Inequity in Organ Donation

The organ donation system is failing patients and donor families of color through every phase of the process – from getting on the waitlist, to finding a match, to becoming a donor.[1] Both donor families and patients of color who need an organ experience different treatments and a system deeply rooted in inequity.[2]

From the outset, people of color are far more likely to need a new organ:

- **Hispanic Americans** are 1.5 times more likely to have kidney failure;[3]
- **Black Americans** are 3 times more likely to have kidney failure;[4]
- **Native Americans** are 4 times more likely to have kidney failure;[5]
- **Asian Americans** are 4 times more likely to have hepatocellular carcinoma (HCC),[6] one of the most common indications for liver transplant.

However, people of color are significantly *less* likely to be put on the waitlist, and also less likely than white patients to receive a life-saving organ transplant even once they are. One study analyzing government data from 1990 - 2009 found the median number of days on the kidney waiting list for a white person was 295, whereas for a Black person it was 87% higher at 553.[7]

The situation is even more dire as COVID-19 persists. Without a kidney transplant, patients are forced to visit dialysis centers multiple times per week, sitting for hours as a machine cleans their blood. This routine is not only painful, costly, and time-consuming, but it is also incredibly risky as vulnerable patients sit close to each other amidst the COVID-19 pandemic.[8]

The following report shows how people of color are disadvantaged through all stages of the organ donation process. While much of the available research looks specifically at Black communities, other patients of color face similar or additional hurdles that are unfortunately not yet studied widely enough to be adequately addressed in this report. Additionally, a lack of standardized and transparent data within the organ donation system contributes to limitations within organ donation policy research as a whole.

Reforming the U.S. organ donation system is a critical health care equity issue that requires rigorous Congressional oversight and Administration action.

"Black Americans face disparities in nearly every step of transplant care. Black Americans are less likely than White Americans to be identified as a transplant candidate,[9] referred for evaluation,[10] put on the kidney transplant waitlist,[11] receive a kidney transplant,[12] receive a higher-quality kidney from a living donor,[13] while also being more likely to receive lower quality kidneys[14] and have poorer transplant graft survival."[15]

— American Society of Nephrology

RACIAL OBSTACLES TO GETTING ON THE WAITLIST

During the first signs of kidney failure, Black people are consistently less likely than white people to get on the waitlist.[16]

In order to get waitlisted for an organ, patients must first get referred by a physician and then evaluated by a medical team to assess whether or not they are a suitable candidate. Since there is a far greater demand for transplantable organs than there is a supply of them, transplant centers must make difficult choices about which of their patients to refer (or not) to the organ waiting list. As illustrated below, this evaluation system is tainted with bias regarding race and socioeconomic status.

Before getting added to the kidney waitlist, patients are assessed by their "estimated glomerular filtration rate" (eGFR). This number is used to determine the need for a new kidney, and in turn get placed on a waitlist. Yet the standard for a white patient is different from a Black patient,[17] stemming from 20-year-old flawed data[18] that presumes Black people

have higher muscle mass. In effect, "[p]atients who are Black automatically have points added to their score, which can make results appear more normal than they might be — which in turn, could delay needed treatment."[19] While some hospitals are starting to move away from this inaccurate testing approach,[20] far too many are still relying on it.

"The criteria for who is prioritized on the wait list is not magically generated. It's just made by people on a committee. And most of those people are white."

- Former OPO Executive

Another study reveals the strong bias against Black people when it comes to assessing the "fit" of getting a transplant. The government requires medical providers to fill out a form on whether or not they have talked to patients with kidney failure about options for transplant. If medical providers have not informed the patient about the potential for a transplant, they must choose one of the listed reasons why. In a study from 2011, Black people were 27% more likely reported as "psychologically unfit" for transplant[21] – a nonclinical assessment that has since been replaced with "medically unfit."

Research found "even after adjusting for medical factors and social determinants of health, African Americans were still 25% less likely to be listed for transplantation than Caucasians."[22]

FEWER MEDICALLY SUITABLE ORGANS AVAILABLE FOR PATIENTS OF COLOR

Once patients of color overcome the hurdle of getting on the waitlist, the odds are still against them for getting the organ they need.

While white people on the waitlist have about a 50% chance of getting a transplant each year, the number is closer to 25% for Black people.[23]

One part of the problem is the lack of organs available for transplant from within communities of color. Only about 35% of all recovered organs come from non-white patients, even though people of color make up 60% of the waitlist. Often, but not always,[24] a recipient's most likely match is from a donor of the same ethnicity. This is because there must be some genetic similarities in an organ for it to be a suitable match. And some tissue types are more common within specific ethnicities compared to others."[25]

The chance of finding a match would be significantly higher for people of color if more organs were obtained in the first place. Tragically, estimates suggest organ procurement organizations (OPOs) are recovering "only one-fifth of the true potential"[26] of available organs from deceased patients.

