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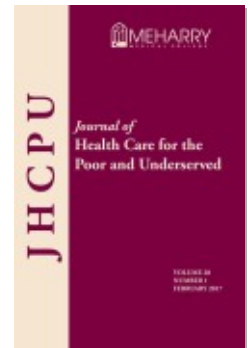
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Journal of Health Care for the Poor and Underserved, Volume 28, Number
1, February 2017, pp. 30-45 (Article)

Published by Johns Hopkins University Press

DOI: <https://doi.org/10.1353/hpu.2017.0005>



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Race, Racism, and Access to Renal Transplantation among African Americans

Kimberly Jacob Arriola, PhD, MPH

Abstract: There are clear and compelling racial disparities in access to renal transplant, which is the therapy of choice for many patients with end stage renal disease. This paper conceptualizes the role of racism (i.e., internalized, personally-mediated, and institutionalized) in creating and perpetuating these disparities at multiple levels of the social ecology by integrating two often-cited theories in the literature. Internalized racism is manifested at the intrapersonal level when, for example, African American patients devalue their self-worth, thereby not pursuing the most aggressive treatment available. Personally-mediated racism is manifested at the interpersonal level when, for example, physicians exhibit unconscious race bias that impacts their treatment decisions. One example of institutionalized racism being manifested at the institutional, community, and public policy levels is the longstanding existence of racial residential segregation and empirically established links between neighborhood racial composition and dialysis facility-level transplantation rates. This paper concludes with clinical, research, and policy recommendations.

Key words: Race, racism, renal transplant, end stage renal disease.

End stage renal disease (ESRD) has become increasingly prevalent in the United States. For example, the prevalence per million population of ESRD in 2012 (1968.2) is more than eight times that of 1980 (240.2).¹ As a result, the number of patients in need of a renal transplant, which is the optimal therapy for many ESRD patients, also continues to increase.¹ Transplantation offers numerous advantages over dialysis such as reduced risk of cardiovascular event, improved quality of life, and lower mortality.² But access to renal transplant varies greatly among ESRD patients. There are clear and compelling disparities in access based on patient race.³⁻¹¹

There are eight key steps involved in obtaining a renal transplant,¹² and there are well-established racial disparities at virtually every step (Table 1). For example, Ayanian and Cleary generated a random sample of 1,392 newly-diagnosed ESRD patients residing in four geographically diverse areas of the country and asked them “Do you want to have a kidney transplant?” and “How certain are you about this decision?” among other things. They found that African American (AA) patients were less likely than White patients to want a transplant and to be “very certain” about this preference for

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a renal transplant than White patients.¹³ This study also found that AA patients were less likely to be referred to a transplant center than White patients even when controlling for patient preferences and other covariates¹³ as have numerous other studies.^{5,12,14} African American ESRD patients are less likely than White ESRD patients to complete the transplant evaluation process,^{5,10,12} to be placed on the deceased donor waiting list,^{5,13-15} to undergo live donor kidney transplant,¹⁶⁻¹⁹ and to undergo transplantation in general.^{5,12-15,20}

The reasons for racial disparities in access to renal transplant are complex. Reviews of this topic have identified a complex array of genetic, biological, psychological, social, cultural, economic, and system-level factors.³⁻⁷ Frequently, the literature situates the cause for the disparities within patients (e.g., their genetic and biological makeup, attitudes, socioeconomic status) and health care providers (as gatekeepers to progression along the eight key steps to transplant). However, this way of framing the issue ignores larger issues of structural violence,²¹ characterized by social and structural forces that bear down on the transplant system, providers, and patients alike, including racism. Racism is increasingly being implicated as a fundamental cause of racial/ethnic health disparities,²²⁻²⁷ in that it inhibits access to resources that help individuals maximize health.²⁸ Link and Phelan theorize that even if intervening mechanisms are changed, an association between a fundamental cause (such as racism) and health will reemerge.²⁸ Yet the transplant literature has remained generally silent on this issue. With a solid foundation of research demonstrating clear and consistent racial disparities in access to transplantation, there remains an unanswered question of the influence of racism on these disparities. This paper seeks to conceptualize the mechanisms through which racism creates and perpetuates racial disparities in access to renal transplant at multiple levels of social ecology. Recommendations are made with relevance to clinical practice, research, and policy that would address racial disparities in access to renal transplant.

