The concept of centering the margins emerged from the seminal work of bell hooks, whose examination of the intersection of race, gender, sexual identity, and class led to what is now referred to as the center/margin theory. In the context of health and public health interventions, centering the margins involves bringing those who have been systematically placed in the margins of society into the forefront of our efforts.

Jenkins et al report the health care experiences of a seldom-centered group, Black veterans, 97% of whom were men with chronic kidney disease (CKD). Black men in the US are the demographic group with the highest lifetime risk of kidney failure and, in 2018, made up 16.6% of patients with kidney failure in the US despite being only 6.4% of the overall US population.

Jenkins et al interviewed 36 Black veterans who received care at the Corporal Michael J. Crescenz Veterans Affairs Medical Center in Philadelphia, Pennsylvania, from 2018 to 2019; participants were kidney transplant recipients, had CKD stages 3 to 5, or were dependent on dialysis. The authors explored participants’ experiences with racism in medical settings and their beliefs regarding the ways in which racism affected their overall health. Participants reported frequent encounters with racism in the health care setting, which produced physical symptoms and strong emotional responses of anger, resentment, and hopelessness that increased their distrust in the health care system. They felt a sense of pressure to prove themselves to clinicians and felt judged, discriminated against, or ignored in return. Participants felt powerless and sometimes used humor to make light of their experiences or skipped appointments altogether. Strategies they undertook to cope with the stress of racism included getting involved with their communities through mentorship of young people, spending time with family, turning to their faith, and, rarely, using substances or alcohol.

Perhaps the most concerning finding was that participants repeatedly experienced symptoms of posttraumatic stress disorder, as suggested by their hypervigilance during health care encounters. Posttraumatic stress disorder develops in response to shocking or dangerous life experiences. It is characterized by a perpetual fight-or-flight response even when not in danger, frequent reexperiencing of traumatic events in the form of flashbacks or frightening thoughts, avoidance of thoughts and places that are reminders of the experience, difficulty sleeping, distorted feelings of guilt and shame, and depression. Participants described feeling unsafe in places that are meant to promote their health and well-being, suggesting that a critical evaluation of the health care system’s role in perpetuating traumatic experiences is needed.

Findings from this study highlight a potential mechanism for how trauma and racism is associated with racial disparities in kidney disease and health in general. Encounters with racism triggered a trauma-like response resulting in avoidance of health care and the occurrence of symptoms associated with chronic stress. For people with CKD, these responses could translate into inadequately controlled comorbidities and faster progression to kidney failure.

Racism could also make interventions intended to narrow disparities less successful. For example, expanded access to insurance has the potential to improve outcomes for socially marginalized groups. All US veterans theoretically have the same insurance and access to health care. However, if experiences of racism are associated with perpetuation of trauma, Black veterans may have worse outcomes compared with non-Black veterans despite having the same insurance coverage. This disparity is evident in reports from Veterans Health Administration data suggesting...
that Black veterans with advanced CKD are more likely to visit a nephrologist than White veterans but are nevertheless more likely to experience CKD progression.7

Trauma and experiences of racism in health care among Black men with CKD could be exacerbated by compassion fatigue and burnout among members of the kidney care team, which may underlie biased attitudes and discriminatory behaviors that perpetuate the sense of betrayal described by participants in the study. Participants who experienced symptoms of trauma during health care encounters described being on edge and reported bursts of anger. Dialysis, in particular, is frequently described as a traumatic life experience, and many patients report symptoms of posttraumatic stress disorder every time they enter the dialysis unit. The emotional trauma from working with traumatized patients in a stressful environment could make staff members in the dialysis unit feel unappreciated and lead them to disengage, worsening patients’ perceived discrimination.

Although racial disparities in kidney disease have been documented for almost 40 years, little progress has been made toward achieving equity in kidney outcomes. The findings of Jenkins et al2 highlight the need to capture Black individuals’ perspectives on their health care experiences to identify potential solutions for profound racial disparities in the care of patients with CKD. The authors conclude by suggesting that trauma-informed care could be a solution to address the consequences of racism and trauma in the health care setting.2 Trauma-informed care involves understanding the impact of trauma for patients, using trauma screening, developing policies to respond to trauma individually and institutionally, and avoiding retraumatization. By understanding an individual’s experience and respectfully avoiding retraumatization, this type of care fosters trust and well-being and promotes activation and engagement rather than stress and disengagement.

Studies of interventions that incorporate trauma-informed care into CKD care are needed, including examination of the impact of these interventions for mitigating disparities in kidney disease outcomes. Equally necessary are studies of approaches to bolster and support the types of positive coping behaviors Black veterans with CKD reported; these approaches may foster resilience even in the face of racism. Centering the margins to achieve kidney health equity requires centering the experiences of Black men, the US population at greatest risk of adverse kidney outcomes and therefore the most likely to benefit from our urgent attention and action.

ARTICLE INFORMATION
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Corresponding Author: Tessa K. Novick, MD, MSW, MHS, Division of Nephrology, Dell Medical School, University of Texas at Austin, 1601 Trinity St, Bldg B, Austin, TX 78712 (tessa.novick@austin.utexas.edu).

Author Affiliations: Division of Nephrology, Dell Medical School, University of Texas at Austin, Austin (Novick); Division of Nephrology, Department of Medicine, Johns Hopkins University School of Medicine, Baltimore, Maryland (Crews). Johns Hopkins Center for Health Equity, Johns Hopkins Medical Institutions, Baltimore, Maryland (Crews).

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