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Association of sociocultural factors with initiation of the kidney transplant evaluation process

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Abstract

Although research shows that minorities exhibit higher levels of medical mistrust, perceived racism, and discrimination in healthcare settings, the degree to which these underlying sociocultural factors preclude end-stage renal disease (ESRD) patients from initiating kidney transplant evaluation is unknown. We telephone surveyed 528 adult ESRD patients of black or white race referred for evaluation to a Georgia transplant center (N = 3) in 2014–2016. We used multivariable logistic regression to examine associations between sociocultural factors and evaluation initiation, adjusting for demographic, clinical, and socioeconomic characteristics. Despite blacks (n = 407) reporting higher levels of medical mistrust (40.0% vs 26.4%, $P < .01$), perceived racism (55.5% vs 18.2%, $P < .01$), and experienced discrimination (29.0% vs 15.7%, $P < .01$) than whites (n = 121), blacks were only slightly less likely than whites to initiate evaluation (49.6% vs 57.9%, $P = .11$). However, after adjustment, medical mistrust (odds ratio [OR]: 0.59; 95% confidence interval [CI]: 0.39, 0.91), experienced discrimination (OR: 0.62, 95% CI: 0.41, 0.95), and perceived racism (OR: 0.61; 95% CI: 0.40, 0.92) were associated with lower evaluation initiation. Results suggest that sociocultural disparities exist in early kidney transplant access and occur despite the absence of a significant racial disparity in evaluation initiation. Interventions to

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DISCLOSURE

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SUPPORTING INFORMATION

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reduce disparities in transplantation access should target underlying sociocultural factors, not just race.

Keywords

disparities; end-stage renal disease; kidney transplant evaluation; race; sociocultural factors

1 | INTRODUCTION

Historical racial bias and discriminatory treatment in healthcare settings have longstanding effects on healthcare access among minority patients.¹ The end-stage renal disease (ESRD) care system is a useful model to examine these effects, where racial disparities in access to kidney transplant have been observed.²⁻⁴ Black ESRD patients are less likely to access steps preceding waitlisting, including completion of transplant evaluation, with inconclusive evidence regarding the existence of racial disparities in referral and initiating evaluation.⁵⁻¹⁰ However, existing studies regarding racial disparities in kidney transplantation often fail to address the socially constructed nature of race.¹¹ Due to the definitional and measurement challenges that exist from using race alone as a proxy for structural racism, discrimination, and disadvantage, a lack of racial differences alone in transplant access and outcomes may not be indicative that underlying sociocultural disparities are ameliorated.¹²⁻¹⁵

Prior evidence indicates high levels of medical mistrust among ESRD patients, suggesting that perceived racism and discrimination is prevalent among the ESRD population.¹⁶⁻¹⁹ Nevertheless, few single-center studies have examined these sociocultural correlates of transplant access due to sparse psychosocial data captured in ESRD databases.¹⁹⁻²² Medical mistrust is hypothesized to be a byproduct of discrimination, which studies have noted to influence kidney transplant access.^{16,17} Furthermore, difficulties in physician-patient communication on the basis of sociocultural differences may produce mistrust among patients and perpetuate disparities in transplant access.¹⁰ Previous research identified reduced healthcare utilization when patients are racially discordant with their provider, suggesting that racially discordant relationships may intensify cultural communication issues.²³

Few studies have examined patient-perceived racism relating to transplant access within the pretransplant ESRD population. Furthermore, no studies have assessed the effects of racism and discrimination on initiation of the transplant evaluation, a critical early step in the kidney transplant process.¹⁷ Evaluating the roles of perceived racism in healthcare, medical mistrust, experienced medical discrimination, and patient-provider race discordance in preventing initiation of the kidney transplant evaluation provides a unique opportunity to examine effects of multiple sources of racism and discrimination on early transplant access. Moreover, an examination of these sociocultural constructs may identify whether race differences, or the lack of, consistently reflect underlying sociocultural disparities in transplant access. We aimed to examine associations between sociocultural factors and initiating kidney transplant evaluation and to determine whether these associations are reflective of an underlying racial disparity in initiating transplant evaluation.

2 | MATERIALS AND METHODS

2.1 Study overview and survey development

We conducted a 48-item cross-sectional telephone survey of adult ESRD patients referred for kidney transplant evaluation in 2014-2016 to any of the 3 transplant centers in the United States state of Georgia: Augusta University Medical Center (Augusta), Emory Transplant Center (Atlanta), and Piedmont Transplant Institute (Atlanta). This survey was administered as part of the Reducing Disparities in Access to kidney Transplantation Regional Study, a community-based study aimed at reducing disparities in kidney transplant access in Georgia, North Carolina, and South Carolina.²⁴ The survey was designed to assess patient-perceived barriers in initiating kidney transplant evaluation once referred, and was guided by a 2011 root cause analysis assessing reasons for low transplant access among ESRD patients in the Southeast.²⁵ Validated and researcher-developed items related to medical mistrust, perceived discrimination, patient-perceived racism, and race discordance were included.^{23,26-28} Survey questions were designed to accommodate a 6th-8th-grade literacy level and were administered by telephone to ensure that patients with any literacy or visual barriers were included.

2.2 Study population

All adult (age ≥ 18) ESRD patients referred to a Georgia transplant center for a transplant evaluation between January 1, 2014 and December 31, 2016 were eligible for the study if they were alive and English-speaking at time of study start (March 2017) (N = 16 469). We excluded patients with attendance to the kidney transplant evaluation or placement on the waitlist prior to 2014 to minimize recall bias (n = 19). We also excluded multiorgan transplant candidates (n = 8), prior transplant recipients (n = 32), patients hospitalized or with significant medical issues at the time of scheduled evaluation (n = 12), and patients with scheduled evaluations at the time of survey administration (n = 13). Furthermore, we excluded patients with administrative data concerns, such as incorrect recording of an evaluation-initiation date or erroneous cancellation of a scheduled evaluation by the transplant center (n = 25). The majority (97.8%) of incident ESRD patients in the state of Georgia are non-Hispanic, black or white single race; thus, we excluded patients of Hispanic ethnicity, multiple race, or other race (n = 31).²⁰ Patients with severe cognitive or hearing impairments identified by research assistants and/or surrogates at verbal consent were also excluded (n = 16).

