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Reem E. Hamoda Date

Racial Differences in Patient Perceived Barriers to Starting the Pre-Kidney Transplant Evaluation

By

Reem E. Hamoda
Master of Public Health

Epidemiology

Rachel E. Patzer, PhD, MPH
Committee Chair

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Reem E. Hamoda

B.S, University of Pittsburgh, 2016

Faculty Thesis Advisor: Rachel E. Patzer, PhD, MPH

An abstract of

A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University

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ABSTRACT

Racial Differences in Patient Perceived Barriers to Starting the Pre-Kidney Transplant Evaluation

By Reem E. Hamoda

Objective: Racial disparities in access to kidney transplantation, the preferred treatment option for end stage renal disease (ESRD), persist along multiple steps of the transplant process. However, it is unclear what patient-level barriers perpetuate disparities in starting the pre-kidney transplant evaluation. We aimed to evaluate racial differences (black versus white, non-Hispanic) in patient-perceived barriers to starting the evaluation at a transplant center.

Methods: In a telephone survey to 528 ESRD patients referred for kidney transplantation in 2016 to one of three Georgia transplant centers, we administered a 17-item Barriers to Transplantation scale assessing patient-perceived barriers to evaluation start. Agreement to each item was rated on a 5-point Likert scale. Using exploratory factor analyses, we derived three subscales representing financial, logistical, or belief-based barriers to transplantation. Multivariable logistic regression was used to evaluate associations between overall scale and subscales and evaluation start, adjusting for patient characteristics and assessing effect modification by race. Effect decomposition methods were used to evaluate the role of each barrier type in the association between race and evaluation start.

Results: After applying relevant exclusion criteria, our study population consisted of 416 patients, 50% of whom did not start the evaluation. Compared to whites, blacks (n=209) were younger (mean: 54 ± 12 years), more likely to have public insurance (27%) ($p<0.01$), and less likely to complete high school (34%) ($p<0.01$). Blacks were 29% less likely to start the evaluation compared to whites (OR for not starting evaluation: 1.71, 95% CI: 1.09, 2.70). Significant barriers experienced among blacks included concerns about transplant wait time, finding a living donor, affording transplantation, and finding transportation. In adjusted analyses, increases in the Barriers to Transplantation (OR: 1.71, 95% CI: 1.09, 2.68) and Logistical Concerns scales (OR: 1.76, 95% CI: 1.25, 2.47) were significantly associated with not starting the evaluation. Associations between each scale and evaluation start did not significantly differ by race; however, logistical concerns explained 21.1% of racial differences in evaluation start.

Conclusion: Black (versus white) patients disproportionately experience barriers to starting the evaluation. Development of interventions targeting barriers to evaluation start may be needed to reduce racial disparities in kidney transplantation.

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BACKGROUND

Chronic kidney disease

Chronic kidney disease (CKD) is the presence of kidney damage or decreased function in the kidneys for three months or more, regardless of etiology (1, 2). Defining CKD has exhibited a paradigm shift from its characterization as a rare and life-threatening illness to its recognition as a disorder of varying causes, pathologies, and severities (1, 2). This change in definition reflects CKD's role as a growing worldwide public health problem that benefits tremendously from both early detection and intervention; CKD affects an estimated 13% of the global population, while generating substantial economic costs for global health systems (2-5). Primary biologic causes of CKD include diabetes mellitus and hypertension, but may also include glomerulonephritis (acute or chronic kidney injury) and polycystic kidney disease (hereditary development of cysts on the kidneys) (2, 6). Additional risk factors for CKD include age, higher body mass index, smoking, and cardiovascular disease (1, 2, 7-9).

Given the diverse etiologies of CKD as well as its asymptomatic nature in early stages, the disease is largely characterized via measurement of an estimated glomerular filtration rate (eGFR) less than 60 mL/min per 1.73 m^2 for three consecutive months (1). This rate is calculated from blood serum creatinine tests, as well as information on age, race, body mass index, and gender (1, 2, 10). CKD can also be identified from renal ultrasonography, or detection of significant albuminuria (protein albumin in the urine) from urine tests, as evidence of kidney damage (1). CKD severity is classified into five stages, each defined by eGFRs ranging from greater than 90 mL/min per 1.73 m^2 (stage one CKD) to less than 15 mL/min per 1.73 m^2 (stage five, or end stage, CKD) (1, 2). CKD is an incurable condition; thus, treatment aims to prevent CKD from progressing to its final stage of renal failure. Pharmacological treatment of CKD includes angiotensin-converting enzyme (ACE) inhibitors and angiotensin II receptor blockers, medications aimed to reduce hypertension (1). Adverse outcomes of CKD include severe hypertension and loss of kidney function; cardiovascular disease is the leading cause of CKD mortality, reflecting its role as both a risk factor and adverse outcome (1, 2, 11, 12).

CKD was the ninth leading cause of death in the United States, according to the 2014 National Vital Statistics Report (13). CKD prevalence in the United States increased since the early 1990's; however, rates have remained stable over the past two decades (14, 15). According to data from the 2015 National Health and Nutrition Examination Survey (NHANES), approximately thirty million Americans had CKD in 2011 through 2014 (6). Prevalent biologic causes of CKD included cardiovascular disease (42.6%), followed by diabetes mellitus (39.4%) and hypertension (32.1%) (6). The most prevalent CKD stage was stage 3 (moderate) CKD; rising stage 3 CKD prevalence in the United States was attributable to rising incidence of diabetes mellitus and hypertension, as well as an aging United States population, with the larger "baby boomer" generation entering retirement age (6, 16). CKD prevalence was highest for adults over the age of sixty (32.6%), with greater average CKD prevalence among women (16.5%) as compared to men (13.0%). CKD awareness was low in the United States, with only 2.8% of NHANES participants reporting having 'kidney disease', despite 14.8% of participants having diagnosed CKD (6, 17, 18).

Non-Hispanic blacks experienced the highest prevalence of CKD (16.9%) among all racial groups, consistent with prior evidence of higher CKD burden among blacks compared to whites (6, 15, 19-21). Disparities in CKD incidence are partially attributable to genetic and epigenetic factors; however, biological variations in CKD susceptibility do not fully explain high rates of CKD among blacks (20). Multiple non-biologic factors affecting disparities in CKD have been identified, including individual-level socioeconomic status (e.g., poverty, lack of insurance, or educational attainment), structural factors (e.g., institutionalized racism), and geography (e.g. residential segregation and spatial access to care) (19-22).

Early detection of CKD is highly valuable in minimizing risk of progression; however, secondary prevention of CKD through population-based screening remains controversial.

Particularly, while screening for albuminuria is appealing due to its ability to predict cardiovascular disease morbidity and risk of eGFR decline, it is also not a cost effective screening program (10, 23). Similarly, screening for eGFR would be effective in targeting older individuals, diabetics, or hypertensive patients; however, eGFR is not very predictive of subsequent CKD progression to renal failure (10, 24). Thus, public health efforts aim to prevent the development of CKD through improved treatment and prevention against the development of diabetes mellitus and hypertension, the two underlying causes of CKD (10, 25). Lifestyle modifications, such as increased exercise and reduced dietary salt intake, have shown to be effective strategies in decreasing the incidence of diabetes mellitus and hypertension in the general population (25).

End-stage renal disease

Progression of CKD to its fifth stage results in end-stage renal disease (ESRD), an irreversible condition signifying kidney failure (1). Patients with advanced ESRD cannot survive in the absence of renal replacement therapy, which acts to restore the blood-filtering function of the kidneys. ESRD is classified through measurement of an eGFR less than 15 mL/min per 1.73 m^2, or by start of renal replacement therapy (1). Biologic risk factors associated with progression of CKD to ESRD include poorly controlled diabetes mellitus, uncontrolled hypertension, cardiovascular disease, obesity, gene variants including apolipoprotein L1 (*APOL1*), and advanced age (26-31).

Data regarding ESRD in the United States are primarily captured through the United States Renal Data System (USRDS), a National Institutes of Health-funded national surveillance system aimed to monitor trends in both CKD and ESRD (6). According to the USRDS 2017 Annual Report, approximately 703,243 Americans were diagnosed with ESRD in 2015. ESRD prevalence has increased over time in the United States, with 3.4% increases since 2014, and increases by nearly 80% since 2000. It is important to note, however, that rising ESRD prevalence may be attributable to both rising ESRD incidence as well as improved ESRD patient survival (6). Adjusted

ESRD incidence rates rose from 87 cases per million/year in 1980 to 357 cases per million/year in 2015, after standardizing for age, sex, and race. However, this rate has gradually decreased since 2000, likely due to improvements in ESRD prevention (6). Nevertheless, nearly 36% of incident ESRD patients received inadequate or no nephrology care prior to ESRD diagnosis, despite evidence demonstrating the importance of pre-ESRD nephrology care in ESRD prevention and outcomes (6, 32, 33). All-cause mortality for ESRD patients has decreased considerably in the United States; adjusted ESRD mortality in 2015 was 136.3 deaths per 1,000 patient-years at risk, a decline from 190.1 deaths per 1,000 patient-years in 2001. Diabetes mellitus remained the most prevalent cause of ESRD death in 2015, followed by hypertension and glomerulonephritis (6).

Numerous studies confirm the presence of significant differences in ESRD incidence and prevalence by demographics in the United States. ESRD incidence and prevalence greatly differed by United States geographic region in 2015, with higher adjusted rates in the Deep South (6). The concentration of ESRD incidence in the Southern United States is largely attributed to high rates of obesity and chronic conditions in the South, as well as lower spatial access to pre-ESRD nephrology care in this area (34-36). Gender differences in ESRD incidence also exist, with male CKD patients having an estimated 22% increased risk of developing ESRD as compared to females; this difference is partially explained by lower average systolic blood pressure in females, contributing to slower rates of CKD progression (37, 38).

Perhaps most evident is longstanding racial disparities in ESRD incidence and outcomes in the United States. In 2015, blacks had an adjusted incidence rate of approximately 900 cases per million/year, compared to 300 cases per million/year among whites (6). This disparity translates to a nearly four-fold increased risk and prevalence of ESRD among blacks as compared to non-Hispanic whites (6, 39). Disparities are not limited to blacks, with a 34% increased rate among Hispanics, a 50% increased rate among American Indians/Alaska Natives, and a nearly 8.4-times increased incidence rate among Native Hawaiians/Pacific Islanders compared to non-Hispanic whites (6). Absolute ESRD incidence has generally decreased over time among all minority groups, with stable incidence rates among whites; this resulted in a net decrease in excess risk over time among minorities. Nevertheless, adjusted ESRD prevalence continues to rise among most minority groups at higher rates than that of whites, with highest ESRD burden among all minority groups (6).

Historically, racial disparities in ESRD incidence were attributed to racial variation in risk factors for ESRD, including increased risk of diabetes and hypertension in blacks (40). However, these factors were identified as insufficient for fully explaining racial differences in ESRD incidence (41, 42). Recently, renal *APOL1* gene variants have been examined as explanatory factors, as high-risk alleles occur more frequently among individuals of West African descent (15, 43-45). In one prospective cohort study, patients in a high-risk *APOL1* group were significantly more likely to develop ESRD, with blacks in this group having more rapid eGFR decline and ESRD incidence as compared to whites (30). However, even among individuals with two *APOL1* alleles, risk of ESRD is high but variable, suggesting the influence of environmental factors modifying the *APOL1* phenotype (44).

