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VIEWPOINTS

How our organ transplant system fails people of color

In the United States, the average wait for Black patients who need an organ transplant is a year longer than for White patients — and that's just one of many inequities. An expert lays out a roadmap for greater transplant justice.

By Jewel Mullen, MD, MPH, MPA

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From disease detection to waitlist referral, Jewel Mullen, MD, MPH, MPA, points out inequitable obstacles in patients' pathways to organ transplantation.

Photo by Bret Brookshire

Editor's note: The opinions expressed by the author do not necessarily reflect the opinions of the AAMC or its members.

In the United States, Black people are four times as likely to develop kidney failure as White people, but they are much less likely to receive a lifesaving kidney transplant. Black people also experience the highest rates of heart failure, but receive heart transplants at lower rates than their White counterparts. These are tragic inequities.

When I consider these realities, I recall Mr. Richardson (not his real name). His story sheds light on the system he entrusted with his medical care, care that was crucial to reducing his risk of developing kidney failure. It also offers insights into how the system that supports organ transplantation can best serve Mr. Richardson and people like him.

I saw Mr. Richardson for an outpatient visit at an urban community health center in the Northeast more than a decade ago. He had come for a blood pressure check and medication refill. As I reviewed his records, Mr. Richardson volunteered that he adhered to his medication regimen, that he did not miss appointments, and that his blood pressure was usually high. A 54-year-old nonsmoking Black man with no other known comorbidities, he shared that his mother and two brothers had high blood pressure and kidney failure and were receiving dialysis. He tried to do whatever possible to be healthy but predicted that eventually he would need dialysis too.

Although he had been our patient for years, it was my first time meeting Mr. Richardson. Our understaffed practice, which served mostly low-income people, struggled to provide continuity of care. Mr. Richardson's blood pressure that day was 150/102, far from the recommended goal of 130/80. As far as I could tell, no recent blood or urine tests — which would monitor for signs of possible hypertension-related kidney damage — had been ordered for him. He had been on the same treatment for almost two years.

In addition to adjusting Mr. Richardson's medication dosages, I ordered lab tests and scheduled an appointment for him to follow up with his assigned primary care doctor in four weeks. As we left the appointment, though, numerous questions swirled in my mind. Had anyone fully explained to Mr. Richardson the importance of hypertension control for protecting his organs? Had clinicians given up trying to get his blood pressure to goal? Did they consider a nephrologist referral? Had they considered checking for early signs of kidney damage so that they could try to prevent its worsening? What kind of care had his family members received?

I was concerned that Mr. Richardson might be heading toward potentially avoidable troubling outcomes, including kidney failure. One disturbing fact about disparities in the U.S. transplant system is that Black patients who develop kidney failure are more likely to remain on dialysis than to receive a transplant — and yet patients who undergo successful transplants live far longer than those who remain on dialysis.

As an internal medicine doctor, I view the primary care system as the starting point on a care continuum in which some patients progress from good health to problems like kidney failure and the need for a transplant. Our clinic's role was to do all we could to help people prevent the onset of chronic conditions like high blood pressure and to minimize negative outcomes like kidney damage. However, as happened elsewhere, some characteristics of our practice stymied high-quality care.

In one example, when our low performance controlling patients' hypertension came up during quarterly quality improvement meetings, some doctors expressed frustration. "It's not us, it's our challenging patients," they asserted, assuming that failure to take medications regularly, eating poorly, being physically inactive, and similar behaviors were the real reasons so many of our patients' blood pressure didn't improve. Some people referred to our practice as a "typical clinic" that offered care that at least was better than nothing. Such attitudes — which often continue today — promote bias, hinder crucial individualized care, and foster a mindset that we can't do better for our low-income or minoritized patients.

Some at our practice acknowledged that to improve care, we needed to make changes that other health centers had already adopted. We needed to improve continuity of care, create care teams, communicate with people in their preferred language, and provide more convenient appointment times. We also needed to improve our ability to collect and analyze data about our care processes and outcomes — and to address disparities, we needed to analyze those data by race and other sociodemographic characteristics.

Over the past decade, the adoption of policies and practices such as those we aspired to have improved primary care performance at many health centers across the United States. Although I never learned what happened to Mr. Richardson, I believe these improvements have helped many people like him. Of course, more still needs to be done to ensure that people like Mr. Richardson don't ultimately need a transplant, but lessons from those improvements can guide the development of a more equitable organ transplantation system.

