HEALTH SENSE

On the border of life and death

A new kind of organ donation raises a hard question:
When does life truly end?

By Judy Foreman, Globe Staff, 3/13/2001

As it turned out, that meant waiting 10 extra, agonizing hours. When the ventilator was finally withdrawn, Paula breathed raggedly on her own for about 15 minutes, then her heart stopped. As the family said a quick, last goodbye, Paula’s body was rushed to the operating room.

"It was a long day," recalls Kerrie. "We wanted it to end for her."

Paula Harrington had joined the small but growing ranks of patients called "non-heart beating" donors. Unlike the roughly 6,000 people a year who donate organs after being declared brain dead (that is, their brain has irreversibly ceased functioning), non-heart beating donors are people whose ventilators are withdrawn while they are still alive because their prognosis is hopeless.

They are then declared dead after their hearts and lungs stop functioning, which usually happens in minutes after the ventilator is withdrawn but can take longer. After the declaration of death by a doctor, their organs are removed for transplantation.

So far, only about 500 people have become non-beating heart donors since the practice began in the 1990s, but the numbers are expected to rise as more and more hospitals write and adopt guidelines for this kind of organ donation. In the last eight years, 122 of the nation’s 261 transplant centers have performed at least one of these transplants.

The possibility of a new source of organs for transplant is
appealing because it might alleviate a small part of the shortage of donor organs. In the United States today, a record 75,000 people are waiting for donated organs, with fewer than 20,000 organs likely to become available this year. In fact, every day, 15 people on average die for lack of an organ transplant.

But the emergence of a form of organ donation where the donor’s heartbeat and breathing have stopped but he is not brain dead unsettles some ethicists and philosophers, and it has made the procedure vulnerable to bad publicity.

Sometimes, families permit the patient to be whisked, still alive and still on the ventilator, to the operating room for organ recovery. Only in the OR is the ventilator removed, the heart and lungs stop, and the patient can be declared dead.

That borders on "ritualized surgical savagery," contends George Annas, professor of health law at the Boston University School of Public Health. "Often, the family likes to be with someone when they die, even if they’re in a coma. They can hold hands; it’s a quiet, calm thing."

If the patient is taken off to die in the operating room, it makes death "more technical and impersonal," says Annas. "This might be justifiable if you could save a lot of lives this way, but you can’t. No one expects non-heart beating donation to have a major impact on the organ shortage."

A more problematic question is this: When is a non-heart beating donor really dead? How long do doctors have to wait after heart and lung function have ceased before deciding that the patient will not spontaneously revive?

At the University of Pittsburgh, death is declared if there has been no spontaneous heartbeat or respiration for two minutes after heartbeat and respiration have stopped. At many other hospitals, doctors wait five minutes, the time period also specified in a 1997 report by the Institute of Medicine, an arm of the National Academy of Sciences.

From the point of view of organ donation, every minute counts, notes Kevin O’Connor, director of donation services at the New England Organ Bank. After a potential donor’s heart and lungs stop working, blood ceases to flow through the kidneys and other organs. Kidneys should be removed for donation within an hour, and they can be stored for only 72 hours before being implanted. (Hearts are not recovered from non-heart beating donors because they are not likely to regain function; livers can sometimes be
In truth, there is simply no good evidence on how long after the heart and lungs stop, a person should be declared dead, notes Dr. Bob Arnold, a medical ethicist at the University of Pittsburgh School of Medicine.

But the lack of uniformity in protocols across the country means that, at least in theory, there could be two similar patients whose hearts have stopped. In one case, doctors might perform cardiopulmonary resuscitation, or CPR, and in the other, they might start recovering organs, says Dr. Walter Robinson, a lung specialist at Children’s Hospital in Boston and a medical ethicist at Harvard Medical School.

Ethicists also worry that the growth of non-heart beating donor protocols may harm public trust in organ donation, something that’s not great to start with. For instance, about 7,500 people every year are declared brain dead and medically suitable as organ donors. Yet, for various reasons, families agree to donate organs only half the time, Arnold says, even though there is no question that the patient is really dead.

With non-heart beating donors, ethicists worry, if there were the merest perception that patients were not really dead or that they were being prematurely withdrawn from ventilators to recover their organs, that fragile trust could be eroded.

"There has to be a separation of the rationale to withdraw care from the indication to recover organs," says Dr. Francis Delmonico, director of kidney transplantation at Mass. General and medical director of the New England Organ Bank.

Some ethicists worry about the trend toward giving certain medications to a dying patient for the purpose of preserving their organs for someone else. In general, medicine is supposed to be given to a patient only if he or she might benefit. The medications at issue - blood thinners and blood vessel dilators - probably don’t harm a dying patient and they clearly help maintain circulation to the organs. But this issue of medication in non-heart beating donors is so thorny that the Institute of Medicine says it should be resolved on a case-by-case basis with the family’s consent.

The bottom line, says Dr. John Potts, director of research at Mass. General and the head of an Institute of Medicine panel that probed these issues in 1997, is that "there are no villains in this piece."

The key, he believes, is to ensure that organ donation, important as
it is, not be allowed to cloud either the actual events around the
death of a patient or, almost as important, public confidence that
the need for organ donation is not being met at the expense of the
dying patient or the sensitivity of the family.

The Harrington family seems to agree with that. One of the
patients who received a kidney from Paula Harrington rejected the
organ and is waiting for a new transplant. The other is doing well.

The knowledge that, out of their tragedy, a life was saved is very
consoling. Says Kerrie: "'None of us has ever had a second
thought.'"

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