The current paradigm for assessing fundamental causes of racial disparities in ESRD focuses on the interplay between biologic and social determinants, given the strong link between lower socioeconomic status (SES) and race (44, 46). Across the life course, several individual-, community-, and system-level factors have been identified as influencing the development and progression of CKD to ESRD (44). Individual socioeconomic factors such as education and household income, as well as community-factors including neighborhood poverty and residential segregation, have pronounced effects on biologic mechanisms affecting lifetime risk of ESRD and its outcomes (44, 47-50). For example, individuals residing in impoverished neighborhoods are more likely to belong to an ethnic minority. Geographic disparities in access to nephrology and pre-nephrology care are attributable to low-resource areas; therefore, these disparities contribute to low or delayed referral to nephrology care among minorities, resulting in increased risk of undetected CKD, increased progression of CKD to ESRD, and adverse ESRD outcomes (33, 49, 51). Nevertheless, the mechanisms by which socio-contextual factors affect ESRD incidence among minorities, as well as the epigenetic influence of these factors on genetic disposition to ESRD, are not yet completely understood (44).

Treatment options for ESRD

For patients with advanced CKD or incident ESRD, renal replacement therapy (RRT) is necessary to mitigate the physiological effects of kidney failure (1, 52). In 2015, nearly 97% of incident ESRD patients initiated RRT by starting dialysis (6). Dialysis is a treatment by which a machine mimics the blood-filtering function of the kidneys by removing excess water, solutes, and toxins from the blood. Thus, dialysis acts as a renal replacement system by maintaining blood metabolite levels as well as blood pressure (1). Dialysis modalities include hemodialysis, by which a patient is connected to an exogenous filtering machine through a vascular access, and peritoneal dialysis, where the peritoneum of the patient's abdomen is used as the filtering mechanism. Dialysis modalities are further classified as in-center dialysis (hemodialysis) versus home dialysis (encompassing both peritoneal dialysis and at-home hemodialysis); home dialysis use has increased considerably over time, accounting for nearly 9% of prevalent dialysis users in 2015 (1, 6). Peritoneal dialysis is associated with improved patient outcomes compared to hemodialysis, including reduced mortality, improved quality of life, and better cost savings (53, 54). However, only 9.6% of incident ESRD patients started RRT with peritoneal dialysis, while 87.3% of patients started with hemodialysis modalities (including center-based and home hemodialysis) (6).

Although dialysis is chosen as the initial treatment option for patients with kidney failure, it underperforms in maintaining fluid and metabolite homeostasis compared to normal-functioning kidneys (1). Therefore, the advent of kidney transplantation in the mid 1950's revolutionized treatment for ESRD patients globally. Kidney transplantation, a procedure by which a patient with damaged kidneys receives functioning kidneys from a donor, currently serves as the optimal treatment option for patients with ESRD. Substantial evidence supports kidney transplantation's superiority compared to dialysis; kidney transplantation provides nearly 64% longer patient survival, 76% reduced risk of adverse cardiovascular events, and 68% reduced long-term mortality as compared to dialysis modalities (55-57). Kidney transplantation also offers significant improvements in patient quality of life compared to remaining on dialysis (58-60). Despite the benefits of early kidney transplantation, however, preemptive transplantation is not widely adopted. In 2016, only 18% of transplanted patients in the United States received a transplant prior to starting dialysis (61). Importantly, kidney transplantation is a highly cost-saving treatment; although the costs of ESRD treatment are higher in the first post-transplant year, transplantation becomes more cost effective long-term compared to dialysis modalities (59, 62). Thus, dialysis initiation is often a temporary measure for incident ESRD patients as they await kidney transplantation (1).

Both the USRDS and the Scientific Registry of Transplant Recipients (SRTR), a national registry of solid organ transplantation with oversight from the Department of Health and Human Services' Health Resources and Services Administration (HRSA) and the Organ Procurement and Transplantation Network (OPTN), monitor trends in kidney transplantation across the United States (61). According to the OPTN/SRTR 2016 Annual Data Report, slightly more than 19,000 patients received a kidney transplant. The number of kidney transplants steadily rose since 2004, largely attributable to increases in deceased donor transplants. 39.5% of adult kidney recipients were 50-64 years of age, followed by individuals aged 35-49 years (28.1%). Females were less likely to receive a transplant in 2016, with 60.5% of recipients being male. Recipients largely had ESRD diagnoses of either diabetes mellitus (28.5%) or hypertension (22.1%). 74.4% of recipients had wait times for transplant of 5 years or less, and 12.5% of transplant conducted in 2016 were re-transplantations (61).

According to SRTR data, 71.9% of transplanted organs in 2016 originated from a deceased donor (61). Given the persistent shortage of organs from living donors of related- or unrelated- origin relative to the recipient, deceased donation significantly reduces patient wait times for kidney transplantation (61, 63). Deceased donor transplant rates have increased considerably in the last decade, with a significant reduction in the number of candidates on the deceased donor waiting list due to changes in organ allocation policies in 2014 (61). However, deceased donor transplantation underperforms in comparison to living donor kidneys, with lower kidney allograft (transplanted kidney) survival and higher rates of acute graft rejection compared to living donor transplantation (64). Nevertheless, while deceased donor transplantation rates have increased over time, living donor transplant rates remain stagnant (61).

There are significant racial disparities in kidney transplantation that mirror disparities in CKD and ESRD incidence (65). For example, in one retrospective cohort study, blacks had a nearly 45% likelihood of deceased donor transplantation compared to whites; this disparity in transplant rates has been confirmed in subsequent studies (66-68). However, implementation of a new kidney allocation system in 2014, which aimed to reduce racial disparities in placement onto the deceased donor waiting list, has shown improvements in narrowing the disparity gap (61, 69-71). In 2016, kidney transplant rates were similar between whites and most other ethnic minorities, reflecting increased access to deceased donor kidney transplantation for minorities (69, 71). However, racial disparities in living donor transplantation remained (72, 73). In 2016, living donor transplant rates were highest for whites and Asians, with blacks exhibiting the lowest transplant rates; this trend has remained fairly consistent since 1998, with declines in unadjusted living donor transplant rates across all racial groups (61).

Access to kidney transplantation

In order to receive a deceased or living donor transplant, patients must undergo an arduous multi-step process, beginning with determining medical suitability for transplantation. Subsequent steps include: patient education regarding their treatment options for ESRD, patient demonstration of interest in kidney transplantation, referral for kidney transplantation to a transplant center, starting and completing the medical and psychosocial evaluation for a kidney transplant, confirmation of candidacy as a suitable kidney transplant recipient, placement on a national deceased donor waiting list, and receipt of a deceased donor or living donor transplant (74). Although each step of the transplant process is necessary prior to receipt of a transplant, there are documented disparities in access to these steps (75). For example, in a prospective cohort study of patients initiating dialysis in the Midwest, Sehgal et al. (1998) found blacks were 32% less likely to be definitely interested in kidney transplantation, 44% less likely to complete the pre-kidney transplant evaluation, and 50% less likely to move up on the deceased donor waitlist to receive a transplant compared to whites (76). These disparities persisted nearly fifteen years later; in a separate retrospective cohort study at a Southeastern transplant center, Patzer et al. (2012) reported black (versus white) ESRD patients were 30% less likely to be referred for transplant, 28% less likely to start the evaluation once referred, and 38% less likely to be transplanted after waitlisting. This disparity remained after adjusting for clinical, demographic, and socioeconomic factors (67).

Several studies have corroborated these findings at individual transplant steps. For example, Epstein et al. (2000) found blacks were significantly less likely to be deemed medically suitable for transplant; blacks were also less likely to be referred for transplant evaluation, even among patients deemed appropriate candidates for transplantation (77). Additionally, Schold et al. (2011) found a 30% lower likelihood of waitlist placement among referred blacks as compared to white referred patients, after adjusting for demographic and clinical factors (78). Waterman et al. (2013) found reduced transplant patient education among blacks as compared to whites, a critical step in the transplant process; this lack of education resulted in reduced likelihood of receiving a living donor kidney transplant among blacks (79). Within this same study, blacks exhibited lower interest in transplantation, with evidence that lower willingness to be placed on the deceased donor waiting list could lead to reduced likelihood of evaluation completion (79). Additional studies found significant racial disparities in referral for and starting of the pre-kidney transplant evaluation, suggesting that factors perpetuating these disparities are concentrated in the early steps of the transplant process prior to placement on a waiting list (68, 79-83).

Identified in previous literature, there are numerous patient-, provider-, neighborhood-, and system-level reasons for disparities in access to each step in the kidney transplant process (84-86). Socioeconomic status has long been recognized as a fundamental barrier in access to kidney transplantation, with significantly reduced transplant rates among individuals of lower income (67, 76, 80, 86, 87). However, this effect on access to transplantation is not limited to the individual level; Patzer et al. (2009) found decreased likelihood of transplant waitlisting for blacks compared with whites with increasing levels of neighborhood poverty, indicating that neighborhood level socioeconomic status also plays a role in perpetuating disparities (88). Nevertheless, while socioeconomic status is a significant mediator in racial disparities in access to transplant steps, it does not fully explain these disparities (67). Geographic factors, including distance to the transplant center and variation in spatial access to transplant centers, have also been identified as significant barriers in access to transplantation for minorities (89-91). However, as with individual- and neighborhood-level socioeconomic factors, geographic barriers to transplantation are not easily modifiable (79).

Barriers related to social support have been a focus of interventions aimed to improve access to kidney transplantation (92-95). For example, Clark et al. (2008) found that in a cross-sectional survey of ESRD patients initiating dialysis, patients with high levels of instrumental support networks (defined as the number of friends and family available to help with daily activities) were more likely to complete the transplant evaluation, even when stratifying on race (96). Transplant knowledge has also been of significant focus in the literature, particularly because patient education is a critical step on the pathway to kidney transplantation (97). Using USRDS data of incident ESRD patients from 2005 to 2007, Kurcirka et al. (2012) found that patients who reported being uninformed about transplant were 53% less likely to either join the deceased donor waiting list or receive a living donor kidney transplant (98). In a separate study, Waterman et al. (2013) found patients with higher transplant knowledge at the time of evaluation were 20% more likely to receive a living donor transplant; importantly, racial differences in living donor transplantation were eliminated after adjusting for transplant knowledge at the time of evaluation (79). Additional modifiable barriers to kidney transplantation previously identified include health literacy, willingness to receive a transplant, and provider practices (79, 98-102).

Although several studies have been conducted to identify patient-level barriers in access to the steps of referral, evaluation completion, waitlisting, and receipt of a living donor or deceased donor kidney transplant, studies related to barriers in starting the evaluation for transplant are sparse. To the best of our knowledge, only two studies have focused on patient-reported barriers existing between the steps of referral and starting the pre-kidney transplant evaluation. Kazley et al. conducted a cross sectional survey of referred patients at a transplant center regarding reasons for not following up on their referral to start the evaluation process. Results of their survey found frequent barriers reported included fear of not passing the medical tests, fear of surgery, and inability to afford transplant or post-transplant medications (103). In a later study, Dageforde et al. (2015) conducted a pilot cross-sectional telephone survey of patients referred and scheduled for an evaluation at a transplant center. Among this cohort, they found evaluation absentees had significantly lower perceived general knowledge about transplantation, as well as less concern about finding a living donor. However, there were no significant differences in reporting of financial concerns, logistical concerns (e.g. having transportation), or understanding of the transplant process. Low generalizability due to being a single site study is a limitation of both studies. Furthermore, neither study examined whether barriers associated with starting the evaluation were more prevalently experienced among minority patients, nor did they identify if the effect of these barriers on evaluation start was modified by race (104). Thus, future work is needed to elucidate patient-level barriers preventing referred patients from starting the pre-kidney transplant evaluation, with particular focus on barriers that may perpetuate racial disparities in access to this transplant step.

Summary

CKD is a growing public health problem, affecting nearly 15% of the United States population. However, despite the high incidence and prevalence of CKD and ESRD among ethnic minorities, these groups exhibit the lowest rates of kidney transplantation. Disparities in access to kidney transplantation persist across the transplant process, especially in the early steps of patient education, referral, and starting and completing the pre-kidney transplant evaluation. However, few studies have evaluated barriers that disproportionately affect minorities at early transplant steps. Kidney transplantation offers substantial benefits in comparison to dialysis; thus, identifying barriers to these early steps that predominately affect minorities is critical for reducing disparities in kidney transplantation.