“Race” and “racism.” For the purposes of this paper, “race” is used to denote a social category, not a category based on shared genetic traits.²⁹ “Race” may be used as a proxy for the experience of racism, which is ubiquitous in the United States.^{30,31} Racism is theorized to exist at three levels:³¹ (a) *Internalized racism* refers to self-devaluation and acceptance of negative messages by members of the stigmatized racial group. It may be seen in feelings of helplessness, hopelessness, and rejection of one’s own cultural expression (e.g., not believing oneself to deserve an invasive medical procedure such as transplantation or feeling helpless to overcome dependency on dialysis and/or Medicare benefits that would expire three years after transplant). (b) *Personally-mediated racism* refers to prejudice (i.e., an evaluative judgment about others’ abilities, motives, and intentions based on their race) and racial discrimination (i.e., differential behaviors towards others based on race). Examples may be seen in providers holding differential assumptions about the value of renal transplant for patients of different races and failing to communicate all available treatment options to AA patients. Finally, (c) *Institutionalized racism* refers to normative, sometimes legalized, customs and practices that result in differential access to goods, services, and opportunities by race. Examples may be seen in the ways in which housing policies create racial residential segregation, educational funding policies create differential access to quality education, and control of the media shapes the types of images that are portrayed.

Table 1.
STEPS INVOLVED IN OBTAINING A RENAL TRANSPLANT IN RELATIONSHIP TO POTENTIAL SOURCES OF RACISM AND RECOMMENDATIONS FOR THE FUTURE

Step	Action ^a	Potential Source of Racism that Might Impede Completion of a Given Step	Recommendations ^b
1	Medical providers determine suitability for referral to transplant center	Personally-mediated racism	<p>C-Acknowledge that we live in a race conscious society</p> <p>C-Participate in interventions that raise awareness of the impact of bias on medical care</p> <p>R-Expand research on the role of unconscious bias in dialysis/transplant settings</p>
2	Patient expresses interest in pursuing transplant	Internalized racism	<p>C-Develop patient education materials (e.g., videos, pamphlets) that describe all available treatment options in a way that demonstrates sensitivity to the history of medical abuse, healthcare inequalities, and potential distrust in healthcare.</p> <p>P-Establish core elements of patient education on chronic kidney disease treatment options</p>
3	Medical providers refer patient to transplant center	Personally-mediated racism	<p>C-Acknowledge that we live in a race conscious society</p> <p>C-Participate in interventions that raise awareness of the impact of bias on medical care</p>
4	Patient makes first visit to transplant center	Internalized racism	<p>R-Expand research on the role of unconscious bias in dialysis/transplant settings</p> <p>P-Require reporting of facility-level referral rates by race</p> <p>P-Financially incentivize dialysis facilities to decrease racial disparities in referral</p> <p>C/R-Develop and test the effectiveness of patient navigation as a model to enhance completion of the evaluation process</p> <p>C-Develop patient education materials (e.g., videos, pamphlets) that describe the evaluation process in a way that demonstrates sensitivity to the history of medical abuse, healthcare inequalities, and potential distrust in healthcare</p>

(Continued on p. 33)

Table 1. (continued)

Step	Action ^a	Potential Source of Racism that Might Impede Completion of a Given Step	Recommendations ^b
5	Transplant center conducts patient evaluation	Institutionalized racism Personally-mediated racism	C/R-Develop and test the effectiveness of patient navigation as a model to enhance completion of the evaluation process P-Expand access to quality health insurance
6	Transplant center establishes the patient as a successful transplant candidate	Institutionalized racism Personally-mediated racism	C-Collect within-center quality improvement data to determine the existence of racial disparities in wait-listing among patients who complete evaluation C-Enhance support services for patients who are face barriers to being established as a successful transplant candidate
7	Patient is placed on the deceased donor waiting list or a living donor is evaluated for suitability	Institutionalized racism Personally-mediated racism	C-Demonstrate cultural sensitivity in the delivery of care during the evaluation process P-Expand Medicare coverage for immunosuppressant medication R-Conduct mixed-methods research to understand not only barriers to but also facilitators of access to transplant for African American patients.
8	Patient undergoes a deceased or living donor transplant	Institutionalized racism Personally-mediated racism	P-Financially incentivize transplant centers to decrease racial disparities in completed transplants R-Conduct mixed methods research on successfully transplanted African American patients

^aAdapted from Alexander & Sehgal (1998).

