Final Decisions
PART ONE:
Questions Arise as Thousands Wait for Life-saving Transplants

By PATTY REINERT

HOUSTON – Transplant surgeon Bud Frazier was first to get the call: A middle-aged man had died, and his family had consented to organ donation. Did he want the heart?

Frazier's 18-year-old patient was at the top of the regional transplant waiting list. But the Houston surgeon didn't want to put the heart of a 50-year-old into the teen-ager's body.

"But I have a 60-year-old patient a little farther down the list, and I'll take this heart for him," he told them.

It doesn't work that way.

When Frazier declined the heart for his young patient, the organ bank was required to offer it to Patient No. 2 on its computer-generated list. The computer ranks transplant candidates based on how close to death they are, how close to the organ they are, how well they match and how long they've been waiting.

In this case, Frazier, chief of transplants at the Texas Heart Institute at St. Luke's Episcopal Hospital, was told there were three other people ahead of his 60-year-old. The organ bank would get back to him. That's not uncommon.

"But by the time they call around to each of the other people and they try to track people down in surgery or at the movies or whatever, it's getting very late and the donor is destabilizing," he said.

Everyone else turned down the heart, but by then it was too late to get it for Frazier's patient.

"The heart was wasted," he said. "That is a result of the system."

It seemed like a good idea: Let a computer make the hard decision of who gets a transplant and who dies waiting for one, disregarding whether the person is a bus driver or a congressman, a movie star or a teacher, a young mother or an aging bachelor.

But 11 years after the United Network for Organ Sharing won the federal contract to set up a distribution system for the country's limited supply of organs, some are beginning to question whether such life-and-death decisions should be left to a government agent and a computer.

"Trust me, if a computer could do this, I'd (want to) use it," said Frazier. "But the computer can't really make medical decisions, and you can't let the computer make you do something stupid. Then you lose organs and nobody benefits."

In the early days of transplant, which weren't so long ago, doctors found organs themselves by spreading the word among their colleagues, scanning news reports of car accidents and canvassing emergency rooms for potential donors. The surgeon who got the call in the middle of the night would just pick someone off his persona waiting list based on his best medical guess of who should go first.

“It was usually a pretty straight-forward decision. I never came to a point where everything was equal and I had to flip a coin,” Frazier said. “To say we always made the right choice would be crazy. But you did your best, using medical reasoning and common sense. That’s all you had to go on.”

Still, doctors are just as prone to prejudice, just as tempted by money and power, and just as susceptible to peer pressure as anyone else. And people don’t trust them like they used to.

So in 1984, Congress passed a law prohibiting the buying and selling of organs for transplant. Two years later, the federal government assigned UNOS, a nonprofit company based in Richmond, Va., to lock the system down tight. Its job was to keep a few hospitals from hogging all the organs, discourage doctors and organ banks from fighting with each other, and stop the rich and powerful from butting in line ahead of the poor and unknown.

But since UNOS began overseeing the country’s transplant programs, the number of people seeking transplants has more than tripled, while the number of organ donors has leveled off, due in part to a decrease in homicides and an increase in seatbelt and motorcycle helmet laws.

More than 55,000 American – 3,000 in Texas – woke up this morning wondering whether today will be the day they get their transplants. This year, fewer than 20,000 will actually get them. More than 4,000 will die waiting.

As more patients and more transplant centers scramble to compete for organs, many insist UNOS’ nationwide computer network, updated every 18 minutes with a new medical profile of another patient, is the most effective method of ensuring that anyone, regardless of income, age, race, gender or social status, has a somewhat equal chance at getting a lifesaving transplant. That is the key, they say, to maintaining the public’s trust and encouraging people to donate organs.

Fighting rumors of organ stealing and organ selling and general misuse of organs is a constant battle in the world of transplants. Every time a sports hero like Mickey Mantle or a TV star like Larry Hagman receives a transplant, someone cries favoritism. Every time the child who appeared on television or in the newspaper gets the transplant, or a wealthy foreign patient goes before a U.S. citizen, someone cries unfairness.