ABSTRACT

Objective: Racial disparities in access to kidney transplantation, the preferred treatment option for end-stage renal disease (ESRD), persist along multiple steps of the transplant process. However, it is unclear what patient-level barriers perpetuate disparities in starting the pre-kidney transplant evaluation. We aimed to evaluate racial differences (black versus white, non-Hispanic) in patient-perceived barriers to starting the evaluation at a transplant center.

Methods: In a telephone survey to 528 ESRD patients referred for kidney transplantation in 2016 to one of three Georgia transplant centers, we administered a 17-item Barriers to Transplantation scale assessing patient-perceived barriers to evaluation start. Agreement to each item was rated on a 5-point Likert scale. Using exploratory factor analyses, we derived three subscales representing financial, logistical, or belief-based barriers to transplantation. Multivariable logistic regression was used to evaluate associations between overall scale and subscales and evaluation start, adjusting for patient characteristics and assessing effect modification by race. Effect decomposition methods were used to evaluate the role of each barrier type in the association between race and evaluation start.

Results: After applying relevant exclusion criteria, our study population consisted of 416 patients, 50% of whom did not start the evaluation. Compared to whites, blacks (n=209) were younger (mean: 54 ± 12 years), more likely to have public insurance (27%) ($p<0.01$), and less likely to complete high school (34%) ($p<0.01$). Blacks were 29% less likely to start the evaluation compared to whites (OR for not starting evaluation: 1.71, 95% CI: 1.09, 2.70). Significant barriers experienced among blacks included concerns about transplant wait time, finding a living donor, affording transplantation, and finding transportation. In adjusted analyses, increases in the Barriers to Transplantation (OR: 1.71, 95% CI: 1.09, 2.68) and Logistical Concerns scales (OR: 1.76, 95% CI: 1.25, 2.47) were significantly associated with not starting the evaluation. Associations between each scale and evaluation start did not significantly differ by race; however, logistical concerns explained 21.1% of racial differences in evaluation start.

Conclusion: Black (versus white) patients disproportionately experience barriers to starting the evaluation. Development of interventions targeting barriers to evaluation start may be needed to reduce racial disparities in kidney transplantation.

INTRODUCTION

Chronic kidney disease (CKD), defined as the progressive loss of kidney function over time, affects nearly 14% of the United States population and is the ninth leading cause of death nationwide (2, 6). Among the 31 million Americans with CKD, nearly 700,000 patients progress to the fifth stage of CKD, or end-stage renal disease (ESRD) (6). These patients suffer from renal failure, and are therefore unable to survive without renal replacement therapies. Kidney transplantation is the gold standard treatment for most ESRD patients, offering better patient survival, improved quality of life, and substantial cost savings as compared to dialysis modalities (52, 57).

Despite the documented benefits of kidney transplantation, inequitable access to kidney transplantation persists among minority ESRD patients. In 2014, blacks were nearly four times more likely to develop ESRD, but were 24% less likely to receive a kidney transplant as compared to whites (6). Moreover, racial disparities in access to kidney transplantation are concentrated in the Southeastern United States (6). Particularly, blacks represented 67% of the prevalent Southeastern ESRD population in 2014, but were 60% less likely to receive a transplant as compared to whites (67, 86). These racial disparities exist along the kidney transplant continuum of care for ESRD patients, including patient education about kidney transplant, patient interest in kidney transplant, referral by a physician to a transplant center, and placement on the national waiting list for a deceased donor transplant (72, 81, 88).

Numerous barriers in access to kidney transplantation exist for blacks, including biological factors, socioeconomic status, and educational attainment (78, 105, 106). However, these factors are not easily modifiable, and may only account for a fraction of the racial disparities in access to kidney transplantation experienced by blacks (67). Several studies suggest more modifiable barriers exist, including fear of surgery, social support, transportation, distance to care, beliefs about transplantation, and transplant knowledge (68, 83, 91, 97, 107-110). These barriers may account more for racial disparities in access to transplantation, and are hypothesized to be concentrated in the steps prior to waitlisting, including transplant referral, start, and completion of the pre-kidney transplant evaluation (79, 86). However, only two prior studies report on patient barriers to starting the transplant evaluation process, a crucial stage where ESRD patients begin a comprehensive medical and psychosocial evaluation to determine candidacy for a kidney transplant (103, 104). Furthermore, no studies report how patient-level barriers to starting the evaluation differ by race, despite several studies reporting racial disparities in initiation and completion of this key stage in the kidney transplant process (111, 112).

Complex interventions targeting modifiable barriers to referral and completion of the pre-kidney transplant evaluation have demonstrated effectiveness in increasing access to the later steps of the kidney transplant process, including waitlisting and receipt of a kidney transplant (72, 113-115). However, these interventions were not specifically designed to increase access to kidney transplant evaluation start, a critical step of the transplant process. Informed development and modification of interventions aimed to reduce disparities in access to transplantation requires identification of barriers to evaluation start that disproportionately affect black ESRD patients, particularly in the Southeastern United States. Therefore, the aim of this study was to identify barriers in starting the evaluation for kidney transplantation that disproportionately affect black (versus white, non-Hispanic) ESRD patients referred to a United States Georgia transplant center.

METHODS

Objective

The aim of this study was to evaluate patient perceived barriers that may perpetuate racial disparities (black versus white, non-Hispanic) in starting the pre-kidney transplant evaluation, using a cross-sectional telephone survey of adult end-stage renal disease patients referred to a

United States Georgia transplant center in 2016. This analysis was part of the Reducing Disparities in Access to kidNey Transplantation (RaDIANT) Regional Study, an ESRD Network 6 quality improvement initiative aimed to increase access to and reduce racial disparities in kidney transplantation in the Southeastern United States (ClinicalTrials.gov identifier: NCT02389387).

Survey development

We designed a forty-eight item telephone survey in SurveyMonkey® aimed to assess patient-perceived barriers to starting the kidney transplant evaluation at a Georgia transplant center. Development of survey items was guided by a 2011 root cause analysis assessing reasons for low transplant access among black ESRD patients residing in the Southeastern United States. The analysis was conducted by members of the volunteer, multidisciplinary organization, the Southeastern Kidney Transplant (SEKTx) Coalition, whose mission is increase kidney transplantation in ESRD Network 6 (Georgia, North Carolina, and South Carolina) by identifying barriers and reducing disparities in access to kidney transplantation (108). Survey design was also guided by previous literature addressing patient-level barriers to kidney transplantation (76, 78, 79, 81, 83, 85-87, 89-91, 94-104, 108-110, 116-120). Survey items included a researcher-developed seventeen-item Barriers to Transplantation questionnaire addressing patient-perceived barriers to starting the evaluation at a transplant center, a seven-item validated Medical Mistrust Index, a four-item validated Perceptions of Racism in Healthcare Settings Scale, a two-item researcher-developed scale assessing transplant knowledge, and additional items pertaining to sociodemographic and clinical characteristics (121, 122). Survey questions were designed to accommodate a 6-8th grade literacy level, and to be administered in a telephone format to ensure patients with any literacy or visual barriers were included in the study.

Study population

Our study population included adult ESRD patients with a documented referral for kidney transplantation to one of three Georgia transplant centers (Augusta University Carlos and Marguerite Solid Organ Transplant Center in Augusta, GA, Emory Transplant Center in Atlanta, GA, and Piedmont Transplant Institute in Atlanta, GA) between January 2016 and December 2016. For patients with multiple referrals to a transplant center, we considered the most recent referral date for analysis. Prior to administration of the telephone survey, we classified patients into two groups based on evaluation start status as documented in the transplant center electronic health record: documented start of the transplant evaluation process versus no documented start of the transplant evaluation process. All study participants were at least 18 years or older, demonstrated English proficiency, had no severe cognitive impairments, and had at least 6 months of follow-up from their documented referral date. Exclusion criteria included lack of documented evaluation start status, transplant recipients re-referred for transplant, dual organ candidates (e.g. heart-kidney and kidney-pancreas transplant candidates), documented hospitalization at the time of a scheduled evaluation, pre-emptive cancellation of the evaluation by the transplant center due to insurance ineligibility, and having a documented evaluation start date prior to 2014. The Institutional Review Boards of Emory University (IRB00079596) and Piedmont Healthcare (IRB1049200-1) approved this study, with execution of a reliance agreement with Emory University's Institutional Review Board to provide oversight for Augusta study activities. We obtained verbal informed consent for all survey participants.

Data collection

Research assistants at each transplant center contacted eligible participants via telephone (up to five attempts) for verbal consent and completion of the fifteen-minute survey (administered via telephone and responses documented by research assistants in the online software, SurveyMonkey®). Surveys were conducted between March 2017 and March 2018, and potential participants were called based on their referral date to minimize recall bias (patients with the most recent referral date were called first). Assistants utilized a master Microsoft Excel spreadsheet populated with electronic health record-abstracted contact and demographic information to track all calls, uphold exclusion criteria, and document patients with incomplete survey information or survey errors. We assigned a unique study identifier to all patients in our study population prior to enrollment, to ensure patient confidentiality across transplant centers. Study site coordinators communicated via monthly conference calls to address issues related to survey implementation, as well as to ensure standardization of patient recruitment, survey administration, and data collection methods across study sites.

Subscale development

The Barriers to Transplantation scale was a researcher-developed questionnaire measuring 17 patient-perceived barriers to starting the pre-kidney transplant evaluation. The questionnaire was prompted differently based on the patient's evaluation start status. If the patient was documented to have started the evaluation, they were asked to recall how they felt prior to starting the evaluation process. If the patient was not documented to have started the evaluation, they were asked to consider the reasons why they had not yet started the evaluation. Each item was rated on a five point Likert scale: "Strongly disagree" (1), "Disagree" (2), "Neither agree nor disagree" (3), "Agree" (4), and "Strongly Agree" (5). An additional option of "Not applicable" was available for barriers that did not apply to a patient's particular scenario; for the purposes of analyses, all responses for "Not applicable" were counted as missing responses.

Face and content validity of individual Barriers to Transplantation items were verified via an expert panel of transplant surgeons, nephrologists, health services researchers, and patients with knowledge and experience of the kidney transplant process. Exploratory factor analysis (EFA) was utilized to extract latent variables for identification of subscales within the Barriers to Transplantation questionnaire. Solutions for two, three, and four factors were examined using exploratory factor analysis with maximum likelihood estimation. Three items ("I thought that I was already waitlisted", "I wasn't able to get childcare or eldercare while I went to the evaluation", and "I wasn't able to take off from work") were eliminated based on their high proportions of missing data or consistent loadings below 0.25, reducing the Barriers to Transplantation scale to from 17 to 14 items. Parallel analysis and scree plots were used to confirm a three-factor structure, and direct oblimin and promax rotations were compared in confirming the final structure (123).

Descriptive names were assigned to scales based on the barriers that loaded highly to each factor: *Affording Transplantation*, *Logistical Concerns*, and *Beliefs and Understanding Transplantation*. A composite score for each scale were calculated as a summed average across item, with each scale ranging from 1 to 5 points. The overall Barriers to Transplantation scale had 14 items, while the Affording Transplantation, Logistical Concerns, and Beliefs and Understanding Transplantation scales had 6 items, 4 items, and 4 items, respectively. Cronbach's alpha statistics were computed to evaluate reliability of each Barriers to Transplantation subscale (Table 1), and bivariate associations with patient characteristics were assessed to evaluate convergent validity of each subscale.

Outcomes of interest

Our primary outcome of interest was start of the pre-kidney transplant evaluation at a transplant center, as documented via an evaluation start date or through documented receipt of transplant education from transplant center staff (e.g. social workers or transplant coordinators) in the electronic health record. We classified absentees as patients who did not start their evaluation, either by not scheduling an evaluation following their most recent referral or by scheduling but failure to present to their evaluation. Attendees were classified as patients with a documented start of the transplant evaluation at any time point after 2014, even if that start date predated their most recent referral date.

