Understanding Structural Racism as a Barrier to Living Donor Kidney Transplantation and Transplant Care

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Abstract

Recent Findings  Black and Hispanic patients carry higher burden of kidney disease, yet have lower access to LDKT. Until recently, these differences were thought to be due to medical co-morbidities and variation in transplant center practices. However, recent studies have shown that systemic and structural inequities related to race may be one of the major drivers.

Purpose of Review  In this paper, we examine the definition of race and systemic racism, then describe patient-, transplant center–, and society-level barriers to LDKT. We identify how social determinants, cultural biases and mistrust in medical system, influence behaviors, and provider racial profiling affects all phases of transplant evaluation. Finally, we discuss initiatives to overcome some of these barriers, starting from federal government, national organizations, transplant centers, and community partners.

Summary  Examining structural biases in transplant practices is an important step to developing solutions to address disparities in health care access and outcomes for patients who need and receive transplants.

Keywords  Living donor kidney transplant · Blacks · Hispanic · Racism · Access · Kidney transplant

Introduction

Kidney transplantation, particularly from a living donor, is the preferred therapy for patients with advanced stages of chronic kidney disease (CKD) [1]. Living donor kidney transplant (LDKT) is associated with shorter dialysis duration, leading to improved patient survival and quality of life [2]. There are significant racial disparities in development of kidney disease and receipt of LDKT [3, 4•]. Black individuals form 13% of general population but constitute 30% of patients with end-stage kidney disease (ESKD). In the Hispanic population, ESKD is almost 50% higher when compared to non-Hispanic whites [5]. Not only are both groups more likely to have ESKD; they are also less likely to receive LDKT when compared to non-Hispanic white patients with ESKD. The reasons for the increased predilection to kidney disease and lower rates of LDKT observed in the Black and Hispanic communities are multifactorial and often overlapping. Among those reasons, social determinants of health and structural racism remain significant contributors to the observed racial disparities [6]. In this paper, we will examine the construction of race, define systemic and structural racism, and understand the patient-, transplant center–, and society-level barriers to LDKT. Finally, we will propose solutions to overcome these structural barriers.

Origin of Concept of Race, its Evolution with Time, and Impact in Health care

Race was initially used in medicine by the eighteenth-century naturalists to differentiate between populations via observable physical characteristics, primarily skin color [7, 8]. This Enlightenment-era construct was used to deem individuals of a dark skin color as inferior to their white counterparts, helping justify the capture of Africans and their enslavement in Europe and North America. While slavery has long been abolished, many historic socioeconomic disparities continue to plague the Black population to date. In
addition, Black patients continue to report differential treatment, often stemming from racial biases and slavery-era stereotypes [9, 10]. Hispanic communities have also been subject to discriminatory treatment in the legal, educational, economic, and health domains. The US immigration policies in the 1980s and 1990s contributed to increased discrimination against Hispanics, resulting in the economic exploitation of a growing segment of the population [11]. One in five Hispanic patients has experienced at least one incident of health care–related discrimination resulting in aversion to seeking follow-up health care [12]. Racial/ethnic discrimination not only affect patient’s trust in the health care system; it also affects treatment options offered by the provider. Van Ryn et al. demonstrated that participating physicians are more likely to rate African American patients as lacking social support and less likely to participate in cardiac rehabilitation. The physician’s ratings of the patients’ support and adherence were independent predictors of recommendations for revascularizations [13]. Systemic re-enforcement of the racial hierarchy has led to examples of practice-level cultural insensitivity cultivating a centuries-long sense of distrust in medicine among Blacks and Hispanics.

Despite the historical emphasis placed upon race, efforts such as the Human Genome Project have illustrated that there are only small genetic differences among different “racial” groups [14, 15•]. These findings help reframe race as a social rather than a biological construct. Race typically refers to a group of individuals based on their common beliefs and cultural practices, including but not dependent on physical characteristics [16, 17]. Despite the scientific evidence that demonstrate similarities between the different “racial” groups, medical practice continues to profile patients based on self-reported, and often provider identified, racial and ethnic categories. There are many fallacies in substituting a biological explanation for a social construct. Among them, the propagation of negative stereotypes and biases in the health care system that directly impact patient’s testing and treatment options and willingness to seek care. This sets the foundation for structural racism, building a system where public policies and institutional practices work in ways to perpetuate racial group inequity.