2.3 Data collection

Between March 2017 and July 2018, trained research assistants at each transplant center contacted eligible participants via telephone (up to 5 attempts) for verbal consent and completion of the ≈15-minute survey. Eligible patients were contacted in order of most recent referral date, starting with patients referred in December 2016. We enrolled patients until we reached target enrollment (n = 600). Each study site enrolled an approximately equal number of patients and an equal number of evaluation attendees versus absentees. Patients were each assigned a unique identifier, and de-identified survey responses were documented by research assistants using an electronic, HIPAA-compliant survey software, SurveyMonkey®. To ensure participants had adequate time to achieve the outcome of

initiating evaluation, all eligible patients were not contacted to participate until 6 months following their most recent referral date.⁶

2.4 | Initiating evaluation measure

The primary outcome was initiation of the kidney transplant evaluation at a transplant center, defined as an evaluation initiation date or receipt of in-center transplant education from transplant center staff. Evaluation attendees were classified as patients with any documented arrival date at the transplant center to begin the medical evaluation or attendance to an in-center transplant education session in 2014-2016. Absentees were classified as patients who (1) did not have a documented evaluation date during the study period or (2) did not attend a scheduled evaluation.

2.5 | Sociocultural measures

Numerous validated and researcher-developed instruments were used to measure patient-reported sociocultural factors, the primary exposures in this analysis (Table 1). *Perceived racism* was measured using a 4-item validated Racism Index measuring patients' perceptions of racism in healthcare settings.²⁷ *Medical mistrust* was measured using an abbreviated version of the Medical Mistrust Index (MMI).²⁶ For analytic purposes, we dichotomized Racism Index and MMI at the median in our study population. Discrimination was measured using a 4-item scale related to patient-experienced discrimination in healthcare settings.²⁸ To assess the role that provider race may play in shaping perceptions of racism, medical mistrust, experienced discrimination, and cultural miscommunications, *patient-provider race discordance* was measured using 2 researcher-developed questions regarding the racial backgrounds of (1) the patient's nephrologist and (2) the clinical provider who most influenced the patient's decision to pursue kidney transplantation (eg, patient's nephrologist, social worker, nurse, or other clinical educator).

2.6 | Patient and neighborhood-level covariates

Additional study variables were assessed using standard measures obtained via self-report, medical record abstraction, or the 2011-2015 American Community Survey Census for patient zip-code data.²⁹ Race, age, and sex were primarily measured via self-report, and missing data were backfilled using electronic medical records (EMR).

Abstracted and self-reported clinical characteristics considered for analysis included patient-reported duration of dialysis from year of dialysis start to date of survey administration, patient-reported preferred ESRD treatment at time of referral, transplant knowledge, perceived health status, distance from patient's residential address to referred transplant center, and Charlson comorbidity index.³⁰ Transplant knowledge was measured using a researcher-developed instrument designed to measure patient knowledge of the survival benefits of (1) kidney transplantation versus dialysis and (2) living donor versus deceased donor kidney transplantation.³¹ We categorized answering both, 1, or none of the items correctly as high, moderate, and low transplant knowledge, respectively. Distance from residential address to referred transplant center address was estimated as miles between centroids of the zip code tabulation areas (ZCTAs) containing the patient's residence

and transplant center. Comorbidities included in the Charlson comorbidity index (eg, hypertension, diabetes mellitus, congestive heart failure) were abstracted from the EMR.

Socioeconomic variables considered for analysis included self-reported zip code, neighborhood poverty (a proxy of household income), degree of urbanity, educational attainment, employment status, and primary insurance type.³² Patient residential ZCTAs were classified into 2010 Rural Urban Commuting Area codes and dichotomized into urban versus rural areas.³³ Neighborhood poverty level, obtained using linked 2015 American Community Survey Census data, was dichotomized at 20% ZCTA-level poverty per the US Census Bureau definition of a “high poverty area.”³⁴ To minimize the degree of nonresponse for insurance type, we backfilled missing responses using the EMR.

2.7 | Statistical analyses

We assessed differences in demographic, clinical, and socioeconomic characteristics by evaluation initiation status using Student *t* tests or nonparametric equivalents for continuous variables, and χ^2 tests (or Fisher exact tests for sparse data) for categorical variables. Student *t* tests were also used to examine racial differences in MMI and Racism Index, and χ^2 tests were used to identify differences in patient-provider race concordance, experienced discrimination, and agreement to individual items in the MMI and Racism Index. Assumptions for normality were assessed for all continuous variables. Due to high degrees of skewness for distance to referred transplant center and Charlson comorbidity score, these variables were either log-transformed (distance to referred transplant center) or categorized into quartiles (Charlson comorbidity score; 0, 1, 2, 3+ comorbidities).³⁵

Multivariable logistic regression models were constructed to assess associations between each sociocultural factor and evaluation initiation. We used regression coefficient variance-decomposition analyses with condition indices to assess for potential collinearity among covariates of interest. All fully adjusted models generated condition indices <30 with no more than 1 covariate variance-decomposition matrix proportions >0.5, consistent with prior literature indicating no collinearity.³⁶ Regression models were adjusted in a stepwise fashion controlling for relevant demographic, clinical, and socioeconomic characteristics.³⁷

In exploratory analyses, we examined whether the association of sociocultural factors with evaluation initiation varied by race by including an interaction term between race and sociocultural factors in each fully adjusted model; Wald tests were used to test the significance of each interaction term. Additionally, multivariable models were used to assess associations between race and sociocultural factors, using stepwise adjustment for demographic, clinical, and socioeconomic characteristics. Hosmer-Lemeshow statistics were computed for fully adjusted models to assess goodness of fit. We considered all 2-tailed $P < .05$ as statistically significant. Data cleaning and analyses were conducted with SurveyMonkey®, Microsoft Excel, and SAS® version 9.4 (Cary, NC). This study protocol was approved by Emory University’s Institutional Review Board (IRB) (IRB00079596) and Piedmont Healthcare IRB (IRB1049200-1), with a reliance agreement executed by Augusta Medical Center under Emory IRB.

