

For heart transplant centers, accessibility may matter as much as quality

March 30 2015, by Jalees Rehman



Credit: AI-generated image ([disclaimer](#))

About five million people in the US suffer from heart failure, and approximately half of them [die within five years of being diagnosed](#). Only about 2,500 hundred people a year receive a heart transplant – the treatment of last resort. A new heart can be life-saving, but it is also life-changing. Even under the best conditions, the surgery is complex, and

recovery carries a heavy physical and emotional burden.

And not all [heart transplant recipients](#) fare equally well after the surgery. Researchers [have found](#) that black [heart transplant patients](#) are more likely to die after surgery than white or Hispanic [patients](#).

While many different factors contribute to the disparity, the research indicates that where patients received their [heart transplants](#) played a big role. Black patients were more likely to have their transplants performed at the worst-performing centers.

This is merely one of many examples of [health disparities](#) faced by black Americans. But as a cardiologist, I find this finding especially troubling because many of the [heart failure](#) patients I treat are black.

So how do patients decide where to have their heart transplants performed? And wouldn't a person who needs a heart [transplant](#) choose to go to a top center?

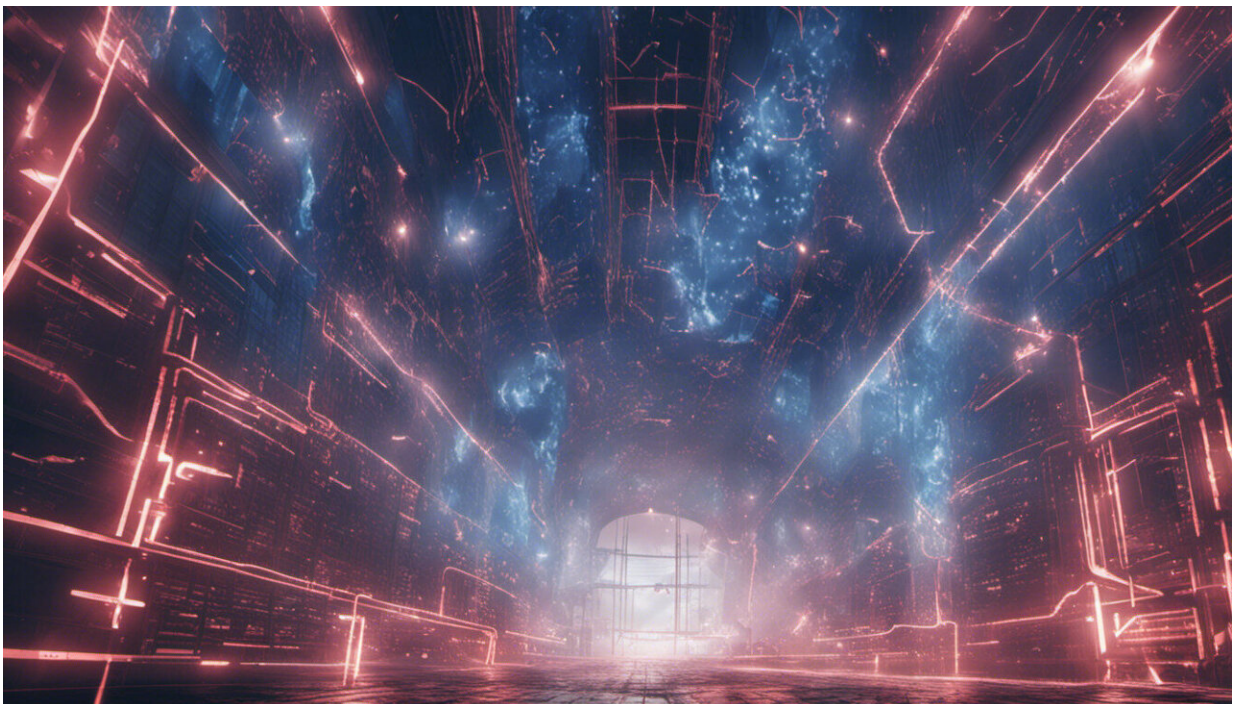
Quality is obviously a major factor. But there is another big consideration in deciding where to get a transplant: accessibility.

Not all transplant centers have the same results

Researchers at Ohio State University [reviewed the records of heart transplants](#) performed at 102 transplant centers in the US from 2000 to 2010. The researchers focused on the rate of death during the first year after the transplant in over 18,000 heart transplant recipients.

They found that black patients had a higher rate of dying within one year of receiving a new heart (15.3%) than either Hispanics (12.5%) or whites (12.8%).

To find out why this was happening, the researchers used a mathematical model to predict the risk of dying within a year after the transplant for every patient based on the severity of their disease and complicating risk factors such as advanced age or reduced kidney function. They then compared the calculated risk with the actually observed death rates. The difference between the prediction and reality allowed them to determine the quality of a transplant center.



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It turned out that a greater proportion of blacks received their heart transplant at centers with higher-than-expected mortality as compared with whites and Hispanics (56.4% versus 47.1% versus 48.1%, respectively).

The contrast was even starker between the top- and worst-performing centers. Blacks had the lowest rate of being transplanted at centers with excellent performance (blacks: 18.5%; whites: 25.3%; Hispanics 28.3%). They also had the highest likelihood of undergoing their transplant surgery at the worst-performing centers.

It turns out that where a person has their transplant is critical. Only 8.7% of [black patients](#) died during the first year after the transplant if they were fortunate enough to undergo surgery at a top center. But this number was more than twice as high (18.3%) for blacks at the worst-performing centers.

The study didn't provide any definitive explanations as to why the majority of blacks underwent heart transplantation at centers with lower than expected outcomes.