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In the United States, the pathway to organ transplantation is complicated, full of potholes that impede access, and riddled with crevasses into which people fall and never emerge. The early stages of that course include primary, specialty, and hospital care, all of which may play a role in patients' clinical evaluations, disease management, education, and referral to evaluation for transplants.

To address transplantation inequities, we must improve the opportunity for all people to access care along the transplant pathway, starting with receiving high-quality primary care and proceeding through the entire journey, including after transplantation. A person's race and other characteristics must not determine the quality of care that systems provide at any point along the pathway.

I recently had the privilege of serving on a National Academies of Sciences, Engineering, and Medicine committee that produced a report released earlier this year, *Realizing the Promise of Equity in the Organ Transplantation System*, that details many obstacles to fair and effective organ transplantation and documents the substantial research demonstrating these obstacles for Black patients and others.

Among the report's findings are that primary care and specialty clinicians identify White patients as good candidates for kidney transplants more often than they do Black patients, and that Black people are half as likely to be placed on a kidney transplant waitlist as are White patients. They also face a transplant wait time that is a year longer than White patients face, and are more likely to die while on the list. In addition, it notes that some Black families may not be approached regarding organ donation requests in the same manner — or as frequently — as White families and that they sometimes view those interactions less favorably.

Although transplant disparities are documented best among Black kidney disease patients, they also affect other racial and ethnic groups, people with physical and cognitive disabilities, undocumented immigrants, lower-income patients, women, and rural patients — and they exist in the transplantation of other organs as well.

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All institutions involved in organ transplant wait-listing and distribution are connected through the Organ Procurement and Transplantation Network (OPTN), which is managed by the nonprofit United Network for Organ Sharing. The federal contract for the OPTN is up for renewal in 2023, so this is a crucial opportunity to heighten accountability requirements, including those ensuring equity.

To promote equity, health systems and the people working in them must recognize and minimize bias and racism, sexism, ableism, and other “isms” that devalue certain groups. Perspectives that stereotype or blame patients lead providers to undertreat those patients and communicate poorly with them. Thorough, effective communication is crucial because it builds trust, helping engage patients to partner in making informed decisions about their care. Equitable transplantation care also must incorporate acknowledging social determinants of health that present obstacles and addressing patients’ health-related social needs.

It is also essential for clinicians to present transplantation as a treatment option for patients who might be eligible without triaging them away from transplant evaluation, wait-listing, and offers of an organ because of their social characteristics. More providers need to be sensitized to clinician tendency to preferentially offer transplants to people who are White, who do not have a disability, or who are in higher socioeconomic classes.

Performance improvement approaches that have been successful in primary care can be the beginning of a roadmap for transplant-related changes. For one, OPTN should use specific, standardized data to measure participating institutions’ performance and improvement — and those data should be disaggregated by race, ethnicity, language, and other sociodemographic factors. It should assess such domains as patient access — including the number of people referred, evaluated, and wait-listed — numbers of patients who receive transplants and their survival rates, and numbers of donated organs that are transplanted as well as those that go unused.

As new metrics are developed, accountability requires seeking patient and family input in their creation, which should then be followed by transparency and public reporting of the data. As OPTN organizations review and report their performance, they should invite members of groups experiencing inequities to participate in determining how to remedy those inequities, and participation should be meaningful, not performative.

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These recommended interventions will have a greater likelihood of success when all people have equitable access to health care. Access is supported when everyone has comprehensive health insurance; when social needs that impact health, such as adequate nutrition and housing, are met; when there are no geographic barriers to obtaining primary, specialty, and specialized transplantation care; and when medications are affordable.

Of course, as many people, including providers like me, continue to push for those much broader goals, we must keep working to improve the parts of the transplantation pathway that we can change now.

As providers, we can hold ourselves accountable for quality, disrupt organizational cultures and individual behaviors that lead to biased and discriminatory care, use data to keep ourselves honest about inequities in our practices — and work hard to remove them. Importantly, we must engage with our patients as partners in their care rather than as reasons why we can't do better for them.

So many disparities in the transplantation system are unfair, avoidable, and unjust. None of us should succumb to a better-than-nothing mindset. Better than nothing is not good enough. Our patients deserve equity.

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Jewel Mullen, MD, MPH, MPA, associate dean for health equity at the University of Texas at Austin Dell Medical School, recently served on a National Academies of Sciences, Engineering, and Medicine (NASEM) committee that produced the 2022 report Realizing the Promise of Equity in the Organ Transplantation System. The opinions expressed here are her own, not those of NASEM or the committee.

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