2.8 | Sensitivity analyses

Multiple imputation methods were utilized for 111 observations with missing covariate data; we report adjusted odds ratios (ORs) with 95% confidence intervals (CIs) from models using imputed values from the SAS procedure PROC MI.³⁸ To assess differences in associations attributable to missing data, we compared ORs and 95% CIs for the associations between sociocultural factors and transplant evaluation initiation between multiple imputation analysis and complete-case analysis. Additionally, we compared select sociodemographic and clinical characteristics of our respondent patient population to a cohort of 2012-2016 incident ESRD patients in the state of Georgia using United States Renal Data System data to assess generalizability.²⁰

3 | RESULTS

3.1 | Study population

After applying inclusion and exclusion criteria, a total of 3583 patients were called to participate in the telephone survey. Following additional screening criteria, we consented 596 patients to complete the survey (304 attendees; 292 absentees) (Figure 1). Among these patients, 37 (6.2%) were missing race and ethnicity information after backfilling using EMR data. Furthermore, 10 patients (1.7%) were of Hispanic ethnicity, 16 patients (2.7%) identified as being multiracial, and 5 patients (0.8%) identified as a race other than black or white and thus were excluded, resulting in a final study population of 528 patients of black or white race.

Among our study population, patients who initiated evaluation exhibited greater educational attainment compared to those who did not initiate evaluation ($P < .01$) (Table 2).

Additionally, patients who initiated evaluation were more likely married or in a domestic partnership (47.4% vs 35.6%) and were less likely to reside in a high poverty neighborhood (29.8% vs 38.3%) compared to patients who did not initiate evaluation. Notably, the proportion of patients exhibiting high transplant knowledge was nearly twice as high among patients initiating evaluation compared to those who did not initiate evaluation (29.4% vs 16.0%). While attendees and absentees did not differ in the degree to which they perceive their health as excellent, very good, or good, patients initiating evaluation exhibited lower levels of comorbidity burden compared to those not initiating evaluation ($P < .01$).

3.2 | Racial differences in sociocultural factors

The proportion of black patients initiating evaluation was slightly less than that of whites (49.6% vs 57.9%) (Tables 3 and S1). However, a greater proportion of blacks exhibited high levels of medical mistrust (40.0% vs 26.4%) and perceived racism (55.5% vs 18.2%) compared to whites. Blacks were also more likely to report experiencing discrimination in healthcare settings (29.0% vs 15.7%), and were more likely to agree with the statements “Mistakes are common in healthcare organizations” (63.3% vs 44.2%) and “Racial discrimination in a doctor’s office is common” (35.1% vs 6.7%) compared to whites (Figure 2). Black patients were more likely to report having a racially discordant relationship with their nephrologist (82.8% vs 52.9%) and with their primary transplant educator (70.5% vs 54.5%). After adjustment for demographic, clinical, and socioeconomic

characteristics, racial differences in experienced discrimination, patient-nephrologist race discordance, patient-transplant educator, and perceived racism remained (Table S2).

3.3 | Associations between sociocultural factors and evaluation initiation

After adjusting for demographic and clinical characteristics, high levels of medical mistrust (OR: 0.59; 95% CI: 0.38, 0.92), perceived racism (OR: 0.63; 95% CI: 0.43, 0.93), and experiencing discrimination in healthcare (OR: 0.65, 95% CI: 0.43, 0.98) were significantly associated with a lower likelihood of initiating evaluation (Tables 4 and S4). Notably, after additional adjustment for socioeconomic characteristics, medical mistrust, perceived racism, and experiencing discrimination remained significantly associated with evaluation initiation. In fully adjusted analyses, racially discordant patient-nephrologist relationships and racially discordant patient-transplant educator relationships were not statistically significantly associated with evaluation initiation.

In exploratory fully adjusted analyses, we found the association between medical mistrust and evaluation initiation was not significantly modified by race (P for interaction = .65) (Table S3). Similarly, we did not find a statistically significant interaction by race for the association between perceived racism and evaluation initiation (P for interaction = .20).

3.4 | Sensitivity analyses

A total of 111 survey responses (21.0%) were missing for 1 or more covariates. In examining differences in associations between sociocultural factors and evaluation initiation using a complete case analysis versus multiple imputation, experienced discrimination was significantly associated with evaluation initiation using complete case analysis (OR: 0.57; 95% CI: 0.35, 0.94), while this association was not statistically significant using multiple imputation (OR: 0.69; 95% CI: 0.45, 1.06) (complete case analysis not shown). However, the relative magnitudes and directions of the association were approximately the same. The direction, magnitude, and statistical significance of all other examined associations were not meaningfully different.

When comparing survey respondents to 2012-2016 incident ESRD patients in the state of Georgia, we found that survey respondents exhibited a higher proportion of black, non-Hispanic patients (77.1% vs 57.2%), were younger (mean: 55.5 [SD: 12.8] years vs 60.4 [SD: 15.1] years, $P < .01$), less likely privately insured (12.3% vs 20.6%), and less likely employed (11.7% vs 40.4%) compared to the general incident ESRD population in Georgia (Table S5). We also observed that survey respondents were less likely to reside in a rural area (14.8% vs 21.8%, $P < .01$). We did not observe statistically significant differences in the proportion of female patients, proportion of patients residing in high poverty neighborhoods, or the distance between residential zip code and nearest transplant center between cohorts.

4 | DISCUSSION

In this study examining ESRD patients referred for kidney transplantation at 3 transplant centers in Georgia, medical mistrust, patient-perceived racism in healthcare settings, and experienced discrimination in healthcare were significantly associated with not initiating the kidney transplant evaluation. These associations persisted despite adjustment for clinical

and socioeconomic characteristics, suggesting that these sociocultural factors serve as significant independent barriers in access to kidney transplantation. Furthermore, these results suggest that racism and its underlying sociocultural correlates, rather than race alone, play critical roles in perpetuating disparities in transplant access. Importantly, we did not find a significant racial disparity in evaluation initiation within our study population, nor did we observe significant differences in associations between sociocultural factors and evaluation initiation by race, reflecting the limited nature of using race alone to measure underlying sociocultural barriers to transplant access.¹⁵

Arriola et al^{22,39} describe a conceptual framework for examining the influence of these sociocultural factors, manifesting at multiple levels within the transplant care system, in producing disparities in transplant access. Among minority ESRD patients, internalized racism may foster negative attitudes regarding worthiness for a transplant, dissuading them from initiating evaluation once referred. Patient uncertainties are theorized to be directed by mistrust of healthcare organizations, fostered by a history of discriminatory treatment and inferior medical care, and have been shown in mixed methods analyses to be associated with lower attitudinal willingness to pursue transplantation.^{16,22} Recent theoretical models examining the effects of racism on health-seeking behaviors have identified the mediating role of medical mistrust in contributing to lower treatment adherence, healthcare utilization, and satisfaction with care.^{26,40} This distrust of healthcare institutions may also contribute to fear of transplantation among ESRD patients.^{41,42} Furthermore, interpersonal processes, including professional contacts with ESRD care providers, may also host opportunities for personally mediated racism. This form of racism may manifest in unconscious biases by providers, such as differential views of the benefits of transplantation among minorities or assumptions regarding medication adherence of minorities posttransplant.²² These provider biases may partially account for racial disparities in early access to transplantation, and could result in discriminatory provision of resources aimed to increase likelihood of evaluation initiation.^{10,22,24,43}