Defining Structural and Institutional Racism in Transplantation

Racial inequities observed in transplantation were thought to be primarily driven by the burden of medical diseases in the patient and transplant center practice patterns. Over the last decade, there has been mounting evidence challenging this paradigm. Several recent studies have demonstrated that social determinants of health have a greater influence on racial variability noted in transplant-related outcomes [18•, 19]. According to World Health Organization, social determinants of health are conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks (Fig. 1) [4•, 20]. In the following paragraphs, we will review how social determinants of health (e.g., demographics, cultural, psychosocial, knowledge factors) and provider biases affect all aspects of transplant starting from increase predisposition to kidney disease, to referral, wait listing, and the occurrence of kidney transplant, particularly from a living donor.

Race and Risk for Chronic Kidney Disease

Rostand and colleagues were the first to highlight racial disparities in the development of ESKD in early 1980s. They reported a fourfold higher risk for developing ESKD among Blacks in Jefferson County, AL, in comparison to their white counterparts [21]. Early on, the racial disparity in development of CKD was thought to be a consequence of biological differences between races, including genetic differences influencing the treatment of hypertension and diabetes. However, over the last decade, the social determinants of health have received more attention and are now thought to be major influencers in development and progression of CKD to ESKD across racial groups [22]. Socioeconomic deprivation results in substandard living conditions, lack of access to quality health care, inadequate medical insurance, poor education system, and limited health literacy. All of these, in turn, influence behaviors that increase the risk of developing obesity, high blood pressure, and diabetes, which subsequently lead to CKD and accelerate its progression [23].

Race and Referral to Transplantation

Among Black patients, a recent study of referral practice patterns demonstrated the odds of being pre-emptively referred for transplant was 37% lower than White patients, persisting after adjustments for patient, clinical, socioeconomic, and neighborhood factors [24]. Recent referral data in the Hispanic population is also concerning. Suliman et al. tracked a large cohort of ESKD patients for 3 years and demonstrated that compared to Hispanic patients, the adjusted odds of referral for transplant for Black patients in this study was 16-fold greater and for White patients was 22-fold greater [25]. The barriers to transplant referral and evaluation are underexplored due to lack of national surveillance data. Patzer et al. evaluated variations in referral for kidney transplant from 690 dialysis facilities to 9 transplant centers in Georgia, North Carolina, and South Carolina. The proportion
of patients referred within 1 year of starting dialysis was 24%, ranging from 0 to 75% [18•]. Facilities with lowest referral rates were more likely to treat patients living in high-poverty neighborhoods, have a higher patient to social worker ratio in the dialysis unit, were more likely to be non-profit dialysis units, and less likely to have a living donor kidney transplant [18•]. In 2011, Kucirka examined whether patients were informed about transplantation and the reasons for not informing patients, adjusted for the dialysis center, patient, and nephrologist characteristics [26]. Approximately 30% of patients reported not being informed about transplant as an option. Of those who were not informed about transplant, 42% of patients were not assessed for transplant options. Black patients were 27% more likely than White patients to be reported as psychologically unfit and therefore not informed about transplant options. On follow-up, only 3.3% of the uninformed and 6.2% of the unassessed patients were wait listed or transplanted, compared to 14.1% of those who were informed, highlighting the impact of an apparent bias among nephrologists and dialysis staff [26]. Physicians may have their own biases about patients’ chances of success with transplantation and financial disincentives that result in differential prioritization of providing education about benefits of transplantation [27, 28].