POTENTIAL DONORS OF COLOR LESS LIKELY TO BE REFERRED

OPOs are responsible for coordinating with hospitals to get donor referrals, identifying viable candidates, and talking to families of those candidates to obtain consent. There are 58 OPOs throughout the U.S., each responsible for a designated geographical area. (See OPO Best Practices for more information.)

The first step in obtaining organs is for the hospital to call the OPO, but often the number of referrals is far lower than it should be. This is in part due to poor OPO and hospital relationships and even guidance by OPOs to not call on specific circumstances to avoid reporting on cases when the OPO believes donation is unlikely.[27]

Studies suggest that implicit bias and preconceptions of who is likely to donate disproportionately affect people of color, and that most health care providers "are poor judges of who wants to donate."[28] This contributes to Black patients being less likely to be referred to OPOs by hospital staff.[29]

OPOS NOT SHOWING UP TO TALK TO DONOR FAMILIES OF COLOR

If a hospital notifies an OPO about a potential donor, the OPO then has discretion to decide whether or not to follow up. (OPOs do not respond to all referrals; see OPO Best Practices for more information on this frequent organ loss point.) Again, implicit bias and preconceptions

of who is likely to donate negatively impact people of color when it comes to OPOs following up.

One comparison study that looked at differences in organ donor experiences found Black families were "less likely to have spoken to an organ procurement organization representative,"[30] with previous research concluding "[t]he odds that a family of a White patient was approached for donation were nearly twice those for a family of an African American."[31]

Researchers believe this is where a large percentage of potentially viable organs are wasted, but the exact number is unknown due to inaccurate OPO self-reporting and lack of transparent data. Additionally, research finds that "[d]onation was seen as a powerful diversion from grief and provided 'relief, tranquility and a sense of purpose' [to donor families]"[32] and yet families of color are systematically denied equal access to that vital component of the bereavement process.

FAILING TO GET AUTHORIZATION

When OPOs do follow up with the families of patients of color, the quality of the interaction is often inadequate.[33] A study comparing experiences between Black donor families and white donor families found Black people experienced "less complete discussions about the possibility of organ donation."[34]

Another study found the most common reasons Black families declined to donate were that the OPO did not "give [them] enough time to discuss important issues... or respond to strong emotion with sensitivity and empathy."[35]

This is a missed opportunity, since families who spend more contact with OPOs are shown to be 3 times as likely to donate.[36] Additionally, Black families were often not told about the strong need for organs within their own communities.[37]

One study showed higher organ donation rates for Black people when the OPO staff discussing donation with them was also Black,[38] yet overall OPO staff remains overwhelmingly white.

“One OPO I work with serves a majority-minority city, and doesn’t employ a single person of color in a role dedicated to providing care to families. When I hear people say ‘Black folks don’t donate,’ I think of that office.”

- Researcher

This dynamic affects other communities of color as well – especially when OPO staff doesn’t speak the same language as the donor family. One study suggests “avoiding translators during the approach process may improve donation rates.”[39] And another study found, “ethnicity-matched requestors leads to increases in donation rates among Hispanics as this helps to break down both cultural and language barriers… [But] despite these convincing data, this is not a practice across OPOs.”[40]

In a separate research study,[41] one surgeon and his team identified several barriers for Black people becoming donors:

- Unawareness of the need within their own community;
- A fear of donation going against religious beliefs; and
- A deep distrust of healthcare workers with the Black community, stemming in part by the 1932 Tuskegee Syphilis Experiment,[42] in which Black men were lied to and purposely left untreated in an effort to study the disease.[43] Once the surgeon and his team effectively addressed these issues, all 40 participants in the study signed on to become donors.[44]

“I always hear that Black Americans don’t donate. That’s not true. I was born here as a Black American. We have to keep in mind what Black Americans have gone through [over] the decades. You need experts and people who look like me to talk to these families. There’s a lot of things that might lead to distrust or being offensive.”

- OPO Leader

FINDING A MATCH

OPOs are also responsible for finding a suitable match within the tight timeframe that an organ is viable and getting it to the recipient. To do this, they use a data match system that connects them with transplant staff.

As mentioned earlier, finding a suitable match for patients of color is harder with a smaller donor pool. This contributes strongly to low transplant rates across communities of color.

