As organ shortage grows, hospitals spar and people die waiting

By Larry Tye, Globe Staff, 3/13/2001

That deadly trend is partly a result of more Americans living long enough for their organs to fail, and partly a result of the increase in eligible patients brought about by improvements in transplant operations. While more transplants are being done today than a decade ago, it is not nearly enough to keep pace with the expanding lists of patients waiting for a lifesaving organ, which this year topped 75,000 for the first time.

In the Boston area, meanwhile, transplant programs at competing hospitals continue to duke it out for who will perform the lucrative and prestigious procedures on the handful of patients lucky enough to secure a new liver or lung. That battle - coming in the midst of a crisis over the organ shortfall - has public health officials calling for new ways to boost organ donations and temper competition.

"We’re setting up the wars by making transplants lucrative, and once they’re lucrative almost every teaching hospital wants a program," says David Mulligan, chairman of the Boston Public Health Commission. "If we had a more cooperative system where someone did livers, someone else hearts and a third hospital kidneys, we’d eliminate the duplication, and transplant teams would be less costly."

Dr. Howard Koh, the state commissioner of public health, is trying to put a different kind of pressure on hospitals, encouraging them to fine-tune their process for encouraging relatives to donate organs of a lost loved one.

"We have something like 2,500 people in Massachusetts on the waiting list for organs at any given time," he says. "This is a major public health challenge."
Federal officials are equally challenged, something that became clear last month when, on his first day in office, Health and Human Services secretary Tommy Thompson announced that he will launch a new initiative encouraging organ donations. At the same time, the United Network for Organ Sharing, which maintains the nation’s transplant waiting list, came out with a disturbing report on trends in transplantation, with data on the New England region released soon after.

The studies show that between 1990 and 2000, the number of Americans awaiting organ transplants more than tripled, from 21,914 to 73,951. Since then the list has risen to 75,069. The waiting list grew even faster over the last decade in New England, from 962 to 3,527.

Those long waits mean more than just inconvenience: An average of 15 Americans die every day waiting for an organ that could save their lives.

More Americans are getting new organs than a decade ago, although that growth has been substantially slower than among those wanting organs. There were 21,990 transplants performed in 1999, up from 15,009 in 1990. That increase was fueled by a rise in the number of transplants involving live donors, who give part of their liver or one of their kidneys.

One explanation for the expanding waiting lists is that each refinement in operative technique brings greater success in treating older and sicker patients, which means more of them sign up for new organs. Beyond that, the reasons for the growing waiting lists are slightly different for each transplantable organ.

Consider liver transplants, which grew tenfold over the last decade. That rise was driven in large measure by an epidemic of hepatitis C, which accounts for more than half of the liver problems that lead people to seek transplants. The growth in hepatitis C, in turn, was caused largely by drug use and sexual contacts that, given the disease’s long lag time, often date back to the 1970s or earlier.

Another critical factor is refinements in the transplants themselves, especially new ways of using live donors. "Our success has to some degree made things harder with the waiting list," explains Dr. Roger Jenkins, chief of liver surgery at the Lahey Clinic. "Now we look at patients with less skepticism in terms of getting a transplant if they have underlying liver disease."

Liver also is an apt organ to illustrate the transplant competition
among Boston-area hospitals. Two years ago Lahey lured away Jenkins’s highly-esteemed team from Beth Israel Deaconess Medical Center, which in turn brought in its own team from the Midwest. Today the competition is even more intense among those liver programs, as well as ones at New England Medical Center, Massachusetts General Hospital and the University of Massachusetts Medical Center.

’’Prestige is a big part of what makes hospitals want to perform transplants,’’ says Dr. Richard Rohrer, chief of the transplant division at New England Medical. Money is another incentive. Then there is what Rohrer calls the ’’halo effect,’’ where patients with liver and other diseases are drawn to hospitals where they have the option of getting a transplant, should they need it someday.

Beth Israel has had concerns recently with the relatively small number of patients using its new liver transplant program, and with a mortality rate of just over 20 percent. That figure has led some to call for an outside review of the program, although a recent internal review at the one-year mark suggested that the death rate was what would be expected for the program’s high-risk patients. The review also suggested that the overall numbers - four deaths out of 18 adult patients - were too small to be statistically meaningful.

The hospital’s review ’’does not raise the concern that we can offer anything less than superior care for our transplant patients,’’ says Dr. Kenneth Sands, Beth Israel’s vice president for health care quality. The review did, however, come up with what Sands called ’’substantive recommendations on how to make the program better.’’

The state and transplant doctors are trying to come up with their own recommendations for freeing up more organs for those on waiting lists, fewer than a third of whom are expected to receive the transplant they need this year. New organs are hard to come by, however, because fewer than 1 percent of people die in a way that their brain expires but their heart keeps blood flowing to organs so they can be saved and reused. That usually happens with car, bicycle or motorcycle accidents, all of which have been reduced by safety programs. In New England, two-thirds of those eligible as donors, and whose families are asked, now agree to donate - so there is not an enormous new market to tap.

’’As our waiting list continues to get longer and we have a shrinking donor pool, we look at it as if every single thing we do counts, whether it’s public education, urging people to talk with
their families about being donors someday, or putting stickers on a license agreeing to donate,’’ says Sean Fitzpatrick, spokesman for the New England Organ Bank. ‘’Just to maintain the current level of organ donation we’re really working on all cylinders.’’

Anyone interested in becoming a donor should begin by making that clear to their relatives, Fitzpatrick says. They also can obtain a donor card from the organ bank at 617-244-8000, and can get a sticker to put on their driver’s license.

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