Less than half the patients referred for transplant started the evaluation process within 6 months of referral. This was particularly prominent among Black dialysis patients [29]. Black patients have expressed mistrust regarding the kidney transplantation process, risks to themselves and their donors, and equitable allocation of organs [30]. This distrust is rooted in population-based post-traumatic stress related to US government-sanctioned eugenic programs in Black communities and institutionalized individuals [31, 32]. These findings emphasize that providers should not perceive patient’s hesitancy as refusal for transplant as a treatment option, but an opportunity for dialogue.

### Race and the Deceased Donor Wait List

There are racial inequities in wait listing for a deceased donor kidney transplant and in who is eventually transplanted. Possible reasons for unequal wait listing are multiple medical co-morbidities and lack of social and financial support resulting in inability to complete tests required for wait listing. Ng et al. prospectively followed 1055 patients evaluated at a single transplant center for a kidney transplant until they were wait listed or considered ineligible or died [33•]. After adjusting for medical factors and social determinants of health, Black candidates were still 25% less likely to be listed for transplantation than Caucasians [33•]. In Veterans Affair health systems, the disparities in wait
listing are almost non-existent due to seamless transfer of medical records, extensive coverage for medications, and testing providing a pathway to overcome social and financial barriers to transplant [34]. These studies highlight that factors beyond medical co-morbidities play a role in disparities to wait listing, possibly related to both the provider and the transplant center.

Race and Living Donor Transplant Access

Receiving a kidney transplant from a living donor requires multiple steps starting with the recipient’s understanding of the benefits of LDKT over dialysis and DDKT, overcoming perceived barriers to discussing LDKT with family or friends, and successful evaluation of the potential living donor. Transplant candidates in predominantly Black communities reported concern that donation would inconvenience the living donor and their family and these feelings were further compounded by their concerns for the donor’s health after donation [35]. Healthy family members and friends in certain Black, Hispanic, and Asian communities may also lack awareness of the benefits of LDKT for the recipient or the risks associated with living donation, which is further exacerbated by high mistrust of the health care system [4•, 36]. There is limited information about the extent to which transplant centers engage their communities in culturally and linguistically competent conversations. The Coalition on Donation conducted interviews with Spanish-speaking adults in the USA to understand attitudes towards transplantation in the Hispanic community [37]. The study found that there was a mistrust and misunderstanding of the transplant process [37]. Frates et al. reported there were families opposing organ donation because they believed that the potential donors were under surveillance and they doubted that organ donation was handled responsibly and was not for profit [38]. Community members reported not understanding the burden of CKD, treatment options for CKD/ESKD, or that it was possible to donate while living. Study participants reported concerns about fertility post-donation, wanting to protect potential donors’ future children, and long-term well-being of the donors, specifically that donation would shorten the donor’s life expectancy [38]. The interplay between the general public, recipients, and donors is significant and complex. The families can be an integral part of the donation process without having any interactions with the transplant evaluation process. Gordon et al. reported family members discouraging potential donors from proceeding and attempting to prevent living donation [39]. This resulted in recipients not approaching potential living donors and potential living donors being prevented from moving forward with the evaluation [39]. In order to improve access to living donors, additional outreach efforts are needed to address the concerns of recipients, donors, and the general population.

Race and Becoming a Living Donor

Even after expressing interest in living donation, Black and Hispanic community members are more likely to be excluded. Using a base population perspective drawn from integrated US Census and transplant registry data, Gill et al. recently reported disparities in living donation rates based on sex and income, whereas donation by race was equivalent [40]. These findings suggest that part of the access disparity among Black and Hispanic patients with kidney disease derives from higher disease burden and need, rather than lower donation rates in the community, per se. There are multiple causes of potential donor disease burden in certain Black and Hispanic communities. Areas with predominant Black or Hispanic populations tend to have a higher density of fast food and convenience stores than predominantly white areas [41, 42]. Such disproportionate exposure to unhealthy food and limited access to healthy options directly contributes to hypertension, diabetes, and obesity in these communities and the likelihood that people will be found unacceptable as donor candidates.