Some OPOs have tried to tie poor performance numbers to the communities they serve. The Los Angeles OPO, for example, recovers only 3 out of 10 potential donors.[45] In a formal response to the Department of Health and Human Services (HSS), it contended that its poor performance is not its fault because it serves a "*population that is substantially non-white.*"[46]

However, Representative Katie Porter points out in a letter why this excuse is invalid: "Despite having similar patient demographics and challenges, the San Diego OPO recovered 65 percent more donors [than the Los Angeles OPO]."[47]

"[W]hile donation rates are lower among people of color versus white communities, it's not because of some inherent lack of generosity; the real problem is that too often these government contractors do not engage with our communities. They hire blindingly white work forces, and seem completely unwilling or unable to adopt culturally competent practices. OPOs cannot decide that they only have to provide higher quality service for white populations."[48]

- Ben Jealous, former President of the NAACP

As one senior HHS official noted, the most successful OPOs are high-performing because they are effective at serving the constituents within the geographic areas they serve. Conversely, if an OPO is deemed failing, this is highly likely to correlate with that OPO's poor performance in communities of color.

Recent case studies suggest that individual OPOs have the power to rapidly improve outcomes for patients of color. For example, after years of chronic underperformance, the San Francisco OPO hired a new CEO in 2019, who chose to focus on better serving communities of color.[49] Within just one year, the OPO's donation rates increased by 29%, with the gains coming almost entirely from minority communities (see increased donation rates below, broken down by ethnicity):[50]

- White: 16%
- Hispanic: 40%
- Black: 70%
- Asian: 95%
- Multiracial: 27%

HHS has recently proposed new OPO accountability measures[51] to help guide better performance. One of the benefits of these measures is that they incentivize OPOs to invest in serving their entire community, which, as the examples above show, could include hiring more diverse staff and investing more time and resources developing relationships with underserved populations and the hospitals that serve them.

Considering these measures and examples of success from the San Francisco OPO, the following recommendations may help address some of the troubling inequities shown throughout the organ recovery and match process. These recommendations are specifically for Centers for Medicare & Medicaid Services (CMS), the agency that oversees OPOs:

- Ensure better OPO staff alignment with demographics and language spoken in their designated service area.
- Require more frequent and higher quality authorization training for OPOs who speak with families of donors. This training should have a clear focus on implicit bias, and how OPO workers can counter those biases.
- Hold OPOs accountable for the entire communities they serve by finalizing proposed OPO outcome measures and decertifying underperforming OPOs. Require objective and verifiable data on the number and timeliness of OPO staff follow-up, and data on demographics of donor families approached for authorization.

A person's ethnicity should not determine how likely they are to receive an organ they need to survive. OPOs and the organ donation system at large must do better to address the glaring inequities that stand in the way of getting the thousands of people of color the organ they need today.

NOTES

1. This article follows a Black patient's journey from listing to transplant. "Good for Harvest, Bad for Planting," Health Affairs, 2007. ↩
2. "Comparison of black and white families' experiences and perceptions regarding organ donation requests," Crit Care Med, 2003. ↩
3. "Hispanics and Kidney Disease," Kidney.org, 2020. ↩
4. "African Americans and Kidney Disease," Kidney.org, 2020. ↩
5. "Access of Native Americans to Renal Transplantation in Arizona and New Mexico," Blood Purif, 1996. ↩
6. "Role of Ethnicity in Risk for Hepatocellular Carcinoma in Patients With Chronic Hepatitis C and Cirrhosis," CGH Journal, 2004. ↩
7. "Twenty years of evolving trends in racial disparities for adult kidney transplant recipients," Kidney Int, 2016. ↩
8. "An Overlooked, Possibly Fatal Coronavirus Crisis: A Dire Need for Kidney Dialysis," New York Times, 2020. ↩
9. "The Role of Race and Poverty on Steps to Kidney Transplantation in the Southeastern United States," *Am J Transplant*, 2012. ↩
10. "Racial Disparities in Access to Renal Transplantation — Clinically Appropriate or Due to Underuse or Overuse?" _N Engl J Med, _2000. ↩
11. "Race and socioeconomic factors influencing early placement on the kidney transplant waiting list," *JASN*, 1998. ↩
12. *Ibid* ↩
13. _ *"Association of Race and Ethnicity With Live Donor Kidney Transplantation in the United States From 1995 to 2014,"* _*JAMA*, 2018. ↩
14. "Racial and Socioeconomic Disparities in the Allocation of Expanded Criteria Donor Kidneys," *Clin J Am Soc Nephrol*, 2013. ↩

15. "Reduced Racial Disparity in Kidney Transplant Outcomes in the United States from 1990 to 2012," *J Am Soc Nephrol*, 2016. ↩

16. "Impact of Race on Predialysis Discussions and Kidney Transplant Preemptive Wait-Listing," *Am J Nephrol*, 2012. ↩

17. "Reconsidering the Consequences of Using Race to Estimate Kidney Function," *JAMA*, 2019. ↩

18. "A yearslong push to remove racist bias from kidney testing gains new ground," *Stat*, 2020. ↩

19. "A yearslong push to remove racist bias from kidney testing gains new ground," *Stat*, 2020. ↩

