

Doctors, patients debate ways to increase organ donation

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Michael Molinaro of Wheaton didn't want to play the odds.

When Molinaro's kidneys failed after a lifetime of type 1 diabetes, his doctors told him he'd probably have to wait five years for a transplant.

Several family members volunteered, but none qualified as a donor. Meanwhile, three days a week, Molinaro spent four hours tethered to a dialysis machine - treatments that drained his energy.

"It just takes so much away from the quality of life," Molinaro said.

Instead of feeling helpless, Molinaro decided to improve his chances. He spent about \$500 to buy a lifetime membership to a Web site that helps match organ recipients with living donors.

"Being away so much and lethargic after dialysis is very difficult on my family, especially my 13-year-old daughter and wife," Molinaro wrote in his ad on MatchingDonors.com. "My desire is to live a more normal life."

Within two months, a woman from Ohio offered a kidney, only to be disqualified after a series of medical tests. A week later a Plainfield man stepped up.

On July 13, 2006, doctors at Northwestern Memorial Hospital in Chicago transplanted one of his kidneys into Molinaro.

An organ market

The United States' system of organ procurement is rooted in altruism, the decisions that individuals make to donate their own or a loved one's organs to save a stranger's life.

But relying purely on altruism isn't supplying enough organs to meet the demand. More than 95,000 people are on the national waiting list, according to the Organ Procurement and Transplantation Network. Roughly 6,700 die each year.

That's about 16 people dying every day.

The desperation of the wait list was highlighted earlier this year in a Dutch reality show that was to feature a dying woman choosing a recipient for her kidneys. At the last minute, producers revealed the show was a hoax.

Some of those waiting for organs expand their options online, searching for live donors like Molinaro did. Some go abroad; transplant surgeons in the Chicago area say every year, a few patients come back from China, India, Pakistan or the Philippines with new organs - and sometimes serious infections.

In light of the dismal statistics, some U.S. transplant doctors are urging lawmakers to be more open to financial incentives.

It's illegal to pay for organs in the U.S., but in 2002, the American Medical Association issued a resolution calling for a study into whether "modest" financial incentives would encourage more people to donate.

Lawmakers in Pennsylvania proposed a pilot program to reimburse donors' families \$300 for funeral expenses.

In the case of living donors, a University of Chicago economist a few years ago calculated the price of a kidney is \$15,000. A liver: \$30,000.

Some doctors say it's only a matter of time.

"A market in organs is way past due," said Dr. Raymond Pollak, a former transplant surgeon who now is director of medical trials at Edward Hospital in Naperville.

Pollak was one of four transplants experts to debate the merits and dangers of a marketplace for organs at an event last month sponsored by the National Kidney Foundation of Illinois.

Pollak argued in favor of paying families for cadaver organs to increase the supply. People already buy and sell other body parts, including blood, tissue and sperm, Pollak said.

"What's more ethical, to use the organs of people who are going to die anyway, or to let people die on the waiting list?" he said.

But retrieving more cadaver organs wouldn't fulfill the need, said Dr. Lanie Ross, a medical ethicist at the University of Chicago. And paying living donors for organs raises a host of thorny ethical issues, she said, including whether it unfairly exploits the poor.

Scientists have little data on the long-term health of living donors, Ross said.

"Thousands are dying, but we have to think about the donors, too," she said.

In Iran, where the government pays donors for their organs, donors don't fare well, said Dr. J. Richard Thistlethwaite, a transplant surgeon at the University of Chicago.

Despite receiving money for an organ, 79 percent of donors could not afford follow-up health care visits, Thistlethwaite said. The stigma associated with selling your organs was so strong that 98 percent did not want to be identified as organ donors.

That stigma doesn't exist with altruistic organ donors, he noted.

What has more support, Thistlethwaite said, is covering the expenses of donors and doing a better job of ensuring their long-term health.