Another factor limiting access to potential donors is the penal system. People of color are over-represented in arrests and incarcerations. Black people are 13 times more likely to be imprisoned than non-Hispanic whites and there are about 9 million different individuals [43, 44]. Chronic diseases are not well managed in this population with about 40% of inmates are diagnosed with diabetes, hypertension, asthma, or other chronic conditions [45, 46]. Incarcerated individuals are both at increased risk for CKD and more likely to be excluded as potential donors due to medical co-morbidities, which particularly impacts Black and Hispanic living donor candidates [4•, 47•, 48]. In the event an incarcerated individual is interested in donation and is healthy to do so, there are several barriers to allow them to do so. They are required to pay for the non-medical costs associated with evaluation and the donation surgery such as transportation, making it difficult for an already financially disadvantaged population. There are concerns that the act of donation is being used to reduce the sentence or achieve other secondary gain, so they are under greater scrutiny by the program to confirm their motivation. Finally, even after release, the well-documented difficulties in finding employment after incarceration may again keep individuals from being in the financial position to consider kidney donation [49, 50].

After donation, Black living kidney donors have higher risks of ESKD and hypertension and Hispanics have higher risks of hypertension compared with non-Hispanic whites.
This is a concerning finding and can give pause when evaluating donors. The lack of guidance and consensus regarding eligibility criteria for accepting individuals of racial and ethnic minorities—particularly young candidates—as living donors may also contribute to lower rates of LDKT, further disenfranchising an underserved community [54].

Race and Systemic Solutions

The results of the studies highlighted above make a good case that increasing access to medical care alone will not improve access to transplant for Black and Hispanic communities. It is crucial to address social and economic factors, transplant center policies, physician biases, cultural and religious values, and mistrust in health care system that fundamentally affect the downstream determinants, such as individual response to medical advice. Although challenging, there have been attempts to improve living donor transplant equity on the individual, community, health care system, and national level (Table 1).

National Level Strategies

The cost of the living donation, not including lost wages and productivity, has been reported as high as $20,000, with the average estimate in the $5000 range. Removing financial disincentives to donation is critical to improving access to kidney transplant.

On July 10, 2019, the Advancing American Kidney Health Executive Order directed the Department of Human Services to take bold action to transform how kidney disease is prevented, diagnosed, and treated within the next decade. The changes in payment models are intended to provide resources to manage patients with CKD stage 4 and 5, encourage home dialysis, and facilitate kidney transplantation [55]. The executive order encourages dialysis providers to refer patients for transplant and rewards them based on rates of wait listing and LDKT. In terms of increase access to transplant, there are multiple obstacles for potential living donors in under-resourced communities. While expanding reimbursements will improve financial barriers, there are also medical contraindications, such as higher risk for CKD in certain populations, and cultural concerns, such as distrust in the medical system, that are not addressed by the initiative. The transition requires a significant shift in CKD and ESRD care, which requires investment in time and money. Under-resourced dialysis centers that serve economically disadvantaged patients may not be able to take advantage of the new incentives and in some cases may be penalized due to their caseloads and case-mix.

In early 2021, there was an expansion of the National Living Donation Assistance Center (NLDAC) support to living kidney donors for lost wages, travel, childcare during evaluation, and surgery. For living donors, the Affordable Care Act (ACA) made it illegal for health insurance providers to charge living donors a higher insurance premium or deny coverage based on defining donation as a pre-existing condition. The Living Donor Protection Act (LDPA) has been introduced in Congress which would prohibit insurance companies from denying, limiting, or charging higher premiums to living organ donors for life, disability, and long-term care insurance and clarifies that living organ donors may use time granted through the Family and Medical Leave Act (FMLA) to recover from donation [56].