Provider-level factors and behaviors are cited as effective targets for reducing sociocultural barriers to transplantation.⁴⁴ On the provider level, recommended solutions to minimize personally mediated racism include acknowledgment of the cultural consciousness of society and participation in interventions that address implicit biases in provision of medical care.^{40,45} Staff education regarding disparities in transplant access is recommended, especially given recent findings that less than a fifth of ESRD providers are aware of racial disparities in transplant waitlisting among low waitlisting dialysis facilities.⁴⁶ Furthermore, disparities in provision of transplant education to patients by staff indicate a need for more robust tracking of educational practices within dialysis facilities.⁴⁷ Although numerous effective transplant educational materials are available, these materials may not adequately consider the historical medical abuses, racial inequalities, and mistrust that may exacerbate insecurities about transplantation.^{18,22,24} Administering robust culturally sensitive educational materials around these insecurities has proven successful in mitigating disparities in transplant access; for example, a culturally targeted education program to improve knowledge and awareness of living donation among black families increased access to living donor transplantation among black ESRD patients.⁴⁸ Early delivery of educational

materials, such as through use of satellite clinics and community outreach, can also foster increased trust in transplant providers and the medical system.

Disparities in healthcare access and outcomes can be significantly improved by promoting shared medical decision making between patients and providers.⁴⁹ ESRD and transplant providers (who are more likely white, male, and of higher economic status) hold significant societal and health system–level power over their patients. These providers serve as gatekeepers to kidney transplantation (via referral, determining transplant candidacy, and organ allocation), and hold valuable “insider” knowledge of the way the transplant care system is organized.⁵⁰ Shared decision making between ESRD patients and transplant providers recognizes and redistributes these contextual power dynamics to promote shared autonomy of medical care.⁵¹ For example, shared decision making tools for comparing ESRD treatment options have proven effective in improving transplant knowledge among minorities.³¹ Culturally sensitive patient navigation is another form of shared decision making that may also enhance transplant access among minorities, facilitating patient trust in transplant providers.^{52,53} Peer mentoring programs have also been cited as effective strategies to promote trust and patient autonomy in ESRD treatment decision making and could promote trust and health-promoting behaviors among ESRD patients by reducing misconceptions and fear.^{54,55}

Several solutions exist to address institutional racism or cultural discrimination that may exist at the dialysis facility, transplant center, and national policy levels.²² For example, the Centers for Medicare & Medicaid Services Statement of Work for ESRD Networks includes a focus on transplant access and disparities reduction.⁵⁶ In the Southeastern region of the United States, findings suggest that participation in these quality improvement activities significantly reduces facility-level racial disparities in access to referral and evaluation initiation.²⁴ Similarly, developing and implementing novel quality metrics that measure equity in access to transplant could also reduce disparities attributable to institutionalized racism and discrimination. This strategy could include a mandate to report facility-level referral rates by race and other sociocultural factors, as well as more widespread screening of these underlying sociocultural constructs (in addition to broader social determinants of health) during the referral and evaluation processes.⁵⁶⁻⁵⁸ Furthermore, fostering better communication between dialysis and transplant center staff may promote continuity of patient-centered care. Increasing representation and diversity among healthcare providers and leadership can potentially ameliorate downstream deleterious effects on patient-provider communication due to racial or cultural discordance, especially given the existing predominance of white membership among policy-driving national transplant organizations.⁵⁰ An important next step in mitigating disparities in transplant access due to racial and sociocultural bias is to expand research on the role of unconscious bias in both dialysis and transplant settings, which requires the cooperation and willingness of both institutions.²² Importantly, underlying sociocultural factors are likely to exist among patients prior to receipt of ESRD care; thus, broader efforts are needed to prevent these barriers from occurring within the US healthcare system, including early training of healthcare professionals to recognize and address implicit bias in medical care.⁴⁵

We acknowledge several limitations to this study. First, because patients self-reported data and were recruited for our study up to 4 years after their most recent referral date, recall bias is possible. However, we attempted to mitigate this bias by recruitment of patients by their most recent referral date. Second, there are complexities in the history of appointment attendance that complicate the distinguishing of an “attende” versus “absentee.” For example, a patient may not initiate evaluation following their most recent referral date but may have a history of initiating evaluation after prior referrals. Although our exclusion criteria attempted to mitigate this potential misclassification bias, residual misclassification may remain. Third, due to lack of national data on referral and evaluation initiation, survey data collection was limited to the 3 transplant centers in Georgia; thus, results may not be generalizable to other states. However, given persistent racial disparities in transplant access in the Southeast, we hypothesize that these sociocultural barriers may be prevalent in other regions with low transplant access.⁵⁻⁷ Fourth, the validity of our developed 2-item transplant knowledge instrument was not evaluated at the time of survey administration; however, items were similar to recently published validated transplant knowledge scales.⁵⁹ Fifth, selection bias is possible due to convenience sampling of survey participants and the relatively low survey response rate; we did find that respondents were more minority, younger, less employed, and less rurally located than the general incident ESRD population in Georgia, but external validity may be limited. Finally, due to the nature of our study design, analyses may have been underpowered. Particularly, due to the large proportion of black patients in our data (77.1%), we had limited power to examine a racial disparity in evaluation initiation and whether the effects we observed between each sociocultural factor and evaluation initiation varied by race. However, this is the largest study to examine sociocultural barriers to transplant access among ESRD patients, reflecting the difficulty in obtaining psychosocial data for this population.

