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Lung Patients See a New Era of Transplants

By [DENISE GRADY](#)

A quiet revolution in the world of lung transplants is saving the lives of people who, just two years ago, would have died on the waiting list.

In the past 16 months, waits have shortened, lists have shrunk, and the number of lung transplants has gone up. Further improvements are expected this year.

The changes have all but erased the need for transplants from live donors — desperate, last-ditch operations requiring two donors per patient, usually relatives and friends who risk major surgery in hopes of rescuing a loved one whose time is running out.

“It’s almost as if it’s a whole new day for lung transplantation,” said Dr. Cynthia Herrington, a surgeon at the University of Minnesota Medical Center, Fairview, in Minneapolis. “It’s amazing.”

Nationwide, it is too soon to tell what the impact of the transplant changes will be.

“Are we actually improving overall survival?” asked Dr. Selim Arcasoy, the medical program director for lung transplantation at New York-Presbyterian Hospital/Columbia University. “Or are we transplanting sicker people who don’t last as long?”

Transplants are given to people whose lungs fail because of [emphysema](#), cystic fibrosis or other, less common diseases. Since demand exceeds supply, patients must join regional waiting lists that are part of a national network.

Recent changes have revitalized lung transplantation. Starting in May 2005, new rules nationwide put patients who needed transplants most at the top of the list — people who would soon die without a transplant, but who had a good chance of surviving after one.

Previously, lungs went to whoever had been waiting longest, even if another patient needed them more. The waiting time was often two years or more, so there was little hope for people with lung diseases that came on suddenly or progressed rapidly.

Another major change is that more lungs from cadavers have become available, for two reasons: more people are becoming organ donors, and doctors have figured out ways to salvage lungs that previously would have been considered unusable. The new methods use drugs, respirator settings and other techniques to prevent damage to the lungs and keep their tiny air sacs open in brain-dead patients.

In the past, lungs could be retrieved from only about 15 percent of organ donors, but at some centers the rates have risen to 40 percent. Dr. Herrington said that in Minnesota, the number of lungs retrieved went to 97 from 25 in a single year.

“Good organs 5 or 10 years ago were probably being buried” because doctors did not know how to save them, said Dr. Kenneth R. McCurry, director of heart and lung transplantation at the [University of Pittsburgh](#).

The number of lung transplants has risen to 1,405 in 2005, 248 more than the year before. Fewer people are dying on the waiting list: 360 in 2005, down from 488 in 2004.

The new rules made the difference between life and death for Hannah Olson, 20, a college student from Waukon, Iowa, with cystic fibrosis, a genetic disease that affects the lungs and digestive system. Ms. Olson was well enough to start college in 2004, but by January 2006, she was on the transplant list. Her status, though, was not yet listed as “active,” because her condition seemed stable and she needed to gain weight.

But in mid-February her lungs gave out. Unable to breathe, Ms. Olson was put on a respirator, and her waiting list status changed to active. Without a transplant, she probably would have died within days. Her desperate condition translated into a numerical score that shot her to the top of the list. Twelve hours later, lungs became available, and she received her transplant at the Fairview center in Minneapolis, one day after being put on the active list.

“I’d probably be gone if the list was the way it was before,” Ms. Olson said.

Her surgeon, Dr. Herrington, agreed, saying, “In the old system she would not have even been listed, because she would have had years to wait.”

Ms. Olson is back in college now, hoping to earn a degree in social work. “I’d kind of like to work with transplant patients,” she said.

Lungs have always been “the bad stepchild” of [organ transplants](#) — harder to get, harder to transplant, more prone to rejection and complications than other organs, said Dr. Scott Palmer, the medical director of [Duke University](#)’s lung transplant program. Lung transplants were not consistently successful until the mid-1980’s, lagging far behind those of kidneys, livers and hearts. From the start, lungs have been offered first to whoever had spent the most time on the waiting list, in the donor’s geographic region.

Changes in the system came about partly because of a 1998 federal regulation requiring that all organ transplants go to patients with the greatest medical need. The intention was to even out waiting times around the country and decrease deaths on the waiting list. Changes have been gradual.

Livers and hearts are already allocated according to patients' needs. Kidneys still depend on waiting time, but the rules may change to factor in patients' odds for survival, according to Annie Moore, a spokeswoman for the United Network for Organ Sharing, or UNOS, the nonprofit organization that manages the transplant network in the United States.

For lungs, figuring out how to measure medical need and rank patients with different diseases took time.

"Our concern was that if we used just severity of illness, we might waste a lot of lungs on patients who were so sick they were unlikely to survive anyway," said Dr. Thomas Egan, a cardiothoracic surgeon at the [University of North Carolina](#), Chapel Hill, who led a UNOS panel that spent several years developing new rules for lung allocation.

The panel studied medical records to figure out which patients were most or least likely to survive after a transplant, and worked that into the scoring system. As a result, lungs are now the only organs with transplant rules that consider the recipient's survival odds.

