

## Non-Medical Barriers in Access to Kidney Transplantation: Perspectives from Dialysis and Transplant Center Staffs Across Four U.S. Regions

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### ABSTRACT

*Understanding regional variation in early transplant access informs tailored interventions. Two comparable surveys assessed perceived access barriers among dialysis and transplant center staff across New England, New York, U.S. Southeast, and Ohio River Valley (August 2021-October 2023). Among 630 dialysis and 34 transplant staff/centers, dialysis staff most often cited patient disinterest (48.75%), transportation challenges (44.75%), and lack of support (37.87%). Transplant staff cited lack of support (74.35%), non-adherence (52.36%), and disinterest (49.03%). Dialysis staff ranked disinterest highest in New York and Ohio River Valley, and transportation challenges highest in the Southeast and New England. Transplant staff ranked anxiety/fear about the transplant process highest in New York, and lack of support highest elsewhere. Regionally tailored strategies are needed to improve access.*

### INTRODUCTION

In the United States, more than 800,000 people live with end-stage kidney disease (ESKD), with a disproportionate burden among Black/African American people and elevated disease concentration in the Southeast, Northeast, and Ohio River Valley regions (United States Renal Data System, 2024). Limited organ availability and disparities in access render kidney transplantation an underutilized medical option for many, despite this treatment option resulting in better survival, quality of life, and less economic strain compared with dialysis, the only other options for those with ESKD (Axelrod et al., 2018; Tonelli et al., 2011; United States Renal Data System, 2024). The kidney transplantation process is complex, requiring patients to navigate multiple, intricate steps, with many patients never reaching kidney transplantation due to a number of potentially modifiable factors (Harding et al., 2021).

Decades of research have highlighted persistent racial, gender, socioeconomic, and geographic disparities in the transplant process informing recent national efforts to collect more comprehensive data to identify and address social determinants contributing to disparities in access to kidney transplantation, (Ashby et al., 2007; Centers for Medicare and Medicaid Services (CMS), 2024; Hall et al., 2011; Harding,

2024; Harding et al., 2021; Patzer et al., 2009; Patzer, Amaral, et al., 2012; Patzer, Perryman, et al., 2012; Patzer et al., 2017; Patzer et al., 2020; Waterman et al., 2010; Waterman et al., 2013;). Much of what is known about geographic differences in transplantation access focuses on waitlisting, transplantation process, and organ availability (Ashby et al., 2007; Davis et al., 2014; King et al., 2019; Zhou et al., 2018). These studies have offered only limited insight into how nonmedical barriers (e.g., low socioeconomic status (SES), gaps in patient and provider knowledge) influence whether patients start or complete evaluation and waitlisting for kidney transplants, and why they vary by region (Browne et al., 2021; Dageforde et al., 2015; Harding et al., 2021; Wilk et al., 2025). These barriers disproportionately affect historically marginalized groups, reflect broader structural barriers, and can be exacerbated by local context (Hamoda et al., 2020).

Data on the non-medical (e.g., transplant knowledge, fear, cultural factors) needs of kidney and transplant patients are not commonly collected, impeding the development of targeted interventions and policy-based solutions to improve access to transplantation. Given the crucial role of dialysis and transplant centers in patients' pursuit of and progression in the transplant process, understanding staff perspectives, alongside patient perspectives, on barriers to early transplant

access (e.g., evaluation start) is essential to efforts to address patients' needs (Kucirka et al., 2012; Kutner et al., 2012). Thus, this study fills critical knowledge gaps by examining how dialysis and transplant staff perspectives on non-medical barriers to transplant access vary across regions.

## METHOD

### Study Design and Population

We conducted a cross-sectional analysis of survey data from dialysis and transplant centers within 13 states across four end-stage renal disease (ESRD) Network (NW) regions (the New England, NW 1; New York, NW 2; U.S. Southeast, NW 6; and the Ohio River Valley, NW 9) as part of the **Reducing Disparities in Access to kidney Transplantation (RaDIANT) Expansion Study** (R01DK122701; [www.clinicaltrials.gov](http://www.clinicaltrials.gov): NCT02389387) (Early Steps to Transplant Access Registry (E-STAR), n.d.).

The Emory University (IRB00113572) and Indiana University (IRB #18998) institutional review boards approved this study, and informed consent was obtained from all participants. From January 2021 to June 2023, members of the Southeastern Kidney Transplant Coalition (comprising patients, providers, ESRD Network staff, and researchers) aided in the development of these two surveys through an iterative process guided by prior research and a multilevel framework of factors influencing access to kidney transplantation, which draws from the Social Ecological Model (Browne et al., 2021; Dageforde et al., 2015; Harding et al., 2021; McLeroy et al., 1998).

### *Dialysis Center Staff Survey*

From August 2021 to August 2022, Emory University research staff emailed a 77-item survey link (**Appendix 2**) via Survey Monkey® (SurveyMonkey, 1999–2025) to center contacts at all 2,000 dialysis centers in New England (NW 1), New York (NW 2), the Southeast (NW 6), and the Ohio River Valley (NW 9), as identified by IPRO (CMS's ESRD quality improvement contractor in these four regions). Center contacts were identified as those responsible for reminding patients of appointments and guiding them through the process (transplant lead), or, if no transplant lead was identified, surveys were sent to the facility administrator and/or social worker. Each center contact was asked to forward the survey to the staff member(s) most involved with transplant education or patient navigation at their center. All participants received a \$40 e-gift card. Because the survey was distributed to multiple staff per facility, in some instances, multiple responses per facility were collected; we restricted data to each facility's first response. Additionally, because many dialysis staff oversee multiple facilities, some completed the survey multiple times, tailoring responses to specific facilities. These facility-specific responses were retained for analysis.

### *Transplant Center Staff Survey*

During June–October 2023, Indiana University research staff emailed transplant center staff identified by IPRO at the 48 transplant centers within the four ESRD Network Regions to solicit participation in a 53-item web-based survey (Survey Monkey, 1999–2025) (**Appendix 3**). Transplant center medical directors, nephrologists, transplant coordinators, administrators, and/or social workers were instructed to forward the survey to the individual most involved with transplant education or patient navigation through pre-transplant care at their facilities.

### *Further Distribution*

The survey link was also distributed to dialysis and transplant staff at the Southeastern Kidney Transplant Coalition and Ohio River Valley Transplant Coalition quarterly meetings (Southeastern Kidney Transplant Coalition (SEKTC), 2022). Staff who completed  $\geq 50\%$  of the survey received a \$40 e-gift card. Consistent with the dialysis staff survey methods, we restricted to one response per facility.

### Survey Measures

#### Dialysis Center Survey

Dialysis center staff roles (collapsed to social worker, clinical manager/facility administrator, and "other," due to small cell sizes [fewer than 11 individuals]), sex, race (collapsed to Black or African American, White, and "other" due to small cell sizes), ethnicity (collapsed to Hispanic or non-Hispanic), and length of time in the role in years (< 1, 1–3, 4–7, 8–10, > 10) were self-reported.

#### *Dialysis Staff Perceived Barriers to Access to Transplant*

We asked staff to identify the top five (in no particular order) barriers preventing patients from being evaluated for a transplant. Informed by our previous survey instrument and evidence of medical and non-medical barriers to kidney transplantation, staff could choose from among 55 barriers to transplant referral and evaluation within seven domains: 1) patient logistical barriers; 2) patient emotional/motivational barriers; 3) health condition barriers; 4) patient knowledge barriers; 5) demographic barriers; 6) financial barriers; 7) dialysis center barriers (Browne et al., 2021; Dageforde et al., 2015; Harding et al., 2021). Since no sequential ranking was required, "top 5" reflects the most frequently chosen barriers. Dialysis staff also responded to an open-ended question: "Research shows that Black [/African American] people with ESRD [ESKD] have less access to living donor (LD) and deceased donor (DD) kidney transplant and early steps in the transplant process. In your experience, what factors do you believe play a role in this disparity?"

#### *Impact of Race on Transplant Access*

Staff rated the impact on a scale of 1 to 10, with 1 being no impact and 10 being a significant impact, for two questions: 1) “How much do you think a person’s race impacts their access to transplant in the U.S.?” and 2) “How much do you think a person’s race impacts their access to transplant at your dialysis facility?”

Relevant survey items for the dialysis center survey are presented in **Appendix 2**.

#### *Other Variables*

The ESRD Network (1 (NE), 2 (NY), 6 (SE), or 9 (ORV)) was determined, based on the state of the selected dialysis or transplant center named by the survey respondent. Dialysis center responses were linked with Dialysis Facility Report (DFR) data (2017–2020) by CMS Certification Number to obtain demographic, clinical, and transplant access characteristics from centers at the end of 2020 (Centers for Medicare and Medicaid Services (CMS), 2017–2020). Characteristics obtained from DFR included: average number of prevalent patients per center; staff-to-patient ratio; profit status (non-profit and for-profit); average age of dialysis patients; patient gender; and the percentages of patients with each of the following characteristics: White race, Black or African American race, Hispanic/Latino ethnicity; insured through Medicare only, Medicaid only, employer-provided insurance, or uninsured; with no pre-ESKD nephrology care; and not informed of transplant options.

