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The Difficult Ethics of Organ Donations From Living Donors

A woman wanted to donate the kidney of her dying husband. And that raised all sorts of hard questions.

Michele, Kim, Daniel, Kathy and Robert Osterrieder in University Park, Pa., in 2008. In 2012, the family became involved in a transplant case that raised a difficult issue with which the organ-donation community is still wrestling. *PHOTO: OSTERRIEDER FAMILY*

By **AMY DOCKSER MARCUS**

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Robert Osterrieder, a 52-year-old project manager, returned home to Pittsburgh from a business trip complaining about problems with his vision. Two days later, he was in the hospital on a ventilator.

For the next five months, Mr. Osterrieder fought for his life. His brain swelled, and he underwent numerous medical procedures. He struggled with pneumonia and needed a feeding tube. Finally, as he lay in the hospital unconscious and with little likelihood of recovery, his family decided to remove his life support. But first, they wanted him to become an organ donor.

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Organ transplants are based on a longstanding rule: You can only take vital organs—a heart, for instance, or both kidneys—from someone who is dead. And removing any organ cannot be the cause of the donor's death.

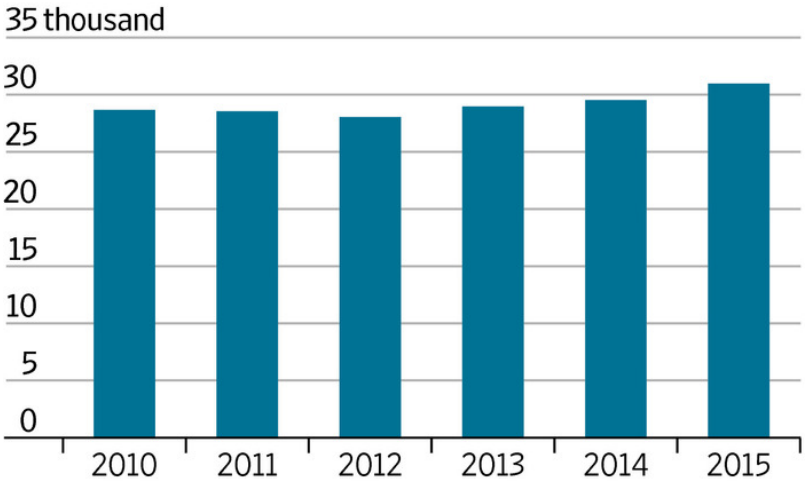
Doctors told the family they expected Mr. Osterrieder's heart to keep pumping for more than an hour after his life support was removed. By the time he died, doctors believed, his organs would no longer be viable for transplantation. That seemed to rule out donating his organs after death. His wife, Kathy, their three children, and their son-in-law decided they wanted to do something else. They proposed that Mr. Osterrieder serve as a living organ donor—even though, unlike a typical living donor, he couldn't directly articulate the decision.

On his driver's license, Mr. Osterrieder had listed himself as an organ donor. He gave blood routinely. At the family's church and at work, Mr. Osterrieder was known as the "go-to guy," his son, Daniel, recalls—the first to volunteer, always willing to help. Amid the difficult decision to remove the ventilator, the prospect of saving someone else's life in the process offered a sliver of comfort. If Mr. Osterrieder likely wouldn't be able to donate any of his organs in death, the family asked, then why not let him donate a kidney as the final charitable act of his life?

It was an idea that raised ethical questions that continue to challenge the organ-transplantation system.

Limited Supply

The number of transplants performed annually in the U.S. has edged up slightly in recent years



Big Need

The number of people awaiting transplants at a given time is far greater than the number of transplants performed in a year. Waiting-list candidates as of June 14:

Kidney	99,803
Liver	14,675
Heart	4,096
Kidney/pancreas	1,911
Lung	1,429
Pancreas	982
Intestine	270
Heart/lung	44
Total	120,566*

*Total candidates are less than the sum of the separate categories due to candidates waiting for multiple organs.

Source: Organ Procurement and Transplantation Network

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The family proposed that doctors put Mr. Osterrieder under anesthesia and perform surgery to remove a kidney for transplant. Like any living donor, he would be expected

to survive the procedure. Then, a few days later, the ventilator would be removed and he would be allowed to die.

"Just the feeling something good would come out of this helped us," says Kim Shuster, 31, one of Mr. Osterrieder's daughters.

Surgeons are wary

A labyrinth of federal and state rules and regulations, as well as those of individual transplant centers, guide organ procurement. The family met with the hospital's ethics committee, spoke with doctors and talked among themselves. Everyone wanted to make sure the choice reflected Mr. Osterrieder's wishes, but there was also discussion about how the family might feel if their decision made news and strangers, not to mention relatives, criticized them.

Kathy Osterrieder says she, her children and son-in-law all agreed, "if any of us are not on board, we won't do this." Whatever happens, she told them, "we have to survive as a unit."

The ethics committee gave its approval, and the hospital reached out to the federally designated organ-procurement service that helps coordinate donations in the region. The organization's leaders were moved. But when they put out a call to 14 different transplant centers to find a surgeon to perform the operation, "we could not find a surgeon who was willing," says Kurt Shutterly, chief operating officer of the Center for Organ Recovery and Education, based in Pittsburgh.

