THE NEW TRANSPLANT REVOLUTION

A rise in transplants that improve lives rather than save them is filled with promise and ethical dilemmas

BY ALEXANDRA SIFFERLIN

Patrick Hardison, 42, received the most extensive face transplant ever, after suffering massive burns as a volunteer firefighter

PHOTOGRAPH BY MARK MAHANEY FOR TIME
For four years, Thomas Manning felt like the luckiest guy in Massachusetts. His misfortune began on a winter afternoon in 2012, when the then 60-year-old bank courier slipped on black ice and a dolly full of packages crashed onto his groin.

At Massachusetts General Hospital, where he was taken for treatment, things became even worse: a doctor examined him and found a lump on his penis. “He looked at me and said, ‘You have cancer,’” Manning says. Following a biopsy, doctors confirmed that Manning was one of the roughly 2,000 U.S. men to be diagnosed each year with penile cancer. To stop the cancer from spreading, his penis would have to be amputated.

Manning’s life changed overnight. He could no longer go to the bathroom standing up, he had to wear a rubber condom while recovering from surgery, and even though he was interested in finding a girlfriend, he couldn’t imagine throwing himself back into the dating pool. “What guy is going to go out and date with this kind of injury?” he says.

Faced with the intolerable, Manning asked his doctor for the unimaginable. “My doctor thought I was crazy, but I said, ‘Listen, I want to live. I want to feel a baby move,’” he says. Soon after McFarland appeared in a press conference about the surgery’s success, the uterus had to be removed because of an infection.

Recent Quality-of-Life Transplants

Breakthroughs in some surgeries aimed at improving quality of life—such as a penis transplant, a uterus transplant and a bilateral hand transplant—have had mixed results so far in the U.S. Experts say that in some cases, that’s the price of being first.

Thomass Manning

After losing his penis to cancer treatment, Manning, 64, became the first man in the U.S. to receive a penis transplant.

Manning’s doctors at Massachusetts General Hospital estimate that the risk that his body will reject the organ is 6% to 18%. “I am not giving it back,” says Manning.

Lindsey McFarland

Born without a uterus, McFarland, 26, became the first woman in the U.S. to receive a uterus transplant.

The surgery’s success, the uterus had to be removed because of an infection.

Even when the risks are explained, it doesn’t always prepare the patient for what life is like postsurgery.

$50,000 to $75,000, a uterus transplant is estimated to range from $150,000 to over $500,000, and a face transplant can cost up to $1 million. As of now, hospitals are largely footing the bills—this is research for them, after all—and in some cases, the physicians are volunteering their time. Since the procedures are experimental, they are not yet covered by insurance.

These surgeries are lauded as major breakthroughs, but they also venture into uncharted territory. Powerful, potentially toxic drugs are required for all transplant recipients in order to ensure that the body lives harmoniously with its new tissue. Those drugs put the people who get the transplants at a higher risk for heart disease, serious infections and a shorter lifespan. People must often take the drugs forever. For now, Manning takes multiple drugs every single day.

Manning will turn 65 in December and says he felt he had nothing to lose. “I am an older guy. How long am I going to be around?” he says. “It’s better they try this on me than try it on some kid who’s 25.”

It’s been more than 60 years since the first successful organ transplant—a kidney—and in the intervening years, scientists have done what scientists do: learn from one experiment in order to conduct ever more sophisticated follow-ups. That kidney was followed by the first successful liver transplant, in 1967, followed the next year by the first successful heart transplant. Those surgeries have become standard care for people who need them, but like the new crop of surgeries, they carry some risk. Some argue that the difference between the two is that you can’t live without a heart, whereas you can, technically, live without a penis. But because these newer surgeries can be life- and mental-health enhancing, they’re slowly growing in acceptance and frequency.

These types of transplants are called vascularized composite allografts (VCAs). That means they include the transplantation of multiple tissues like skin, blood vessels, muscles, nerves, bone and connective tissue. In 2014, the U.S. government announced that VCAs—which include penises, uteri, hands, faces and limbs—would be treated like any other organ, and Americans could be put on a national waiting list for them.

Before that, hospitals worked directly with transplant groups to identify a possible match. Since 1999, when the first hand transplant in the U.S. was performed, there have been 52 VCA procedures in the U.S., including 11 face transplants, 17 single hand or arm transplants and 11 double hand or arm transplants.