"I believe in the transplant community there is support for paying for lost wages," he said. "Most of us support paying for health insurance for them."

If it were up to him, people wouldn't have a choice; once you die, your organs would become available for transplant.

Presumed consent is already the model in some countries, including Spain and Belgium.

Reciprocity

All of those proposals have a common problem, according to Dave Undis.

At this point, they're mostly rhetorical. They all require politicians to pass new laws.

"From a political standpoint, it's a nonstarter," he said.

Undis thinks he has a better idea. The former insurance broker was struck by the fact that people can receive an organ even if they hadn't registered to donate themselves.

So Undis founded LifeSharers, a nonprofit Web site in which people sign a contract saying if they die, they'll donate their organs first to other people who are members of LifeSharers. If none is a match, the organs go to the top person on the national waiting list.

You have to be a member at least six months before you're eligible for a transplant.

So far, that hasn't happened to anyone. LifeSharers has 9,300 members, of whom 52 are on the transplant waiting list. Undis hasn't calculated how membership improves your chances of finding a donor.

"Every time we add numbers, that probability goes up," he said. "The chance to improve your odds even a little could mean the difference between life and death," he said.

Dozens of people in the Chicago area have already joined LifeSharers, including Catherine Rajcan, a court reporter who lives in Wheaton.

Before she heard of LifeSharers, Rajcan supported organ donation, but she likes the idea of being able to designate a recipient for her organs.

"I think people have a right to have some say in where they'd like their organs to be donated," she said. "It's our bodies."

Growing demand

Web sites like LifeSharers and MatchingDonor.com elicit ethical complaints that organs should go to the neediest patient, not the one with the best online plea or access to the Internet. Doctors at one Chicago-area hospital refused to perform Molinaro's surgery on ethical grounds.

In terms of logistics, LifeSharers would add another layer of bureaucracy in the time-pressed process of matching organs to needy recipients, said Kim McCullough, spokeswoman for Gift of Hope Organ and Tissue Donor Network.

"It adds extra time to go through those lists of names," she said.

The organ shortage is not so much a problem of too little supply; the number of organ donors has actually grown steadily. It's just that the number of patients eligible for organs has mushroomed much faster.

In the past six years, the waiting list has grown from 75,000 people to over 96,000.

Conditions that used to kill patients at a young age, such as cystic fibrosis, now can be medically managed to the point where such patients become eligible for organ transplants. And rising rates of obesity, high blood pressure and diabetes have driven more people into organ failure.

Any discussion about improving the transplant system ought to include preventing disease in the first place, Ross said.

"Maybe one of the reasons we have such a large gap is because we haven't done a good job in prevention," she said.

Some reforms are already under way. In 2006, Illinois Secretary of State Jesse White established a new, stronger donor registry. In the old system, families could decline to donate their loved one's organs even if that person had registered as an organ donor. The new registry is a legally binding document that does not require family members' consent.

"Before the introduction of the new registry in Illinois, we found families overturned their loved one's intent to donate about 20 percent of the time," McCullough said.

"That translates to about 100 transplants that could have taken place every year," she said.

In Illinois, 250 to 300 people die every year waiting for transplants.

Since the new registry opened, more than 2.3 million have signed up, compared to 6 million in the old registry.

"The challenge we have is most people wait until they go in to renew their driver's license," McCullough said. "That only takes place every four years, so we're trying to encourage people to take advantage of the online registration."

Illinois residents can register at www.ilsos.gov/organdonorregister/.

Gift of Hope's goal is to ensure consent for every donation that's possible, McCullough said.

It's a system that continues to rely on the kindness of strangers.

In one sense, that's no different than Molinaro, other than the direct appeal in his case.

Molinaro's donor did not wish to be identified, and has had only limited contact with Molinaro since the operation.

"He's a very religious person of faith," Molinaro said. "His goal was to help somebody. He didn't care who it was, he didn't care what they looked like, what their story was. He just wanted to help."