Exposure of interest and additional measures

Our primary exposure of interest was self-reported race (black or African American versus white, non-Hispanic). We considered the overall Barriers to Transplantation scale, as well as the Affording Transplantation, Logistical Concerns, and Beliefs and Understanding Transplantation subscales, as potential mediators in the association between race and evaluation start. Additional covariates examined included self-reported patient demographics (age and sex), self-reported sociodemographic characteristics (insurance type, education, employment status, marital status, household income level), and self-reported clinical characteristics (pre-emptive referral (referral before initiating dialysis), preferred ESRD treatment option at referral, perceived health status (ranked on a 5-point Likert scale ranging from "Poor" to "Excellent"), and transplant knowledge. Transplant knowledge was categorized into three categories based on correctly answering two items (high knowledge, assigned 2 points), one item (moderate knowledge, assigned 1 point), or zero items (low knowledge, assigned 0 points) on the 2-item researcher-developed scale (range: 0 to 2 points). Due to high levels of non-response to the household income item (n=123), we linked survey responses to Census data from the 2015 American Community Survey via zip code to obtain census-tract level proportions of residents residing below the federal poverty line ($20,090 for three person households in 2015); for subsequent analyses, we utilized this neighborhood-level poverty item as a proxy for household-level income (13).

Data analyses

To assess differences between black and white, non-Hispanic participants in our study, as well as differences between evaluation attendees and absentees, we compared demographic, clinical, and socioeconomic characteristics using two-sample Student's *t* tests or non-parametric equivalents for continuous variables, and chi-square tests (or Fisher's exact tests for sparse data) for categorical variables. To evaluate congruent validity of the Barriers to Transplantation subscales, we conducted bivariate associations between all patient characteristics of interest and each continuous subscale using two-sample Student's *t* tests or one-way analysis of variance

(ANOVA) tests for all variables. Bivariable and multivariable logistic regression analyses were used to evaluate associations between the Barriers to Transplantation scale and subscales and evaluation start. An all-subsets approach for adjusting for relevant demographic, socioeconomic, and clinical characteristics was used with a 10% reduced versus full model decision rule for selection of the final models. Combinations of race, age, sex, treatment preference, transplant knowledge, education, insurance, marital status, and neighborhood poverty were retained as potential confounders. To evaluate if race significantly modified each association, we assessed the significance of a (race × scale) interaction term for each model. To decompose the role of each type of barrier (operationalized by each scale) in explaining the association between race and evaluation start, we examined multivariable logistic regression models adjusting for each Barriers to Transplantation subscale, using sequential addition of demographic, clinical, and socioeconomic characteristics for adjustment. To quantify the proportion of racial differences in evaluation start explained by each type of barrier in the Barriers to Transplantation scale, we used the equation [odds ratio $(\mathrm{OR})_{\mathrm{crude}}-\mathrm{OR}_{\mathrm{adjusted}}]/[\mathrm{OR}_{\mathrm{adjusted}}-1]$. We considered all *P* values less than 0.05 as statistically significant. All data cleaning and analyses were conducted with SurveyMonkey®, Microsoft Excel, and SAS® version 9.4 (Cary, North Carolina).

RESULTS

Study population

After applying inclusion criteria, we enrolled 528 eligible patients into the survey, reflecting an overall consent rate of 23% and completion rate of 95%. We excluded responses from participants with missing race (n=37), missing one or more items from the Barriers to Transplantation scale (n=44), Hispanic race (n=9), multiple races (n=14), and other races (n=8), resulting in a final study population of 416 patients of either black (n=314) or white (n=102) race. Among our study population, the mean age at enrollment was 55.7 ± 12.5 years, 75.5% were black, 44.0% were female, 43.5% had low transplant knowledge, 24.6% had public health insurance coverage only, and 54.1% were unemployed.

Compared to whites, black ESRD patients were significantly younger (54.4 years versus 59.6 years), more likely to have public insurance only (27.4% versus 15.2%), not complete high school (14.0% versus 2.9%), and be unemployed (62.4% versus 28.4%), but were less likely to be married or in a domestic partnership (37.3% versus 59.8%) (Table 2). Black patients were also more likely to have low transplant knowledge (48.7% versus 27.5%), and less likely to prefer transplant as their ESRD treatment option at the time of referral (31.2% versus 46.1%). Additionally, blacks were more likely to report income levels less than $20,000 (33.8% versus 15.7%), and reside in a neighborhood with higher levels of poverty (41.4% versus 16.7%).

When stratifying on evaluation attendees (n=207) versus absentees (n=209), absentees were more likely to have public insurance (30.6% versus 18.4%), not complete high school (13.9% versus 8.7%), be unemployed (59.3% versus 48.8%), be married (35.4% versus 50.2%), and reside in a high poverty neighborhood (41.2% versus 29.5%) (Table 3). Absentees were also less likely to prefer transplant as their preferred ESRD treatment option at referral (31.0% versus 38.7%), but were more likely to have low transplant knowledge (52.6% versus 34.3%) compared to evaluation attendees.

Descriptive analyses

Table 4 describes agreement (responding “Agree” or “Strongly “Agree”) to experiencing barriers to starting the transplant evaluation, overall and stratified by race. Among the overall survey population, frequently reported responses to the Barriers to Transplantation scale included: “I was worried about how long the wait for a kidney would be” (54.3%), “I couldn’t afford the medications I would need after my transplant” (34.9%), and “I didn’t think anyone would serve as a donor for me” (34.6%). The top three reported barriers among black patients included “I was worried about how long the wait for a kidney would be" (53.2%), "I couldn't afford the medications I would need after my transplant" (37.9%), and "I didn't think anyone would serve as a donor for me" (34.4%); among whites, top barriers reported included "I was worried about how long the wait for a kidney would be" (57.8%), "I didn't think anyone would serve as a donor for me" (35.3%), and "I couldn't afford the medication I would need after my transplant" (25.5%). Barriers significantly more reported among blacks compared to whites included: "I couldn't afford the medications I would need after my transplant" (37.9% versus 25.5%, p=0.02), "There were too many medical tests that I had to complete" (20.1% versus 9.8%, p=0.02), "I didn't have transportation to get to the transplant center for evaluation" (15.9% versus 6.9%, p=0.02), and "I didn't think anyone would be able to take care of me after my transplant" (15.0% versus 2.0%, p<0.01).

When comparing evaluation absentees to attendees, top barriers reported among absentees included "I was worried about how long the wait for a kidney would be" (50.2%), "I couldn't afford the medicines I would need after my transplant" (41.2%), and "I couldn't afford to get a transplant" (34.5%) (Table 5). Barriers significantly more reported among absentees included, but were not limited to: "I couldn't afford the medications I would need after my transplant" (41.2%), "I couldn't afford to get a transplant" (34.5%), and "I did not think I would pass the medical tests" (31.1%).

Congruent validity of Barriers to Transplantation subscales

In bivariate associations between Barriers to Transplantation score and its associated sub-scores with evaluation start, evaluation absentees reported significantly higher mean Barriers to Transplantation (2.53 versus 2.31, p<0.01), Affording Transplantation (2.73 versus 2.53, p<0.01), Logistical Concerns (2.47 versus 2.17, p<0.01), and Beliefs and Understanding Transplantation (2.28, 2.13, p<0.01) scores compared to attendees (Table 6). Similarly, black patients reported significantly higher Barriers to Transplantation scores (2.46 versus 2.30, p<0.01), as well as higher Affording Transplantation (2.67 versus 2.52, p=0.03), Logistical Concerns (2.36 versus 2.19, p=0.02), and Beliefs and Understanding Transplantation (2.24 versus 2.09, p=0.01) subscores compared to whites. Characteristics significantly associated with higher Affording Transplantation scores included having public health insurance (p<0.01), having lower levels of education (p<0.03), being unmarried (p<0.01), having lower household income (p<0.01), residing in a high-poverty neighborhood (p<0.01), and having a fair or poor perceived health status (p<0.01). Higher Logistical Concerns scores were significantly associated with lower levels of education (p<0.01), being unemployed (p<0.02), being unmarried (p<0.01), having lower household income (<0.01), residing in a high poverty neighborhood (p<0.03), having a fair or poor perceived health status (p<0.01), and having low transplant knowledge (p<0.01). Characteristics associated with higher Beliefs and Understanding Transplantation scores included residing in a high-poverty neighborhood (p=0.01), preferring dialysis as the ESRD treatment option at referral (p<0.01), and having a fair or poor perceived health status (p<0.01). Although Beliefs and Understanding Transplantation scores were not associated with having lower levels of education (p=0.13), higher scores were also associated with having low transplant knowledge (p<0.01).

Associations between scales and evaluation start

In unadjusted analyses, a 1-unit increase in the 14-item Barriers to Transplantation score was associated with a 2.4-times increased likelihood of not starting the evaluation (OR: 2.36, 95% CI (confidence interval): 1.57, 3.54) (Table 7). This association remained significant even after adjusting for relevant patient, clinical, and socioeconomic characteristics (OR: 1.71, 95% CI: 1.09, 2.68) in the overall sample, as well as among blacks (OR: 1.73, 95% CI: 1.05, 2.85). Increases in the 6-item Affording Transplantation score (OR: 1.56, 95% CI: 1.16, 2.09), 4-item Logistical Concerns score (OR: 2.02, 95% CI: 1.47, 2.76), and 4-item Beliefs and Understanding Transplantation score (OR: 1.63, 95% CI: 1.16, 2.30) were also significantly associated with not starting the evaluation in unadjusted analyses. After adjusting for relevant demographic, clinical, and socioeconomic characteristics, increases in the Logistical Concerns scale remained significantly associated with not starting the evaluation (OR: 1.76, 95% CI: 1.25, 2.47); the Logistical Concerns scale was also significantly associated with not starting the evaluation among blacks (OR: 1.57, 95% CI: 1.08, 2.28) and whites (OR: 2.87, 95% CI: 1.26, 6.54). However, the Affording Transplantation scale and Beliefs and Understanding Transplantation scale were not significantly associated with evaluation start in adjusted analyses. Modification by race was not statistically significant across subscales, indicating that the association between each Barriers to Transplantation subscale on evaluation start did not significantly differ by race.

The role of Barriers to Transplantation in racial differences in evaluation start

In unadjusted analyses, blacks were 29% less likely to start the evaluation as compared to whites (OR for not starting evaluation: 1.71, 95% CI: 1.09, 2.70); however, racial differences in evaluation start were eliminated after adjusting for demographic, clinical, and socioeconomic factors (adjusted OR: 1.07, 95% CI: 0.59, 1.93). In multivariable logistic regression models, Barriers to Transplantation explained 23.9% of the association between race and evaluation start, and this proportion increased after sequential adjustment for demographic (30.8%) and clinical (35.0%) characteristics. Logistical Concerns explained a considerable (21.1%) proportion of this association, which remained true even after adjustment for demographic and clinical characteristics (28.2%), while Affording Transplantation barriers (12.7%) and Beliefs and Understanding barriers (12.7%) explained a lower but still meaningful proportion of the difference.

DISCUSSION

In our study of racial differences in perceived barriers to starting the kidney transplant evaluation at a transplant center, referred black ESRD patients were significantly more likely to experience barriers to starting the evaluation as compared to whites. Particularly, black patients were significantly more likely to report concerns about lack of available care post-transplant as well as lack of affordability of post-transplant medications. We also found that blacks were more likely to report lacking transportation to the transplant evaluation as well as concerns with the amount of medical testing required for the evaluation. In adjusted analyses, logistical concerns about transplantation were significantly associated with evaluation start for both black and white patients; furthermore, logistical barriers considerably explained racial disparities in evaluation start, relative to barriers related to affording transplantation or understanding transplantation. Our results regarding barriers to starting the kidney transplant evaluation are corroborated by a growing body of evidence regarding factors affecting access to kidney transplantation (85). Specifically, frequently reported barriers among our cohort mirror results of prior studies which identified inability to afford transplant and post-transplant medications, fear of transplantation, and concerns about finding a living donor, as top barriers affecting ESRD patients from starting the evaluation once referred (102, 103).