The field of nonlifesaving organ and tissue breakthroughs is still nascent, but it reached a turning point in the past year. In August 2015, doctors at NYU’s Langone Medical Center accomplished a groundbreaking feat—the most complete face transplant ever performed—on a volunteer firefighter named Patrick Hardison, 42, of Staten Island, Miss., whose fire-burned face was reconstructed with the face of a deceased cyclist. A month earlier, an 8-year-old boy became the first child to receive a double hand transplant after an illness in infancy required double amputation.

There is a price for going first: not all of these procedures have gone according to plan. Jeff Kepner, the recipient of the first ever double hand transplant in the U.S., in 2009, says his hands have never worked and he’d like them removed so he can use prostheses instead, but he doesn’t want to endure additional surgeries. “I can do absolutely nothing,” he says. Meanwhile, his family has racked up about $40,000 in bills for travel for medical care and related costs.

There are many complications and risks associated with these transplants, and I do not think a good job is done by the doctors explaining all of them beforehand.

Even when the risks are explained, patients aren’t always prepared for what life is like postsurgery. In March 2016, Lindsey McFarland, 26, was rolled in a wheelchair into a Cleveland Clinic press conference with her husband and welcomed to the world as the first successful uterus transplant recipient in the U.S. McFarland was born without a uterus.

She and her husband were keen to start a family anyway, and so through foster care and adoption, they now have three boys.
ages 20 months, 5 years and 6. While they’re thrilled to be parents, McFarland never stopped wanting to give birth and maintain a five-year email correspondence with a physician studying uterus transplants. “I wanted to feel a baby move,” she says of her desire to become a biological mom. “I wanted to find out the gender and the voice.”

Once McFarland’s 10-hour surgery was done, the plan was for her to undergo monitoring for one year by experts in vitro fertilization. At the press conference announcing her successful surgery, McFarland’s voice shook with nerves. She thanked the donor’s family as well as her surgical team. “I prayed that God would allow me the opportunity to experience pregnancy,” she said on camera.

That evening, it was discovered she had contracted an infection, and soon she had to have the uterus removed. “It was heartbreaking,” says McFarland. “It’s one of those times where you want to scream and cry, but it’s really hard to grieve in a hospital room. The night I was discharged was one of the first times I really sat down and cried. I take it day by day.”

It was a blow to her surgeons’ hopes too. “This had been years and years in the making for many of us,” says Dr. Rebecca Flyckt, an OB-gyn surgeon on the Cleveland Clinic team. “To have things initially be so promising and then have it end with removing the uterus was a real feeling of disappointment for us as well as the patient.” The team is changing some of the technical aspects of how a uterus is transferred and transplanted to avoid infections in the future. They’re also changing the informed-consent process, so women know that what happened to McFarland could happen to them too.

PUBLIC ACCEPTANCE of procedures like this has both questions and skepticism remain. Ko, the surgeon who performed Manning’s penis-transplant operation, says he doesn’t think Manning didn’t tell his own mother he was training to do it, even though it was a career high point. She found out about his project while reading his picture in the newspaper, “Three years ago when we mentioned this to our colleagues, the first thing we got was ‘A snicker,’” Ko says. “The second thing we got was ‘You are crazy.’ I think society is more accepting now. We think the world is willing to come to terms with what we are doing.”

Part of the unease stems from people’s discomfort with seeing a loved one’s body part on someone else. Donating genitalia or other reproductive organs—which feel more like integral parts of a person’s body identity than, say, a kidney—can also give donors and their loved ones anxiety. “Your daughter is now dead, but her uterus is transplanted, and that person now has a baby,” says Arthur Caplan, director of medical ethics at NYU Langone Medical Center, who studies the ethics of VCsAs. “That’s a lot of emotional and psychological baggage.”

Two years ago the U.S. government added VCsAs to the list of transplants covered by federal regulation, but for the time being, the more than 50% of Americans who are registered as organ donors do not automatically sign away their VCA organs. Instead, when they die, people who work for organ-procurement organizations ask families for consent. All surgeries carry the threat of complications, and these can be especially dangerous. About 65% of face-transplant recipients have shown signs of rejection within the first year, and about half of 12 uterine transplants have failed so far. These advancements in science mean doctors and patients face a new dilemma: How much burden should a person bear for a procedure that is not lifesaving?