#### Transplant Center Survey

Transplant staff roles (collapsed to transplant administrator, transplant nephrologist, transplant nurse coordinator, transplant social worker, transplant surgeon, and “other,” due to small cell sizes), sex, race (collapsed to Black or African American, White, “other,” due to small call sizes), ethnicity (collapsed to Hispanic or non-Hispanic), and length of time in the role in years (< 1, 1–3, 4–7, 8–10, > 10) were self-reported.

#### *Transplant Staff Perceived Barriers to Access to Transplant*

One survey item asked transplant center staff to identify their top five (in no particular order) perceived barriers to transplant access from a list of 30 barriers within six domains: (1) patient logistical barriers, (2) patient emotional/motivation barriers, (3) medical and psychosocial barriers, (4) patient knowledge barriers, (5) financial barriers, and (6) demographic barriers. Provided barriers were identified through relevant prior research on completed evaluations and instruments developed in our previous work (Browne et al., 2021; Harding et al., 2021). In parallel with the dialysis staff survey, the “top five” refers to the barriers that survey staff most frequently selected as part of their top five, regardless of the ranking order within their responses.

#### *Transplant Staff Awareness of Disparities in Access to Transplantation*

Two items assessed awareness of racial disparities: 1) “Nationally, do you think there are existing racial differences in rates of transplant evaluation?” and 2) “At your facility, do you think there are existing racial differences in rates of patients being evaluated for a transplant?” Staff reported their awareness by responding “Yes,” “No,” “Unsure,” or “Prefer not to answer.”

Relevant survey items for the transplant center survey are presented in **Appendix 3**.

#### **Statistical Analyses**

Descriptive analysis of closed-ended survey questions and center-level characteristics was performed overall and by the ESRD Network region (New England (NW1), New York (NW2), Southeast (NW6), Ohio River Valley (NW9)), using t-tests and chi-squared tests to assess differences across regions for continuous and categorical variables, respectively.

SAS 9.4 (SAS Institute Inc., 2024) was used for data cleaning and analyses. R version 4.3.1 (R Foundation, 2023) was used for data visualization.

Thematic analysis was used to analyze open-ended survey item responses from dialysis staff, identifying codes deductively from the study’s guiding theoretical framework and inductively through iterative identification of topics emerging from the data to produce the codebook (Guest et al., 2012; McLeroy et al., 1998). Two qualitative researchers independently coded each question, and discrepancies were reconciled via discussion to reach consensus. Coded segments were then analyzed to describe and categorize the emerging themes and subthemes fully. MAXQDA20 software was used to facilitate the management and analysis of all qualitative data (MAXQDA/VERBI GmbH, 2020). Further qualitative analysis details can be found in the **Appendix 1**.

## **RESULTS**

### **Dialysis Center Unit Staff Survey**

A total of 862 individuals completed the survey (August 2021–August 2022). Responses were excluded if informed consent was not provided ( $n = 23$ ), < 25% of the survey completed ( $n = 117$ ), missing dialysis center identifiers ( $n = 2$ ), duplicate responses (same email and center,  $n = 52$ ), or duplicate response within a single dialysis center ( $n = 38$ ; first response retained in cohort). Our final study sample included survey responses from 630 dialysis staff members representing 630 dialysis centers (center-level response rate 31.50%; **Figure 1**).

Of respondents, 10.32% were from New England (NW 1), 18.25% from New York (NW 2), 40.95% from the Southeast (NW 6), and 30.48% from the Ohio River Valley (NW 9). The vast majority were social workers (80.16%) or clinic managers/facility administrators (14.60%), with 27.30% in their role > 10 years (27.46% 1–3 years; 26.51% 4–7 years, and 7.30% for 8–10 years). Dialysis staff were 68.41% White, 20.32% Black or African American, and 4.76% Hispanic/Latino; 90.95% were women. Staff characteristics varied by region (Table 1). For example, the Southeast (NW 6) had a greater proportion of staff who were Black or African American (36.05%) relative to the other regions, while about half were White (53.88%). In contrast, staff in New England (NW 1) (83.08%) and the Ohio River Valley (NW 9) (85.42%) were largely White. Among the 630 dialysis centers represented, 83.81% were for-profit, and the median number of patients per center was 65.00 (IQR: 46.00–86.00) with a mean patient age of 63.93 (standard deviation (SD): 4.61) years. Center characteristics, such as the staff-to-patient ratio, mean age of patients, the percentages of patients by sex, race, ethnicity, insurance type, and access to pre-ESRD nephrology care varied by region (Table 1).

#### *Impact of Race on Access to Transplant*

The overall mean rating for the perceived impact of race on access to transplant overall in the U.S. and at their own dialysis centers was 4.97 (SD: 2.94) and 2.94 (SD: 2.70), respectively, on a scale from 1 (no impact) to 10 (significant impact). Stratifying by region, dialysis staff perceptions of the impact of race *nationally* were the highest and lowest in the Southeast (mean: 5.30; SD: 2.97) and Ohio River Valley (mean: 4.45; SD: 2.84), respectively. The mean ranking was 5.08 (2.82) in New England and 5.03 (3.05) in New York. Staff ratings of the impact of race *at their center* were consistently lower than national ratings across all regions (Figure 2). Mean rankings within their home center were 2.80 (2.62), 2.79 (2.56), 3.39 (2.94), 2.45 (2.37) in New England (NW 1), New York (NW 2), the Southeast (NW 6), and the Ohio River Valley (NW 9), respectively.

#### *Dialysis Center Staff Perceived Barriers to Access to Evaluation for Kidney Transplant by ESRD Network*

Patient disinterest in kidney transplantation (48.75%), transportation challenges (44.75%), lack of support from family and/or friends to assist with medications and appointments (37.87%), body-mass index (BMI) > 30 (26.91%), and the distance to the transplant center (24.77%) were the top barriers to referral and evaluation identified by dialysis center staff overall. Patient disinterest was the leading barrier in New York (NW 2) and the Ohio River Valley (NW 9) (47.46% and 50.28%, respectively), while transportation challenges were the top barrier in New England (NW 1) and the Southeast (NW 6) (38.72% and 53.21%, respectively). Unique to New

York, staff cited anxiety about the surgical procedure and patients losing interest after the initial evaluation appointment as two top barriers. BMI > 30 was a commonly identified top barrier in New England, the Southeast, and the Ohio River Valley (but not New York), while age was identified as a top barrier only in New England (Figure 3).

#### *Contributors to Racial Disparities in Access*

A total of 616 dialysis staff (97.78%) provided an open-ended response to the subject of contributors to racial disparities in access to kidney transplantation. Qualitative analysis identified four key themes: 1) Systemic racism, bias, and stigma hinder access to living donor (LD) and deceased donor (DD) kidney transplantation for Black/African American patients; 2) Disparate education practices contribute to deficits in knowledge and understanding of the kidney transplant process among Black/African American patients; 3) Adverse social determinants of health (SDoH) exacerbate disparities in access to kidney transplantation for Black/African American patients; and 4) Cultural factors and mistrust of the healthcare system within the Black/African American community affect decision-making and willingness to pursue kidney transplantation. A subtheme emerged within the second theme: Limited educational opportunities and encouragement to pursue living donation within the Black/African American community contribute to lower rates of awareness and engagement with living donation, exacerbating disparities in access to this transplant option (Table 2).

When asked about factors that contribute to these disparities in access based on their experiences as dialysis providers, one staff member stated, “...*distrust in medical system... unconscious bias and racism in hospitals...*” Further, dialysis providers commented that discriminatory practices and providers who have biased attitudes based on the patient’s perceived race exist within dialysis centers and play a major role in continuing disparities in access for Black/African American patients moving through the transplant process. One respondent stated “...[Black/African American patients] *are less likely to be encouraged to have a living donor or educated on why this would be a benefit,*” and often these patients “...*receive less information and resources on the kidney transplant process and are assumed to not understand.*”

Providers often cited the importance of education and cited that disparate education among Black/African American patients contributes to limited knowledge and understanding of transplantation as a treatment option, with one respondent stating disparities are due to “*lack of education access*” and the need for “*simple-language explanations*” to improve patient understanding and education.

Dialysis staff most often cited adverse social determinants of health (SDoH), such as limited access to preventative healthcare/health maintenance, transportation, financial insecurity, insurance status, lack of access to social support and resources, education, and health literacy, as leading barriers to transplant access and exacerbating other barriers. To illustrate, some staff identified disinterest in transplantation among Black/African American patients as an explanation for disparities in access; however, others asserted that an apparent lack of interest may be explained by these adverse social determinants of health (SDoH) commonly observed among “historically marginalized” populations.