Unlike prior studies, which have reported financial- and education-related barriers to transplantation as most prevalent among the ESRD population, we found that logistical concerns about transplantation, including concerns about medical testing for evaluation and transportation to the transplant center, were most significantly associated with evaluation start. Given the concern for the amount of testing required in the evaluation were significantly reported by blacks and evaluation absentees in our study, it is possible that patients may feel overwhelmed by the evaluation process, potentially due to lack of support available to manage the process. Social support has been cited as a significant barrier in access to transplantation, and previous studies have found lower levels of instrumental support among blacks (96). Patient navigators have been previously utilized to help patients better traverse the complicated requirements for kidney transplantation; in a randomized trial testing the use of kidney transplant recipients as trained navigators at dialysis facilities, intervention participants has significantly increased completion of transplant process steps compared to control participants (124). Furthermore, in a recently published randomized controlled trial testing the use of a trained patient navigator at a transplant center with a high risk population (including minority and socioeconomically disadvantaged patients), Basu et al. found statistically significant increases in transplant waitlisting long term in intervention patients compared to controls (125). However, it is unclear whether navigators are able to mitigate racial disparities in access to steps to transplantation prior to waitlisting; future work should evaluate the use of these navigators in minimizing disparities in access to early transplant steps (126).

Black patients were also significantly more likely to report transportation as a barrier to evaluation start, particularly between the steps of referral and evaluation start. Dageforde et al. found transplant evaluation absentees were significantly more likely to report not having transportation to the transplant center as compared to attendees (104). However, to our knowledge, no prior studies report lack of transportation as a barrier disproportionately affecting black versus white ESRD patients' access to kidney transplantation, and it is significant that this barrier persists among blacks among our study population. Blacks may be more likely to lack transportation resources needed to access transplant center appointments, possibly due to disparities in provision of these resources. For example, previous studies investigating effects of transportation availability on access to employment suggest significantly lower transportation access among minorities, resulting in lower employment rates and subsequently lower household incomes (127). Furthermore, our finding that transportation is a persistent barrier in access to the evaluation is corroborated by evidence from transplant providers. In a recent study surveying transplant center staff, lack of access to transportation was cited most frequently as a patient-level barrier to evaluation, but no transplant center in the study offered patients free transportation or park and ride services (128). More research is needed to evaluate transportation barriers in access to ESRD care, and future work should evaluate both dialysis facility and transplant center practices in provision of transportation resources to access the transplant evaluation.

Financial barriers are also commonly cited as factors affecting access to transplantation, and they have previously been identified as persisting between the steps of referral and evaluation start. For example, Patzer et al. found that referred blacks residing in the Southeastern United States were more than twice as likely to live in poverty as compared to whites, with approximately 10% of the effect of race on time to starting the evaluation explained by individual- and neighborhood-level socioeconomic factors (67). Furthermore, experiencing financial barriers have previously been shown to result in the development of patient-level barriers, such as transportation; thus, targeting these barriers is likely crucial in improving access to transplantation (127). Prior interventions aimed to reduce disparities in access to transplantation have included financial transplant education to minimize barriers to referral; however, results of these studies suggested a need for increased provision of financial resources for future implementations (129, 130). Therefore, future interventions should emphasize targeting socioeconomic barriers to evaluation start, as these barriers are likely to be prevalent among minority populations (106, 131, 132).

Concerns about finding a living donor have also been a focus of interventions aimed to reduce disparities in access to kidney transplantation, especially given reduced rates of living donor kidney transplantation among blacks. A number of interventions have been proposed to increase access to living donor kidney transplantation, including expanding patients' social support networks and increasing education for both patients and donors (72). For example, Project Living ACTS (About Choices in Transplantation and Sharing) is a set of culturally tailored educational materials aimed to improve black patients' motivation and efficacy in order to talk to friends and families about living donor kidney transplantation. Results of a trial testing effectiveness of Living ACTS found that participants receiving the intervention were more willing to talk to their families about living donation than control participants (133). A second intervention, the House Calls study, aimed to increase living donor inquiries and evaluations for blacks on the transplant waitlist, found delivery of an at-home education session on living donor kidney transplantation for patients and members of their social network significantly increased living donor inquiries for those patients compared to controls(134). Nevertheless, more research is needed to determine if interventions such as House Calls are effective at improving living donor inquiries among patients at steps prior to waitlisting.

Although knowledge and belief-based barriers were not significantly associated with evaluation start among our study population, black patients were significantly more likely to demonstrate low transplant knowledge compared to whites; furthermore, evaluation absentees were significantly more likely to have low transplant knowledge compared to attendees, and Belief and Understanding-related barriers explained approximately 13% of racial differences in evaluation start. Thus, these results suggest that minority patients may be susceptible to reduced access to starting the evaluation due to low understanding of transplantation and its associated benefits. Transplant knowledge has been of significant focus in intervention efforts to increase access to transplantation, particularly because patient education is a critical step on the pathway to kidney transplantation (97). Waterman et al. (2013) found patients with higher transplant knowledge at the time of evaluation were 20% more likely to receive a living donor transplant; importantly, racial differences in living donor transplantation rates were eliminated after adjusting for transplant knowledge at the time of evaluation (79). Improving transplant education has been central in intervention efforts aimed to reduce disparities in kidney transplantation. For example, a 2014 randomized trial examining the effectiveness of a multicomponent educational intervention in increasing referral for kidney transplantation across Georgia dialysis facilities found a significant reduction in racial disparities in referral among intervention facilities compared to controls; particularly, the OR for referral between black versus white patients at intervention facilities increased by nearly 60% between baseline and post-intervention time points (129). These results suggest that educational interventions are highly effective in improving access to early transplant steps among blacks, thus being pivotal strategies to reducing racial disparities in access to transplantation.

While among our study population, racial disparities in evaluation start disappeared after adjusting for measured variables, it is likely that additional barriers may persist that disproportionately affect access to kidney transplantation among blacks. Particularly, disparities in access to healthcare services has previously described to be partially mediated by structural and institutional racial bias, as well as cultural factors that may dissuade minorities from seeking care (132, 135). Although psycho-cultural factors such as medical mistrust have previously been identified as persisting in access to transplantation, these barriers have not been fully explored (79). However, these factors may play an indirect or direct role in the prevalence of measured barriers experienced among blacks in our study population, particularly for logistic barriers in access to the transplant evaluation. Increasing access to kidney transplantation among minorities requires a thorough understanding of the cultural factors influencing healthcare assess, including medical mistrust, perceived racism and discrimination in healthcare settings, and the influence of race concordance with medical providers in increasing motivation to pursue healthcare (121, 122). We argue that investigating these barriers is critical for the development of culturally sensitive interventions aimed to increase access to transplantation among minorities. Thus, future work such explore the prevalence of these factors in the minority ESRD population.

We acknowledge some limitations to this study. First, because evaluation attendees were not surveyed at the time of presentation for the evaluation, barriers reported may have occurred after starting the evaluation. However, we attempted to minimize this recall bias by framing our Barriers to Transplantation questionnaire for attendees to recall how they felt before their evaluation. Second, because patients frequently demonstrated multiple referrals to a center, we attempted to consider only their most recent referral date for analyses. However, there are complexities in the history of appointment attendance that complicate the distinguishing of an "attendee" versus "absentee". For example, a patient may not present for an evaluation following their most recent referral date, but may have a history of presenting after prior referrals. Although our exclusion criteria attempted to mitigate some of this misclassification bias, it is likely that we have residual measurement error as well as selection bias from this methodology. Third, our Barriers to Transplantation questionnaire may not fully reflect the wide range of barriers that ESRD patients may face when attempting to start the evaluation process. However, inclusion of more barriers in our questionnaire would have considerably lengthened our survey, thereby hindering completion rates. Fourth, given that our study was limited to the three transplant centers in Georgia, these results may not be generalizable to populations in other states. Fifth, it is likely that we have selection bias due to convenience sampling of survey participants as well as our low survey response rate. Finally, due to the nature of our study design, we may have been underpowered for these analyses. However, this is the largest study to date examining barriers to evaluation start, reflecting the difficulty in obtaining data from this hard-to-reach population.

Our study does have several strengths, however. To our knowledge, this is the first study to examine barriers that may disproportionately affect access to starting the pre-kidney transplant evaluation among blacks, a population that comprises the majority of ESRD patients but a minority of kidney transplant recipients. Second, this is the largest study to date examining barriers to starting the pre-kidney transplant evaluation, as prior studies were limited to a single center. Third, our study was able to highlight barriers that may be prevalent among ESRD patients residing in the Southeastern United States, a region with a high concentration of blacks but historically low rates of kidney transplantation.

In conclusion, we identified patient perceived barriers to starting the pre-kidney transplant evaluation that significantly affect black referred ESRD patients, including barriers related to affording transplantation, logistical barriers, and barriers related to understanding transplantation. The presence of barriers that disproportionately affect blacks prior to the transplant evaluation highlights that interventions aimed to increase access to kidney transplantation should not only target steps of the transplant process prior to waitlisting, but also should also aim to promote racial equity in access to each of these steps. Future studies should evaluate the multi-level determinants of barriers perpetuating disparities in starting the evaluation, in order to inform development, modification, and implementation of patient-centered interventions aimed to reduce racial disparities in access to the early steps of kidney transplantation.

PUBLIC HEALTH IMPLICATIONS

Summary

From a public health perspective, results of our study adds to a growing body of evidence regarding patient-level barriers to accessing kidney transplantation, the preferred treatment modality for most end stage renal disease patients in the United States. Particularly, our study identifies key barriers that may disproportionately affect minorities from accessing this treatment option, even after demonstrating interest and pursuing referral for transplantation. By identifying the patient-level barriers perpetuating racial disparities in evaluation start, we can inform development or modification of existing interventions aimed to increase access to transplantation.

Reducing disparities in access to transplantation through community engagement

This study was conducted as part of the Reducing Disparities in Access to kidney Transplantation (RaDIANT) Regional Study, an initiative aimed to increase access to kidney transplantation in ESRD Network 6, the region of the United States with the lowest kidney transplant rates and persisting racial disparities in access to transplantation. The RaDIANT Regional Study expands on the RaDIANT Community Study, a dialysis facility-level multicomponent intervention aimed to increase access to and reduce disparities in kidney transplant referrals in Georgia. Particularly, the RaDIANT Regional Study extends beyond its parent study by also aiming to improve access to evaluation start; this aim is informed by prior literature suggesting that both referral and evaluation are critical steps where more modifiable barriers to kidney transplantation are concentrated (79). Results of our study on identifying patient-perceived barriers perpetuating racial disparities in starting the evaluation will inform modifications of the RaDIANT intervention for implementation across ESRD Network 6 dialysis facilities. For the remainder of this chapter, we briefly describe current projects under the RaDIANT Regional Study, as well as related projects aimed to reduce disparities in access to the early steps of kidney transplantation.

Assessing cultural barriers to the transplant evaluation

As part of our survey assessing patient-perceived barriers to the transplant evaluation, we included three items related to medical mistrust, perceived racism in healthcare settings, and experiences of discrimination (121, 122). These factors have been identified has being prevalent among minority patients, and have been hypothesized to play a role in racial disparities in transplant access (79). We hope to examine these factors among the black participants of our survey, to determine if these factors perpetuate racial disparities in evaluation start, and potentially intervene on these factors on the patient, provider, and system levels.