Harhay et al. studied the impact of expanded Medicaid access related to ACA on the number of individuals preemptively wait listed for kidney transplants [57]. The authors found that in states with Medicaid expansions, there was a 59% relative increase in pre-emptive listing, with the largest proportional increase in Black and Hispanic candidates and also greater increase in living donor transplants than states without Medicaid expansion. Of the many factors that contributed to the changes observed above, including economic recovery and its effects on household financial security, increased access to health insurance was particularly relevant for transplant.

| Table 1 Measures to improve disparities in the transplant community |
|-------------------------------------------------------------|
| **Domain**                                               | **Measures**                                    |
| Economic stability                                       | -National Living Donor Assistance Center         |
|                                                        | -Family Medical Leave Act                        |
|                                                        | -Living Donor Protection Act                     |
| Neighborhood and physical environment                    | -Outreach programs                              |
| Education                                                | -RaDIANT                                        |
|                                                        | -Living Donor Education Toolkit                  |
| Food                                                     | -Barbershop and Salon Health Outreach Program    |
| Community and social context                             | -Peer Mentor Programs                            |
| Health care System                                       | -Affordable Care Act                             |
|                                                        | -Inclusion, Diversity, Equity, and Access to Life |
**Professional Organization**

American Society of Transplantation (AST) and American Society of Nephrology (ASN) have extended its mission to work in support of the elimination of systemic racism in the field of CKD and transplantation and made a commitment to organizational change to elevate the issues of diversity and equity within the Society. The Inclusion, Diversity, Equity, and Access to Life (IDEAL) Task Force established to spearhead AST’s evolution in this area. The recent white paper by the Organ Procurement and Transplant Network (OPTN) offers an analysis of ethical considerations associated with non-medical criteria commonly used by transplant programs in listing decisions [58, 59]. It addresses the use of adherence, incarceration status, immigration status, and social support as transplant evaluation criteria. The intent of this white paper is to advise transplant programs to support patients with social adversity and provide additional resources to improve their likelihood of listing for transplant [54].

The AST has created a live donor educational toolkit for patients and those considering live donation [60]. The chapters are written by experts in the field and the goal is that this information can be disseminated by transplant centers, dialysis units, and general nephrologists. The chapters are available in both English and Spanish languages and are written at a 6th grade reading level so they can be understood by most patients.

**Transplant Centers**

Transplant centers have adopted various patient-focused strategies to offer their transplant services to dialysis patients in remote areas. Many programs have established outreach clinics closer to underserved communities to offset the need to travel to the transplant center. In addition, the use of electronic medical records shared via common platforms between different centers has led to improvement in communication between referring physician, transplant center, and patient.

With regard to LDKT, most centers have developed educational videos and community event programs to disseminate information about benefits of transplant particularly from a living donor. Some programs have a “peer mentor” or “navigator” to help donor and recipients through the transplant process.

**Community Level Strategies**

Given the long history of mistrust of the medical community among Blacks and Hispanics, we need to have culturally sensitive liaisons, preferably representatives of those populations we want to reach and to talk about kidney disease and strategies to improve health. Gordon et al. designed a living donor outreach program, the Hispanic Kidney Transplant Program (HKTP), to serve the growing Hispanic ESRD population [61•]. There were bilingual and cultural members at all levels of the transplant team, including physicians, transplant center schedulers, and educators, interfacing with the community. Participants overwhelmingly reported thinking more favorably about kidney transplant and 97% were more in favor of living donation after completing the program [55]. A financial analysis was performed to estimate the cost of the HKTP and found that the staffing time involved in establishing and implementing the program was less than 1% of the center’s annual total cost [62]. The findings demonstrate that culturally sensitive interventions can reduce transplant disparities in a fiscally responsible manner.

**Conclusion**

Our goal, as the transplant community, should be to “eliminate racial disparities, elevate collegial diversity, deconstruct barriers to a culture of racial equality, and hold the transplant community accountable to zero-tolerance for racism [63].” Research suggests that access to kidney transplantation is not equitable or just. This paper highlighted some of the systemic barriers that result in disparate living donor transplant access and outcomes in different communities. We have the responsibility to focus on our actions, recognize the impact of racial bias on our patients and their communities, and develop systemic solutions that address inequities that arise from longstanding structural racism.

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