Dialysis staff recognized the impact of culture and medical mistrust within the Black/African American community on decisions to pursue transplantation. Many acknowledged the historical mistreatment of Black/African American patients in the healthcare system and the impact that this has had on patient and social support attitudes and health status, breeding reluctance to pursue transplant and access to a living donor. One respondent suggested that Black/African American patients are “...fearful of going to see doctors and not being provided with appropriate education.” Another mentioned that this medical mistrust has hindered living donation because “...not many family members are willing to donate and [there are] skepticisms about transplants.”

### Transplant Center Staff Survey

Of the 111 eligible responses, we excluded responses if they did not give informed consent ( $n = 22$ ) or were < 25% complete ( $n = 16$ ), missing transplant center name ( $n = 4$ ), or duplicate responses within a transplant center ( $n = 35$ ; first response retained in cohort). Our final study sample includes responses from 34 transplant center staff representing 34 transplant centers (center-level response rate 70.83%; **Figure 1**).

Of respondents, 10 were from New England (NW 1), seven from New York (NW 2), 10 from the Southeast (NW 6), and seven from the Ohio River Valley (NW 9). The majority were transplant administrators (35.29%) or transplant nurse coordinators (26.47%) and had been in their roles for > 10 years (35.29%). Transplant staff were 82.35% White, 5.88% Black or African American, and 85.29% were women. Transplant staff characteristics were similar across regions. (**Table 1**).

#### *Transplant Staff Perceived Barriers to Completion of Evaluation for Kidney Transplant by ESRD Network*

Across all four regions, top perceived barriers to completing the kidney transplant evaluation process were lack of social support (74.35%), treatment non-adherence (52.36%), patient disinterest (49.03%), transportation challenges (41.71%), and low health literacy (40.48%). Stratified by

region, lack of social support was the top barrier in New England (NW1), the Southeast (NW6), and the Ohio River Valley (NW9), while anxiety or fear surrounding the transplant process was the top barrier in New York (NW2). Other factors identified as major barriers were relatively similar across regions, with a few regionally unique barriers. For example, lack of patient understanding of the benefits of transplant (39.29%) was selected as one of the top five barriers in New York only. In the New England (NW 1), New York (NW 2) and Ohio River Valley (NW 9), patient disinterest was identified as a top barrier, but this was not true in the Southeast (NW 6). Inability to afford the co-pay was a barrier most often included for staff in the Ohio River Valley (NW 9) only (30.96%), and distance to the transplant center (33.33%) appeared only in the Southeast. (**Figure 4**).

#### *Transplant Staff Awareness of Disparities in Access to Transplantation*

Almost two-thirds (63.64%) of transplant center staff ( $N = 33$ ) indicated that there are racial differences in rates of transplant evaluation nationally, with agreement among 66.67% of staff in New England (NW 1), 57.14% in New York (NW 2), 70.00% in the Southeast (NW 6), and 57.14% in the Ohio River Valley (NW 9). However, a much smaller portion believed racial differences exist at their center (18.18%) or were unsure (24.24%), with relatively similar proportions across regions (**Table 3**).

## DISCUSSION

In this study, we observed regional variation in transplant and dialysis center staff perceived barriers to referral and evaluation for kidney transplantation. Across both clinical settings, most staff consistently perceived race to have minimal or no impact within their own centers, but were aware it was a national problem. Transplant staff emphasized deficits in social support and treatment non-adherence as key barriers, while dialysis staff most often cited patient disinterest and transportation challenges. Among transplant staff in the Ohio River Valley (NW9) only, patients' inability to afford co-pays emerged as a top barrier. Dialysis staff in New England (NW 1) identified age as a top barrier, though it was not a leading barrier in other regions. These findings underscore the complexity of improving transplant access across multiple clinical systems, suggesting that, at least from staff's perspectives, there is likely not a one-size-fits-all solution and that regionally tailored interventions are needed to promote improved transplant access nationwide.

Our findings of moderate awareness of the impact of race on access among dialysis providers—and even lower awareness of the impact of race within their own centers across all four regions—are consistent with prior studies (Britton et al., 2016; Goodman et al., 2023; Kim et al., 2018). Kim et al.

(2018) reported that < 20% of dialysis providers were aware of racial disparities in waitlisting, and among centers with documented disparities, only 5% of providers were aware of these disparities. We additionally explored awareness of racial differences among transplant center staff, particularly regarding access to evaluation. We report high (63.64%) awareness of racial differences in access to evaluation nationwide, but less than one-fifth (18.18%) of all respondents believed such disparities existed within their own facilities (Table 3; Figure 2). This finding aligns with broader trends of under-recognition of in-center disparities observed in prior studies in other specialties, such as cardiology, cardiovascular surgery, and general surgery (Britton et al., 2016; Lurie et al., 2005; Taylor et al., 2006). Limited acknowledgment of local racial disparities in access among both dialysis and transplant staff broadly reflects a lack of provider recognition of their clinics', centers', and communities' roles in contributing to modifiable barriers and disparities in access nationally and may help explain their persistence (Schold et al., 2021).

Regional differences in provider awareness of racial disparities were observed. A greater proportion of transplant staff in the Southeast (NW 6; 50.00%) were unsure of the presence of within-center disparities, while perceptions of the absence of disparities ranged widely across regions, from 30.00% in the Southeast to 71.43% in the Ohio River Valley (NW 9). Our findings suggest that, despite decades of research and targeted interventions—such as the Reducing Disparities in Access to Kidney Transplant (RaDIANT) Community and Regional studies—in the Southeast aimed at addressing racial disparities by increasing transparency in center-level pre-waitlisting performance, gaps in knowledge remain (Early Steps to Transplant Access Registry (E-STAR), n.d., Patzer et al., 2015; Patzer et al., 2017; Patzer et al., 2020). These findings suggest that continued provider education is needed across all regions, particularly around implicit bias and personally mediated racism, both of which have been shown to influence access to starting the transplant evaluation (Clark-Cutaia et al., 2024; Hamoda et al., 2020).

Consistent with prior studies, we highlight differences between dialysis and transplant center staff-perceived barriers to access, likely reflecting differences in their roles along the care continuum and the siloed transplant process (Browne et al., 2021; Harding et al., 2021). While some barriers were consistently identified across regions, others varied in frequency of selection, reflecting regional variation in the perceived magnitude of these barriers. Transportation challenges were a common barrier across all regions and for both dialysis centers (responsible more for transplant referral) and transplant centers (responsible for medical evaluation for transplant), consistent with prior studies (Browne et al., 2021; Dageforde et al., 2015). However, transportation barriers appear to affect patients in regions other than

New York more acutely, where access to public transportation within New York City and surrounding counties likely mitigates these challenges (Probst et al., 2007). Increases in dialysis and transplant staff perception of the impact of transportation access and the transplant center distance in the Southeast (NW 6), Ohio River Valley (NW 9), and New England (NW 2) likely reflect the longer distances patients must travel to reach transplant centers in these states (Kasiske et al., 2008). Reasons for the emergence of anxiety and fear as a barrier to access by transplant staff in New York (NW 2) and the Southeast (NW 6) only are not clear; however, they may be explained by differences in patient experiences of medical mistrust, racism, and discrimination—previously linked to lower access to evaluation start—along with other difficult-to-measure influences on access. We may also infer that other unmeasured factors, such as center-level practices around education and communication, could contribute to the observed regional variations (Hamoda et al., 2020; Harding et al., 2021).

Our findings underscore the need for further research to understand regional differences in patient-level barriers to access and how they shape disparities in access to early steps in the transplant care continuum (Early Steps to Transplant Access Registry (E-STAR), 2024). The collection of referral and social risk factor data within the CMS-2728 form, initiated in October 2024 (Centers for Medicare and Medicaid Services (CMS), 2024) and Health Resources and Services Administration's forthcoming national collection of pre-waitlisting-focused data (Organ Procurement and Transplantation Network (OPTN), 2024) signal an opportunity for improved understanding of variation in access and quality improvement efforts within dialysis and transplant centers to help patients receive transplants. There is also a critical need for standardized collection of psychosocial information from patients, a key persistent gap in current and forthcoming data infrastructure (Wilk et al., 2025). By combining these data with insights into region-specific patient-level barriers, healthcare providers, policymakers, and researchers can develop targeted interventions within dialysis and transplant centers to support patients on their path to kidney transplantation.