To our knowledge, this is the first study to identify sociocultural factors that may disproportionately affect access to transplant steps prior to evaluation completion. The results of this study, which found medical mistrust and perceived racism in healthcare settings were significantly associated with not initiating transplant evaluation, are consistent with models examining these sociocultural factors outside of the renal care system.^{26,27,40,60} This is the largest study to date examining sociocultural barriers to accessing pretransplant steps that includes all transplant centers in an entire state. Our study highlighted sociocultural barriers that may be prevalent among ESRD patients residing in the Southeastern United States, a region with a high concentration of black ESRD patients but historically low rates of kidney transplantation. This study provides evidence that racism and its correlates, as opposed to race alone, drives disparities in kidney transplant access. This suggests that measuring and addressing racial disparities alone may not be sufficient to address underlying sociocultural barriers in transplant access and that a more systemic, multilevel and multifactorial approach to addressing the longstanding sociocultural barriers to transplant access is needed.

5 | CONCLUSION

Medical mistrust, patient-perceived racism, and experienced discrimination in healthcare settings are significantly associated with reduced access to kidney transplant evaluation

among ESRD patients. These disparities occur independently of socioeconomic and clinical characteristics and in spite of a lack of racial disparity in evaluation initiation, suggesting that race may be a poor proxy for these underlying sociocultural factors. These underlying sociocultural factors should be considered in place of race in assessing disparities in transplant access and outcomes. Future interventions aimed to reduce disparities in access to transplantation should consider the accumulation of internalized racism and discrimination across the life course and at early transplant steps in order to improve equity in kidney transplantation.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Abbreviations:

CI	confidence interval
EMR	electronic medical record
ESRD	end-stage renal disease
IRB	Institutional Review Board
MMI	Medical Mistrust Index
OR	odds ratio
ZCTA	zip-code tabulation area

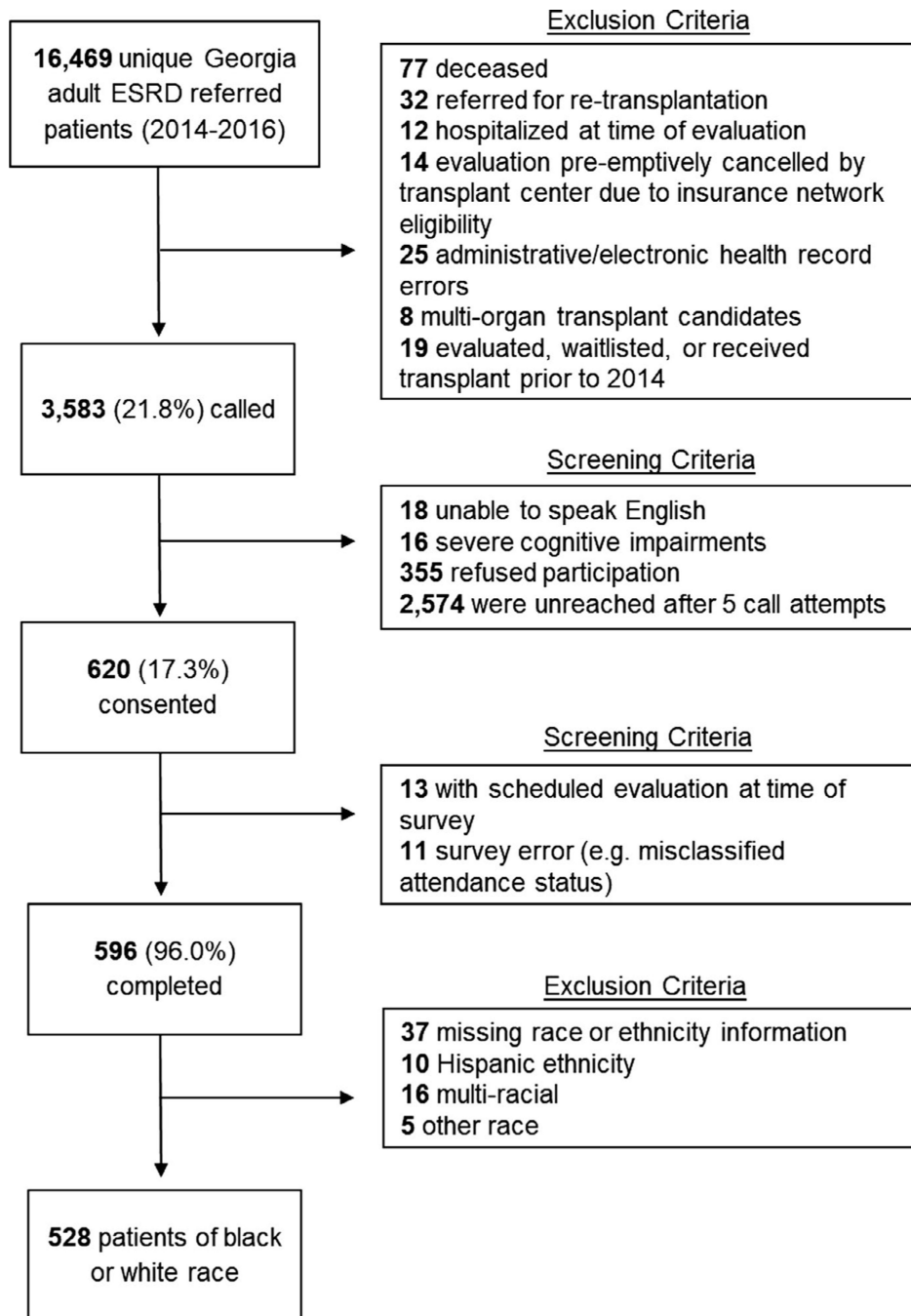
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**FIGURE 1.**

Enrollment flow chart for telephone survey administration among all unique GA adult ESRD referred patients, 2014-2016. Exclusion criteria included the following: multiorgan candidates, referrals for secondary kidney transplantation, hospitalization or significant morbidity at time of scheduled evaluation, administrative error, having a scheduled evaluation at time of survey, documented evaluations, waitlisting, or transplant receipt before 2014. Inclusion criteria included English proficiency and lack of severe cognitive or hearing impairments. Consent and complete rates are calculated using total patients called and total

patients consented as denominators of interest, respectively. ESRD, end-stage renal disease; GA, Georgia

