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## Title Page

**Title: Will Universal Access to Healthcare Mean Equitable Access to Kidney Transplantation?**

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The 2019 Advancing American Kidney Health Initiative has called for a substantial increase in pre-emptive kidney transplantation, with the objective that 80% of those with incident end-stage kidney disease (ESKD) in the United States (US) be treated with a transplant or home-based dialysis by 2025.(1) A fundamental barrier to achieving such an ambitious goal is the uniquely high cost of healthcare in the US, a burden that impedes many younger and lower-income individuals with chronic kidney disease (CKD) from early detection and timely nephrology care. However, even if US health policy evolves to provide truly universal healthcare coverage, the nephrology community must remain vigilant about identifying and mitigating many other pervasive factors that prevent our most vulnerable patients from receiving the optimal treatments for ESKD.

In this issue of the *Clinical Journal of the American Society of Nephrology*, Pruthi and colleagues (2) assessed patient and treatment center-related barriers to kidney transplantation in the United Kingdom (UK). Like the US, there are challenges facing kidney transplantation in the UK, with the number of patients on the kidney transplant waiting list exceeding the supply of donor organs.(3) However, unlike the US, the UK provides universal healthcare access. The National Health Service (NHS) was established in the UK in 1948 with the overriding principles that it is free at the point of need and treatment is based on clinical need and not an individual's ability to pay. In the UK, transplant recipients are covered for lifelong immunosuppressive therapy, and there are no differences in physician financial reimbursements associated with ESKD treatment modality. The UK also provides reimbursement for living donor lost wages, travel expenses, dependent care, and other non-medical costs related to organ donation. Therefore, the UK has avoided many of the barriers to kidney transplantation that exist in the US, not only by minimizing the costs to patients and donors but also by eliminating financial disincentives for physicians to refer dialysis patients for transplant.(4) However, there is evidence of substantial variability in transplant wait-listing practices between centers in the UK,

(5) and racial and ethnic minority transplant candidates have lower rates of living donor transplant and longer waiting times to transplant compared to white candidates.(3)

To examine potential determinants of transplant inequity in the UK, Pruthi and colleagues (2) analyzed data from the Access to Transplantation and Transplant Outcome Measures (ATTOM) study, a prospective, national cohort study that recruited 4885 adults age 18-75 with incident ESKD across the UK between November 1, 2011 and March 31, 2013. Among 2676 individuals with incident ESKD (treated with dialysis or transplant), the authors examined whether patient and center-related factors were associated with differences in pre-emptive wait-listing for kidney transplantation. Among 1970 individuals who initiated dialysis without pre-emptive wait-listing, the authors also examined associations between patient and center-level factors and the outcome of being wait-listed within the first two years of starting dialysis.

Approximately 26% of the UK cohort with ESKD was either pre-emptively wait-listed or transplanted. Consistent with findings in the US,(6) Pruthi and colleagues found that UK patients who were racial minorities were far less likely to be pre-emptively wait-listed than patients who were white. However, these differences in wait-listing were attenuated or even reversed in the case of Asian patients after starting dialysis. In the US, racial disparities in pre-emptive transplant may be partially explained by differences in access to private insurance coverage.(6) In the UK, where healthcare coverage is universal, these findings speak to the many other reasons that could also underly racial disparities in kidney transplant access, including differences in the availability of living donors,(3) and cultural or systematic barriers that prevent access to, or engagement with the healthcare system.

