Title
Georgia's dialysis crisis: Living, and dying, on a mechanical kidney

Permalink
https://escholarship.org/uc/item/6r49b16j

Author
Palomino, Joaquin

Publication Date
2015-02-27
Georgia’s dialysis crisis: Living, and dying, on a mechanical kidney

In the state with the lowest transplant rate in the US, dialysis clinics fail to refer patients to the organ donation list

Abstract: Below is a version of my thesis that published in Al Jazeera America on 02/27/2015. The story unpacks the cause of Georgia’s dismal kidney transplant rate, and how residents in the southern state—particularly low-income African Americans—spend a disproportionate amount of time on dialysis.

ATLANTA — Three days a week Chardae Sanders, a senior at Kennesaw State University, has excess fluid, waste and toxins filtered from her blood at a for-profit dialysis clinic downtown. She doesn’t flinch when a clinician pokes a needle the size of a coffee straw into her leg; the only part that still seems unnatural is when the clean blood is reintroduced into her body at the end of the treatment. “It’s like when you drink a glass of ice-cold water really fast,” she says. “It feels like a part of you is in the machine, and then you get her back.”

Sanders found out that her kidneys had failed the same week as her 21st birthday, in November of 2007. They had been ravaged by the autoimmune disorder lupus, which she had been suffering from since high school. She’s been on dialysis ever since.

The procedure keeps Sanders alive — there’s no comparable remedy for people whose livers fail, for example. But it’s brutal: Chronic pain afflicts close to two-thirds of dialysis patients, who often complain of fatigue, cramping and nausea. To prevent health complications, doctors recommend a strict diet that regulates patients’ water, potassium and sodium intake. The treatment also restricts movement; most patients on dialysis need to be tethered to a machine four hours a day, three days a week.

Sanders follows her doctor’s orders: She eats well, stays active and is on top of her medication. But she knows that she can’t stay on dialysis forever. While some people spend decades hooked up to a mechanical kidney, the average life expectancy on dialysis is five to six years. Like most patients, Sanders views it as an interim treatment while waiting for a kidney transplant, which is considerably cheaper, adds an average of 10 years to people’s lives and allows patients to resume a relatively normal life.

Whether or when Sanders will receive a transplant, though, is particularly uncertain because she lives in Georgia, which has the lowest transplant rate in the nation. In 2013, less than three percent of Georgians with end-stage renal disease received a new kidney, according to data from the United Network for Organ Sharing. And Emory University researchers found that between 2005 and 2011, people living in some northeastern states were four times more likely to get a transplant than Georgians. As a result, many patients in the southern state spend a disproportionate amount of time on dialysis; they live and die hooked up to the machine.
The problem will most likely become more pronounced in the future, and not just in Georgia. Kidney disease is approaching a state of crisis in the United States. From 1980 to 2009, the rate of people living with end-stage renal disease increased nearly 500 percent nationwide. The number of patients is still climbing, albeit at a slower pace. Meanwhile, after a sharp uptick in the 1990s, the national organ-donor pool is relatively stable and will most likely continue to remain steady, experts say.

As a result, the wait list for a new kidney is growing, and transplants will become more and more scarce. “There’s going to keep being a huge gap [between supply and demand], and people will keep dying waiting for a kidney,” says Stephen Pastan, medical director of Emory University’s kidney and pancreas transplant programs.

The reasons for Georgia’s dismal transplant rate are varied. The Commonwealth Fund, a health-policy research group, ranked Georgia the fifth-worst state for health last year, and poor health can disqualify some from receiving the surgery. A large population of uninsured patients and a shortage of transplant centers also play a role. Dialysis clinics, however, can themselves be a major impediment to receiving a transplant.

Dialysis facilities function as gatekeepers between kidney patients and new organs. By federal law, clinic staff are required to educate patients about transplants and send them to hospitals to be screened for the national waitlist. But in Georgia, clinics often fail to adequately assist patients navigating the transplant process. From 2007 to 2010, nearly nine out of 10 dialysis clinics in the state performed below the national average when it came to transplants, and many continue to do a poor job teaching patients about the life-saving procedure. As a result, misinformation is widespread. It isn’t uncommon for people to think they’re on the transplant waitlist when they’re not, sometimes for years on end, according to researchers. Others believe they have to raise thousands of dollars for post-surgery immunosuppressive medication, a policy abandoned by most transplant centers in the state.

As one Georgian told researchers for a soon-to-be-published paper, “I’m a new dialysis patient and I know absolutely nothing about the transplant process … they don’t say anything about it.”

Lack of funding also contributes to poor dialysis services. About 85 percent of dialysis clinics in the nation and 90 percent in Georgia are for-profit. And past academic studies have found for-profit facilities have fewer resources to offer and significantly higher mortality rates than nonprofit clinics. Nationally, for-profit clinics also tend to employ fewer staff, which has been linked to lower transplant rates.