“That’s why the best part about this system is the computer program,” said Jim Cutler, who heads the Southwest Transplant Alliance, the Dallas organ bank that handled Mantle’s controversial liver transplant in 1995. Southwest, along with LifeGift Organ Donation Center in Houston and San Antonio’s South Texas Organ Bank, controls organ distribution in Texas.

“Computers are not star-struck,” Cutler said. “They don’t get paid. They don’t read *People* magazine. They don’t know who you are or anything about you other than medical information. The computer doesn’t know what a baseball player is. It is either too smart or too stupid to care who gets the transplant.”

Mantle, a 63-year-old recovering alcoholic with hepatitis, was given a liver transplant at Baylor University Medical Center in Dallas on June 8, 1995, just two days after he was added to the transplant list. When doctors operated, they discovered the baseball great also had cancer. He died a short time later.

UNOS investigated the case because of the public’s suspicion that Mantle’s celebrity may have given him an advantage. If found nothing amiss.

Millions of fans had rallied around Mantle, including some at the *Houston Chronicle,* which published an editorial saying, “If the fact that he is Mickey Mantle had something to do with it, that is fine … He is, after all, an American legend.”

Still, many were left wondering, why didn't that liver go to someone who stood a better chance of surviving?

Dr. Pat Wood, who oversees Houston's liver transplant programs, cringes when Mantle's name is mentioned.

"More damage is done to us by a celebrity begin transplanted than anything else," he said. "Any bad publicity about suspected unfairness in the system is really hard to combat. In the case of Mickey Mantle, though, he and his family got involved and helped us publicize the need for donors, so maybe something good will come of that.

"What would do us more good is if a celebrity dies while waiting for an organ."

Wood, who also serves as a UNOS committee member, conceded the system isn't perfect. But he said it does allow enough flexibility for doctors to practice good medicine and do the best they can for their patients.

A perfect example, he said, is what happened last year in the case of Robbie Mooneyham, a 16-year-old Cypress Creek High School football player who slipped into a coma after his liver malfunctioned, possibly because of a viral infection.

As doctors at Hermann Hospital waited for a liver, Mooneyham's classmates passed out organ donor cards and raised money to help his family with medical expenses. Radio, television and newspapers carried numerous stories on Mooneyham and drummed up publicity for organ donation.

When a liver became available, it was offered first to a patient in Galveston, but that patient's doctor knew the seriousness of Mooneyham's condition. His own patient was relatively stable and could wait, he said.

"He didn't have to call me and say, 'I'll give you this liver,'" Wood said. "He just said, 'I'll decline it,' and Robbie was the next person on the regional list, so he knew it would go to him."

Mooneyham regained consciousness for brief periods after the transplant, but his body rejected the new liver within a couple of weeks. Doctors hoped to try a second transplant, but the teen-ager died before another donor could be found.

In spite of the outcome, Wood said the system worked well because the patient with the most urgent need got the liver.

But some wondered whether publicity surrounding Mooneyham's case played a role in his getting the organ. Others questioned in hindsight whether the liver was wasted trying to save someone who may have been beyond hope in the first place.

They worried that a second liver, had it come through in time, could also have been lost, resulting in three potential deaths – Mooneyham's and the two other patients who could have been helped if doctors had made a different decision.

Transplant doctors aren't gods. It's not always obvious and they don't always agree which patient is closer to the grave. They aren't accustomed to making rationing decisions for the whole population; they are trained to be advocates for individual patients.

“If your patient is dying, you want the liver. You want to do everything you can to give him a chance,” Wood said. “These are very difficult decisions of who gets the transplant because it involves life and death and we just don’t have enough organs.”

Yet Wood said the system is fairer now than it’s ever been and it’s getting fairer as time goes on. Many in the transplant world disagree – loudly. Last year, as UNOS struggled to come up with a new policy to prioritize liver patients on the waiting list, doctors fought bitterly over whether to push the newly ill ahead of those suffering from chronic liver disease.