This study has several limitations. First, while the surveys distributed to dialysis and transplant staff were not identical (by design), both assessed barriers to early transplant steps, and our analysis harmonized the interpretation of disparate survey items. Second, findings may be subject to response bias, as staff were representing their center of employment. Despite assurances of confidentiality and regional aggregation of responses, some may have been hesitant to acknowledge disparities at their centers. Third, while center-level response rates were moderate (31.50% for dialysis and 70.83% for transplant centers), we did not have 100% participation

from all centers across the four regions, and non-responding centers may differ from those represented. Additionally, only three (8.82%) transplant social workers were captured in these results, despite their critical role in patient progression through the transplant process. Moreover, this study was limited to four US regions, limiting generalizability. However, our findings align with barriers to early transplant access identified in prior studies (Harding et al., 2021; Park et al., 2022). Lastly, the dialysis survey was distributed during the COVID-19 pandemic, and it is possible that dialysis staff reporting of patient-level barriers was influenced by the disruption in referral and evaluation care patterns (Perez et al., 2022). However, it is unlikely that this had a major impact on the results, as the dialysis center survey was distributed late in the COVID pandemic (August 2021 to August 2022), when most centers had already implemented changes to address pandemic-related barriers.

This study identified regional variation in staff-perceived barriers and awareness of racial disparities in access to key steps in the kidney transplant process across two key clinical settings: the dialysis facility and the transplant center. These findings may inform the design of targeted interventions, support the training and capacity-building of healthcare staff to properly address psychosocial barriers to access, and contribute to the development and implementation of new federal initiatives focused on improving transplant access. Dialysis and transplant center staff play instrumental roles in patients' transplant outcomes; therefore, their perspectives should be leveraged in ongoing efforts to improve access.

### DISCLOSURES

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Directors (BOD) of ESKD Network 6 and BOD of the National Forum of Networks, and is on the Advisory Board for the non-profit Kidney Transplant Collaborative. Stephen O. Pastan's wife owns Johnson & Johnson stock.

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### DATA SHARING STATEMENT

The survey data supporting the findings of this study are not publicly available due to privacy concerns. Dialysis Facility Report (DFR) data used in this study is openly available for public use at <https://data.cms.gov/quality-of-care/medicare-dialysis-facilities>.

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## APPENDICES

### eAppendix 1. Qualitative Analysis Methods

Thematic analysis was used, identifying codes deductively from the study's guiding theoretical framework and inductively through iterative identification of topics emerging from the data to produce the codebook. (Guest et al., 2012; McLeroy et al., 1998) The two analysts performed first-cycle coding of the open-ended survey questions, individually examining the survey questions and coding the content for patterns. To ensure the reliability of the codebook, the coders met to discuss and refine the codebook after its initial creation and the coding of the first 25 responses to each open-ended question. Once intercoder agreement was ascertained (>0.80), each coder independently coded the open-ended responses. After individual coding, the coders convened and discrepancies in code application were resolved via discussion to reach a consensus on the coding of each response. Provider non-responses (blanks) were not included in the analyses. Major categories of responses were identified, and coded segments were aggregated to create relevant themes in the responses. After this initial analysis, the authors reviewed, discussed, and synthesized the findings to create a list of the final themes and subthemes, based on group consensus. MAXQDA20 software (MAXQDA/VERBI GmbH) was used to facilitate the management and analysis of all qualitative data. (MAXQDA 2020)

### eAppendix 2. Dialysis Center Survey Instrument; Select Items Relevant to the Present Study

Q2. What state is your facility in?

Q3–15. What are your dialysis facility name and facility number (CCN)?

#### Q17. What is your role at the facility?

- Medical director
- Clinic manager/facility administrator
- Nurse
- Social worker
- Dietitian
- Other (Please specify.): \_\_\_\_\_

#### Q18. Approximately how many years have you worked in this position?

- < 1 year
- 1–3 years
- 4–7 years
- 8–10 years
- > 10 years

#### Q19. What is your race? (Select all that apply.)

- White
- Black or African American
- American Indian or Alaskan Native
- Asian
- Native Hawaiian or other Pacific Islander
- Hispanic
- Prefer not to answer.
- Other (Please specify.): \_\_\_\_\_

#### Q20. What is your ethnicity? (Select all that apply.)

- Hispanic
- Non-Hispanic
- Prefer not to answer.

**Q21. What is your sex?**

- Female
- Male
- Other
- Prefer not to answer.

Q50. On a scale of 1 to 10, how much do you think a person's race impacts their access to transplant[-ation] in the U.S.? [Scale: 1 = No impact, 10 = Significant impact] [Dropdown menu]

Q51. On a scale of 1 to 10, how much do you think a person's race impacts their access to transplant[-ation] at your dialysis facility? [Scale: 1 = No impact, 10 = Significant impact] [Dropdown menu]

Q52. Research shows that Black[/African American] people with ESRD [ESKD] have less access to living donor (LD) and deceased donor (DD) kidney transplant and early steps in the transplant process. In your experience, what factors do you believe play a role in this disparity? [Open-ended text response]

*Barriers to Kidney Transplantation*

**Please mark each item below according to the scale to indicate the level in which you agree that the following are barriers to referral and evaluation for kidney transplantation for patients at your facility:**

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither agree nor disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
[Domain #1] Q60. Patient Logistical Barriers					
Lack of transportation to the transplant center					
Distance to the transplant center					
Lack of time off work/school for transplant evaluation appointment					
Lack of childcare or elder care during transplant evaluation appointment					
Lack of communication between patient and staff at transplant center regarding appointment					
Timing of appointment (e.g., conflicts with work or dialysis schedule)					
[Domain #2] Q61. Patient Emotional/Motivation Barriers					
Patients feel uncomfortable or unwelcome at transplant center					
Patients not interested in kidney transplantation					
Anxiety about the transplant evaluation					
Anxiety about the transplant surgical procedure					
Fear of receiving bad news at the evaluation					
Worried about not "passing" medical tests at the evaluation					
Fear that no one will serve as a donor					
Fear that family member or friend serving as a living donor will have an adverse experience					
Lost interest in continuing the evaluation process after initial appointment					
Evaluation doesn't seem urgent as patient "does not mind dialysis"					
Lack of support from family and/or friends to assist patient with medications and appointments					
Religious or other beliefs about donated organs					
Patient's fear of losing friends made/socializing at dialysis center					
Medical or physician mistrust					
[Domain #3] Q62. Health Condition Barriers					
Diabetes					
Hypertension					
Anemia					
Cardiovascular Disease					
Decreased functional status/needs assistance with daily activities					

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Neither agree nor disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
Cancer					
HIV/AIDS					
BMI > 30					
Untreated mental health issues					
Active substance use issues					
<b>[Domain #4] Q63. Patient Knowledge Barriers</b>					
Patients believe that starting dialysis or being referred means that they are already waitlisted					
Lack of understanding about the purpose of the evaluation					
Lack of understanding about the transplant process itself					
Lack of understanding about the transplant center's scheduling system (e.g., impact of not showing up to the appointment)					
Lack of understanding about the benefits of transplant					
Low literacy					
Low health literacy					
<b>[Domain #5] Q64. Demographic Barriers</b>					
Socioeconomic status					
Age					
Race					
Language					
Undocumented immigrant					
<b>[Domain #6] Q65. Financial Barriers</b>					
Type of insurance					
Cannot afford co-pay					
Cannot afford medications post- transplant					
Patient-perceived fundraising requirements					
Lack of motivation to fundraise					
Misuse of fundraised money for kidney transplant					
Patients believe that starting dialysis or being referred means that they are already waitlisted					
<b>[Domain #7] Q66. Dialysis Facility Barriers</b>					
Insufficient staffing resources (e.g., time, staff)					
Insufficient training for staff on transplantation					
Insufficient patient educational resources					
Transplant center requirements or process not clear					
Unsure who is eligible for kidney transplantation					
Insufficient social support for patients					
Facility staff and/or leadership don't believe transplant is best option for most patients.					

Among the barriers you agreed are patient barriers to transplant in the previous questions, what do you believe to be the top 5 (in no particular order) preventing patients from being evaluated for a transplant?

Q67. Barrier #1 \_\_\_\_\_

Q68. Barrier #2 \_\_\_\_\_

Q69. Barrier #3 \_\_\_\_\_

Q70. Barrier #4 \_\_\_\_\_

Q71. Barrier #5 \_\_\_\_\_

**[Open-ended question:]** Research shows that Black [/African American] people with ESRD [ESKD] have less access to living donor (LD) and deceased donor (DD) kidney transplant and early steps in the transplant process. In your experience, what factors do you believe play a role in this disparity?

**eAppendix 3. Transplant Center Staff Survey Instrument; Select Items Relevant to the Present Study**

Q2. Please select the name of your transplant center affiliation. (Select one.) [Dropdown menu]

Q3. Please select your job title at the transplant center. (Select one)

- Administrative assistant/receptionist
- Clinical nurse (Not transplant coordinator)
- Nurse practitioner
- Outreach coordinator
- Physician assistant
- Transplant administrator
- Transplant financial coordinator
- Transplant nephrologist
- Transplant nurse coordinator
- Transplant social worker
- Transplant surgeon
- Other (Please specify.): \_\_\_\_\_

Q4. Approximately how many years have you worked in your role? (Select one.)