Almost immediately, the new system cut the waiting list in half. Because waiting time no longer mattered, people who had been listed early in their illness just to hold a place in line dropped in rank or were deleted (unless they needed a transplant right away) but could rejoin the list later if they became sicker.

Overnight, some patients who had waited for years to reach the top of the list suddenly found themselves at the bottom, or even crossed off. Nobody was grandfathered in.

"We tried our best to educate and communicate, but many felt they had been cheated," Dr. McCurry said. But at his center in Pittsburgh there were no deaths among those who lost their places in line, he said, adding that many still received transplants.

Those who remained on the list needed transplants soon. As a result, it became much easier to find recipients quickly, which was a huge improvement, because once an organ donor is brain dead, organs start to deteriorate. The lungs are especially fragile.

In the past, transplant coordinators might have spent hours calling hospitals, only to hear again and again that the patient at the top of the lung list was not sick enough for a transplant. Meanwhile the clock would be ticking; patients would have been found who needed the heart, kidneys and liver; and surgeons would be standing by, ready to remove them. Doctors say some lungs were probably wasted because recipients simply could not be found fast enough.

“Placement is easier now,” Dr. Egan said. “It takes four or five calls. It used to be 16.”

The new system has also changed the types of patients who receive the most transplants. Before, a majority had emphysema, a lung disease nearly always brought on by [smoking](#). They received transplants because the disease moves slowly and they could wait, outlasting patients — often younger ones — with other lung diseases.

“People with pulmonary fibrosis or pulmonary [hypertension](#) can be diagnosed and go downhill very, very rapidly,” said Dr. G. Alexander Patterson, a surgeon at [Washington University](#) in St. Louis, which has one of the country’s largest lung transplant programs, with about 55 to 60 adult patients and 25 to 30 children a year.

Pulmonary fibrosis causes extensive lung scarring, and its cause is often unknown. Patients can die within a year of the diagnosis. But patients with emphysema can often live for a long time. As a result, Dr. Patterson said, many people thought the old system gave an unfair advantage to emphysema patients.

On the waiting list, 5 to 10 percent with emphysema died each year, compared with 30 to 40 percent among those with cystic fibrosis or pulmonary fibrosis.

“It was an ethical dilemma,” Dr. Patterson said, adding that some doctors were troubled to see so many transplants go to people with emphysema, which is caused by smoking, whereas “others have disease they didn’t produce.”

Now, at most centers, more patients with pulmonary fibrosis are getting transplants.

Dr. Jonathan B. Orens, medical director of the lung transplant program at Johns Hopkins, said that in the past year, more than half the 28 recipients there were people who, under the old system, would have died on the waiting list.

Dr. Orens said he and his colleagues had just performed a preliminary analysis of the nationwide data on the first patients treated under the new system, and found that so far, one-year survival rates appeared to have dropped, to about 70 percent, from about 80 percent over all.

“At first blush, that may seem like a bad thing,” he said. But, he said, it may mean that the new system is doing exactly what was intended: giving transplants to the patients who need them most, rather than to people who do not need them yet.

Past survival rates might have been higher because the recipients were healthier. But a transplant might not have prolonged those patients’ lives because they might have survived just as long without it. Sicker patients may not live as long as others after a transplant but may still live longer than they would have

without it.

“You get only a limited longevity from a lung transplant,” Dr. Orens said. “In the old system, the average survival was a little under five years.”

Earlier studies suggested that although people with emphysema might have felt better after transplants, they did not necessarily gain time, whereas those with pulmonary fibrosis or cystic fibrosis did. That finding means that the emphysema patients may have been getting transplants too soon, Dr. Orens said.

“This is important,” he said. “If you transplant patients prematurely, you may shorten their lives.”

Slightly lower survival rates under the new system, he said, “may be the best we can do with lung transplants when patients are this sick.”

The rates may still represent a net benefit, he said, “compared to shortening the lives of patients who did not quite need the transplant.”