^bC = Clinical recommendations; Research = Research recommendations; P = Policy recommendations.

Institutionalized racism explains why socioeconomic status and race are so inextricably tied in the United States.³¹ As a result of these strong linkages, socioeconomic status is part of a discussion of racial disparities in access to renal transplant. There is strong evidence, for example, that access to private health insurance is associated with receipt of a renal transplant.^{11,32,33} However, socioeconomic status in general, and even health insurance status, do not fully explain these disparities. Studies have found that racial disparities in receipt of renal transplant remain even after controlling for indicators of socioeconomic status.^{5,14} Moreover, calls to focus attention on socioeconomic status as a key factor in access to renal transplant in lieu of race prohibit an understanding of the ways in which race and socioeconomic status interact to shape patients' health and their experiences of health care.³⁴ A focus on socioeconomic status also creates a tendency to divert the cause of the problem to the individual and away from the broader social structures and policies that maintain these disparities.

Racism and Access to Renal Transplantation

The impact of racism on access to renal transplantation may be understood through a social-ecological lens. Social-ecological models acknowledge that health behaviors are influenced by factors at multiple levels and that influences on behavior interact across these multiple levels.³⁵ One social-ecological framework in particular proposes the following levels of influence: intrapersonal, interpersonal, institutional, community, and public policy.³⁶ Below I demonstrate how racism may operate within each level to influence access to renal transplant (Figure 1). Specifically, the model illustrates how internalized racism is manifested in intrapersonal processes, personally-mediated racism is manifested in interpersonal processes, and institutionalized racism is manifested at the institutional, community, and public policy levels.

Intrapersonal factors are located within the individual and include one's genetic makeup, biological makeup, knowledge, attitudes, and behaviors.³⁶ One way internalized racism is manifested at the intrapersonal level is AA patients not viewing themselves as worthy of a transplant, which is theorized to result from histories of oppression.³⁷ Additionally, in keeping with the notion that influences on behavior interact across multiple layers of social ecology, several key intrapersonal factors are rooted in histories of institutionalized racism. For example, it has been found that AA patients have a greater "preference" for dialysis than White patients.¹³ However, patient preferences are shaped by a context of distrust of the medical establishment,³⁸ and this distrust may rest on a foundation of racial discrimination and a history of segregated and inferior medical care.³⁹ In this context it is conceivable that one would prefer the least invasive treatment that has come to be known (through personal experience) as a life-sustaining, non-optional treatment (dialysis) over one that is more invasive and seemingly carries greater risk. It is critical to place patient "preferences" in the context of centuries of medical abuse and experimentation, which rests in the collective consciousness of AAs.

Interpersonal processes include formal and informal social relationships and professional contacts.³⁶ It is the professional contact with health care providers (e.g., dialysis and transplant center nurses, social workers, physicians, and mental health providers) that creates a potential for personally-mediated racism to be manifested. One possible