Identifying provider and facility level barriers to the transplant evaluation

In parallel to our survey assessing patient-perceived barriers to evaluation among referred ESRD patients, we have also conducted a survey assessing transplant staff perspectives regarding patient barriers to evaluation, among staff at the nine transplant centers in ESRD Network 6 (128). Specifically, we assessed both staff-perceived barriers affecting patient access to evaluation, as well as transplant center practices that may ameliorate or exacerbate barriers to evaluation. Preliminary results of this survey suggested that lack of transplantation and distance to the transplant center were among the most frequently reported patient barriers to the evaluation; however, few transplant centers offered transportation-specific resources, with no transplant center offering free park and ride services or transportation from patients’ homes to the transplant center. Future research is needed to determine whether staff perceived barriers to transplant evaluation and variation in center practices are associated with racial disparities in access to transplantation (128).

Network-level surveillance of access to kidney transplantation

Despite the importance of improving access to early steps in the transplant process, patient-level information regarding these steps are not monitored through national surveillance systems, such as USRDS, OPTN/SRTR, or the United Network for Organ Sharing (UNOS). We have previously tested the feasibility of system-level monitoring of these transplant steps in the state of Georgia, and are currently in the process of expanding this surveillance system across Network 6. This data collection reflects a model of successful collaboration between competing transplant centers, which can inform other regions to share these data in the form of a national registry (136, 137). Results of this Network-level data collection will be used to inform quantitative analysis of patient- and facility-level factors associated with start of the transplant evaluation process.

Expansion of the RaDIANT intervention across Network 6

To address low transplant rates and disparities in transplantation in the Southeastern region of the United States, we intend to modify and expand the existing RaDIANT intervention for implementation throughout Network 6, which encompasses dialysis facilities and transplant centers in Georgia, North Carolina, and South Carolina. The prior RaDIANT multicomponent intervention utilized for the RaDIANT Community Study consists of standard quality improvement activities, patient-level and staff-level educational materials and webinars, and peer mentoring strategies aimed to improve referral rates in dialysis facilities. Expansion of this intervention includes web-based tracking of transplant steps and transplant communications (discussed below), increased provision of educational materials, and refinement of a peer mentoring program to help mentor dialysis patients for transplant. Effectiveness of this refined intervention in improving access to referral, evaluation, and waitlisting will be assessed via a randomized trial across dialysis facilities referring to the nine transplant centers in Network 6.

Development and implementation of a Transplant Referral EXchange platform (T-REX)

Communication between dialysis facilities and transplant centers presents a major challenge to ensuring streamlined tracking of patients through the complex process leading to transplantation. Thus, as part of the RaDIANT Regional expanded intervention, we have developed and piloted a multi-module, web-enabled software (T-REX) aimed to enhance communication between dialysis and transplant center staff (138). The platform allows dialysis staff to electronically refer (versus fax) ESRD patients for the transplant evaluation, while keeping these staff abreast of referral receipt by the transplant center as well as subsequent tracking of their patients throughout the transplant process. The platform has been piloted and implemented at multiple dialysis facilities in Georgia, and is scheduled to be implemented across Network 6 facilities as part of the RaDIANT Regional intervention.

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TABLES

Table 1. Summary of Exploratory Factor Analysis Results for Barriers to Transplantation Scale Among Adult ESRD Patients Referred to a GA Transplant Center in 2016[a]

	Factor Loadings[b]		
Item	Affording Transplantation	Logistical Concerns	Beliefs and Understanding Transplantation
I couldn't afford to get a transplant	**0.88**	-0.06	-0.03
I couldn't afford the medications I would need after my transplant	**0.85**	0.09	-0.16
My health insurance would not cover the cost of transplant	**0.52**	0.00	0.06
I didn't think anyone would be able to take care of me after my transplant	**0.33**	0.24	0.10
I was worried about how long the wait for a kidney would be	**0.30**	-0.01	0.05
I didn't think anyone would serve as a donor for me	**0.26**	0.08	0.17
The transplant center was too far away from where I lived	0.04	**0.71**	-0.10
I didn't have transportation to get to the transplant center for evaluation	-0.01	**0.67**	-0.03
There were too many medical tests that I had to complete	0.05	**0.45**	0.17
I did not think I would pass the medical tests	0.02	**0.38**	0.02
I did not understand the benefits of transplantation.	0.07	-0.09	**0.83**
I did not understand the transplant process	0.07	0.09	**0.61**
I was afraid of getting a transplant	-0.06	0.23	**0.26**
Kidney transplantation is against my religion or moral values/beliefs	0.23	0.01	**0.25**
Eigenvalues	5.9	1.2	0.9
Percent of variance	82.9	17.4	12.1
Cronbach's alpha	0.75	0.65	0.64

a. Exploratory factor analysis using maximum likelihood estimation and direct oblimin rotation

b. Factor loadings greater than or equal to 0.25 appear in bold

Table 2. Characteristics of Telephone Survey Participants Reporting Perceived Barriers to Starting the Kidney Transplant Evaluation Among Adult ESRD Patients Referred to a GA Transplant Center in 2016, Overall and by Race[a]

	Total respondents (n=416)[b]	**Black (n=314)**	**White, non-Hispanic (n=102)**	**P-value[c]**
Started evaluation[d]	207 (49.8)	146 (46.5)	61 (59.8)	0.02
Sociodemographics[e]				
Age (years); mean (SD)	56(12.5)	54 (12.1)	60 (13.1)	<0.01
Female; n (%)	183 (44.0)	146 (46.5)	37 (36.3)	0.07
Insurance type; n (%)				<0.01
Medicare only	78 (18.8)	65 (20.7)	13 (12.8)	
Medicaid only	24 (5.8)	21 (6.7)	3 (2.9)	
Private only	60 (14.4)	35 (11.2)	25 (24.5)	
Multiple insurance	241 (57.9)	183 (58.3)	58 (56.9)	
Other governmental insurance	3 (0.8)	3 (1.0)	0 (0.0)	
None	4 (1.0)	4 (1.3)	0 (0.0)	
Missing	6 (1.4)	3 (1.0)	3 (2.9)	
Education; n (%)				<0.01
Grade school or less	47 (11.3)	44 (14.0)	3 (2.9)	
High school diploma/GED	131 (31.5)	106 (33.8)	25 (24.5)	
Some college, no degree	113 (27.2)	88 (28.0)	25 (24.5)	
Associate's or Bachelor's Degree	84 (20.2)	51 (16.2)	33 (32.4)	
Graduate or Professional Degree	36 (8.7)	22 (7.0)	14 (13.7)	
Missing	5 (1.2)	3 (1.0)	2 (2.0)	
Employment; n (%)				<0.01
Employed	50 (12.0)	28 (8.9)	22 (21.6)	
Unemployed	225 (54.1)	196 (62.4)	29 (28.4)	
Retired	135 (32.5)	84 (26.8)	51 (50.0)	
Missing	6 (1.4)	6 (1.9)	0 (0.0)	
Marital status; n (%)				<0.01
Single	129 (31.0)	116 (36.9)	13 (12.8)	
Married or domestic partnership	178 (42.8)	117 (37.3)	61 (59.8)	
Divorced/widowed	103 (24.8)	76 (24.2)	27 (26.5)	
Missing	6 (1.4)	5 (1.6)	1 (1.0)	
Household income**;** n(%)				<0.01
Less than \$20,000	122 (29.3)	106 (33.8)	16 (15.7)	
\$20,000 - 60,000	113 (27.2)	86 (27.4)	27 (26.5)	
\$60,000 - 80,000	25 (6.0)	12 (3.8)	13 (12.8)	
Greater than \$80,000	33 (7.9)	14 (4.5)	19 (18.6)	
Prefer not to answer	121 (29.1)	94 (29.9)	27 (26.5)	
Missing	2 (0.5)	2 (0.6)	0 (0.0)	
Neighborhood poverty; n (%)[f]				<0.01
Less than 5%	22 (5.3)	10 (3.2)	12 (11.8)	
5.0 - 9.9%	64 (15.4)	30 (9.6)	34 (33.3)	
10% - 14.9%	85 (20.4)	59 (18.8)	26 (25.5)	

15% - 19.9%	90 (21.6)	79 (25.2)	11 (10.8)	
Greater than 20%	147 (35.3)	130 (41.4)	17 (16.7)	
Missing	8 (1.9)	6 (1.9)	2 (2.0)	
Clinical characteristics[e]				
Preemptively referred; n (%)	73 (17.6)	43 (58.9)	30 (41.1)	<0.01
Preferred ESRD treatment option at referral; n (%)				<0.01
Hemodialysis	199 (47.8)	169 (53.8)	20 (29.4)	
Peritoneal dialysis	48 (11.5)	31 (9.9)	17 (16.7)	
Transplant	145 (34.9)	98 (31.2)	47 (46.1)	
No preference	7 (1.7)	2 (0.6)	5 (4.9)	
Do not remember	15 (3.6)	13 (86.7)	2 (13.3)	
Missing	2 (0.5)	1 (0.3)	1 (1.0)	
Excellent, very good, good health; n (%)	255 (61.3)	184 (58.6)	71 (69.6)	0.05
Missing	0 (0.0)	0 (0.0)	0 (0.0)	
Transplant knowledge; n (%)[g]				
High transplant knowledge	90 (21.6)	49 (15.6)	41 (40.2)	<0.01
Moderate transplant knowledge	144 (34.6)	111 (35.4)	33 (32.4)	
Low transplant knowledge	181 (43.5)	153 (48.7)	28 (27.5)	
Missing	1 (0.2)	1 (0.3)	0 (0.0	
Barriers to Transplantation scale; mean (SD)	2.42 (0.52)	2.46 (0.53)	2.30 (0.44)	<0.01
Affording Transplantation subscale; mean (SD)	2.63 (0.67)	2.67 (0.70)	2.52 (0.58)	0.03
Logistical Concerns subscale; mean (SD)	2.32 (0.67)	2.36 (0.69)	2.19 (0.59)	<0.01
Beliefs and Understanding Transplantation subscale; mean (SD)	2.21 (0.58)	2.24 (0.60)	2.09 (0.50)	<0.01

a. Abbreviations: ESRD, end stage renal disease; GA, Georgia; SD, standard deviation; GED, general equivalency degree

b. Excludes missing race or ethnicity (n=37), missing for barrier items (n=44), Hispanic race (n=9), multiple races (n=14), and other races (n=8).

c. By Student's t-test for continuous variables and χ^2 test for categorical variables. Wilcoxon rank-sum tests used for skewed continuous variable, and Fisher's exact test for categorical variables with sparse data. Statistically significant at $p<0.05$

d. Defined as starting the kidney transplant evaluation at a transplant center, as documented in the electronic health record

e. Defined via self-report

f. Defined as percentage of residents living below federal poverty level in patient's census tract of residence

g. High transplant knowledge defined as correctly completing both items on a short transplant knowledge scale; moderate transplant knowledge defined as correctly completing one item; low transplant knowledge defined by correctly completing no items

Table 3. Characteristics of Telephone Survey Participants Reporting Perceived Barriers to Starting the Kidney Transplant Evaluation Among Adult ESRD Patients Referred to a GA Transplant Center in 2016, Overall and by Evaluation Start Status[a]

