

Final Decisions

Part Two: The Cost of a Life

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HOUSTON – Almost everybody thought Rickey Jendry would be dead by now – the Medicare people he kept calling, the doctors he saw at four emergency rooms, the hospitals that turned him away instead of putting him in line for a heart transplant he couldn't afford.

"I guess they thought I'd just give up, but they kept sending me home to die and I just kept living," he said.

For two long years, Jendry held on.

Then – at one minute after midnight on the day his Medicare was to kick in – he stumbled from his bed to the phone, dialed 911, and asked for an ambulance ride to St. Luke's Episcopal Hospital, where he hopes to get a transplant now that he could pay for it.

When he arrived, doctors rushed him into open-heart surgery and later tethered him to a mechanical pumping device the size of a small shopping cart.

When he woke up, he was finally added to the waiting list.

That was six months ago.

The United Network for Organ Sharing, the federal government contractor charged with making the transplant system as fair as possible, insists that once you're in its database of potential transplant recipients, there's no way you can jump ahead of someone else, regardless of who you are or how much money you have.

Getting to the list, though, is a different story. Patients who have money or good insurance can pay for better healthcare from the start. When it comes time to arrange a transplant, they can shop around – go to transplant centers in different cities for testing. If they pass through each hospital's screening process, their names could pop up whenever any hospital in those areas gets a suitable donor, increasing the chances of getting a transplant quicker.

In Texas, for example, patients seeking some types of transplants could be approved at three hospitals – one in each area controlled by the state's three organ banks. They also could travel to Oklahoma and Louisiana and be approved for transplant there, giving them five or more areas where they would be in the pool of potential transplant recipients when an organ becomes available.

On the other hand, patients without money or insurance – people like Jendry – have to resort to government medical assistance if they are poor enough to qualify. If not, they either raise the funds themselves, or they die.

Nationwide, individual heart recipients paid an average of \$253,200 in 1996 for the operation and follow-up care for the first year, according to Milliman & Robertson Inc., a Wisconsin health care consulting firm that tracks transplant costs. Liver patients were billed an average of \$314,500 per transplant, while kidney patients paid about \$116,100 each.

Then there are the immunosuppressants. The drugs, which trick the body's immune system into accepting the new organ, must be taken for life. Milliman & Robertson estimates that those drugs, plus any follow-up doctor visits, cost heart patients on average \$29,100 a year and kidney patients, \$15,900.

About 90 percent of kidney transplants are covered by Medicare through the federal End-Stage Renal Disease Program, which also pays for anti-rejection drugs for three years after the transplant and the cost of dialysis before.

The government pays for kidney transplants because they are cost-effective: Maintaining one Medicare patient on dialysis costs about \$47,100 a year, more than five times the cost of care for a Medicare patient with a functioning transplant.

Heart and liver transplants, which are no longer considered experimental, are covered by most insurance companies.

But often, transplant patients can't get insurance because of their pre-existing conditions. Or they lose their insurance when they become too ill to work and are unable to make premium payments. Even patients with good insurance may reach their \$1 million lifetime coverage limit before getting a transplant.

Insurers also negotiate price discounts with certain transplant hospitals considered "centers of excellence," forcing patients to move hundreds of miles away to get their transplants, even though there may be an equally qualified hospital closer to home. If they make the choice to stay with a local "unapproved" hospital, coverage is denied.

Like millions of Americans, however, 44-year-old Rickey Jendry was taking his chances. He had a good job at a Houston foundation drilling company, but it did not include insurance benefits. When he suddenly became ill, he was on his own.

Surrounded by his computer, his guitar and photos of his family and friends in his 12th-floor hospital room, Jendry recently recounted the past two years of his life.

He smiled when he told it, but it is a disturbing story of a seriously ill man, showing up in emergency room after emergency room in hopes of finding out why he had trouble breathing and felt nauseated.

One doctor told him he had indigestion. Another was convinced he needed a liver transplant. By the time Jendry was correctly diagnosed with heart disease, it was too late to do much for him.

And without insurance, he couldn't get a referral for the one thing that could save his life – a heart transplant.

Eventually, Jendry's heart became so weak that he could barely walk. His boss set him up in an office job and provided a couch so he could rest whenever he needed.

As Jendry's condition worsened, he couldn't work at all and his medical bills began piling up.

"I lost almost everything I had," he said. "My boss took me in, with a hospital bed and oxygen machine and everything. I couldn't believe anyone would do this."