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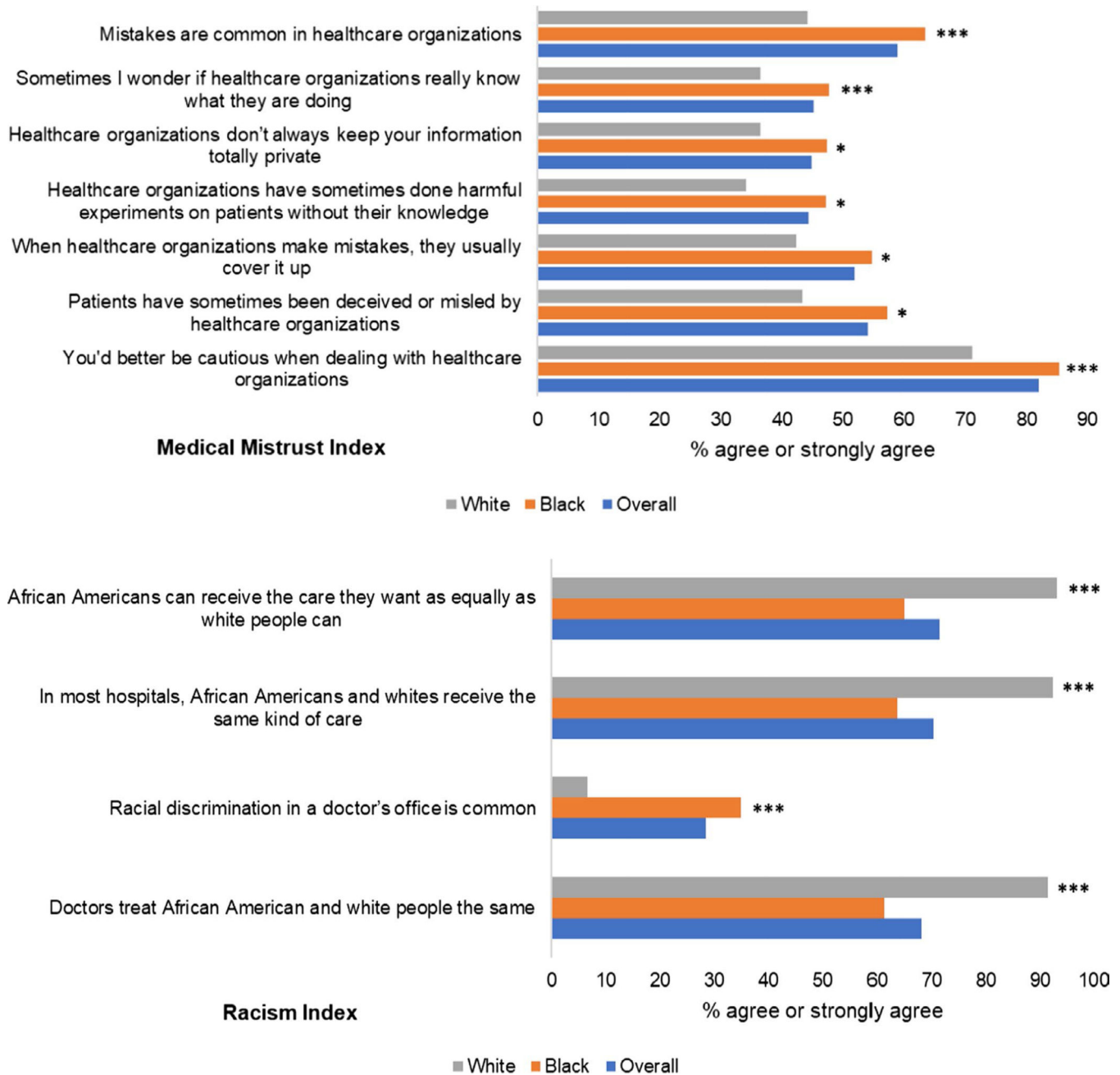


FIGURE 2. Percent agreement to individual (A), Medical Mistrust Index, and (B) Racism Index items among adult ESRD patients referred for transplant evaluation to a GA transplant center in 2014-2016, overall and by race (n = 528). Via χ^2 test of 2 proportions. *Indicates $P < .05$, ***indicates $P < .01$. ESRD, end-stage renal disease; GA, Georgia

Sociocultural factors represented in telephone survey of adult ESRD patients referred for transplant evaluation to a Georgia transplant center in 2014–2016

TABLE 1

Sociocultural factor	Definition	Measures	Properties	Sample items
Perceived racism in healthcare settings	Perceived evaluative judgments about others' abilities, motives, and intentions based on their race. May also include perceived differential access to goods, services, or opportunities on the basis of race ²²	Racism Index ²⁶	4-item instrument Each item ranked on 4-point Likert Scale, ranging from "Strongly Agree" to "Strongly Disagree" High internal reliability (Cronbach's $\alpha = 0.76$) Scores range 1 (low racism) to 4 (high racism) points, calculated as a simple average across items	Doctors treat African American and white people the same Racial discrimination in a doctor's office is common
Medical mistrust	Distrust or suspicion towards healthcare organizations, institutions, and/or providers ²⁶	Medical Mistrust Index ²⁶	7-item instrument Each item ranked on 4-point Likert Scale, ranging from "Strongly Agree" to "Strongly Disagree" High internal reliability (Cronbach's $\alpha = 0.76$) Scores range 1–4 points, calculated as a simple average across items	You'd better be cautious when dealing with healthcare organizations Patients have sometimes been deceived or misled by healthcare organizations
Experiences of medical discrimination	Experiences of unfair treatment in medical settings, the frequency of these experiences, and the perceived cause for the unfair treatment experienced	National Heart, Lung, and Blood Institute's Jackson Heart Study Discrimination Form (2003) ²⁸	4-item instrument Experiencing medical discrimination measured dichotomously (yes vs no) Self-reported items related to number of instances of medical discrimination and the date of the most recent experience Item related to main reason for most recent experience of discrimination (age, sex, race or ethnicity, language/ accent, sexual orientation, other)	Have you ever felt unfairly treated in getting medical care? (For example, you were denied or provided inferior or poor medical care, you were made to wait long periods of time before getting care, or you could not get care from a medical specialist such as a heart doctor)
Patient-provider race discordance		Patient-nephrologist race discordance Patient-transplant educator race discordance	Researcher-developed	Do you remember the race of your kidney doctor/nephrologist? What was his or her racial background? Do you remember the role of the clinical provider who discussed kidney transplantation with you (eg, social worker, nurse, nephrologist, etc)?

ESRD, end-stage renal disease; α , alpha.