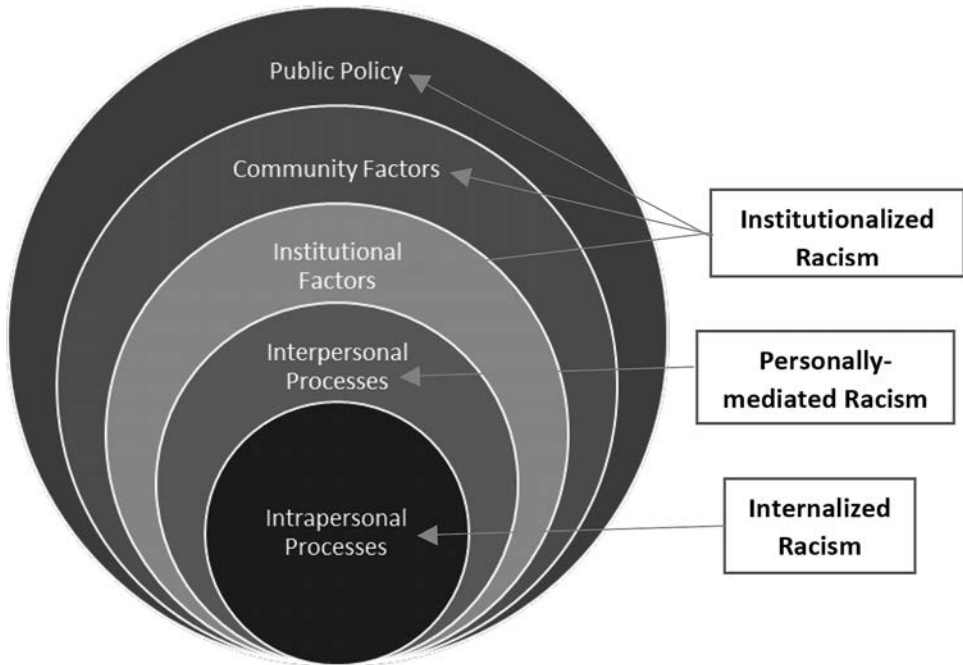


Figure 1. Levels of racism relevant to each level of the social ecology.

Note: Adapted from theories described by Jones (2000) and McLeroy, Bibeau, Steckler, & Glanz (1988).

explanation for disparities in clinical encounters that has been advanced is physician stereotypes about AA patients.⁴⁰ These stereotypes can easily manifest themselves in the form of personally-mediated racism by virtue of differential assumptions about the abilities, motives, and intentions to adhere to the prescribed medical regimen post-transplant.³¹ Nephrologists may hold different views about the differential benefits of renal transplantation for Black and White patients, and this can affect how they present this treatment option to patients.⁴¹ Research suggests that perceived discrimination is associated with longer time to acceptance for renal transplant.^{42,43} There is growing evidence that physicians' unconscious race bias may be associated with medical treatment decision-making;^{44,45} nevertheless, there are deleterious health effects for AA patients regardless of whether the stereotypes generate conscious *or* unconscious bias.

Institutional factors include social institutions (e.g., related to health care delivery, education, religion, employment) that may have formal or informal rules of operation.³⁶ Institutionalized racism exists when the different social institutions operate in ways that give individuals of one race advantages over those of another. Racial disparities in access to renal transplantation exist, in part, because racial groups have differential access to material conditions (e.g., quality education and gainful employment lay a path for access to quality health insurance) and power (e.g., access to information about the benefits and success of deceased and living donor transplantation, resources to demonstrate the ability to pay for immunosuppressant medication, and a voice in one's health care decision-making process).³¹ Institutionalized racism has as its foundation

multiple historical insults (in this case forced enslavement and the subsequent subjugation of AAs through federal, state, and local laws that limited AAs' civil liberties and civil rights) that created an overrepresentation of AAs in poverty. Cumulative disadvantage, which represents the effect of multiple forms of discrimination (e.g., race and class), across multiple domains (e.g., education, employment, and health care), across an individual's lifetime, and even across generations can have tremendous impact on whether an individual will have access to the most advanced medical procedures.⁴⁶

The term *community factors* refers to the relationships and networks among individuals, organizations, and institutions within defined boundaries.³⁶ Perhaps no fixture of institutionalized racism has had as profound an effect on AA communities as that of racial residential segregation. Segregation "was imposed by legislation, supported by major economic institutions, enshrined in the housing policies of the federal government, enforced by the judicial system, and legitimized by White supremacy that was advocated by the church and other cultural institutions."⁴⁷[p. 405] Thus, racial residential segregation exemplifies influences at the institutional, community, and policy levels of social ecology; it serves to create neighborhoods with concentrated poverty that stifle access to educational and employment opportunities for AAs, thereby truncating their socioeconomic mobility.⁴⁷

Cohen et al. describe a theoretical framework of how social structures influence individual health behavior.⁴⁸ They theorize that availability/accessibility of consumer products is one of four structural mechanisms that influence health (along with physical structures, social structures, and cultural and media messages). Applied to the current context, accessibility to dialysis facilities that have high facility-level rates of renal transplant and lower mortality rates may be health promoting for any single patient. Yet there is evidence that dialysis facilities located in neighborhoods with greater proportions of residents who are poor, AA, and lower in educational attainment also tend to have lower facility-level rates of renal transplantation and higher mortality rates.^{49,50}