- < 1 year
- 1–3 years
- 4–7 years
- 8–10 years
- > 10 years

Q5. What is your race? Please select all that apply.

- American Indian or Alaskan Native
- Asian
- Black or African American
- Native Hawaiian or other Pacific Islander
- White
- Other (Please specify.) \_\_\_\_\_
- Prefer not to answer.

Q6. What is your ethnicity? (Select one)

- Hispanic  
 Non-Hispanic  
 Prefer not to answer.

Q7. What is your sex? (Select one.)

- Female  
 Male  
 Other  
 Prefer not to answer.

*Barriers to Kidney Transplantation*

**Please mark each barrier below according to the scale to indicate the level to which the following are barriers to completion of kidney transplant evaluation for patients at your center:**

Transplant Evaluation Barriers

	Yes, for all patients	Yes, for most patients	Yes, for a few patients	No	Unknown
[Domain #1] Q37. Patient Logistical Barriers					
Lack of transportation to the transplant center					
Distance to the transplant center					
Lack of communication between patient and staff at transplant center regarding appointment (e.g., confusion of appointment time/date)					
Timing of appointment (e.g., dialysis schedule, lack of time off)					
Bad weather					
Patient health on day of the appointment (e.g., patient is sick during appointment time/date)					
Hospitalization prior to their appointment					
Mortality prior to their appointment					
[Domain #2] Q38. Patient Emotional/Motivation Barriers					
Anxiety or fear surrounding the transplantation process (e.g., transplant evaluation, surgical procedure, access to donor)					
Lack of patient interest					
Religious or other beliefs about donated organs					
Medical or physician mistrust					
[Domain #3] Q39. Medical and Psychosocial Barriers					
Lack of social support					
Timing of appointment with caregiver's schedule (e.g., center requests caregiver to be present at evaluation appointment)					
Untreated mental health issues					
Active substance use					

	Yes, for all patients	Yes, for most patients	Yes, for a few patients	No	Unknown
Treatment non-adherence					
[Domain #4] Q40. Patient Knowledge Barriers					
Lack of understanding about the purpose of the evaluation					
Lack of understanding about the transplant process itself					
Lack of understanding about the benefits of transplant					
Low health literacy					
[Domain #5] Q41. Financial Barriers					
Lack of health insurance					
Cannot afford co-pay					
Cannot afford medications post-transplant					
Patient understanding of fundraising requirements					
Q42. Demographic Barriers					
Age					
Race					
Gender					
Primary language					
Undocumented immigrant					

Q43. Among the barriers you agreed are patient barriers to transplant in the previous questions, what do you believe to be **the top 5** preventing patients from being evaluated for a transplant at your center? Please rank below as follows: (1 = Top Barrier, 2 = Second Barrier, 3 = Third Barrier, 4 = Fourth Barrier, 5 = Fifth Barrier).

Barrier #1 \_\_\_\_\_

Barrier #2 \_\_\_\_\_

Barrier #3 \_\_\_\_\_

Barrier #4 \_\_\_\_\_

Barrier #5 \_\_\_\_\_

*Awareness of Disparities in Access to Transplantation*

Q44. Nationally, do you think there are existing racial differences in rates of transplant evaluation? (Select one.)

- Yes  
 No  
 Unsure  
 Prefer not to answer.

Q45. At your facility, do you think there are existing racial differences in rates of patients being evaluated for a transplant? (select one)

- Yes  
 No  
 Unsure  
 Prefer not to answer.

### **AUTHORS' NOTES**

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### **AUTHOR CONTRIBUTIONS**

*Research idea and study design: Jade Buford, Adam S. Wilk, Jessica L. Harding, Stephen O. Pastan, Rachel E. Patzer; data acquisition: Jade Buford and Emma Blythe; statistical analysis: Jade Buford and Mengyu Di; data interpretation: Jade Buford, Adam S. Wilk, Jessica L. Harding, Mengyu Di, Megan Urbanski, Emma Blythe, Stephen O. Pastan, Rachel E. Patzer; supervision: Adam S. Wilk and Rachel E. Patzer; funding acquisition: Rachel E. Patzer. Each author contributed important intellectual input during manuscript drafting or revision. All authors approved the final version of this manuscript.*

## TABLES

**Table 1.** Characteristics of ESRD New England (NW 1), New York (NW 2), Southeast (NW 6), & Ohio River Valley (NW 9) dialysis and transplant centers that completed the survey (N = 630 dialysis staff representing 630 dialysis centers, center-level response rate: 31.50%; N = 34 transplant center staff representing 34 transplant centers, center-level response rate: 70.83%), 2021–2023<sup>a,b,f</sup>

<b>Dialysis Facility Staff Survey</b>					
	<b>Total (N = 630)</b>	<b>NW 1 (n = 65; 10.32%)</b>	<b>NW 2 (n = 115; 18.25%)</b>	<b>NW 6 (n = 258; 40.95%)</b>	<b>NW 9 (n = 192; 30.48%)</b>
<b>Dialysis Staff Characteristics</b>					
Sex, n (%) <sup>b</sup>					
Male	38 (6.03%)	6 (9.23%)	12 (10.43%)	10 (3.88%)	10 (5.21%)
Female	573 (90.95%)	58 (89.23%)	102 (88.70%)	235 (91.09%)	178 (92.71%)
Race, n (%) <sup>c</sup>					
White	431 (68.41%)	54 (83.08%)	74 (64.35%)	139 (53.88%)	164 (85.42%)
Black or African American	128 (20.32%)	2 (3.08%)	18 (15.65%)	93 (36.05%)	15 (7.81%)
Other	23 (3.65%)	3 (4.62%)	10 (8.70%)	8 (3.10%)	2 (1.04%)
Ethnicity, n (%) <sup>d</sup>					
Hispanic	30 (4.76%)	5 (7.69%)	10 (8.70%)	8 (3.10%)	7 (3.65%)
Non-Hispanic	571 (90.63%)	58 (89.23%)	101 (87.83%)	231 (89.53%)	181 (94.27%)
Role at facility, n (%) <sup>e</sup>					
Clinic manager/facility administrator	92 (14.60%)	8 (12.31%)	18 (15.65%)	34 (13.18%)	32 (16.67%)
Social worker	505 (80.16%)	46 (70.77%)	88 (76.52%)	218 (84.50%)	153 (79.69%)
Other	33 (5.24%)	11 (16.92%)	9 (7.83%)	6 (2.33%)	7 (3.65%)
Length of time in role (years), n (%)					
< 1	72 (11.43%)	11 (16.92%)	13 (11.30%)	22 (8.53%)	26 (13.54%)
1–3	173 (27.46%)	20 (30.77%)	35 (30.43%)	79 (30.62%)	39 (20.31%)
4–7	167 (26.51%)	16 (24.62%)	36 (31.30%)	59 (22.87%)	56 (29.17%)
8–10	46 (7.30%)	2 (3.08%)	9 (7.83%)	22 (8.53%)	13 (6.77%)
> 10	172 (27.30%)	16 (24.62%)	22 (19.13%)	76 (29.46%)	58 (30.21%)
<b>Facility-Level Characteristics<sup>f</sup></b>					
Prevalent patients within facility, median (IQR)	65.00 (46.00–86.00)	66.00 (44.00–80.00)	81.00 (62.00–118.00)	65.00 (47.00–83.00)	53.00 (39.00–75.00)
Staff: 100 patients ratio, mean (SD) <sup>g</sup>	23.75 (10.11)	26.72 (12.79)	25.75 (12.09)	21.59 (5.73)	24.47 (11.76)
Patient age in years, mean (SD)	63.93 (4.61)	65.80 (4.31)	64.92 (4.34)	62.34 (4.30)	64.45 (4.78)
% Female sex, mean (SD)	42.64 (12.63)	38.76 (12.4)	39.97 (12.13)	44.81 (12.66)	43.52 (12.59)
Patient race/ethnicity, mean (SD)					
% Black or African American	37.23 (27.06)	14.30 (19.97)	29.95 (24.01)	55.49 (22.41)	28.28 (23.65)
% White	58.29 (27.74)	80.94 (20.63)	59.81 (27.50)	41.67 (22.29)	70.22 (24.31)
% Hispanic/Latino	7.15 (11.21)	9.34 (9.99)	14.60 (16.11)	3.65 (5.27)	4.40 (8.58)
Profit Status <sup>h</sup>					
For-profit	528 (83.81%)	51 (78.46%)	76 (66.09%)	231 (89.53%)	170 (88.54%)
Non-profit	87 (13.81%)	11 (16.92%)	35 (30.43%)	21 (8.14%)	20 (10.42%)
% patients with insurance type, mean (SD)					
Medicare only	34.76 (17.81)	26.22 (16.11)	25.93 (16.16)	38.44 (16.30)	40.67 (17.74)
Medicaid only	14.45 (12.21)	11.12 (9.04)	20.44 (13.85)	9.62 (8.07)	16.50 (13.29)
Employer-provided insurance	12.47 (10.24)	14.22 (11.67)	11.53 (9.67)	13.97 (10.49)	10.79 (9.67)
Uninsured	3.58 (6.93)	0.6 (2.26)	0.3 (1.24)	7.8 (7.94)	2.09 (6.83)
% patients with no pre-ESKD nephrology care, mean (SD)					
	14.73 (16.76)	11.03 (10.08)	17.71 (17.84)	16.05 (18.78)	11.75 (14.27)
% patients not informed of transplant options, mean (SD)					
	3.11 (4.69)	5.23 (5.78)	2.88 (5.27)	2.77 (4.28)	3.00 (4.12)
<b>Transplant Center Staff Survey<sup>a</sup></b>					
	<b>Total (N = 34)</b>	<b>NW 1 (n = 10; 29.41%)</b>	<b>NW 2 (n = 7; 20.59%)</b>	<b>NW 6 (n = 10; 29.41%)</b>	<b>NW 9 (n = 7; 20.59%)</b>