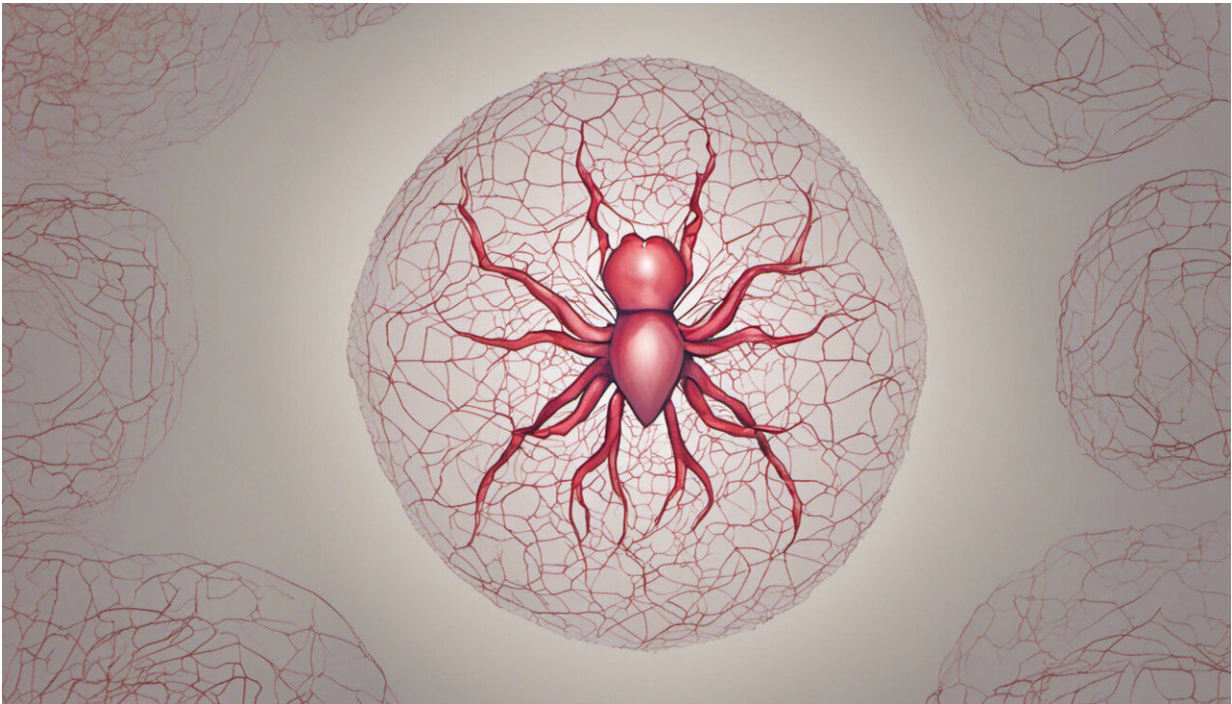
Choosing a transplant center isn't much of a choice

Patients do not "choose" a transplant center by simply looking it up in a catalog or on a website. While performance statistics for each organ transplant center in the United States are publicly available in the [Scientific Registry of Transplant Recipients](#), those statistics are only part of the decision for where a patient will get their transplant. The "choice" is often made for the patients by the doctors who refer them to a transplant center and by the accessibility of the center.

I'm a cardiologist, and in the Chicago area, where I practice, there are five active heart transplant centers. We can show the numbers for the centers to our patients when discussing the possibility of a heart transplant and also provide some additional advice based on our prior experiences with the respective transplant teams. Because our patients are nearly all based in the Chicagoland area, most of these programs are reasonable options for them. However, patients and doctors in cities or

regions that don't have as many transplant centers, or who live in more remote areas may not have the luxury of choice.

Accessibility matters because care doesn't end with the surgery



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Unless you've had a heart transplant, or know someone who has, it's hard to understand just how life-changing the surgery is. I've noticed that many people are unprepared for the emotional and physical toll from the surgery and recovery. And it's this toll that can makes accessibility such an important factor when choosing a transplant center.

After surgery, patients spend a couple of weeks recovering in the hospital. Even when they can go home, their health is closely monitored with frequent lab tests and check ups.

After transplant, patients will start taking medications to suppress their immune systems and keep their body from rejecting the new heart. And they have to stay on these medications for their rest of their lives. This means a lifetime of close monitoring to make sure that their heart is functioning well and that there aren't any complications from the immune suppression.

For instance, during the first couple of months after surgery, patients have heart biopsies, where a small piece of the heart is removed to check for signs of rejection, every one to two weeks. As recovery progresses, biopsies may become monthly. The heart sample is so small that it does not damage the heart, but the biopsy is still an invasive procedure requiring hospitalization. And waiting for results can be stressful.

All of this means heart recipients spend a lot of time during the first year after their transplant seeing doctors and waiting for test results. Being close to a [transplant center](#) is important – it's just easier to get to appointments. But accessibility isn't just about the patient. It's also about their support network. Imagine going through all of that alone.

On a practical level, family members and friends provide rides to the hospital, keep track of medications and doctor's appointments and help with household chores during the recovery period. But what is most important is the emotional support that they provide.

So why do black transplant patients tend to wind up in transplant centers that don't perform as well? Right now, we don't know. Is it because they were referred to these centers by their cardiologists despite other feasible alternatives? What role does the health insurance of patients

play in determining where they receive the heart transplant? Why are centers with a high percentage of black transplant recipients performing so poorly? And most importantly, what measures need to be taken to improve the quality of care?

These are important questions that physicians, public health officials and politicians need to ask themselves in order to address these disparities.

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