Shorter durations of nephrology care were also associated with lower odds of pre-emptive listing in the study by Pruthi and colleagues,(2) a finding that may reflect both the importance of early referral to nephrology care and the rate of CKD progression in determining access to pre-emptive transplant. For example, 54% of patients in the ATTOM cohort who had

polycystic kidney disease as their cause of ESKD were pre-emptively listed, compared to 16% of patients with diabetes. Several prior studies have also found that some racial and ethnic minority groups are at higher risk of rapid CKD progression than whites, even in settings with equal access to healthcare. In a study of US Veterans who received healthcare coverage through the US Department of Veterans Affairs, although black and Hispanic patients with CKD were more likely to receive nephrology care than their white counterparts, they were also more likely to experience CKD progression.(7) These findings underscore the need to test strategies, such as expedited transplant workup or earlier transplant referral, to improve access to pre-emptive transplant for those who are at higher risk of rapid disease progression or more likely to require detailed testing.

The study by Pruthi and colleagues (2) also suggests that although the financial burdens of kidney transplantation are attenuated by universal healthcare, financial insecurity is a pervasive barrier to kidney transplantation. The authors found that being unemployed was associated with a 50% lower odds of being pre-emptively waitlisted than being employed, whereas home and car ownership were associated with nearly double the odds of pre-emptive wait-listing compared to home rental and lack of car, respectively. These findings align with the evidence that crowd-funding efforts to mitigate patient and caregiver costs related to transplant are increasing, including in countries with universal healthcare coverage.(8) Further, although car ownership may simply be a surrogate for socioeconomic status, lack of transportation might also hinder patients' abilities to travel to clinic appointments or to complete a transplant workup in a timely manner. In a 2010 US study, Axelrod and colleagues found that living farther from a transplant center was associated with reduced access to transplant, whereas having a greater ability to travel to more than one donation service area for transplant wait-listing was associated with a near doubling in the rate of transplant.(9) In light of these findings, transplant programs could consider implementing strategies such as satellite clinic sites or telehealth evaluations to ease the burden of travel before kidney transplantation.

In addition to the insights about patient-related barriers to transplantation, some of the most important knowledge to be gained from the study by Pruthi and colleagues (2) comes from their rigorous examination of center-level variables that might influence access to transplant. They found that patients who received care at kidney centers with more than 6 nephrologists, where transplant was discussed with all patients, and where transplant was performed at the center had a higher likelihood of pre-emptive wait-listing. Further, a written wait-listing protocol was independently associated with a lower rate of wait-listing within two years of starting dialysis. These center-related factors suggest that inconsistency in systems and processes for determining transplant candidacy have important implications for access to transplantation. For example, centers with fewer nephrologists per patient might have less capacity to engage patients in discussions about transplant. Centers that limit discussions about transplant to only those patients who are deemed to be the best candidates and those that use inflexible wait-listing criteria, such as strict age or body mass index cut-offs, might reduce access for many candidates that could derive substantial benefit from transplantation.

One of the strengths of the study by Pruthi and colleagues (2) is that ATTOM investigators collected rich demographic information on study participants, enabling the authors of the study to examine granular measures of socioeconomic status (e.g., car and home ownership) and social support as potential predictors of transplant access. As such, the study provides insight on the many social determinants of transplant access that typically go unmeasured in studies of registry data. One limitation, due to the design of ATTOM, is that there is no information on individuals who were pre-emptively listed during the study period but did not start dialysis or receive a transplant. Further, as ATTOM did not recruit individuals with non-dialysis-dependent CKD, it does not provide information about the total “denominator” of potentially eligible pre-emptive transplant candidates.

The important study by Pruthi and colleagues (2) has underscored some of the challenges that persist in kidney transplantation even when healthcare access is universal. Of

course, the US remains a long way from achieving that goal. In 2016, approximately 20% of younger adults who initiated dialysis in states that did not expand Medicaid were uninsured,(10) and the number of uninsured Americans has grown larger still in more recent years. Yet, findings from the UK make it apparent that barriers to transplantation are not limited to the availability of healthcare coverage. This knowledge should motivate the nephrology community to examine the equity implications of our processes to educate, evaluate and select kidney transplant candidates. Although only health policy can ensure that the door to kidney transplantation is open for all patients who could benefit, equity in transplantation will only be achievable if we are also ready to clear the path beyond the door.

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