In hindsight, Kepner says he would not go through the double-hand-transplant surgery again. With prosthetics, Kepner says, he was 75% functional, but today, he says, he feels “0%” functional. “I know that there are success stories out there, and I am thankful for those,” says his wife Valerie. “But Jeff is not one of them, and the issues that he now deals with on a daily basis are much greater than those he had when he was an amputee.” Still, Kepner does not criticize the doctors who undertook the operation. “That’s the chance you take,” he says, “and that’s the chance I took.”

Meanwhile, other transplant recipients have reported remarkable outcomes and lives that changed for the better. In Sweden, five of the nine women who have undergone uterus transplants from living donors (many of the donors are mothers or other relatives of the recipients) have given birth to healthy children.

SOME EXPERTS ARGUE that quality-of-life transplants are, in fact, lifesaving in some cases. “Surely a heart transplant is in another category, but I think there is more of a continuum than we have talked about,” says Jeffrey Kahn, director of the Johns Hopkins Herman Institute of Bioethics. “I think people who have face transplants would argue they cannot even have a life prior to having a transplant.” NYU’s Caplan, who has interviewed people wanting to undergo face transplants, says the procedure can help prevent suicide. “People don’t like to say it, but it’s true,” he says.

Hardison, the face-transplant recipient, says his children are the reason he is still alive. “I would’ve given up a long time ago if it wasn’t for them,” says the father of five. In 2001, Hardison, then a volunteer firefighter, suffered a massive burn injury to his face when he ran into a burning house and the ceiling collapsed. The fire burned off his ears, lips, eyelids and the majority of his nose. His life took a dark turn. Over 14 years he grew depressed, lost his tire-selling business, became addicted to painkillers and split with his wife of 10 years. Though he had undergone more than 70 surgeries to improve the look and function of his face, he almost always shrouded it in a baseball cap and sunglasses. But when his doctor told him he was losing his sight as a result of living without eyelids, that was the last straw. “I hated life,” he says.

On Aug. 14, 2015, Hardison underwent a 26-hour surgery to replace his face with that of a 26-year-old brain who had been killed in a cycling accident. Though 37 face transplants had been done since the first was performed in France in 2005, but when his doctor told him he was losing his sight as a result of living without eyelids, that was the last straw. “I hated life,” he says. “When it’s your time to go, you’ll go—whether you’re walking down the street and get hit by a car or you’re lying on the operating table.”

His medical team says even more than they fear that a new organ or tissue will be rejected by the body, they fear people receiving face transplants will not identify with their new appearance or, worse, will feel like they have a “third eye.”

WHEN IT CAME to why before his surgery at NYU, Hardison met with an ethicist, a psychologist and a social worker, among others. “I’d told him I had good social support,” says Rodriguez. “We have to ensure that patients truly understand what they are getting into,” says Rodriguez. “Do they dream that someday they will look like the person they were? I’m sure they do. But they will not look like the person they used to be.”

Hardison’s new face is forming to his muscles and bone structure, and the swelling from the operation has significantly lessened over time. His facial expressions don’t always sync with his emotions, but that will come with time. For now, walking down the street and blending into a crowd is a milestone. “I went into Macy’s, and nobody stared at me,” he says. “I didn’t scare anyone.” So I’m taking my kids to Disney World. We’re a family that can do that now.”

Even when things go well, life after a transplant requires vigilance. Hardison, for his part, takes three different antirejection pills twice a day. Scientists are trying to develop innovative strategies using bone-marrow cells from an organ donor to reduce rejection risk. The method has worked in some kidney transplants. For now, quality-of-life transplants will largely be considered on a case-by-case basis. “I wouldn’t stop any of these procedures, but you really have to look at them carefully,” says Caplan, the NYU ethicist. “I think there is a choice to put an end to his bad luck was too good to pass up. “Right now I may be one of the lucky ones to live with a transplanted penis,” he says. “I got it. And I am not giving it back.”

Most transplant recipients agree it will inevitably be up to people and their families to weigh the operation for risk against their desire to feel normal. For people like Manning, that future is full of potential. “My story has a sad beginning,” he says. “But a very exciting ending.”