**Transplant Staff Characteristics**

Sex, <i>n</i> (%)					
Male	5 (14.71%)	2 (20.00%)	2 (28.57%)	1 (10.00%)	0 (0.00%)
Female	29 (85.29%)	8 (80.00%)	5 (71.43%)	9 (90.00%)	7 (100.00%)
Race, <i>n</i> (%) <sup>i</sup>					
White	28 (82.35%)	8 (80.00%)	5 (71.43%)	9 (90.00%)	6 (85.71%)
Black or African American	2 (5.88%)	0 (0.00%)	1 (14.29%)	1 (10.00%)	0 (0.00%)
Other	4 (11.76%)	2 (20.00%)	1 (14.29%)	0 (0.00%)	1 (14.29%)
Ethnicity, <i>n</i> (%)					
Non-Hispanic	34 (100.00%)	10 (100.00%)	7 (100.00%)	10 (100.00%)	7 (100.00%)
Role at facility, <i>n</i> (%) <sup>j, k</sup>					
Transplant administrator	12 (35.29%)	4 (40.00%)	4 (57.14%)	3 (30.00%)	1 (14.29%)
Transplant nephrologist	4 (11.76%)	2 (20.00%)	0 (0.00%)	2 (20.00%)	0 (0.00%)
Transplant nurse coordinator	9 (26.47%)	2 (20.00%)	2 (28.57%)	2 (20.00%)	3 (42.86%)
Transplant social worker	3 (8.82%)	0 (0.00%)	0 (0.00%)	3 (30.00%)	0 (0.00%)
Transplant surgeon	2 (5.88%)	1 (10.00%)	0 (0.00%)	0 (0.00%)	1 (14.29%)
Other	2 (5.88%)	1 (10.00%)	0 (0.00%)	0 (0.00%)	1 (14.29%)
Length of time in role (years), <i>n</i> (%)					
< 1	1 (2.94%)	1 (10.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)
1–3	9 (26.47%)	3 (30.00%)	0 (0.00%)	5 (50.00%)	1 (14.29%)
4–7	9 (26.47%)	2 (20.00%)	3 (42.86%)	1 (10.00%)	3 (42.86%)
8–10	3 (8.82%)	1 (10.00%)	1 (14.29%)	0 (0.00%)	1 (14.29%)
> 10	12 (35.29%)	3 (30.00%)	3 (42.86%)	4 (40.00%)	2 (28.57%)

Abbreviations: CI, confidence interval; ESKD, end-stage kidney disease; IQR, interquartile range; *N* = total number; *n* = subset; *SD* = standard deviation.

<sup>a</sup>Data shown as No. # (%), unless indicated otherwise.

<sup>b</sup>Sex information missing for 19 (3.02%) dialysis staff respondents

<sup>c</sup>Race information missing for 48 (7.62%) dialysis staff respondents. Other: staff who identified as “American Indian or Alaskan Native,” “Asian,” “Native Hawaiian or Other Pacific Islander,” or “multi-racial” (staff who identified as multiple races).

<sup>d</sup>Ethnicity information missing for 29 (4.6%) dialysis staff respondents.

<sup>e</sup>Due to small cell sizes, participants who reported their roles as “medical director,” “nurse,” or “dietitian” were included in an “other” category for these measures.

<sup>f</sup>Calculated using *Dialysis Facility Report (DFR)* data for 2020, unless noted otherwise. Facility characteristics missing for some staff.

<sup>g</sup>Calculated as the sum of the number of full-time staff positions divided by the total number of prevalent patients per facility.

<sup>h</sup>Dialysis facility profit status missing for 15 (2.38%) facilities.

<sup>i</sup>Other: staff who identified as “American Indian or Alaskan Native,” “Asian,” “Native Hawaiian or Other Pacific Islander,” or “multi-racial” (staff who identified as multiple races).

<sup>j</sup>Due to small cell sizes, participants who identified their role as “administrative assistant/receptionist,” “clinical nurse” (not transplant coordinator), “nurse practitioner,” “outreach coordinator,” “physician assistant,” or “transplant financial coordinator” were included in an “other” category.

<sup>k</sup>Two (5.88%) of transplant center staff were missing information about their roles.

**Table 2.** Identified themes in dialysis staff responses regarding reasons for racial disparities in referral, evaluation, and receipt of a transplant (living donor (LD) and deceased donor (DD)) (total responses  $N=616$ )

Themes and sub-themes	Description	Illustrative quotations
1.) Systemic racism, bias, and stigma hinder access to living and deceased donor kidney transplantation for Black/African American patients.	Dialysis staff recognize the large impact that systematic racism, bias, and stigma from providers have on Black/African American patients accessing kidney transplants. Staffs acknowledge the role that discriminatory practices and biased attitudes within dialysis facilities have in perpetuating Black/African American versus White disparities in the transplantation process.	<p>“Distrust in medical system. Unconscious bias and racism in hospitals. More co-morbidities”</p> <p>“AA [Black/African American pts] are less likely to be encouraged to have a living donor or educated on why this would be a benefit. AA[s] receive less information and resources on the kidney transplant process and are assumed to not understand.”</p>
2.) Disparate education practices contribute to deficits in knowledge and understanding of the kidney transplant process among Black/African American patients.	Dialysis staff acknowledge that there are disparate educational practices among Black/African American patients, resulting in limited knowledge and understanding of the kidney transplantation process. Additionally, some providers may mistakenly interpret this lack of information among Black/African American patients as disinterest in their own healthcare. This misunderstanding can lead to unintentional biases, affect the quality of care provided, and hinder communication between staff and patients.	<p>“...lack of education access, lack of motivation to follow up due to fear, simple-language explanations.”</p> <p>“Doctors [are] not delivering early diagnoses and education. Transplant centers could give out more detailed information as well on the process...Lack of proper education and early diagnoses when a person has HTN [hypertension] or diabetes, which are leading causes of ESRD.”</p> <p>“Not sure but my Black patients are not interested in transplant; so, more education? More outreach?”</p>
2A.) (subtheme) Limited educational; opportunities and encouragement to pursue living donation for the Black/African American community contribute to lower rates of awareness and engagement with living donation, exacerbating disparities in access to this transplant option.	Dialysis staffs point out that there are disparities in encouragement regarding living donor transplantation among Black/African American patients, which leads to lower rates of awareness and engagement. This lack of education also contributes to limited understanding and a reluctance to become living donors within the Black/African American community, ultimately hindering access to living donor transplants as a viable option for Black/African American patients.	<p>“In my experience, the factor that plays a key role in this disparity is lack of information and/or education. It is critical that I, as a social worker, educate patients regarding living donor[-ation] and deceased donor[-ation] options.”</p> <p>“Living donor[s]: ESRD patient[s] are reluctant to discuss with family members. Deceased donor[s]: Negative talk about risk with kidney transplant, multi-steps to completing the process. Lack of [a] support system or lack of education on how to identify people in their support system.”</p> <p>“Misunderstanding of the transplant process. Include the family as a support system throughout the process.”</p>
3.) Adverse social determinants of health (SDoH) exacerbate disparities in access to kidney transplantation for Black/African American patients.	Dialysis staff recognize that adverse social determinants of health (SDoH) act as barriers to the transplant process for patients. Patients lack access to transportation to medical appointments and social support networks, hindering their progression through the process and leading to perceptions of lack of follow-through or interest in transplantation.	<p>“Barriers that may impact this include: a patient's social and financial support system for after surgery, patient's living situation, personal knowledge and education toward transplant, where a patient was born, transplant team biases toward minorities, income level, literacy issues during transplant evaluation process, and so on.”</p> <p>“...people who belong to a are connected to generational poverty. It's not difficult to get patients interested in transplant[ation] but</p>