Finally, *public policy* refers to local, state, and national laws and policies.³⁶ Notably, these policies may not have been created with the intention to disadvantage AAs. However, in some cases, the unintended consequence results in clear disadvantage for AAs. For example, until 2004, match algorithms relied heavily on histocompatibility testing in matching organs and recipients, which disadvantaged AAs because the serological reagents used for testing were developed primarily in Whites and because of AAs' greater heterogeneity in their histocompatibility antigens.^{9,51} Changes in the match algorithm have been made since then, including a recent overhaul of the kidney allocation system that became effective December 4, 2014, which had as one of its goals to reduce disparities in access to transplant for racial/ethnic minorities and other groups.⁵² Aside from the revised match algorithm, the landscape of federal health care policy related to the delivery of ESRD care is rapidly changing, yet the impact of these changes on racial/ethnic disparities in access to renal care remains unclear.⁵³

Recommendations for Clinical Practice, Research, and Policy

Public health scholars and others must move beyond documenting the presence of racial/ethnic disparities in access to renal transplantation to explaining why these

disparities exist. Table 1 offers a list of specific recommendations with relevance to clinical practice, research, and policy. Recommendations for clinical practice include the need for greater acknowledgement (on behalf of health care professionals and the general public alike) that the United States is a race conscious society with racism embedded in its social fabric.³⁰ This would affect how people think and feel about the topic of unconscious bias and their willingness to acknowledge its role in the delivery of medical care.

Work is being conducted to raise awareness of unconscious bias in clinical settings. Blair et al.⁵⁴ argue that interventions to reduce the effect of unconscious bias in clinical settings could take at least three forms. They could (a) reduce unconscious bias directly, (b) empower patients to defend against the bias, or (c) alter health care delivery structures to minimize the effects of bias. There is some work to suggest that changing the cue (i.e., the promotion of counter stereotypes) may reduce unconscious bias, demonstrating its malleability.⁵⁵ Blair et al.⁵⁴ go on to offer six specific suggestions for clinicians to address unconscious bias (e.g., consider the situation from the patient's perspective), and there is initial evidence to support these strategies.⁵⁶⁻⁵⁹ Nevertheless, more work is needed in clinical settings to understand how to intervene on unconscious bias among medical students and practitioners in ways that do not confront or single out individuals with evidence of bias.

Clinical settings could also be a place for interventions and research on the influence of patient navigation.⁶⁰ Originally conceived to facilitate access to cancer screening and treatment among socioeconomically disadvantaged patients, these programs could be a tool for enhancing initiation and completion of the transplant evaluation process among AA patients if delivered in a way that reflects deep structure cultural sensitivity.⁶¹ If delivered earlier in the chronic kidney disease continuum, patient navigation could be used as a vehicle to prevent progression to ESRD for AA chronic kidney disease patients, thereby reducing the number of AA patients who even need a transplant.

Another point of intervention involves patient education. While there have been calls for standardized treatment decision education for ESRD patients,⁶² addressing racism explicitly would require the availability of culturally-tailored patient education (which could entail peer education and/or the use of social media) and decision-making support tools. For example, there are interventions that have been developed explicitly to improve knowledge and motivation to pursue living donor transplant with cultural sensitivity among African American ESRD patients.⁶³ This work could speak to internalized and personally-mediated racism.

Additionally, the research agenda focusing on racial/ethnic disparities in access to renal transplant has largely focused on lower levels of the social ecology (such as the individual level) with much less attention paid to the influence of higher levels (such as community and policy-level factors). Multi-level studies are increasingly exploring higher levels of influence as more advanced statistical methods have been developed over the past 20 years (such as the use of multilevel modeling and structural equation modeling). Moreover, there is a need to understand not only the barriers to but also the facilitators of access to renal transplant for AAs—ideally through the use of mixed-methods research (i.e., studies that integrate both qualitative and quantitative data). Despite its challenges (such as greater expertise required, more time consum-

ing, and more complex), such work is able to take advantage of the strengths of each method while also complementing the weaknesses of the other and provides more comprehensive evidence for answering a research question than either method alone.⁶⁴ For example, a study of dialysis facilities with the lowest disparities in Black/White referral rates that integrates quantitative data on patient characteristics, funding, and staffing structure with qualitative data on organizational culture could inform the development of an organizational intervention to decrease disparities in Black/White referral rates for those facilities with the highest disparities. This type of intervention could address institutionalized and personally-mediated racism.