Some argued that patients like Robbie Mooneyham, who suddenly become sick, stand a better chance of surviving after a transplant than those who have been battling their illnesses for years. But others disputed that notion, saying the two groups of patients have essentially the same survival rate.

In the end, UNOS gave a slight advantage to patients who suddenly become ill, revising the long-standing policy of putting the sickest patients at the top of the waiting list, regardless of their chances.

The debate rages on.

“This is triage,” said Wood, who supports the new policy. “We have a very limited supply. You have to worry about two lives for every transplant you do. If you pick the wrong person and they die anyway, you’ve risked losing not only that patient who got the transplant but another patient who could have been transplanted with that liver.”

Susan Groneman, director of outpatient transplant at Hermann, also favors transplanting patients with the best chance of surviving before those who are closer to death.

“Some of these people are just barely hanging on, and you know they aren’t going to do well even with the transplant,” she said. “Come on, let God do his job. I think we try to play God too much.”

The problem, though, is that a short supply of organs means a long waiting list, and a long waiting list means patients are sicker before they rise to the top. Always giving priority to the patient with the best chance of a good outcome means those people who stood in line could be left to die.

Even more contentious than the debate over which patients should have priority on the transplant waiting list is the basic question of how and when to add patients to the list in the first place. The computer may not care who gets the transplant, but humans do, and they put their mark on the transplant system long before a patient’s medical profile is punched into UNOS ‘ electronic network.

This is something over which UNOS has no control: Any hospital can accept or reject patients for the transplant waiting list based on its own medical, psychological, social or financial criteria – and hospital officials won’t reveal exactly what those criteria are.

After the patient submits to an extensive evaluation, including numerous medical tests, a psychological exam and a meeting with the hospital’s financial counselor, a transplant review committee essentially votes on his or her candidacy for transplant.

One doctor may try to lobby the others on a patient’s behalf. But other committee members may have reservations about the patient’s emotional state or the commitment of his family or his ability to pay for the expensive surgery.

Because waiting time is factored into UNOS’ computer program, doctors also debate when to start each patient’s clock running.

For example, some believe kidney patients should be on dialysis before they are deemed sick enough for the transplant list. But others say being tethered to a machine that filters their blood for several hours a day, three or four times a week is grueling to the psyche and has its own risks for the body. Why shouldn't a patient be allowed to skip it and go straight for a transplant?

In an effort to limit the number of people on the list, some factions in the transplant community are calling for strict age cutoffs, exclusion of foreign patients, and even moral criteria for denying transplants to patients they feel are underserving of one of medicine's most precious commodities.

Some suggest, for example, that alcoholics should go to the back of the liver transplant line, arguing that they are partly responsible for their condition. Others counter that because alcoholism is a disease, patients who suffer from it should be treated no differently than victims of heart disease, which is often brought on by smoking, bad diet or lack of exercise.

Most transplant centers don't exclude alcoholics seeking liver transplants, but their requirements on how long a recovering alcoholic must stay sober before seeking a transplant vary widely.

And for every person who wants to limit the pool of candidates to give patients a realistic expectation of actually getting organs, there is another trying to force the transplant door open wider.

Just last summer, two of the nation's largest liver transplant centers, the University of California at San Francisco and the University of Pittsburgh, began accepting HIV-infected patients onto their waiting lists, hoping to save patients whose other options have run out.

Some complain the move was akin to throwing livers into the trashcan. But others say that with drug therapy virtually eliminating signs of the human immunodeficiency virus in some people, patients with the virus that causes AIDS could survive as long as other transplant patients.

In Houston, Frazier said he is proud of the fact that St. Luke's has stretched the age limit for heart transplant patients, offering transplants even to those in their early 70s at a time when other hospitals wont touch a patient past the age of 60.

