Two high profile surgical cases recently demonstrated that even for citizens with health insurance, America has a multi-tiered health care system. The champion of universal health care, Senator Edward Kennedy, chose to have his brain tumor surgery at Duke rather than accept the consensus recommendation from a panel at the Massachusetts General Hospital. Similarly Steve Jobs, CEO of Apple computer, traveled from northern California to Tennessee, for a liver transplant to treat a metastatic neuro-endocrine tumor. The New York Times opined, “Whenever someone rich and famous receives a transplant, suspicions inevitably arise about whether that person managed to jump to the head of the waiting list and take an organ that might have saved the life of somebody just as desperate but less glamorous.”

When celebrities obtain organs quickly, it heightens awareness that inequalities may exist and compels people to question the process. In 1995, baseball’s Mickey Mantle presented with a chief complaint of stomach pain. He was diagnosed with cirrhosis and liver cancer. Nine days later, he was placed on a waiting list for a liver transplant; two days, later he was transplanted.

We know that wealthy patients have greater access to care than poor patients; white patients receive better care than black patients; the insured receive better care than the uninsured; and celebrities receive greater care than the average person. These disparities assume greater importance in organ transplantation because of the limited supply of organs. These observations drive at the heart of the debate between balancing equity and utility.

Given the complexities of the organ allocation system, the public might understandably feel that the playing field is not level. Nonetheless, organs are allocated through a computer-generated list that is based on objective criteria (laboratory data, HLA matching and waiting time). Deviations from the list are investigated and the few cases that have been identified resulted in harsh penalties for transplant centers. Why is it then that the Mickey Mantles of the world receive transplants expeditiously while other patients are relegated to long waiting times? The possibility is that personal resources allow them access to a nation-wide system whereby they are able to make use of super-specialized physicians and services or, in the case of organ allocation, to gain admission to centers with shorter waiting times.

Recently, Steve Jobs received a liver transplant in Memphis. The median waiting time for a liver in Tennessee was 143 days in 2007 compared to 1851 days in California for the commonest blood group. Organs procured from deceased donors are kept within designated regions in the United States. Patients may be listed
in one or more region, but must travel to each center for the complex medical evaluation and the transplant procedure when an organ becomes available. Listing in regions with shorter waiting times increases the chances of obtaining an organ more quickly. This, of course, is more readily available to people able to pay for transportation and lodging.

The average waiting time between each of the eleven US organ allocation regions varies with respect to organ. Not much regional variation exists in kidney waiting time, likely reflecting the disproportionately large demand relative to the supply, the United Network for Organ Sharing (UNOS) criteria that place priority on waiting time over medical illness and the universal availability of dialysis. On the other hand, there is significant regional variation in waiting times for liver transplantation, reflecting varying donor potential (number of deceased donors per million population) and families’ consent rates (35-60% of potential donors actually donate). In 2005 the median time spent on a waiting list for a liver in Region 1 (CT, ME, MA, NH, RI) was 1347 days. Compare this to 75 days for Region 3 (AL, AK, FL, GA, LA, MS).

One study showed that geographic variation in organ availability was the greatest reason that Hispanics are less likely to receive a liver transplant. This difference likely reflects the clustering of certain ethnic and income groups. Proximity to a transplant center and socioeconomic factors influence one’s access to transplantation. One study from California found lesser rates of transplant referral for Medicaid patients compared with age-matched Medicare recipients. Notably, however, once in the system, insurance status did not influence receipt of a deceased donor kidney.

The process from organ failure to obtaining a transplant has many steps, each a potential source of inequity. From the onset of symptoms not all patients have equal access to primary care. Once a diagnosis is established, physicians have different personal attitudes and biases toward placing patients on waiting lists. There is often delayed referral to transplant centers and a protracted pre-transplant work-up, most often related to logistic challenges for individual patients. The required long regimen of expensive immunosuppressive drugs exacerbate the vulnerability within groups.

The allocation of kidneys is largely based on wait time and HLA matching. Since dialysis is available as a lifesaving therapy, little of the allocation is based on the burden of medical disease. Conversely, livers are allocated based on the severity of medical illness with time waiting serving only as a tie-breaker. Also, the inevitability of death without liver transplantation lessens the impact of cultural beliefs and patient understanding. Access to the health care system is important, but even patients presenting to Emergency Departments with end-stage cirrhosis undergo rapid evaluation and listing for transplantation, and when sick enough by objective medical criteria often receive prompt transplantation with minimal waiting time. Availability of an organ for transplantation becomes paramount and geographic disparities can be exploited for the recipient’s benefit.

UNOS continually reviews the fairness of organ allocation and revises policies. In 2006 it noted that the sickest heart failure patients were dying on the wait list as healthier patients received organs in some regions. The geographic boundaries for each allocation were expanded, resulting in the shipping of more hearts to sicker patients and a dramatic decrease in deaths on the waiting list. The development of objective scoring systems for liver and lung allocation and a kidney allocation system with reduced weight on HLA all improved the fairness of organ allocation.

Technologically we have made great strides in organ transplantation. However, the scientific advances have paved the path to perhaps the greatest moral challenge in medicine—the necessity to allocate scarce resources to needy patients. An unbiased system is evolving but disparities in race, socioeconomic status, gender, and regional variation remain and demand attention. In today’s environment, uninsured patients are less likely to gain transplant listing; those with kidney failure are relegated to dialysis and those with other end-organ failure cling to the hope of access to transplant wait lists through emergent hospitalization.

Conversely, those with financial resources take advantage of shorter waiting times in certain regions or unique therapies at specialized centers. It is a very American concept for patients to make personal choices and individualize treatment. However, this requires a system that provides unique opportunities and a patient with resources to exploit them. Variability in organ allocation is diminishing, but until a completely level playing field is established prominent patients will take advantage of the benefits inherent in the system.

The liver model of end-stage liver disease (MELD) places wait-listed patients on a continuum of medical illness based on renal function (creatinine), coagulopathy (PT INR) and liver function (bilirubin).

The liver model of end-stage liver disease (MELD) places wait-listed patients on a continuum of medical illness based on renal function (creatinine), coagulopathy (PT INR) and liver function (bilirubin).