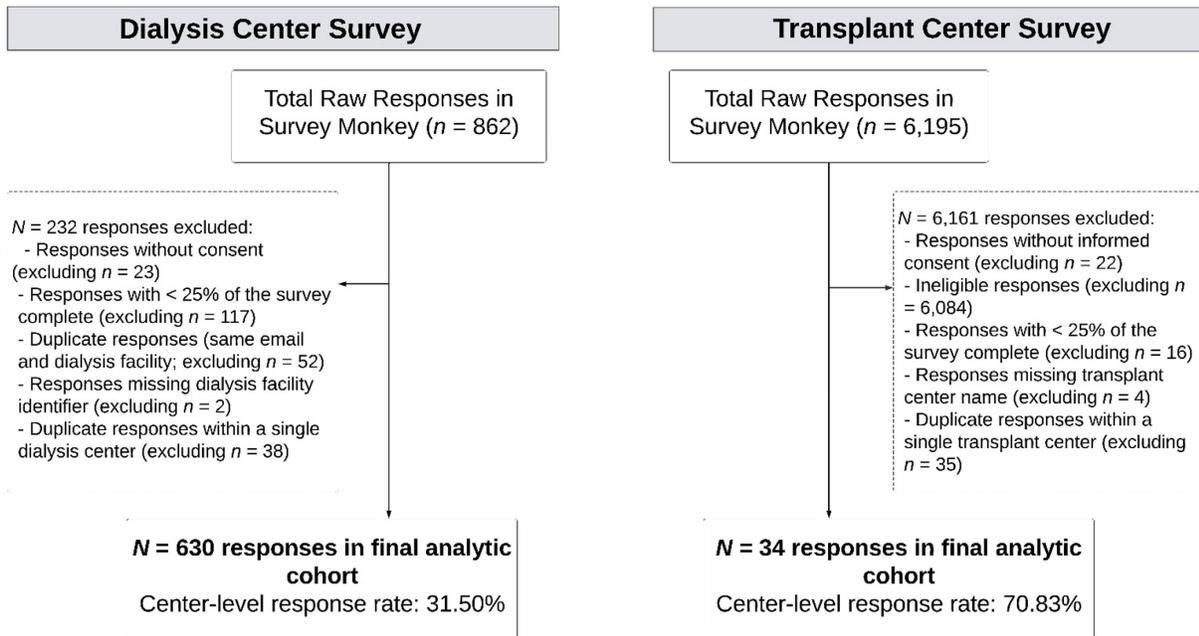
Themes and sub-themes	Description	Illustrative quotations
		it is very difficult to get them through all the appointments and meetings that lead to the determination of eligibility.”  “...lack of transportation to appointments in my area, therefore they don't go to the appointments.”
4.) Cultural factors and mistrust of the healthcare system within the Black/African American community affect decision-making and willingness to pursue kidney transplantation.	Dialysis staff acknowledge the influence that cultural factors within the Black/African American community have on medical decisions and the pursuit of a kidney transplant. Additionally, dialysis staff understand that deep-seated mistrust of the healthcare system and skepticism within the Black/African American community surrounding kidney transplantation can create additional barriers for patients, such as fears of judgment and disapproval from their community. This mistrust and skepticism among Black/African American patients may arise from historical mistreatment, myths, and misconceptions, leading to reluctance to pursue transplantation (deceased donor (DD) and living donor (LD)).	“Fearful of going to see doctors and not being provided with appropriate education.”  “Not many family members are willing to donate and skepticisms about transplants.”  “Patient may be uncomfortable talking about living donation with family/friends. Patient may have distrust of the medical system (resulted[sic] from historic systemic oppression). Family members are not candidates due to their own health issues. Fear associated with required workup testing (colonoscopy). Belief that certain medical conditions are contraindicated and unchanging.”

**Table 3.** Transplant center staff awareness of racial disparities in kidney transplant evaluation in the United States and within their dialysis facility, overall and by region

Question	Overall (N = 33)	New England (NW 1) (n = 9)	New York (NW 2) (n = 7)	The Southeast (NW 6) (n = 10)	The Ohio River Valley (NW 9) (n = 7)
<u>Nationally</u> , do you think there are existing racial differences in rates of transplant evaluation?					
No	3 (9.09%)	0 (0.0%)	2 (28.57%)	1 (10.00%)	0 (0.00%)
Yes	21 (63.64%)	6 (66.67%)	4 (57.14%)	7 (70.00%)	4 (57.14%)
Unsure	9 (27.27%)	3 (33.33%)	1 (14.29%)	2 (20.00%)	3 (42.89%)
Prefer not to answer.	0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)
<u>At your facility</u> , do you think there are existing racial differences in rates of patients being evaluated for a transplant?					
No	18 (54.55%)	6 (66.67%)	4 (57.14%)	3 (30.00%)	5 (71.43%)
Yes	6 (18.18%)	2 (22.22%)	1 (14.29%)	2 (20.00%)	1 (14.29%)
Unsure	8 (24.24%)	1 (11.11%)	1 (14.29%)	5 (50.00%)	1 (14.29%)
Prefer not to answer.	1 (3.03%)	0 (0.00%)	1 (14.29%)	0 (0.0%)	0 (0.00%)