TABLE 2

Characteristics of survey participants among adult ESRD patients referred for transplant evaluation to a Georgia transplant center in 2014–2016, overall and by evaluation initiation status, n = 528

	Total respondents (n = 528) ^d	Initiated evaluation (n = 272) ^a	Did not initiate evaluation (n = 256) ^b	P value for difference ^b
Sociocultural factors				
High medical mistrust (vs low); n (%) ^c	195 (36.9)	82 (30.2)	113 (44.1)	<.01
High perceived racism (vs low); n (%) ^c	248 (47.0)	107 (39.3)	141 (55.1)	<.01
Discordant patient-nephrologist race; n (%) ^d	401 (76.0)	215 (79.0)	186 (72.7)	.09
Discordant patient-transplant educator race; n (%) ^e	353 (66.9)	188 (69.1)	165 (64.5)	.26
Experienced discrimination in healthcare settings; n (%) ^f	137 (26.0)	57 (21.0)	80 (31.3)	<.01
Reported reason for discrimination experienced; n (%) ^g				
Race	53 (38.7)	19 (33.3)	34 (42.5)	.28
Age	17 (12.4)	8 (14.0)	9 (11.3)	.63
Sex	6 (4.4)	3 (5.3)	3 (3.8)	.70
Language	3 (2.2)	1 (3.5)	1 (1.3)	.57
Sexual orientation	3 (2.2)	0 (0.0)	3 (3.8)	.27
Sociodemographic characteristics				
Race; n (%) ^h				
Black, non-Hispanic	407 (77.1)	202 (74.3)	205 (80.1)	.11
White, non-Hispanic	121 (22.9)	70 (25.7)	51 (19.9)	
Age (y); mean (SD)	55.5 (12.8)	55.5 (13.0)	55.6 (12.6)	.92
Female; n (%)	236 (44.7)	124 (45.6)	112 (43.8)	.86
Primary insurance type; n (%) ⁱ				
Medicare	410 (77.7)	211 (77.6)	199 (77.7)	.11
Medicaid	36 (6.8)	13 (4.8)	23 (9.0)	
Private insurance	65 (12.3)	41 (15.1)	24 (9.4)	
Other governmental insurance	7 (1.3)	2 (0.7)	5 (2.0)	
None	6 (1.1)	2 (0.7)	4 (1.6)	

	Total respondents (n = 528) ^a	Initiated evaluation (n = 272) ^a	Did not initiate evaluation (n = 256)	P value for difference ^b
Education; n (%) ^f				
Grade school or less	63 (11.9)	30 (11.0)	33 (12.9)	<.01
High school diploma/GED	165 (31.3)	71 (26.1)	94 (36.7)	
Some college, no degree	147 (27.8)	79 (29.0)	68 (26.6)	
Associate's or bachelor's degree	106 (20.1)	60 (22.1)	46 (18.0)	
Graduate or professional degree	40 (7.6)	27 (9.9)	13 (5.1)	
Employment; n (%) ^f				
Employed	62 (11.7)	40 (14.7)	22 (8.6)	.06
Unemployed	288 (54.5)	138 (50.7)	150 (58.6)	
Retired	171 (32.4)	90 (33.1)	81 (31.6)	
Marital status; n (%) ^f				
Single	165 (31.7)	81 (29.8)	84 (32.8)	.02
Married or domestic partnership	220 (41.7)	129 (47.4)	91 (35.6)	
Divorced/widowed	135 (25.6)	60 (22.1)	75 (29.3)	
Neighborhood poverty; n (%) ^k				
<20%	333 (63.1)	181 (66.5)	152 (59.4)	.049
20%	179 (33.9)	81 (29.8)	98 (38.3)	
Resides in a rural (vs urban) area; n (%) ^f	78 (14.8)	35 (12.9)	43 (16.8)	.21
Clinical characteristics				
Duration on dialysis (y); n (%) ^f				
Not on dialysis	62 (11.7)	35 (12.9)	27 (10.6)	.30
<1 y	21 (4.0)	15 (5.5)	6 (2.3)	
1	149 (28.2)	77 (28.3)	72 (28.1)	
2	89 (16.9)	48 (17.7)	41 (16.0)	
3	62 (11.7)	27 (9.9)	35 (13.7)	
4	42 (8.0)	24 (8.8)	18 (7.0)	
5+ y	99 (18.8)	46 (16.9)	53 (20.7)	
Distance to referred transplant center (miles); median (IQR) ^m	37.1 (15.4, 103.8)	38.4 (16.7, 109.0)	36.4 (14.4, 98.1)	.39
Preferred ESRD treatment option at referral; n (%) ^f				

	Total respondents (n = 528) ^a	Initiated evaluation (n = 272) ^d	Did not initiate evaluation (n = 256)	P value for difference ^b
Hemodialysis	252 (47.7)	118 (43.4)	134 (52.3)	.06
Peritoneal dialysis	68 (12.9)	36 (13.2)	32 (12.5)	
Transplant	180 (34.1)	105 (38.6)	75 (29.3)	
Excellent, very good, good health; n (%) ^f	326 (61.7)	176 (64.7)	150 (58.6)	.15
Transplant knowledge; n (%) ^g				
High transplant knowledge	121 (22.9)	80 (29.4)	41 (16.0)	<.01
Moderate transplant knowledge	175 (33.1)	91 (33.5)	84 (32.8)	
Low transplant knowledge	231 (43.8)	100 (36.8)	131 (51.2)	
Charlson comorbidity index; n (%)				
0 comorbid conditions	263 (49.8)	99 (36.4)	164 (64.1)	<.01
1 comorbid condition	69 (13.1)	40 (14.7)	29 (11.3)	
2 comorbid conditions	68 (12.9)	49 (18.0)	19 (7.4)	
3+ comorbid conditions	128 (24.2)	3 (30.9)	44 (17.2)	

ESRD, end-stage renal disease; GED, general equivalency degree; IQR, interquartile range; SD, standard deviation.

^aDefined as initiated the kidney transplant evaluation at a transplant center, as documented in the electronic health record.

^bBy Student *t* test for continuous variables and χ^2 test for categorical variables. Wilcoxon rank-sum tests were used for skewed continuous variable, and Fisher exact test for categorical variables with sparse data. We considered all *P*-values statistically significant at *P* < .05. Categories may not add up to total due to missing data.

^cDichotomized at the median Medical Mistrust Index: 2.57 (IQR: 2.29, 2.86; range: 1-4); Racism Index: 2.00 (IQR: 2.0, 2.5; range: 1-4).

^dDefined by responding to "Do you remember the race of your kidney doctor/nephrologist? What was his or her racial background?"

^eDefined by responding to "Do you remember the race of the clinical provider who spoke with you about transplant prior to referral? What was his or her racial background?"

