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Improving Access to Kidney Transplantation: Referral is Not Enough

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Kidney transplantation (KT) is the optimal treatment for eligible patients with end-stage renal disease (ESRD), offering longer life expectancy and better quality of life compared with chronic dialysis treatment (1). However, only 13% of patients who develop ESRD join the deceased donor waitlist or receive a transplant from a live donor within 1 year (2), and many patients predicted to have excellent post-transplant outcomes lack access to KT (3). Furthermore, pervasive disparities in access to KT persist despite decades of recognition and efforts to improve equity in transplant access (1, 4), with African-Americans, Hispanics, women, older adults, patients of lower SES or without private insurance, those living in high poverty neighborhoods, and those receiving dialysis at a for-profit center less likely to undergo KT (5-9).

Although disparities in access to KT have been widely characterized, less is known about their underlying mechanisms. There are multiple steps in the path from development of ESRD to receipt of a KT, beginning with education about the option of transplantation and referral to a transplant center, requiring a comprehensive multi-step medical and psychological evaluation, and ending with acceptance of a deceased donor kidney offer or identification of a suitable live donor. Dialysis facilities, where many patients with ESRD receive most of their nephrology care, have an important role in delivering transplant education and referring for transplantation. Patient level factors, such as race/ethnicity, age, and insurance status, are also important determinants of the quality and timing of transplant education and referral (6, 10). In a study of United States Renal Data System (USRDS) data, Johansen *et al.* (10) reported that black patients and those without private health insurance were less likely to be informed about a kidney transplant due to lower likelihood of being assessed for transplant eligibility around the time of dialysis initiation. Kucirka *et al.* reported that older, uninsured, and Medicaid-insured patients, as well as those at for-profit dialysis centers, were less likely to be assessed for transplant eligibility (6). However, little is known about which patients are referred to a transplant center, and the role of referral in driving disparities in access to transplant, as these data are not captured in the USRDS.

In this issue of JAMA, Patzer *et al.* (11) present a novel, innovative, study of this previously unexamined critical step in access to transplantation, conducted through a state-wide collaboration between 308 Georgia dialysis facilities and 3 Georgia transplant centers. The investigators designed an important study to investigate a timely research question, and were able to obtain data from a complex network of dialysis and transplant centers. Rather than relying on the end point of joining the waitlist or receiving a KT, the authors, for the first time, collected data on whether a patient was referred to a transplant center to better understand disparities in this important intermediate step. They created a novel linkage between the referral data reported by transplant centers and the USRDS to study 15,279 adult patients who had initiated dialysis between January 2005 and September 2011 in Georgia, the state with the lowest rates of KT. Previously, low rates of access to KT were assumed to be largely explained by a lack of initial referral. However, the findings of Patzer et al suggest this is not the case: among the 28% of patients who were referred to a Georgia transplant center within one year of ESRD-onset, 80% did not join the deceased donor waitlist or receive a live donor transplantation within one year of referral.

While referral to a transplant center is a critical step in the path to transplantation, it is only the beginning of a long process. This new study makes it clear that disparities in access are not primarily driven by patients' inability to "get into the system" via the initial referral, but may largely result from difficulty navigating the complexities of the KT evaluation and waitlist process. In light of these findings, efforts to improve access should not only focus on improving dialysis center KT referral rates, but also on identifying and targeting barriers for the 80% of referred patients who ultimately did not achieve access. Were these patients unable to complete the medical evaluation process? Were they deemed medically ineligible? Were opportunity costs or inadequate medical insurance coverage barriers to access? Racial/ethnic minorities appear to encounter distinct barriers that contribute to disparities in receipt of kidney transplantation, including at the patient level, the clinician level, and the policy/community level (12) and may be particularly vulnerable to post-referral barriers. These findings underscore the complexities involved in obtaining access to care, and should serve as a reminder that it may not be sufficient to provide a referral for care in the absence of guidance and support throughout the process.