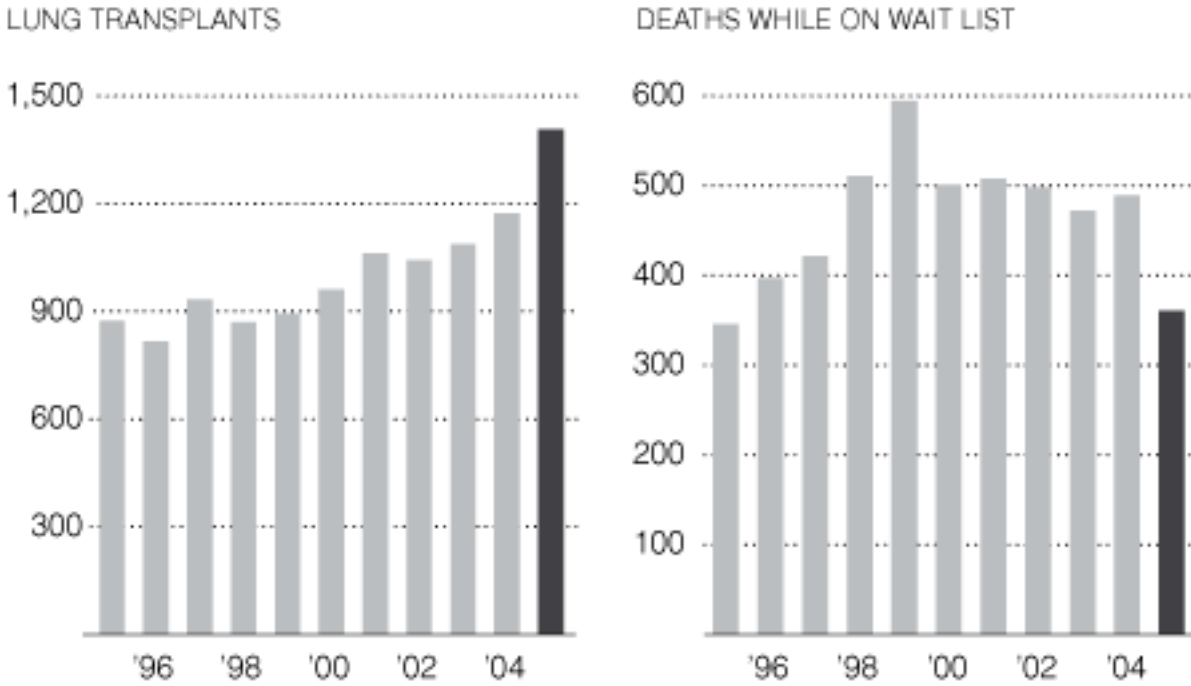
As more data comes in, the rules may need to be adjusted, Dr. Orens said. “We’re trying to capture just the right patients at just the right time.”

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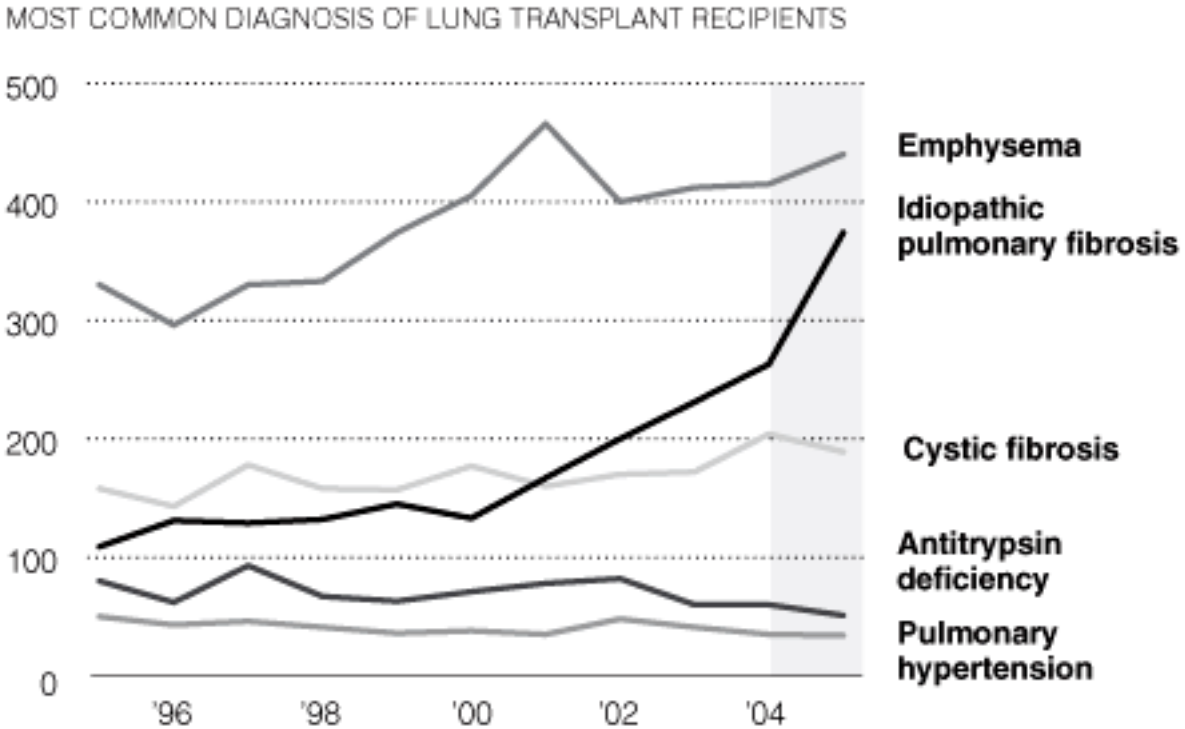
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Favoring the Sickest Patients

Lung transplants have increased and deaths on the transplant waiting list have dropped because more lungs have become available and new rules put the sickest patients at the top of the list.



Before a May 2005 rule change, patients who had diseases that progressed slowly, like emphysema, got most transplants. Now, those with rapidly progressing diseases, such as pulmonary fibrosis, are catching up.



Source: Organ Procurement and Transplantation Network

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