The surgeons didn't feel it was ethical to remove Mr. Osterrieder's kidney without his direct authorization, Mr. Shutterly recounts. They also worried, he says, that if a living donor died soon after the procedure, it might jeopardize an institution's entire transplant program.

"It was crushing," says Daniel Osterrieder, 29, when the family learned about the decision. Robert Osterrieder's ventilator was removed shortly afterward. He died 48 hours later; none of his organs could be donated.

Still arguing for changes

The Osterrieder case took place in 2012, but it raised an issue with which the organ-donation community is still wrestling. Kathy Osterrieder continues to advocate for rule changes, regularly speaking about her family's experiences to doctors, nurses and organ-donation professionals. The case has been cited in a New England Journal of Medicine article and presented to the ethics committee of the United Network for Organ Sharing, which administers the national organ-transplant system for the federal

government and sets policies for procurement organizations.

Robert Osterrieder in Sudbury, Canada, during a 2010 trip. *PHOTO: OSTERRIEDER FAMILY*

At Hartford Hospital in Connecticut, inquiries by families about living donation before withdrawal of life support recently prompted the hospital's organ-donation committee to study the feasibility of the concept. There was an emerging outline of what a policy might look like—the request needs to come from the family, not the doctors, and the person must already be a registered organ donor—but concern arose about moving forward without the approval of UNOS. "Right now," says Patricia Sheiner, Hartford Hospital's chief of transplantation surgery, "if someone asks, we have to say no."

Earlier this year, an Organ Procurement and Transplantation Network and UNOS working committee wrote a report about the ethical considerations of a type of "imminent-death donation," in which a living donor through a surrogate donates an organ before the planned withdrawal of ventilator support. The committee found that, under certain circumstances, the practice may be ethical, but some people who read the report expressed significant enough concerns that the committee determined, for now at least, that it didn't want to move forward with trying to change UNOS policy. The report is expected to be posted soon for public comment.

"It is powerful to think that someone at the end of life, who has suffered a lot of illness, would want to do something to help someone else by being a living donor," says Peter Reese of the University of Pennsylvania, chairman of the OPTN/UNOS ethics committee.

And yet, despite the fact that offering an organ is an exquisitely personal decision, transplantation is a highly communal process, from the involvement of many medical disciplines in the extraction of the organ to the decision about who receives it. "If all those people don't agree and we try to push this forward, we run the risk of undermining the whole enterprise," Dr. Reese says. "Organ transplantation requires public trust to a massive degree."

Growing importance?

Robert Truog, director of Harvard Medical School's Center for Bioethics and an intensive-care doctor who has been involved in many organ-transplant decisions, says the issue's importance will continue to grow as people insist on more control over how they die. "One way they want control is the opportunity to help others as part of their own dying process," he says. By giving individuals and families greater ability to postpone death, he adds, "technology has sharpened this debate."

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Dr. Truog says in his view, the key ethical issue is "whether they will be harmed by donating the organs and whether it is their request to donate the organs." But Neil Wenger, chairman of UCLA Medical Center's ethics committee, says it isn't always easy to determine "whose preference is being followed: the patient's preference or the surrogate's preference?" Dr. Wenger's team published a 2004 paper about a case in which the family of a 20-year-old firefighter who collapsed from a brain hemorrhage wanted to donate a kidney to a first cousin and then withdraw ventilator support. The ethics committee struggled with the request, Dr. Wenger says, especially since the firefighter wasn't a registered organ donor. But ultimately, the panel approved the transplant, believing it was in keeping with the way the patient had lived his life.

"We believed if he had the chance, he would definitely want to consent under these circumstances," says Dr. Wenger, "which for some people is a leap of faith that is unconscionable and for others a reasonable extension of the way we approach these cases."

Drawing the line

Joseph Darby, who previously treated Mr. Osterrieder in the intensive-care unit and is the leader of the institutional organ-donor support team at UPMC Presbyterian Hospital in Pittsburgh, says he supported the family's request to donate a kidney before withdrawing life support. Under certain circumstances, he says, he would go even

further and allow not just donation of a single kidney but vital organs, too.

"I have been thinking about this for a long time," Dr. Darby says. "In cases where you have a person who is committed to death by family deciding to withdraw life support, the question is what would be so wrong about doing the same but taking the organs prior to death? Is there something fundamentally unethical about that since it doesn't serve your own interest and you die in the process, but you've done something laudable and courageous for another person?"

Today, Daniel Osterrieder says his view about cases like his father's is, "Anything he could have donated healthy walking in there himself, we saw no reason why he couldn't donate that on his death bed." But taking two kidneys, a heart, organs vital for survival? Even knowing his father was going to die shortly afterward anyway, such a situation, Mr. Osterrieder says, feels wrong. "That," he says, "is where I personally draw the line."

The Osterrieders say they still reflect on their experiences with their husband and father, in life and death, when thinking about the ethics of organ donation. Robert Osterrieder, one of nine siblings, loved the outdoors and was an avid fisherman. He used to take different family members on trips to Maine, hiking part of the Appalachian Trail. One summer as teenagers, Daniel and Kim, along with their father and other family members, went hiking in one of Robert Osterrieder's favorite spots. They climbed Mount Katahdin, crossing the tricky and aptly named Knife's Edge together. It is the kind of place that reminds you of how difficult it can be to navigate so close to the edge without falling off.

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