	Total respondents (n=416)[b]	**Absentees (n=209)**	**Attendees (n=207)**	**P-value[c]**
Sociodemographics[d]				
Race; n (%)				0.02
Black	314 (75.5)	168 (80.4)	146 (70.5)	
White, non-Hispanic	102 (24.5)	41 (19.6)	61 (29.5)	
Age (years); mean (SD)	56 (12.5)	56 (12.1)	55 (12.9)	0.59
Female; n (%)	183 (44.0)	92 (44.0)	91 (43.0)	0.99
Insurance type; n (%)				0.02
Medicare only	78 (18.8)	46 (22.0)	32 (15.5)	
Medicaid only	24 (5.8)	18 (8.6)	6 (2.9)	
Private only	60 (14.4)	24 (11.5)	36 (17.4)	
Multiple insurance	241 (57.9)	115 (55.0)	126 (60.9)	
Other governmental insurance	3 (0.7)	1 (0.5)	2 (1.0)	
None	4 (1.0)	3 (1.4)	1 (0.5)	
Missing	6 (1.4)	2 (1.0)	4 (1.9)	
Education; n (%)				<0.01
Grade school or less	47 (11.3)	29 (13.9)	18 (8.7)	
High school diploma/GED	131 (31.5)	79 (37.8)	52 (25.1)	
Some college, no degree	113 (27.2)	53 (25.4)	60 (29.0)	
Associate's or Bachelor's Degree	84 (20.2)	35 (16.8)	49 (23.7)	
Graduate or Professional Degree	36 (8.7)	12 (5.7)	24 (11.6)	
Missing	5 (1.2)	1 (0.5)	4 (1.9)	
Employment; n (%)				<0.01
Employed	50 (12.0)	69 (33.0)	36 (17.4)	
Unemployed	225 (54.1)	124 (59.3)	101 (48.8)	
Retired	135 (32.5)	14 (6.7)	66 (31.9)	
Missing	6 (1.4)	2 (1.0)	4 (1.9)	
Marital status; n (%)				0.01
Single	129 (31.0)	72 (34.5)	57 (27.5)	
Married or domestic partnership	178 (42.8)	74 (35.4)	104 (50.2)	
Divorced/widowed	103 (24.8)	59 (28.2)	44 (21.3)	
Missing	6 (1.4)	4 (1.9)	2 (1.0)	
Household income**;** n(%)				0.14
Less than $20,000	122 (29.3)	67 (32.1)	55 (26.6)	
$20,000 - 60,000	113 (27.2)	56 (26.8)	57 (27.5)	
$60,000 - 80,000	25 (6.1)	9 (4.3)	16 (7.7)	
Greater than $80,000	33 (7.9)	12 (5.7)	21 (10.1)	
Prefer not to answer	121 (29.1)	64 (30.6)	57 (27.5)	
Missing	2 (0.5)	1 (0.5)	1 (0.5)	
Neighborhood poverty; n (%)[e]				0.03
Less than 5%	22 (5.3)	10 (4.8)	12 (5.8)	
5.0 - 9.9%	64 (15.4)	23 (11.0)	41 (19.8)	
10% - 14.9%	85 (20.4)	39 (18.7)	46 (22.2)	

15% - 19.9%	90 (21.6)	48 (23.0)	42 (20.3)	
Greater than 20%	147 (35.3)	86 (41.2)	61 (29.5)	
Missing	8 (1.9)	3 (1.4)	5 (2.4)	
Clinical characteristics[d]				
Preemptively referred; n (%)	73 (17.6)	29 (13.9)	44 (21.3)	0.05
Preferred ESRD treatment option at referral; n (%)				<0.01
Hemodialysis	199 (47.8)	110 (52.6)	89 (43.0)	
Peritoneal dialysis	48 (11.5)	21 (10.1)	27 (13.0)	
Transplant	145 (34.9)	65 (31.0)	80 (38.7)	
No preference	7 (1.7)	0 (0.0)	7 (3.4)	
Do not remember	15 (3.6)	13 (6.2)	2 (1.0)	
Missing	2 (0.5)	0 (0.0)	2 (1.0)	
Excellent, very good, good health; n (%)	255 (61.3)	123 (58.9)	132 (63.8)	0.30
Transplant knowledge; n (%)[f]				<0.01
High transplant knowledge	90 (21.6)	30 (14.4)	60 (29.0)	
Moderate transplant knowledge	144 (34.6)	69 (33.0)	75 (36.2)	
Low transplant knowledge	181 (43.5)	110 (52.6)	71 (34.3)	
Missing	1 (0.2)	0 (0.0)	1 (0.5)	
Barriers to Transplantation scale; mean (SD)	2.42 (0.5)	2.53 (0.56)	2.31 (0.44)	<0.01
Affording Transplantation subscale; mean (SD)	2.63 (0.7)	2.73 (0.76)	2.53 (0.57)	<0.01
Logistical Concerns subscale; mean (SD)	2.32 (0.7)	2.47 (0.72)	2.17 (0.58)	<0.01
Beliefs and Understanding Transplantation subscale; mean (SD)	2.21 (0.6)	2.28 (0.62)	2.13 (0.52)	<0.01

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a. Abbreviations: ESRD, end stage renal disease; GA, Georgia; SD, standard deviation; GED, general equivalency degree

b. Excludes missing race or ethnicity (n=37), missing for barrier items (n=44), Hispanic race (n=9), multiple races (n=14), and other races (n=8).

c. By Student's t-test for continuous variables and χ^2 test for categorical variables. Wilcoxon rank-sum tests used for skewed continuous variable, and Fisher's exact test for categorical variables with sparse data. Statistically significant at p<0.05

d. Defined via self-report

e. Defined as percentage of residents living below federal poverty level in patient's census tract of residence

f. High transplant knowledge defined as correctly completing both items on a short transplant knowledge scale; moderate transplant knowledge defined as correctly completing one item; low transplant knowledge defined by correctly completing no items

Table 4. Percent Agreement to Barriers to Transplantation Scale Items, Overall and By Race[a]

Barriers to Transplantation scale item	**Overall (N=416)**	**Black (n=314)**	**White, non-Hispanic (n=102)**	**P-value[c]**
I couldn't afford to get a transplant	121 (29.1)	99 (31.5)	22 (21.6)	0.05
I couldn't afford the medications I would need after my transplant	145 (34.9)	119 (37.9)	26 (25.5)	0.02
My health insurance would not cover the cost of transplant	60 (14.4)	51 (16.2)	9 (8.8)	0.06
I didn't think anyone would be able to take care of me after my transplant	49 (11.8)	47 (15.0)	2 (2.0)	<0.01
I was worried about how long the wait for a kidney would be	226 (54.3)	167 (53.2)	59 (57.8)	0.41
I didn't think anyone would serve as a donor for me	144 (34.6)	108 (34.4)	36 (35.3)	0.87
The transplant center was too far away from where I lived	81 (19.5)	64 (20.4)	17 (16.7)	0.41
I didn't have transportation to get to the transplant center for evaluation	57 (13.7)	50 (15.9)	7 (6.9)	0.02
There were too many medical tests that I had to complete	73 (17.6)	63 (20.1)	10 (9.8)	0.02
I did not think I would pass the medical tests	28 (6.7)	22 (7.0)	6 (5.9)	0.70
I did not understand the benefits of transplantation.	49 (11.8)	42 (13.4)	7 (6.9)	0.08
I did not understand the transplant process	82 (19.7)	65 (20.7)	17 (16.7)	0.37
I was afraid of getting a transplant	108 (26.0)	86 (27.4)	22 (21.6)	0.24
Kidney transplantation is against my religion or moral values/beliefs	5 (1.2)	5 (1.6)	0 (0.0)	0.34

a. Reporting "agree" or "strongly agree" to each 5-point Likert scale item (versus "neither agree nor disagree", "disagree", or "strongly disagree")

b. Excludes missing race or ethnicity (n=37), missing for barrier items (n=44), Hispanic race (n=9), multiple races (n=14), and other races (n=8).

c. By $\chi 2$ test or Fisher's exact for sparse data. Statistically significant at $p<0.05$

Table 5. Percent Agreement to Barriers to Transplantation Scale Items, Overall and By Evaluation Start[a]

Barriers to Transplantation scale item	Overall (N=416)	Absentees (n=209)	Attendees (n=207)	P-value[c]
I couldn't afford to get a transplant	121 (29.1)	72 (34.5)	49 (23.7)	0.02
I couldn't afford the medications I would need after my transplant	145 (34.9)	86 (41.2)	59 (28.5)	<0.01
My health insurance would not cover the cost of transplant	60 (14.4)	44 (21.1)	16 (7.7)	<0.01
I didn't think anyone would be able to take care of me after my transplant	49 (11.8)	34 (16.3)	15 (7.3)	<0.01
I was worried about how long the wait for a kidney would be	226 (54.3)	105 (50.2)	121 (58.5)	0.10
I didn't think anyone would serve as a donor for me	144 (34.6)	72 (34.5)	72 (34.8)	0.94
The transplant center was too far away from where I lived	81 (19.5)	54 (25.8)	27 (13.0)	<0.01
I didn't have transportation to get to the transplant center for evaluation	57 (13.7)	45 (21.5)	12 (5.8)	<0.01
There were too many medical tests that I had to complete	73 (17.6)	41 (19.6)	32 (15.5)	0.26
I did not think I would pass the medical tests	103 (24.8)	65 (31.1)	38 (18.4)	<0.01
I did not understand the benefits of transplantation.	49 (11.8)	33 (15.8)	16 (7.7)	0.01
I did not understand the transplant process	82 (19.7)	49 (23.4)	33 (15.9)	0.05
I was afraid of getting a transplant	108 (26.0)	55 (26.3)	53 (25.6)	0.87
Kidney transplantation is against my religion or moral values/beliefs	5 (1.2)	4 (1.9)	1 (0.5)	0.37

a. Reporting "agree" or "strongly agree" to each 5-point Likert scale item (versus "neither agree nor disagree", "disagree", or "strongly disagree")

b. Excludes missing race or ethnicity (n=37), missing for barrier items (n=44), Hispanic race (n=9), multiple races (n=14), and other races (n=8).

c. By $\chi 2$ test or Fisher's exact for sparse data. Statistically significant at $p<0.05$

Table 6. Bivariate Associations between Barriers to Transplantation Scores (and Subscale Scores) and Characteristics of Telephone Survey Participants Reporting Perceived Barriers to Starting the Kidney Transplant Evaluation Among Adult ESRD Patients Referred to a GA Transplant Center in 2016[a,b]

	Overall Barriers to Transplantation Score (N=416)	**P-value[c]**	**Affording Transplantation Score**	**P-value[c]**	**Logistical Concerns Score**	**P-value[c]**	**Beliefs and Understanding Transplantation Score**	**P-value[c]**
Evaluation start status[d]		<0.01		<0.01		<0.01		<0.01
Started evaluation	2.31 (0.44)		2.53 (0.57)		2.17 (0.58)		2.13 (0.52)	
Did not start evaluation	2.53 (0.56)		2.73 (0.76)		2.47 (0.72)		2.28 (0.62)	
Sociodemographics[e]								
Race[d]								
Black	2.46 (0.53)	<0.01	2.67 (0.70)	0.03	2.36 (0.69)	0.02	2.24 (0.60)	0.01
White, non-Hispanic	2.30 (0.44)		2.52 (0.58)		2.19 (0.59)		2.09 (0.50)	
Age (years, in quartiles)		0.67		0.80		0.11		0.29
Under 46	2.37 (0.49)		2.63 (0.66)		2.23 (0.65)		2.11 (0.56)	
46-56	2.41 (0.53)		2.63 (0.71)		2.29 (0.68)		2.20 (0.62)	
57-65	2.44 (0.55)		2.68 (0.72)		2.27 (0.65)		2.25 (0.60)	
Over 65	2.45 (0.49)		2.59 (0.61)		2.44 (0.67)		2.24 (0.54)	
Sex		0.35		0.44		0.31		0.66
Female	2.45 (0.52)		2.66 (0.66)		2.36 (0.71)		2.22 (0.60)	
Male	2.40 (0.51)		2.61 (0.68)		2.29 (0.64)		2.20 (0.56)	
Insurance type		0.12		0.01		0.41		0.91
Medicare only	2.57 (0.52)		2.88 (0.72)		2.45 (0.67)		2.24 (0.57)	
Medicaid only	2.44 (0.34)		2.76 (0.60)		2.20 (0.60)		2.20 (0.38)	
Private only	2.32 (0.52)		2.46 (0.61)		2.20 (0.62)		2.21 (0.59)	
Multiple insurance	2.39 (0.52)		2.58 (0.66)		2.31 (0.69)		2.19 (0.60)	
Other governmental insurance	2.55 (0.11)		2.78 (0.35)		2.33 (0.52)		2.42 (0.38)	
None	2.39 (0.69)		2.63 (1.04)		2.56 (1.13)		1.88 (0.63)	
Education		0.01		0.03		0.02		0.13