"We were throwing away older donors, so we thought why not use them for older patients? Even if they just live a few more years, they can watch their grandchildren grow up. Now we've found older patients have a very good survival rate, particularly older men. Why not give them the best shot they can get?"

Groneman said the system might be less confusing for patients if every hospital had the same criteria for listing transplant candidates, though it wouldn't necessarily be more fair.

Under the current system, she said, hospitals can compete by tailoring their product, the transplant, to a certain clientele. The system works to the patients' benefit, too, she said, because those who don't qualify under one hospital's rules can shop around and try to get a transplant elsewhere.

UNOS' president, Dr. Lawrence Hunsicker, a transplant physician at the University of Iowa Hospital, said UNOS has no intention of interfering with how hospitals list patients.

"We have guidelines for listing, but we're not going to try to second-guess you from Richmond," he said. "We have to have some faith in doctors, and we have to believe that doctors will try to do the best thing for their patients. In most cases, we assume they would lean toward listing them.

"However, once they are listed, we have to be more hard-nosed than that because unfortunately, not every patient on the list will get a transplant."

But Hunsicker agrees with Frazier that the price for trying to keep the system fair is strict adherence to the computer list, even thought it doesn't always work perfectly. Far too many organs, especially hearts, are lost, he said. The problem, Hunsicker said, is that it takes too long for organ banks to alert doctors once a patient has been declared dead, and doctors then take too long to decide whether to accept or reject the offers.

Unlike kidneys, which can be preserved for up to 72 hours before being transplanted, and the liver, which can last up to 24 hours, surgeons have only four to six hours to get the heart into the recipient's chest once it is taken from the donor. Because of that, a heart surgeon doesn't want to remove the donor's heart until a recipient is identified and on his way to the operating room.

But if doctors trying to collect the kidneys or the liver wait too long for the heart surgeon to arrive, they risk losing all the other organs as the donor's body begins to shut down completely.

"What the list does is it makes people aware of the existence of the organ and makes them want it for another patient," Hunsicker said. "But just because you become aware of that heart, should you be able to jump over people to get it? No.

"But we do need to work harder to make the offers very rapidly so we don't lose as many hearts."

Most organ banks now alert the doctors of the top few candidates on the heart transplant list to speed up their response time if others above them on the list decline. If a doctor fails to give the organ bank an answer within an hour, the organ bank can move down the list and make another offer.

Teresa Shafer, executive vice president of LifeGift, the Houston-based organ bank, is a strong proponent of the current UNOS system. But she concedes it can sometimes be frustrating for organ banks, too.

For example, when the organ bank tried to place organs from an infant door, the list of potential recipients included patients weighing up to 300 pounds. Because livers must be matched by size, a child's liver would not be appropriate for a large adult.

"We were on the phone for hours," said Shafer, who works in LifeGift's Fort Worth office. "We know there's no way you're going to use a 3-month-old liver in a 300-pound patient, but we have to call each person on the list, and make the offer anyway, even though we know they'll say no."

The problem is not the computer system, Hunsicker said. "The problem is the doctor who wants to consider all potential organs for his patient and he casts his net too wide (to capture as many offers as possible). You know damn well he can't take a 3-month-old liver for a 250-pound patient," he said.

"When doctors do that, it backfires because then the organ bank has to make a bunch of calls that are useless and we lose organs. We try to remind doctors to set the limits realistically."

Hunsicker said the real problem is that the relatively young field of transplant is in constant evolution, and the more doctors learn, the more they debate the best way to proceed.

"People still don't agree on everything, but the signal contribution of UNOS is that we as a transplant community have been able to agree on rules for sharing organs – sometimes grudgingly – but nonetheless, we have come up with a consensus on many issues.

"If you ask me, 'What is the highest point in Texas?' I can look that up and give you a very precise answer," he said. "But I you ask me, 'Is the system fair?' the answer would be imprecise. What I can say is that the system we have now has evolved from a huge amount of discussion and consensus.

“And nobody’s come up with a better way.”