The problem is compounded in Georgia, which, along with North and South Carolina, has some of the most understaffed dialysis clinics in the nation. As a result, many clinic workers struggle to offer adequate care. “When people’s kidneys fail, it’s often their first time dealing with doctors, let alone so many different specialists,” says Arietta Maney, a former social worker in a Georgia dialysis clinic. “When I was [working in] dialysis my patients needed way more than I could give them; I was just putting out fires.”
Leighann Sauls, director of quality improvement for the Southeastern Kidney Council, a government-funded organization that oversees kidney care in Georgia and the Carolinas, isn’t convinced financial incentives lead to poor care. “When I was dialysis staff I never worried about whether we were for-profit or nonprofit,” she says. “I just did my job.”

In any event, there’s no denying that patients in the southern state suffer due to its low transplant rate. For the past few years, a group of physicians, academics and patients from Georgia and the Carolinas who make up the Southeastern Kidney Transplant Coalition have been trying to make the transplant system more equitable in the region — particularly for low-income African-Americans, who tend to spend longer on dialysis and have worse odds of getting a transplant. “We’re obviously really failing somewhere, and we’re failing the most vulnerable people in the country,” says Teri Browne, a professor at the University of South Carolina and former dialysis social worker.

One of the coalition’s main goals is to increase the number of dialysis patients referred to transplant centers to be evaluated for the organ waitlist, the first step toward getting a new kidney. Between 2007 and 2010, there were 99 dialysis clinics in the country that didn’t refer a single patient for a transplant. A quarter of those clinics were in Georgia, and 10 only a few miles from two large transplant centers in Atlanta.

Jane Hardwick-Triplett, a nurse working with a Georgia transplant center to help improve dialysis referral rates, recently came across one clinic in a mountainous region of Georgia that had only referred two people in three years. Most of its patients were poor and black, and the physician decided it didn’t make sense to refer them. She was told that: “he felt like they couldn’t afford a transplant. … No one has the right to make that decision for someone else.”

Last year the coalition started encouraging low-performing dialysis clinics to send every patient to a transplant center to be evaluated for the waitlist, and preliminary results from the effort look positive, says Emory researcher Rachel Patzer; referrals appear to be increasing.

But some experts think that in order to solve Georgia’s transplant problem, the state first has to fix its obesity, diabetes and hypertension problems — all root causes of kidney failure. That’s a tough task, considering the state is one of the poorest in the nation. “When you go into a grocery store, fruits and vegetables are expensive; fats, sugars and high-fat meats are cheap,” says Titte Srinivas, a nephrologist at the Medical University of South Carolina, adding that poor diet is one of the leading causes of kidney failure. “You can’t help but wonder, where do you even start solving this problem?”

Even for people like Chardae Sanders — who not only eats well and stays active but also has support from physicians, social workers and dialysis clinicians — getting out of Georgia’s dialysis trap is an uphill battle.

Sanders defied the odds once and received a kidney transplant in 2009; a stranger from her parish had donated the organ. She was elated, but the celebratory mood didn’t last
long. A few weeks after surgery Sanders was infected by a water parasite that killed the transplant. She was quickly put back on dialysis. “Imagine you’re on a high, you’re free, no more treatment,” she says. “Then, boom, you’re not free, you’re angry, you’re hurt.”

Shortly after her transplant died, Sanders’ father’s kidneys also failed, due to his unmanaged diabetes. The two wound up at the same dialysis clinic four hours a day, three days a week. Unlike Sanders, her father was unable to adjust to the taxing treatment. He became bitter, withdrawn, she says, and his health deteriorated. He died last March.

Sanders’ mother, Regina, who accompanies her daughter to each treatment, worries that her daughter will meet the same fate. “You hear the buzzers go off and you run back there to make sure it’s not your young one,” Regina says, reading a magazine in the clinic’s lobby. “Every day I’m praying she comes out, because there are people that have gone in and not come out.”

Still, while Sanders knows the odds are stacked against her, she is hopeful that she will survive dialysis. “I want to have kids, I want to get married, I want to do the whole corny white-picket-fence-and-a-dog-named-Lassie thing,” she says. “But I gotta get there first.”

Source List:

- Chardae Sanders, Georgia dialysis patient. csande52@students.kennesaw.edu
- Stephen Pastan, medical director of Emory University’s Kidney and Pancreas Transplant Programs. stephen.pastan@emoryhealthcare.org
- Teri Browne, professor at the University of South Carolina. brownetm@mailbox.sc.edu
- Jane Hardwick-Tripplett, former nurse. jane.hardwicktriplett@emoryhealthcare.org
- Titte Srinivas, nephrologist at Medical University of South Carolina. srinivat@musc.edu