Grade school or less	2.57 (0.45)		2.79 (0.60)		2.43 (0.61)		2.39 (0.52)	
High school diploma/GED	2.51 (0.51)		2.73 (0.68)		2.44 (0.70)		2.25 (0.54)	
Some college, no degree	2.35 (0.54)		2.51 (0.70)		2.31 (0.71)		2.16 (0.60)	
Associate's or Bachelor's Degree	2.35 (0.52)		2.62 (0.68)		2.16 (0.63)		2.15 (0.61)	
Graduate or Professional Degree	2.29 (0.42)		2.53 (0.59)		2.13 (0.56)		2.09 (0.63)	
Employment		0.16		0.09		0.02		0.26
Employed	2.27 (0.48)		2.52 (0.58)		2.06 (0.58)		2.12 (0.59)	
Unemployed	2.45 (0.51)		2.71 (0.69)		2.33 (0.67)		2.20 (0.59)	
Retired	2.42 (0.54)		2.57 (0.67)		2.39 (0.69)		2.23 (0.56)	
Marital status		<0.01		0.01		0.01		0.23
Single	2.51 (0.49)		2.75 (0.65)		2.39 (0.71)		2.27 (0.58)	
Married or domestic partnership	2.31 (0.48)		2.51 (0.64)		2.20 (0.60)		2.14 (0.55)	
Divorced/widowed	2.49 (0.57)		2.68 (0.73)		2.43 (0.71)		2.24 (0.63)	
Household income		<0.01		<0.01		<0.01		0.14
Less than $20,000	2.49 (0.54)		2.74 (0.75)		2.33 (0.67)		2.26 (0.67)	
$20,000 - 60,000	2.46 (0.46)		2.69 (0.61)		2.38 (0.66)		2.18 (0.50)	
$60,000 - 80,000	2.24 (0.48)		2.41 (0.68)		2.10 (0.60)		2.11 (0.57)	
Greater than $80,000	2.04 (0.43)		2.17 (0.54)		1.89 (0.41)		1.98 (0.52)	
No answer	2.46 (0.52)		2.62 (0.62)		2.40 (0.70)		2.26 (0.56)	
Neighborhood poverty level (quintiles)^{f}		<0.01		<0.01		0.03		0.01
Less than 5%	2.24 (0.56)		2.46 (0.68)		2.08 (0.70)		2.07 (0.65)	
5.0 - 9.9%	2.20 (0.51)		2.35 (0.70)		2.15 (0.60)		2.02 (0.48)	
10% - 14.9%	2.39 (0.40)		2.65 (0.58)		2.26 (0.57)		2.13 (0.45)	
15% - 19.9%	2.46 (0.48)		2.62 (0.63)		2.42 (0.66)		2.25 (0.60)	
Greater than 20%	2.54 (0.56)		2.78 (0.70)		2.41 (0.74)		2.32 (0.64)	
Clinical Characteristics								

Preemptively referred[e]		0.26		0.28		0.19		0.93
Yes	2.36 (0.53)		2.55 (0.64)		2.23 (0.65)		2.20 (0.58)	
No	2.43 (0.51)		2.65 (0.68)		2.34 (0.67)		2.20 (0.58)	
Preferred ESRD treatment option at referral[e]		0.18		0.93		0.14		<0.01
Hemodialysis	2.42 (0.55)		2.61 (0.70)		2.35 (0.69)		2.21 (0.59)	
Peritoneal dialysis	2.45 (0.42)		2.65 (0.59)		2.31 (0.62)		2.30 (0.53)	
Transplant	2.40 (0.50)		2.64 (0.67)		2.29 (0.66)		2.14 (0.56)	
No preference	2.08 (0.44)		2.52 (0.76)		1.79 (0.51)		1.71 (0.37)	
No answer	2.68 (0.37)		2.79 (0.54)		2.53 (0.54)		2.67 (0.58)	
Health status[e]		<0.01		<0.01		<0.01		<0.01
Excellent, very good, good health	2.34 (0.52)		2.56 (0.68)		2.22 (0.66)		2.14 (0.59)	
Fair, poor health	2.54 (0.49)		2.74 (0.64)		2.48 (0.66)		2.31 (0.56)	
Transplant knowledge[g]		<0.01		0.11		<0.01		<0.01
High transplant knowledge	2.23 (0.51)		2.48 (0.66)		2.09 (0.62)		1.98 (0.53)	
Moderate transplant knowledge	2.42 (0.47)		2.67 (0.66)		2.30 (0.62)		2.17 (0.52)	
Low transplant knowledge	2.51 (0.53)		2.68 (0.69)		2.44 (0.71)		2.34 (0.61)	
Overall	**2.42 (0.52)**		**2.63 (0.67)**		**2.32 (0.67)**		**2.21 (0.58)**	

a. Abbreviations: ESRD, end stage renal disease; GA, Georgia; SD, standard deviation; GED, general equivalency degree

b. Excludes missing race/ethnicity (n=37), missing barrier item (n=44), Hispanic race (n=9), multiple races (n=14), and other races (n=8)

c. By Student's two-sample t-test or 1-way analysis of variance tests. Statistically significant at $p<0.05$

d. Defined as attending the initial appointment for a kidney transplant evaluation at a transplant center, as documented in the electronic health record

e. Defined via self-report

f. Defined as percentage of residents living below federal poverty level in patient's census tract of residence

g. High transplant knowledge defined as correctly completing both items on a short transplant knowledge scale; moderate transplant knowledge defined as correctly completing one item; low transplant knowledge defined by correctly completing no items

Table 7. Unadjusted and Adjusted Analyses of the Association between Barriers to Transplantation Subscales and Evaluation Start, Overall and Stratified by Race[a,b]

	Overall (N=416)		Black (n=314)		White, non-Hispanic (n=102)		P-value for interaction by race[d]
Models	**OR[a,c]**	**95% CI**	**OR[a,c]**	**95% CI**	**OR[a,c]**	**95% CI**	
Barriers to Transplantation scale							
Unadjusted	2.36	1.57, 3.54	2.35	1.49, 3.73	1.90	0.76, 4.78	- -
Adjusted for demographic characteristics[e]	2.23	1.48, 3.36	2.32	1.46, 3.67	1.89	0.75, 4.76	0.70
Adjusted for demographic + clinical characteristics[f]	2.06	1.35, 3.14	2.14	1.34, 3.43	1.74	0.67, 4.48	0.70
Adjusted for demographic + clinical + SES characteristics[g]	1.71	1.09, 2.68	1.73	1.05, 2.85	1.64	0.60, 4.50	0.92
Affording Transplantation subscale							
Unadjusted	1.56	1.16, 2.09	1.66	1.19, 2.33	1.02	0.52, 2.03	- -
Adjusted for demographic characteristics[e]	1.52	1.13, 2.05	1.66	1.18, 2.32	1.04	0.53, 2.08	0.24
Adjusted for demographic + clinical characteristics[f]	1.48	1.09, 2.01	1.61	1.14, 2.26	1.04	0.51, 2.11	0.28
Adjusted for demographic + clinical + SES characteristics[g]	1.21	0.87, 1.69	1.31	0.90, 1.89	0.88	0.41, 1.86	0.35
Logistical Concerns subscale							
Unadjusted	2.02	1.47, 2.76	1.81	1.28, 2.56	2.79	1.31, 5.97	- -
Adjusted for demographic characteristics[e]	1.94	1.41, 2.66	1.79	1.26, 2.53	2.74	1.28, 5.86	0.30
Adjusted for demographic + clinical characteristics[f]	1.82	1.32, 2.50	1.69	1.19, 2.40	2.48	1.16, 5.28	0.36
Adjusted for demographic + clinical + SES characteristics[g]	1.76	1.25, 2.47	1.57	1.08, 2.28	2.87	1.26, 6.54	0.18
Beliefs and Understanding Transplantation subscale							

Unadjusted	1.63	1.16, 2.30	1.61	1.10, 2.37	1.43	0.64, 3.19	- -
Adjusted for demographic characteristics[e]	1.55	1.10, 2.20	1.59	1.08, 2.34	1.39	0.62, 3.12	0.77
Adjusted for demographic + clinical characteristics[f]	1.31	0.90, 1.91	1.35	0.89, 2.04	1.15	0.48, 2.78	0.75
Adjusted for demographic + clinical + SES characteristics[g]	1.22	0.82, 1.83	1.26	0.81, 1.96	1.07	0.41, 2.74	0.75

a. Abbreviations: OR, odds ratio; CI, confidence interval; SES, socioeconomic

b. Using multivariable logistic regression for adjusted analyses with inclusion of a race x scale interaction term for race comparisons.

c. Referent group is starting the evaluation

d. Via likelihood ratio test for significance of (race x score) interaction terms

e. Demographic characteristics include age, sex, and race (for overall model) for all scales

f. Clinical characteristics include transplant knowledge for all scales, and preferred treatment option at referral for the Beliefs and Understanding Transplantation subscale

g. Socioeconomic characteristics include insurance type, educational attainment, marital status, and neighborhood poverty level for all scales

Table 8. Decomposition of the Role of each Barrier to Transplantation Scale in the Association between Race and Evaluation Start[a]

	Association between Race and Evaluation Start		% Total effect explained[b]
Models	**OR[c]**	**95% CI**	
Unadjusted total effect	1.71	1.09, 2.70	
Adjusted for Barriers to Transplantation score	1.54	0.97, 2.45	23.9
Adjusted for Affording Transplantation score	1.62	1.03, 2.57	12.7
Adjusted for Logistical Concerns score	1.56	0.98, 2.49	21.1
Adjusted for Beliefs and Understanding score	1.62	1.02, 2.55	12.7
Total effect adjusted for demographic factors[d]	1.78	1.12, 2.83	
Adjusted for Barriers to Transplantation score	1.54	0.97, 2.45	30.8
Adjusted for Affording Transplantation score	1.62	1.03, 2.57	20.5
Adjusted for Logistical Concerns score	1.56	0.98, 2.49	28.2
Adjusted for Beliefs and Understanding score	1.62	1.02, 2.55	20.5
Total effect adjusted for demographic + clinical factors[d,e]	1.20	0.72, 2.01	
Adjusted for Barriers to Transplantation score	1.13	0.67, 1.90	35.0
Adjusted for Affording Transplantation score	1.15	0.69, 1.94	25.0
Adjusted for Logistical Concerns score	1.14	0.68, 1.92	30.0
Adjusted for Beliefs and Understanding score	1.18	0.70, 1.97	10.0
Total effect adjusted for demographic + clinical + SES factors[d,e,f]	1.07	0.59, 1.93	
Adjusted for Barriers to Transplantation score	1.08	0.60, 1.96	-14.3
Adjusted for Affording Transplantation score	1.07	0.59, 1.94	0.0
Adjusted for Logistical Concerns score	1.09	0.60, 1.97	-28.6
Adjusted for Beliefs and Understanding score	1.07	0.59, 1.94	0.0

a. Abbreviations: OR, odds ratio; CI, confidence interval; SES, socioeconomic status

b. Quantified by [ORcrude-ORadjusted]/[ORadjusted-1] x 100%

c. Referent group is starting the evaluation

d. Demographic characteristics include age and sex

e. Clinical characteristics include transplant knowledge and preferred treatment option at referral

f. Socioeconomic characteristics include insurance type, educational attainment, marital status, and neighborhood poverty level