^fDefined by responding "yes" to "Have you ever felt unfairly treated in getting medical care?"

^gCalculated among those responding "yes" to "Have you ever felt unfairly treated in getting medical care?" (n = 137).

^hExcludes missing race or ethnicity (n = 37), Hispanic race (n = 10), multiple races (n = 16), and other races (n = 5).

ⁱDefined via self-report, with backfill from electronic medical records for missing responses.

^jDefined via self-report.

^kDefined as percentage of residents living below federal poverty level (2014) in patient's census tract of residence.

^lDefined using 2010 Rural Urban Commuting Area (RUCA) Codes dichotomized into urban vs rural areas at the census-tract level.

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Defined as the distance (in miles) between the geographic latitudinal and longitudinal coordinates of the centroids of the patient's residential zip code tabulation area (ZCTA) and the referred transplant center's ZCTA.

High transplant knowledge defined as correctly completing both items on a 2-item researcher-developed transplant knowledge scale; moderate transplant knowledge defined as correctly completing 1 item; low transplant knowledge defined by correctly completing no items.

TABLE 3

Racial differences in evaluation initiation status and sociocultural factors among adult ESRD patients referred for transplant evaluation to a Georgia transplant center in 2014–2016 (n = 528)

	Total respondents (n = 528)	Black, non-Hispanic (n = 407)	White, non-Hispanic (n = 121)	P value for race ^a difference ^b
Initiated evaluation; n (%) ^c	272 (51.5)	202 (49.6)	70 (57.9)	.11
Sociocultural factors				
High medical mistrust (vs low); n (%) ^d	195 (36.9)	163 (40.0)	32 (26.4)	<.01
High perceived racism (vs low); n (%) ^d	248 (47.0)	226 (55.5)	22 (18.2)	<.01
Discordant patient-nephrologist race; n (%) ^e	401 (76.0)	337 (82.8)	64 (52.9)	<.01
Discordant patient-transplant educator race; n (%) ^f	353 (66.9)	287 (70.5)	66 (54.5)	<.01
Experienced discrimination in healthcare settings; n (%) ^g	137 (26.0)	118 (29.0)	19 (15.7)	<.01
Reported reason for discrimination experienced; n (%) ^h				
Race	53 (38.7)	51 (43.2)	2 (10.5)	<.01
Age	17 (12.4)	12 (10.2)	5 (26.3)	.05
Sex	6 (4.4)	6 (5.1)	0 (0.0)	.31
Language	3 (2.2)	3 (2.5)	0 (0.0)	.48
Sexual orientation	3 (2.2)	3 (2.5)	0 (0.0)	.48

ESRD, end-stage renal disease.

^aExcludes missing race or ethnicity (n = 37), Hispanic race (n = 10), multiple races (n = 16), and other races (n = 5).

^bBy Student *t* test for continuous variables and χ^2 test for categorical variables. Wilcoxon rank-sum tests were used for skewed continuous variable, and Fisher exact test for categorical variables with sparse data. We considered all *P* values statistically significant at *P* < .05. Categories may not add up to total due to missing data.

^cDefined as initiated the kidney transplant evaluation at a transplant center, as documented in the electronic health record.

^dDichotomized at the median Medical Mistrust Index: 2.57 (IQR: 2.29, 2.86; range: 1–4); Racism Index: 2.00 (IQR: 2.0, 2.5; range: 1–4).

^eDefined by responding to “Do you remember the race of your kidney doctor/nephrologist? What was his or her racial background?”

^fDefined by responding to “Do you remember the race of the clinical provider who spoke with you about transplant prior to referral? What was his or her racial background?”

^gDefined by responding “yes” to “Have you ever felt unfairly treated in getting medical care?”

^hCalculated among those responding “yes” to “Have you ever felt unfairly treated in getting medical care?” (n = 137).

Unadjusted and multivariable logistic regression to examine associations between sociocultural factors and evaluation initiation among adult ESRD patients referred for transplant evaluation to a Georgia transplant center in 2014-2016^a

TABLE 4

Modeling association between sociocultural factor and evaluation initiation	OR for initiating evaluation	95% CI
Medical mistrust (high vs low)		
Unadjusted	0.54	0.36, 0.79
Adjusted for patient factors ^b	0.55	0.37, 0.81
Adjusted for patient + clinical factors ^c	0.59	0.38, 0.92
Adjusted for patient + clinical + socioeconomic factors ^d	0.59	0.39, 0.91
Experienced discrimination (yes vs no)		
Unadjusted	0.59	0.41, 0.86
Adjusted for patient factors ^b	0.61	0.42, 0.88
Adjusted for patient + clinical factors ^c	0.65	0.43, 0.98
Adjusted for patient + clinical + socioeconomic factors ^d	0.62	0.41, 0.95
Patient-nephrologist race discordance (vs concordant)		
Unadjusted	1.19	0.98, 1.45
Adjusted for patient factors ^b	1.13	0.80, 1.61
Adjusted for patient + clinical factors ^c	1.21	0.95, 1.55
Adjusted for patient + clinical + socioeconomic factors ^d	1.24	0.96, 1.60
Patient-transplant educator race discordance (vs concordant)		
Unadjusted	1.09	0.91, 1.31
Adjusted for patient factors ^b	1.12	0.92, 1.35
Adjusted for patient + clinical factors ^c	1.15	0.93, 1.43
Adjusted for patient + clinical + socioeconomic factors ^d	1.13	0.91, 1.40
Perceived racism (high vs low)		
Unadjusted	0.60	0.43, 0.83
Adjusted for patient factors ^b	0.62	0.44, 0.87

Modeling association between sociocultural factor and evaluation initiation	OR for initiating evaluation	95% CI
Adjusted for patient + clinical factors ^c	0.63	0.43, 0.93
Adjusted for patient + clinical + socioeconomic factors ^d	0.61	0.40, 0.92

ESRD, end-stage renal disease; OR, odds ratio.

^aUsing sequential multivariable logistic regression models for adjusted analyses, using multiple imputation for missing covariate data.

^bPatient characteristics include age, sex, and race.

^cClinical characteristics include duration on dialysis, distance to referred transplant center, transplant knowledge, preferred treatment option at referral, perceived health status, and Charlson comorbidity index.

^dSocioeconomic characteristics include insurance, educational attainment, marital status, employment, degree of urbanity, and neighborhood poverty level.