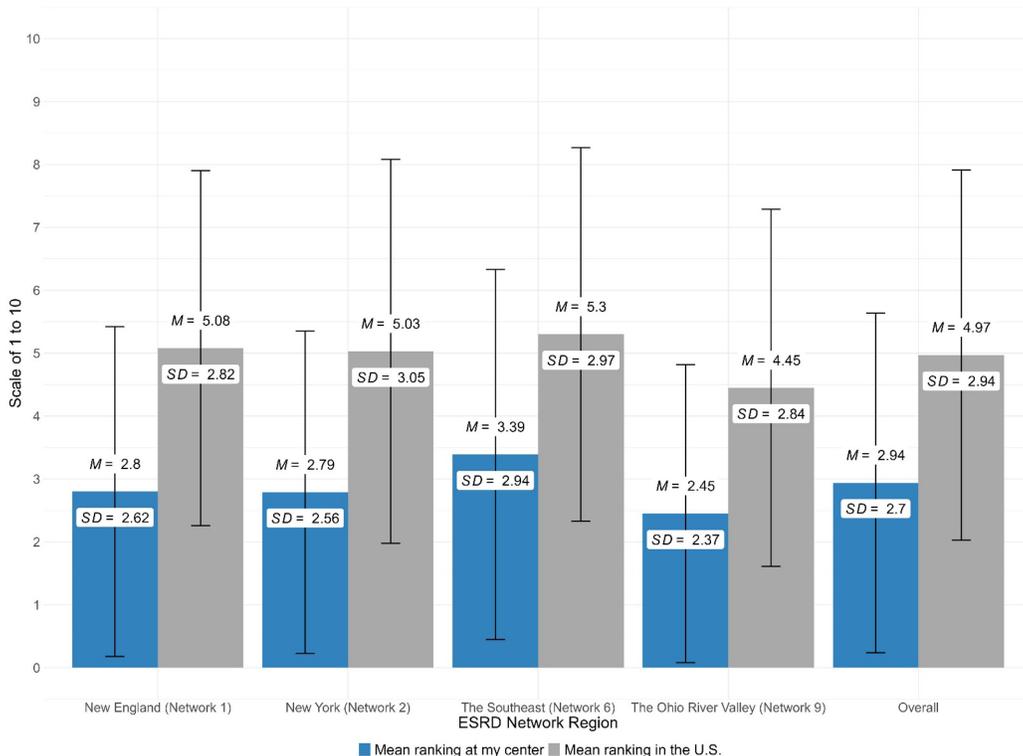
FIGURES

Figure 1. Flow Diagram of Survey Cohort Creation\*



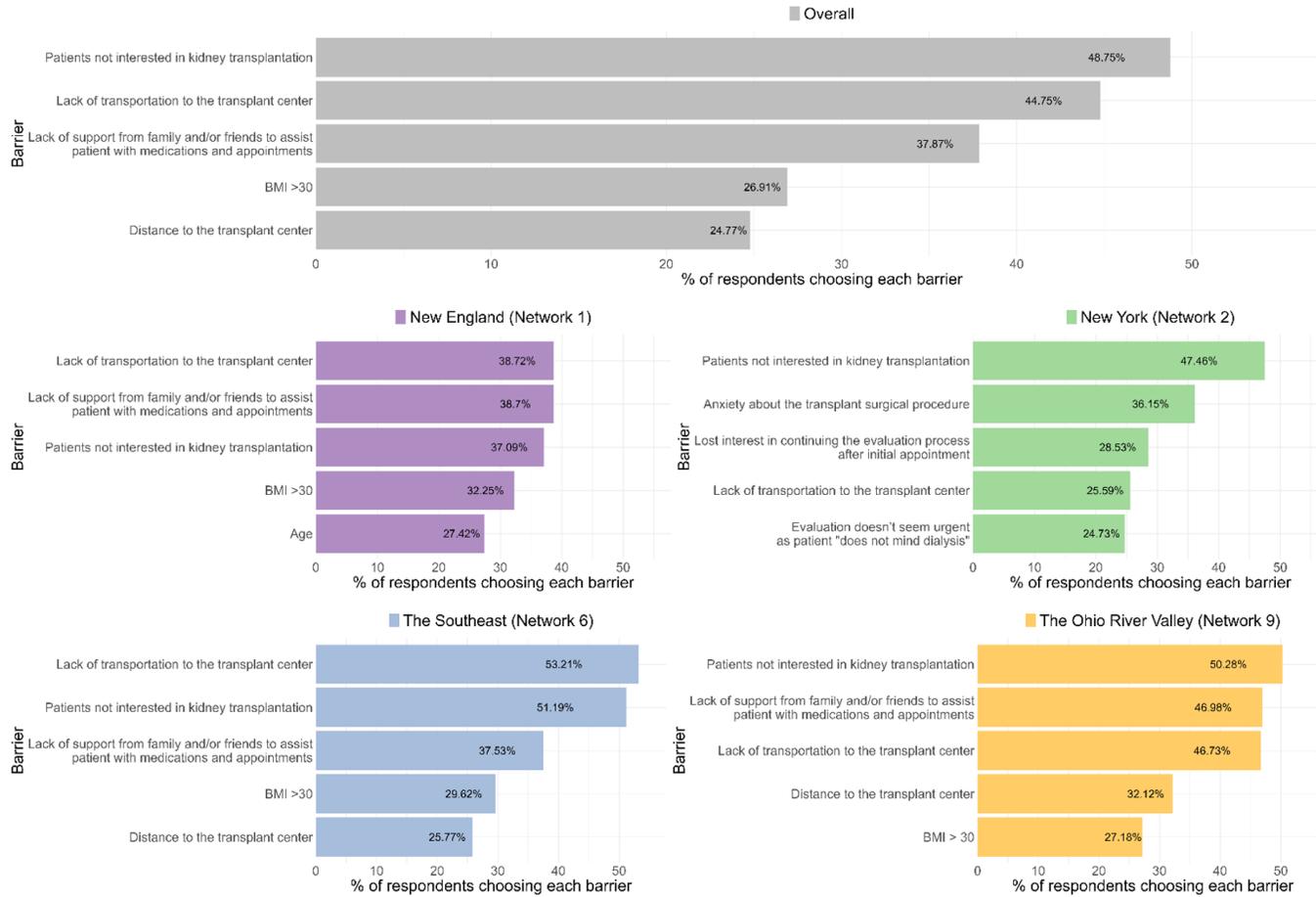
\*Responses collected between 9/11/23–9/14/23 (prior to the creation of a new distribution link on 9/14/23) for the transplant center survey were deemed ineligible and excluded (n = 6,084) due to evidence of fraudulent response activity. As advised by the Indiana University IRB, these responses were identified based on three factors: poor response quality, use of non-university-affiliated email addresses, and inability to reasonably verify employment at the indicated transplant centers.

Figure 2. Dialysis facility staff perceived impact of race on access to transplant in the United States and within their dialysis facility, overall and by region.\*



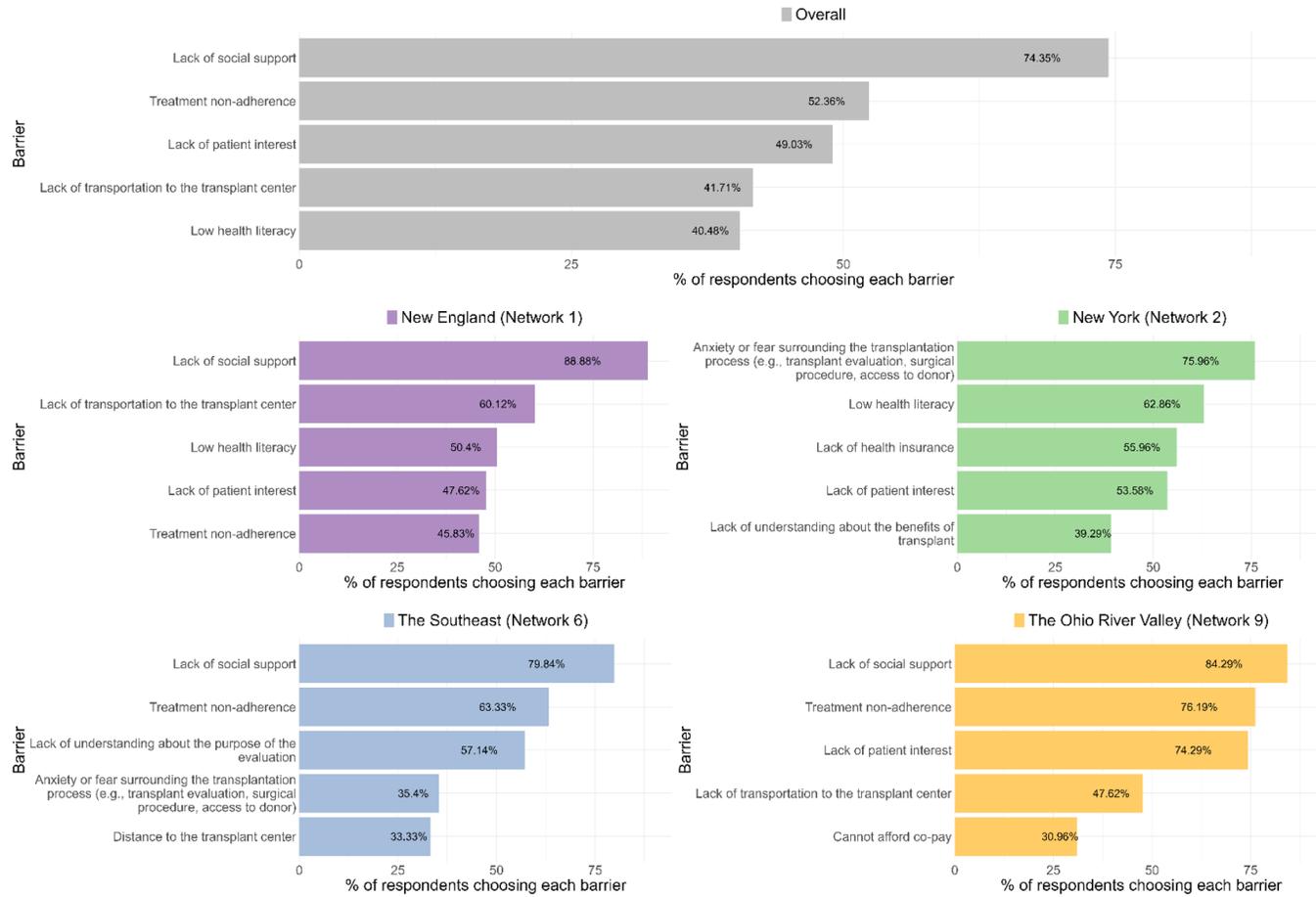
\*Abbreviations: M = Mean, SD = standard deviation. Survey participants were asked to rate the impact on a scale of 1 to 10 (1 = no impact; 10 = significant impact), for two questions: 1) “How much do you think a person’s race impacts their access to transplant in the U.S.?” and 2) “How much do you think a person’s race impacts their access to transplant at your dialysis facility?”

**Figure 3. Dialysis Center Staff Perceived Barriers to Evaluation for Kidney Transplantation by ESRD Network.\***



\*The top five dialysis center staff perceived barriers to kidney transplant evaluation by ESRD Network. Survey participants were asked to select from a list of 55 barriers previously shown to affect access to evaluation/transplant in response to the question, "Among the barriers you agreed are patient barriers to transplant in the previous questions, what do you believe to be the top 5 (in no particular order) preventing patients from being evaluated for a transplant?"

**Figure 4.** Transplant Center Staff Perceived Barriers to Evaluation for Kidney Transplantation by ESRD Network.\*



\*The top 5 transplant center staff perceived barriers to kidney transplant evaluation by ESRD Network. Survey participants were asked to select from a list of 30 barriers previously shown to affect access to evaluation/transplant in response to the question "Among the barriers you agreed are patient barriers to transplant in the previous questions, what do you believe to be the top 5 (ranked from top to fifth barrier) preventing patients from being evaluated for a transplant at your center?"