

TRIBUNE SPECIAL REPORT: URBAN EPIDEMIC

The transplant gap keeps more blacks waiting for kidneys

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An occasional series about chronic diseases and their impact on urban communities.

Walk into virtually any urban dialysis center, and chances are a disproportionate number of patients tethered to the machines will be African-American.

The preferred treatment for kidney failure is an organ transplant. But although African-Americans suffer from kidney disease at higher rates than whites, they are less likely to be referred for transplants, less likely to be placed on a waiting list and less likely to get kidneys once on the list, according to a large body of research.

With transplant lists growing, it can be daunting for a person of any race to get a life-sustaining kidney. But many African-Americans face additional hurdles—whether it's piecing together insurance to cover expensive anti-rejection drugs or searching for loved ones healthy enough to serve as living donors.

The result is a glaring racial disparity in which many black kidney patients remain on dialysis, a treatment associated with lower quality of life and higher death rates.

African-Americans account for 37 percent of people receiving dialysis but make up only 19 percent of the transplant population, according to the United States Renal Data System, a government database.

"The question is why—when we know that transplantation is the best treatment option for patients with end-stage renal disease," said surgeon Dr. Clive Callender, director of the Howard University Hospital Transplant Center in Washington.

It's a question that vexes transplant professionals.

"You can explain most of the discrepancy, but you still have a gap that you can't explain,"

said Dr. Robert Gaston, a transplant nephrologist who is medical director of kidney and pancreas transplantation at the University of Alabama at Birmingham.

Gaston, also a board member at the American Society of Transplantation, has studied the issue and says part of the reason lies with the national system that distributes kidneys.

For example, allocation policies seek to match donors and recipients based on their tissue types, to maximize the chances the kidney will not be rejected. But that puts black patients at a disadvantage because they are more likely to find a compatible tissue match with another African-American and a smaller percentage of donors are black.

Changes in recent years have put less emphasis on tissue matches, giving greater weight to factors such as geographical proximity. (Even if organs are not close matches, the powerful immune-suppressing drugs that patients must take for the rest of their lives often can prevent rejection.) That has narrowed the gap in wait times somewhat between whites and African-Americans, Gaston said.

Efforts to increase the number of donors also have been paying off. Callender said 15 percent of organ donors nationally were minorities in 1995. Now it's 30 percent.

But that's still not enough, said Jack Lynch, community affairs director for Gift of Hope Organ and Tissue Donor Network, the agency responsible for distributing organs in northern Illinois and northwest Indiana.

Because African-Americans suffer from higher rates of hypertension and diabetes, leading to higher rates of kidney failure, the need is greater than black donors on their own can meet.

"Minorities make up over 50 percent of patients waiting for transplants while we comprise 25 percent of the population," Lynch said. "That's makes it extremely difficult for us, alone, to be the solution."

Studies have reported that black patients are less likely to desire a transplant, but a recent National Kidney Foundation survey suggests education may erase that gap.

"There was a significant racial difference in who knew of the option at the time they began dialysis," said Gaston, who is writing a paper on the survey findings. "But within the first year of dialysis, once education is provided, the differences disappeared."

That's important because the earlier patients receive a new kidney, the better, said Callender, who founded the National Minority Organ Tissue Transplant Education Program in 1993.

"The longer you stay on dialysis, the less likely you are to have a successful transplant," he said.

Other studies have reported that physicians are less likely to refer black patients for evaluation for a transplant, which can cause a dangerous delay.

A study published in 2004 in the American Journal of Kidney Disease found that nephrologists, or doctors who are specialists in kidney disease, were significantly less likely to believe that transplantation would improve the survival odds of a patient if the patient was black.

Lack of financial resources can be another barrier.

Americans diagnosed with kidney failure are entitled to lifetime coverage of dialysis treatments under the federal Medicare program. But Medicare, which covers 80 percent of medical and drug costs, ends three years after a successful transplant if the patient is under 65 and not disabled. Paying for medication is a concern for Bronzeville resident Emily Nuttal, who has put off trying to get a transplant for seven years because she doesn't think she can afford the drugs. Anti-rejection drugs can range from \$10,000 to \$20,000 annually.

"The medications are a huge cost," said Nuttal, 27, a student at the University of Illinois at Chicago. "It's a lot of pressure worrying about how I would pay for all of it."

Nuttal recently began the process of getting evaluated for a transplant because she is no longer doing well on dialysis. But she remains torn.

"It's really frustrating and a tough predicament to be in," she said.

The kidney foundation and other groups have been pressing Congress to eliminate the three-year Medicare coverage limit.

"If you are economically or socially disadvantaged, it's very challenging," said Willa Lang, president and chief executive officer of the National Kidney Foundation of Illinois.

Lang and her colleagues say they hear stories like Nuttal's all the time. In the biggest bind are people who work and don't qualify for Medicaid, but still can't afford the drugs, Lang said.

Such patients have to be creative in weaving together a patchwork of coverage, she said. Some patients obtain free or discounted medicine through special programs offered by pharmaceutical companies. But eligibility varies, and the programs typically require patients to re-apply every several months.

"To have to worry about how you're going to pay for transplant medications 36 months down the road is a shame," Lang said. "It's cheaper to support someone long-term on transplant than to keep them on dialysis, and you're also sending a productive person into the workforce."

To avoid a long wait on the transplant list, patients of all races increasingly are looking for a living kidney donor. But that can be problematic for black patients, who Gaston said are two-thirds less likely to find one.

Illnesses that can cause kidneys to fail, such as hypertension and diabetes, often run in black families, shrinking the pool of potential donors.

None of Patrick Clark's close family was healthy enough to give him a kidney after he found out he needed a transplant. Clark has high blood pressure, a condition he shares with other relatives, and his brother also undergoes dialysis and is looking for a kidney donor.

Clark has been undergoing peritoneal dialysis five times a day for the last three years as he awaits a transplant.

"Initially, I felt disappointed because you figure in any situation you would be in medically, your immediate family would be able to come to your rescue or be able to help," said Clark, 44, of the Chatham neighborhood. "When I hear about other people who were able to get transplanted, I think, wow, they got theirs, when will I get mine? Sometimes it kind of gets to me."

Research suggests African-Americans fare better on dialysis than other racial and ethnic groups, but Callender said the studies might be skewed because "healthier blacks stay on the machine, while healthier whites get transplants."

"People think it is positive data," he said, "but it's not."

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