommendations from the Transtheoretical Model of Behavioral Change suggest that optimal education could assess patients’ level of DDKT and LDKT attitudinal willingness first and then provide factual information and recommendations that are individually tailored for the patient (37–42). For example, patients in earlier stages of willingness for DDKT might need more discussion about how transplant may improve their quality of life and the advantages of starting the waiting list clock sooner; patients in later stages may need specific coaching about how to efficiently complete the medical tests required for evaluation. Similarly, in discussing LDKT, dialogue about learning more about living donation with their support network may be the right recommendation for patients in earlier stages of LDKT willingness instead of coaching about how to ask loved ones to be donors. Research has shown that health care interactions that honor patients’ level of willingness

### Table 2. Multivariable model predicting successful completion of evaluation within 1 year (n=636)

<table>
<thead>
<tr>
<th>Less- and More-Modifiable Patient Characteristics</th>
<th>ORa (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less-modifiable characteristics</td>
<td></td>
</tr>
<tr>
<td>Had polycystic kidney disease</td>
<td>3.7 (1.9, 7.1)</td>
</tr>
<tr>
<td>Reported trusting hospitals</td>
<td>3.0 (1.7, 5.6)</td>
</tr>
<tr>
<td>Had hypertension</td>
<td>1.9 (1.3, 2.9)</td>
</tr>
<tr>
<td>Had more comprehensive insurance coverage</td>
<td>1.9 (1.1, 3.3)</td>
</tr>
<tr>
<td>Race: white</td>
<td>1.8 (1.1, 2.9)</td>
</tr>
<tr>
<td>More-modifiable characteristics</td>
<td></td>
</tr>
<tr>
<td>Later stages of willingness to get on the deceased donation waiting listb</td>
<td>3.4 (2.1, 5.7)</td>
</tr>
<tr>
<td>Later stages of willingness to allow a living donor to volunteerb</td>
<td>2.7 (1.8, 4.0)</td>
</tr>
<tr>
<td>Received adequate prior transplant education</td>
<td>2.2 (1.5, 3.2)</td>
</tr>
<tr>
<td>Higher transplant knowledgec</td>
<td>1.8 (1.2, 2.7)</td>
</tr>
</tbody>
</table>

OR, odds ratio; CI, confidence interval.

aAll variables were significant at P=0.05 or lower.
bVariable dichotomized such that later stages of willingness are action/maintenance and earlier stages of willingness are pre-contemplation/contemplation/preparation.
cTwelve-item scale dichotomized such that greater knowledge=9–12 answers correct and lower knowledge=0–8 answers correct.

### Table 3. Final transplant outcomes by race (n=695)

<table>
<thead>
<tr>
<th>Transplant Outcomes</th>
<th>Black % (n)</th>
<th>White % (n)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living donor kidney transplant</td>
<td>8.7 (16)</td>
<td>21.9 (112)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Deceased donor kidney transplant</td>
<td>19.1 (35)</td>
<td>29.5 (151)</td>
<td>0.006</td>
</tr>
<tr>
<td>Medically ineligible</td>
<td>10.4 (19)</td>
<td>7.8 (40)</td>
<td>0.28</td>
</tr>
<tr>
<td>Deceased</td>
<td>2.7 (5)</td>
<td>5.7 (29)</td>
<td>0.16</td>
</tr>
<tr>
<td>Dropped out of transplant pursuit</td>
<td>45.9 (84)</td>
<td>25.6 (131)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>at Barnes-Jewish Transplant Center</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Listed and actively pursuing transplant at any transplant center</td>
<td>13.1 (24)</td>
<td>9.6 (49)</td>
<td>0.21</td>
</tr>
</tbody>
</table>


can double the chance of patients taking actions, like completing evaluation, in the following 6 months (43,44). Educational interventions tailored to patients’ level of willingness in dialysis settings and through home-based visits have been shown to increase pursuit of DDKT and LDKT for black and white patients (29,45).

Like others, we confirmed that patients who were white (12), had PKD or hypertension (13), and had more comprehensive health insurance coverage (13) were more likely to complete evaluation. Although a patient’s health insurance is not modifiable by health care providers in transplant or dialysis centers, we recognize that policy-level interventions could influence the impact of these variables. Evidence presented in this paper and by others (11,13,15) that insurance type predicts evaluation completion should be taken under consideration by policymakers. Similarly, there are factors considered less modifiable in this study (for example, depression and anxiety) that actually could be modified for transplant patients with more comprehensive psychological interventions (46,47). Unlike other published research, we also found that having less medical mistrust was predictive of completion of transplant evaluation (18). Although published attempts to reduce medical mistrust have yielded limited success (48), future studies should continue to explore the impact of medical mistrust with providers, hospitals, and health care systems in general.

This study had several limitations. First, our data are from a single transplant center, reflecting only regional trends, and the results may not generalize to other transplant centers. Second, we studied disparities between black and white patients; future work should include Hispanics and Asians. Third, although our DDKT and LDKT measures have now been validated (24,49), our transplant knowledge scale is still being validated. Fourth, it was outside the scope of this study to investigate the reasons why patients, especially black patients, dropped out of evaluation. Understanding the barriers to evaluation completion faced by patients will be key to reducing them, and therefore, future research must work to define and intervene to reduce these barriers. Fifth, there are other patient, provider, and system variables that were not assessed in this study, including perceived discrimination by the medical care system (18), health literacy (17), size of a patient’s social network (9), and distance from a transplant center (50), that may also be very important in planning successful interventions to reduce racial disparities that should continue to be explored in future studies.

In transplant centers, where the patient care load is very high, it is sometimes assumed that patients who drop out of evaluation are not as interested in transplant as those patients that remain. Often, the patients who drop out in high numbers are members of racial/ethnic minority groups (3). This study’s main finding, that patients who began transplant evaluation with greater transplant knowledge and motivation to receive transplant were ultimately more successful at receiving transplants years later, shows that behavioral and educational interventions may be very successful strategies in helping to reduce and hopefully, overcome racial disparities in transplant.

Table 4. Multivariable competing risks model predicting receipt of living donor kidney transplant (n=636)

<table>
<thead>
<tr>
<th>More-Modifiable Characteristics</th>
<th>HRa (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Later stages of willingness to allow a living donor to volunteerb</td>
<td>4.3 (2.7, 6.8)</td>
</tr>
<tr>
<td>Higher transplant knowledgec</td>
<td>1.2 (1.1, 1.3)</td>
</tr>
<tr>
<td>Race: white</td>
<td>1.2 (0.7, 2.1)</td>
</tr>
</tbody>
</table>

HR, hazard ratio; CI, confidence interval.

All variables were significant at P<0.05, excluding race. No less-modifiable variables were significant in this model.

Variable dichotomized such that later stages of willingness are action/maintenance and earlier stages of willingness are pre-contemplation/contemplation/preparation.

Twelve-item scale dichotomized such that greater knowledge=9–12 answers correct and lower knowledge=0–8 answers correct.

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This study used data from the Scientific Registry of Transplant Recipients (SRTR). The SRTR data system includes data on all donors, wait-listed candidates, and transplant recipients in the United States submitted by the members of the Organ Procurement and Transplantation Network (OPTN), and it has been described elsewhere. The Health Resources and Services Administration (HRSA), US Department of Health and Human Services provides oversight of the activities of the OPTN and SRTR contractors. The authors alone are responsible for reporting and interpretation, and all or part of the data used for these publications was collected pursuant to Department of Health and Human Services, Health Resources and Services Administration Contract HHSH25020100018C.

Disclosures.

None.

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