20. "A yearslong push to remove racist bias from kidney testing gains new ground," *Stat*, 2020. ↩

21. "Psychologically unfit" has since been removed from CMS' form. The term "medically unfit" remains. "Disparities in Provision of Transplant Information Affect Access to Kidney Transplantation," A_m Journal of Transplantation_, 2011. ↩

22. "Social Determinants of Health: Going Beyond the Basics to Explore Racial Disparities in Kidney Transplantation," *Transplantation*, 2020. ↩

23. "Organ Donation and African Americans," *Minority Health, HHS*, 2020. ↩

24. "Access of Native Americans to Renal Transplantation in Arizona and New Mexico," *Blood Purif*, 1996. ↩

25. "How a surgeon helped solve the problem of far too few black organ donors," _Center for Health Journalis_m, 2018. ↩

26. OPTN Deceased Donor Potential Study (DDPS), 2015. ↩

27. *"Many OPOs have instructed hospitals to NOT call on [to refer] certain patients thus eliminating organ donors before they even get to the OPO."* OPOs do this to tamper with the numbers they have to report as referrals, to avoid documentation of a case if the healthcare providers (HCPs) or OPO anticipate that it will be an unlikely donation. "OPO Best Practices," *Bloom Works*, 2020. ↩

28. "Factors Influencing Families' Consent for Donation of Solid Organs for Transplantation," *JAMA*, 2001. ↩

29. "Comparison of black and white families' experiences and perceptions regarding organ donation requests," *Crit Care Med*, 2003. ↩

30. "Comparison of black and white families' experiences and perceptions regarding organ donation requests," *Crit Care Med*, 2003. ↩

31. "The influence of race on approaching families for organ donation and their decision to donate," *Am J Public Health*, 2009. ↩

32. "Family Perspectives on Deceased Organ Donation: Thematic Synthesis of Qualitative Studies," *Am J Transplantation*, 2014. ↩

33. "Don't Let the COVID-19 crisis delay reforms to our organ transplant system," *Roll Call*, 2020. ↩

34. "Comparison of black and white families' experiences and perceptions regarding organ donation requests," *Critical Care Medicine*, 2003. ↩

35. "A Comparison of the Content and Quality of Organ Donation Discussions with African American Families Who Authorize and Refuse Donation," *J of Racial and Ethnic Health Disparities*, 2020. ↩

36. "Factors Influencing Families' Consent for Donation of Solid Organs for Transplantation," *JAMA*, 2001. ↩

37. "Comparison of black and white families' experiences and perceptions regarding organ donation requests," *Critical Care Medicine*, 2003. ↩

38. "The impact of race on organ donation authorization discussed in the context of liver transplantation," *Transactions of the American Clinical and Climatological Association*, 2012. ↩

39. "Variables such as race and sex of OPO representative and time of day should be considered before approaching a family for organ donation. Avoiding translators during the approach process may improve donation rates." From "Improving organ donation rates by modifying the family approach process," T_he Journal of Trauma and Acute Care Surgery_, 2014. ↩

40. "Rejecting bias: The case against race adjustment for OPO performance in communities of color," *Am J Transplantation*, 2020. ↩

41. "How a surgeon helped solve the problem of far too few black organ donors," *Center for Health Journalism*, 2018. ↩

42. "The Tuskegee Timeline," *CDC.gov*, 2020. ↩

43. A new book, "Organ Thieves," also details the story Bruce Tucker, "a black man, went into Virginia's top research hospital with a head injury, only to have his heart taken out of his body and put into the chest of a white businessman," in 1968. ↩

44. At the beginning of the study, only 2 out of the 40 participants said they would be willing to sign an organ donation card. "How a surgeon helped solve the problem of far too few black organ donors," *Center for Health Journalism*, 2018. ↩

45. Donation rates between 2012 and 2014 (actual donors/potential donors) are 30.9% for Los Angeles & S. California. "Reforming Organ Donation in America," *Bridgespan*, 2019. ↩

46. "A proposal from the Department of Health and Human Services noted that a majority of OPOs were failing minimum compliance standards, and seeks to transform the way OPOs are evaluated. So rather than continuing to deny the problem entirely, OPOs are now resorting to blaming others for their failures — and pointing their fingers directly at communities of color." From Ben Jealous in "Don't Let the COVID-19 crisis delay reforms to our organ transplant system," *Roll Call*, 2020. ↩

47. Letter from Representative Katie Porter to HHS, 2019. ↩

48. "Don't Let the COVID-19 crisis delay reforms to our organ transplant system," *Roll Call*, 2020. ↩

49. As of the time of writing, the San Francisco OPO CEO remains the only Black OPO CEO in the country. ↩

50. Data available via OPTN. ↩

51. "Revisions to the Outcome Measure Requirements for Organ Procurement Organization," HHS. ↩

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