While the most striking finding reported by Patzer et al was how few referred patients achieved access within 1 year, lack of initial referral is likely still a component of observed disparities. It is difficult to determine how many patients should have been referred in Georgia; however, 28% is probably low. There are only a handful of absolute contraindications to kidney transplant; barring any of these, the decision to pursue transplantation requires complex discussions between the patient, the nephrology team, and the transplant team. Furthermore, the field is evolving rapidly and many previous contraindications are now considered routine: for example, patients over the age of 65 comprised 18.4% of kidney transplant recipients in 2011, compared to only 3.4% in 1990 (13), outcomes have improved substantially for pediatric and African-American recipients over the past two decades (14), and, although HIV was an absolute contraindication to kidney transplant prior to 2000, there have been more than 800 successful kidney transplants in HIV+ patients between 2000 and 2014 (15). Given the complexity of these decisions,

most patients who are interested in pursuing this modality should be referred for further evaluation by transplant professionals. Although it is possible that lack of patient interest is a component of the low referral rate, this is probably an unlikely factor; in a previous study, only 1.5% of patients nationally declined to receive counselling about kidney transplant (6).

The findings by Patzer et al raise important and challenging policy questions, including how to correctly identify “under-referring” dialysis facilities, and how to improve referrals and ultimately access to transplantation for patients at these facilities. One potential approach to identify under-referring facilities may be to generate case-mix adjusted expected referral rates for each facility, and compare those to actual referral rates. Resources could then be targeted to underperforming facilities in hopes of improving referral rates. However, given the complexity of the KT evaluation and waitlisting process, referral in the absence of comprehensive education is less likely to be successful. As such it is critical that any intervention to improve referral rates also focuses on the importance of concurrent provision of education. In a national study of 236,079 patients, 30% were not informed about the option of KT by their nephrologist within 3 months of initiating dialysis, most commonly because they had not yet been assessed, and unassessed patients had a 53% lower rate of access to transplantation (6). In a national survey of 906 nephrologists, 57% reported spending <20 minutes on transplant education, with lack of reimbursement and lack of time cited as major reasons (16). Interventions should address these systems level barriers to providing education in addition to encouraging more referrals. For example, several long-term interventions to improve access to KT by providing personalized education, assistance in reducing socioeconomic barriers, and other engagement activities are currently being evaluated in a randomized controlled trials and could potentially improve both referral rates and a patient's ability to navigate the evaluation process (17).

The authors also described several patient and center level factors associated with referral; however, some of these are inconsistent with previous findings. For example, Patzer et al reported that African-American race and receiving dialysis at a for-profit center in Georgia were associated with higher rates of referral, whereas previous studies have shown both factors to be associated with significantly lower rates of access to KT (6, 8). It is possible that these inconsistencies identify differences in mechanisms affecting referral versus mechanisms affecting access. However, several limitations must be taken into consideration when evaluating these results. The authors were only able to obtain referral information from transplant centers in the state of Georgia; however, 21% of patients in Georgia reside closer to a transplant center in Tennessee, Florida, or South Carolina. It is possible that patients living in more rural areas (at the periphery of the state) were actually referred to transplant centers outside of Georgia and thus incorrectly classified as non-referred. A brief exploration of USRDS revealed that patients in Georgia who lived closer to within-state transplant centers were more likely to be African-American (65.9% versus 58.5%, $p < 0.001$) and to receive dialysis at a for-profit center (92.9% versus 66.6%, $p < 0.001$) (18). It is possible that African-Americans and those receiving dialysis at for-profit centers only appeared to be referred more often because they were more likely to receive dialysis at centers referring to transplant centers in Georgia (where referral data were obtained) rather than to transplant centers outside of Georgia (where referral data were not obtained). African-Americans of all ages are over 50% less likely to receive a transplant when

compared to their white counterparts, and for-profit dialysis centers may have significant financial incentives to keep transplant referral rates low. As such, it is critical to ensure that referral rates for these groups are appropriate, and that these findings do not engender complacency with the need to improve relatively low rates of transplantation previously identified in both groups. National collection of referral data is needed to better understand factors driving disparities in referral, explore how these may differ in geographic regions outside of GA, and identify and target interventions to under-referring dialysis facilities.

In summary, this important report by Patzer et al. has established that major barriers in access to transplantation exist even after a patient has been referred to a transplant center, with 80% of referred patients failing to join the transplant waitlist within one year of referral. Furthermore, the initial rates of referral were likely low and varied widely between dialysis centers, suggesting that some facilities may have been under-referring patients. Future research to better understand and target post-referral barriers, as well as interventions to identify and improve referral rates in the context of comprehensive transplant education, will be crucial for improving access to kidney transplantation for patients with ESRD.

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