Later, his boss bought a lot across the street and moved Jendry into a trailer home.

There was a two-year waiting period to qualify for Medicare, a federal government program that provides health care for the disabled and elderly.

“They hope you’ll die,” Jendry said of the Medicare office. “I hate to say that ... but I know it’s true. They couldn’t believe it when I’d call in and tell them I’m still here.”

After all he’s been through, it’s hard to call Jendry a lucky man.

But he is.

He could easily have died on the transplant waiting list along with more than 4,000 others this year. \$150,000 deposit required for a heart transplant at St. Luke’s.

But on Oct. 25, Rickey Jendry got a new heart.

Penny Powers, director of St. Luke’s transplant program, said the hospital’s financial counselors try to work with patients, signing them up for financial assistance programs or pointing them toward organizations that help with transplant fundraising. Sometimes, they refer patients to other hospitals that accept indigent patients for transplant, and they inform all patients that St. Luke’s will not deny emergency care.

But until he patient makes the deposit, no transplant.

Patients like Rickey Jendry know the system and how it works.

“When I got to St. Luke’s, the doctors told me, ‘What took you so long to get here? We wouldn’t have let you die!’” Jendry said. “But they don’t understand. There’s a whole process you have to go through. I was trying to do things right.”

“Transplants are expensive. Health care is expensive,” Powers said. “There is some question as to whether you can actually offer everyone the latest technology. But when someone has a heart transplant, they can go back to work and have a relatively normal, healthy life. In a way, that’s much more cost-effective than treating them for a lifelong heart illness.”

Dr. Pat Wood, who oversees Houston’s liver transplant programs, said the same is true for his patients.

“A dead patient is a cheap patient. That’s the problem,” he said. “If you just look at the numbers, liver transplants are much more expensive than letting people die – *if* they were to die right away.”

But with 85 percent to 90 percent of his patients returning to work or school after their transplants, Wood said the surgery can be cost-effective.

So patients race against death to raise funds any way they can, getting their churches to host spaghetti dinners, selling raffle tickets, or placing donation cans in grocery stores.

The Internet is filled with pleas from people like Terry Jones of Sugar Land, who is trying to raise \$100,000 to finance his liver transplant, and Daniel Andrews of Cypress, who seeks \$50,000 for his. They are among dozens of Texans and hundreds of people throughout the country who have resorted to cyberspace to reach would-be contributors. They post their photos and a short biography and beg strangers to send money.

“People are so desperate,” said Cathy Goodrich of the National Transplant Assistance Fund, a nationwide organization that helps with fundraising. “Even people who were well-to-do once have a hard time funding transplants. They have to quit work because they’re sick. Then they lose their insurance benefits, then they end up giving up their house.”

“They call us and say, ‘The hospital wants \$50,000 upfront before my husband can get on the waiting list.’ Unless you’re rich, who can pay that?”

“These people have no place else to go,” added Ellen Gordon Woodall, a Missouri City woman who took to the streets to finance her own liver transplant 12 years ago and now helps other patients do the same through her nonprofit American Organ Transplant Association.

“Liver patients come to me and they’ve been to a Houston hospital and they say, ‘They won’t take me unless I have \$350,000. I don’t know what I’m going to do.’ And I say, ‘I know what you’re going to do. You’re going to go to Baylor in Dallas. They’ll do it for \$150,000.’”

“There is no excuse for the unadulterated greed. How can Baylor do a liver transplant for \$150,000 and Hermann Hospital needs \$350,000?” asked Woodall, an outspoken critic of the transplant system.

“If you don’t have the money, you don’t get on the waiting list. They will turn you away. These people will let you die instead of telling you to go around the corner and get the surgery for \$200,000 cheaper.”

Arden Biggar, controller for revenue operations administration at Hermann Hospital, strongly rebutted Woodall’s figures, saying the hospital charges \$150,000 to \$172,000 for all but the most difficult liver transplant cases.

“That might be an aberrant case, but it is certainly not the norm,” she said. “And in almost every case, there is a big difference in what we charge and what we are able to collect.”

Biggar insisted no one is denied a transplant at Hermann because he cannot pay for it.

“They may come in with an inability to pay, but our financial advisers work with them and try to find a way to finance their transplant,” she said.