Nevertheless, there is probably no stronger impact on racism than structural change. Changes in policies, laws, and social structures affect entire populations and could be augmented by interventions delivered at lower levels (e.g., individual and interpersonal) such as those described above. This understanding aligns with calls for placing the greatest emphasis on addressing institutionalized racism because of its trickle down effects on the other two forms of racism.³¹

The landscape of health care policy relative to kidney transplant is rapidly changing, in part because racial disparities in access to transplant are so well-documented. Williams's⁵³ review of how public policy shapes kidney care concludes that new care delivery and reimbursement models must be created with the expressed purpose of reducing health disparities. There is a need for mandated data reporting systems for dialysis centers to report facility-level referrals for medical evaluation to a transplant center by race in order to identify facilities for which disparities are greatest or smallest. A similar initiative is being piloted in the Southeast region of the country.⁶⁵ With such data, one could implement "carrot and stick" approaches that incentivize or fine clinics/centers based on performance, in the spirit of the ESRD Quality Incentive Program.⁵³ With enough political will, Medicare reimbursement could even be tied to the decreasing racial disparities or increasing AA transplantation rates.

In addition to policies that link performance to pay, there are additional policy initiatives that the transplant community could pursue in order to address the influence of racism on disparities in access to renal transplant. For example, there is a need to expand Medicare immunosuppressant coverage and to establish core elements of patient education on chronic kidney disease treatment options. Another point of policy intervention relates to the new match algorithm. Whereas the new kidney allocation policy⁵² does not affect racial disparities in accessing the waiting list (nor was it intended to), there is early evidence that it may improve access to transplant for AA patients who are already waitlisted.⁶⁶ Undoubtedly, changes to the U.S. health care system that eliminate disparities in health insurance coverage would go far in reducing racial disparities in access to renal transplant as well.

All of the proposed recommendations face obstacles at the relevant level of social ecology. Individual attitudes and belief systems would impede implementation of the proposed clinical and research recommendations. Interpersonal processes and institutional practices could impede progress on the proposed policy recommendations. They could be further impeded by a lack of political will, disagreement about the importance of racism in transplant, and other competing disparities (including income disparities, regional disparities). However, there is a movement that is gaining traction.

This movement is increasingly calling for attention to the role of racism in health. For example, in fall 2015, the American Public Health Association, announced its partnership with other organizations to initiate a National Campaign Against Racism as one way to increase political to address this issue.⁶⁷ By fueling the conversation, there could be increased awareness among the general public, clinicians, and policymakers on the role of racism in access to renal transplant.

Conclusions

In some ways, racial disparities in access to renal transplant arise from the perfect storm. There is an insufficient supply of all organs, but renal failure in particular, represents the nexus at which key factors converge to create racial disparities: (a) AAs' faster progression from chronic kidney disease to ESRD in comparison with Whites; (b) the existence of a two-tiered treatment approach whereby greater access to information and resources confers greater access to the treatment associated with better quality of life and reduced mortality; and (c) the existence of incentives in the current Medicare payment system and the Social Security Disability payment system that encourage for-profit dialysis centers and patients to maintain dialysis treatment (with the greatest impact on poor patients that are disproportionately AA). Viewed positively, the renal transplant system has great potential to serve as a model for how to address racial disparities in access to the most advanced medical technologies. It might seem logical to wait until, for example, there is equal access to health care in the U.S. before implementing multi-level interventions to address racism in renal transplantation. But such an approach limits the vast potential for change that begins at local sites and grows upward: There could be interventions that address racism in the transplant arena that inform the larger health care delivery system. Moreover, policy-level interventions in the transplant arena have great potential to affect factors that influence racial disparities in access to renal transplant at lower levels of social ecology. Current efforts to address racial disparities in access to renal transplant are stymied by a lack of acknowledgement of the influence of multiple levels of racism, perhaps because such an acknowledgement creates a responsibility to pursue worthwhile solutions. The charge to dismantle the effects of racism on access to renal transplant is undoubtedly daunting, but a clear acknowledgement of its role in creating and perpetuating disparities in access to renal transplant is a critical place to start.

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