“We try to negotiate (with managed care companies) to cover our cost, but we haven’t had to limit our access. We probably lose money on kidneys. On livers, we break even or do a little better,” she said. “But lack of money has not been a deterrent to getting a transplant here.”

While some hospital administrators downplayed the role of money, several Houston transplant surgeons – and many would-be transplant patients – said ability to pay is given serious consideration. Money plays a role both before patients are referred to the hospital and once they reach the hospital’s review committee, which makes the final decision on whether to add their names to the waiting list.

“Oh year, there’s no question,” said famed heart transplant pioneer Dr. Denton Cooley, when asked if patients have to prove their financial worth before making the waiting list.

Cooley, who performed the country’s first successful heart transplant at St. Luke’s in 1968, said surgeons often donate their services to advance the field of transplant medicine and to help patients who can’t afford the surgery.

“I never got paid for a single transplant. I did it for the same reason I got into medicine – to help people who were sick,” he said. “Mother Teresa isn’t the only one who ever lived who helped people.”

Hospitals aren’t always so generous, though, he said. After his team had done about 15 transplants that first year, Cooley said he got a call from an accountant in the hospital administrator’s office.

“He said that I personally owed them \$425,000 because that’s what he said the hospital lost on the transplant program. They thought I owed them! That idiot expected me to pay,” he said.

“You know what I told him? I told him the amount of publicity the transplant program has brought to the hospital, Coca-Cola would pay \$15 million for it. I told him that without the transplant program, St. Luke’s would be just another community hospital.”

But Cooley agreed hospitals do lose money on some transplants.

“They might tell the patient he has to raise \$50,000, but the transplant may cost the hospital \$75,000 or \$100,000. It’s not a big moneymaking program,” he said. “The follow-up care, after the transplant, they can make something off of that. But it’s like a baseball game – you lose money on the peanuts but you make it up on the popcorn. What it gives the hospital is prestige.”

Dr. George Noon, a transplant surgeon at Methodist Hospital, agreed.

“Initially some hospitals could transplant a lot of patients, but now there are so many on the waiting list,” he said. “There’s a limit to how many free transplants we can do.”

It’s unfair that anybody should be denied appropriate, needed medical care just because they are poor, said UNOS president Dr. Lawrence Hunsicker. “And I think it is particularly unfair if people are asked to be donors but could never have been recipients because they couldn’t pay,” he said.

But it isn’t UNOS’ job to police hospitals that deny transplants based on finances.

“And I cannot fault the hospitals that say they can’t do transplants for free,” Hunsicker said. “If they did, then everybody would go there and they’d go broke and have to shut down.”

Wood, who also is a UNOS committee member, said that with such a shortage of organs, hospitals are justified in screening out patients who can’t pay – especially in the case of liver transplants, which can range up to \$500,000 for the sickest patients.

“It’s suicide to transplant people who can’t afford the transplant,” he said. “If they can’t afford the transplant and they can’t afford the immunosuppressants after transplant, the organ is going to be wasted.

“That’s two lives that are lost – this person’s and the person who would have gotten that organ if the first patient didn’t get it.”

While he would like to see the cost of transplants and anti-rejection drugs reduced so more people could afford them, Wood criticized efforts by managed care companies and hospitals to contract for transplant services.

“If they tell the hospital they are willing to pay \$100,000 for a liver transplant, that shifts the risk onto the doctors and the hospitals. Then only relatively healthy people will get transplants and we’ll have to let the rest die. Because of the organ shortage, those relatively healthy people can’t get a liver until they are really sick, so they die, too.”

Woodall, founder of the transplant advocacy group, said hospitals and insurance companies unfairly abandon sick people who cannot pay their bills. But she said patients also are to blame.

Some have known for years they would need a transplant but wait until they are desperate to figure out how to pay for it, she said. Too many put a price tag on their own life and decide against a transplant so that their families aren't left hundreds of thousands of dollars in debt.

"By the time they come to me, they're scared. Now they're turning yellow. They're itching. Their brain is not working. And they're telling me, 'I can't ask anybody for money,'" she said. "I say, 'You don't have a choice. If you don't ask for help, you're going to die.' I ask them, 'Do you want to live? Do you want to see your grandchildren? Do you care? If you don't do this, you're gonna die. You get your butt out of your chair and do it.'

"A lot of people get angry with me and my tone of voice, but sometimes you've got to be verbal and aggressive," Woodall said. "If I hadn't been, I'd be dead."