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# Supply, Demand, and Kidney Transplants

by **Sally Satel**

A bad incentive structure creates a dire shortage

**I**N MAY 2002, Clois Guthrie, an 85-year-old retired osteopathic surgeon, got the phone call he was waiting for: A suitable kidney had just become available for him. A renal transplant would mean liberation from the dialysis machine to which he had been tethered for two miserable years. Elated, Guthrie and his wife raced to the Porter Adventist Medical Center from their home in North Denver one hundred miles away. <sup>1</sup> Yet mere hours before the operation was to take place, the center's transplant surgeons were engaged in anguished deliberation over whether Guthrie was actually the right person to get that kidney. He was, after all, 85 years old. How much longer would he live with a new kidney? Shouldn't the organ, taken from a healthy 30-year-old motorcyclist who had died from head trauma, be given to a younger person who would get many more years of life from it?

The doctors decided to proceed, but in the end, there was a technical glitch and the operation did not take place. Guthrie went back on dialysis. Two-and-a-half years later he was dead of a heart attack at age 88. The ethical dilemma sparked by his case, however, did not die with him. Indeed, the question of "how old is too old for a transplant?" is being asked with increasing urgency by transplant professionals as the chasm between supply and demand widens inexorably.

Uneasy questions of allocation arise in environments of scarcity. Who will get to stay on the crowded lifeboat and who will be tossed overboard? This age-old tension between utility to society — the maximum good for the maximum number — and fairness to the individual is notoriously hard to resolve. In the case of the shortage of transplantable kidneys, it is made gratuitously more difficult by a "transplant community" that resists experimenting with bold ideas to increase the supply.

## DIRE SHORTAGE, MODEST REMEDIES

**O**RGAN TRANSPLANTATION IS one of the crowning achievements of medical science. Yet from 1954 — the year of the first renal transplant — to the present, there have never been enough organs to meet demand. The dearth includes all transplantable organs — hearts, livers, lungs, pancreases — but because dialysis can keep patients with renal failure alive, the shortage of kidneys is most acute in terms of volume. Indeed, over three-quarters of the national wait-list population comprises those waiting for a kidney.

In January 2007, roughly 70,000 people were waiting for a kidney, according to the United Network for Organ Sharing (unos), which maintains the national registry of transplant candidates under monopoly contract with the Department of Health and Human Services. In



big cities, where the ratio of needy patients to available organs is highest, the wait for a kidney ranges from five to eight years. This time is spent undergoing dialysis, a procedure that circulates the patient's blood through a machine (once called an "artificial kidney") that purifies it, siphons off accumulated water, and returns it to the body. Patients typically visit a dialysis center for treatment three times a week, for four hours each time. Many patients are deeply ambivalent about dialysis. They acknowledge its life-preserving role yet resent it as a vast intrusion into daily life that is often uncomfortable and debilitating.

Commitment to dialysis ends when a patient receives a transplant or dies. In 2006, only 17,804 people — or about one-quarter of the population waiting at the beginning of the year — received kidneys. Meanwhile, over 3,813 died waiting and 1,190 became too sick to transplant. It is a grim picture that is guaranteed to worsen. By 2010, the median waiting time is projected to be at least ten years long, extending well beyond the length of time that most adults, especially those over 65, are able to survive on dialysis.

Despite decades of public education about the virtues of donating organs at death, the supply of cadaver organs has remained disappointingly steady over the years. Half of all Americans have designated themselves as donors on their driver's licenses or on state-run donor registries, yet if family members are unaware of a loved one's preference, they are just as likely as not to grant permission for the organs to be taken. This is understandable considering that the request generally comes at the worst possible time. Not only is their relative dead, but he may well have met a sudden and violent end. It is just this kind of victim — a young, healthy individual with severe head trauma (think helmetless motorcycle accident) — who is the optimal deceased donor.

In response to the crying demand, transplant centers have been rethinking the definition of a transplantable organ. Consequently, kidneys from so-called expanded-criteria donors have become an important new source. These are deceased donors, over 60 years of age, or those between 50 and 59 years who had hypertension in life or died of a stroke. The retrieval of organs from moribund patients who may never meet the criteria for brain death is also being advanced. Such potential donors are called "non-heart-beating" because they died of cardiac arrest. Finally, there is an effort to boost the numbers of transplants using kidneys from living donors through so-called kidney exchanges. In such an arrangement, two or more prospective donor-recipient couples who are incompatible with each other match with a member of the other pair.

## ZERO-SUM GAME

**M**UCH AS THESE procurement innovations are welcome, they are likely to make only a modest contribution to supply.<sup>2</sup> The burden on transplant bureaucrats at unos, then, is how to allocate the limited reserve of cadaver kidneys in order to make optimal use of them. It is a problem unos has been working on for some time, and last winter the agency sponsored its Public Forum to Discuss Kidney Allocation Policy to unveil its new proposal. Central to the new allocation model was the concept of "Life Years from Transplant" — that is, how much longer a patient would likely survive after a transplant compared to how long he would live if he continued on dialysis instead.

The agency was seeking to maximize the number of additional years lived. In comparison with the first come, first served rule that currently guides kidney allocation, a scheme that prioritizes on the basis of life-years gained is more utilitarian. Starkly put, it views a healthy organ as wasted if it outlives its recipient — and the goal of optimizing longevity is to avoid a Clois Guthrie situation, in which a young kidney, able to prolong by decades the life of a 40-year-old, instead goes to an 85-year-old who dies a few years later, taking the organ with him.

In addition to penalizing older candidates, justifiable though this may be, the new unos proposal also disfavors candidates who have waited the longest. Indeed, it is the very fact of having waited years that weakens a candidate's prospect for receiving a kidney. This is because the more time he spends on dialysis, the more medical deterioration he suffers and, as a result, the fewer years of added life a new kidney will confer.

Proponents of the new unos scheme denied that a rigid age cut-off would be applied. Yet they acknowledged that older candidates, as a class, would indeed be disadvantaged. This was a flashpoint. A number of physicians and transplant recipients took the microphone during the comment period to object. A few predicted the American Association of Retired Persons would lobby strongly against the proposal, as the new plan appeared to “discriminate” against older people. Others speculated that the thriving international black market in kidneys would get a further boost from well-to-do elderly who would become “transplant tourists” — the term used to describe patients who go overseas to purchase a transplant on the black market.

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One transplant recipient in the audience expressed worry that patients who had logged years on the list already would become demoralized if waiting time became a minor factor in assignment. “It will destroy hope,” she said; knowing you will get a kidney “is what keeps you going.” Another recipient wondered: “Who’s to say an older person’s five years of life are any less important than a younger person’s nine years? . . . That’s playing God and people aren’t going to like it.”<sup>3</sup>

That is not playing God; that is playing man — the all-too-human affair of people deliberating strenuously and in good faith to determine what is right. The unos meeting dramatized the timeless “tragic choice” dilemma. The phrase comes from a classic 1978 book called *Tragic Choices* (W.W. Norton & Co.) by esteemed legal theorists Guido Calabresi and Philip Bobbitt. The authors delineate the conflicts society faces when it is compelled to distribute limited resources. Most wrenching for citizens and policymakers are choices among fundamental values. A transplant surgeon who cares for patients in a milieu of scarcity is no less a healer. He still wants his patients — young and old — to receive kidneys. Without question, a transplant will afford them a better quality and quantity of life — irrespective of age — not only in terms of liberation from dialysis but because they will be spared its cardiovascular complications. Yet, on the other hand, the surgeon is torn between his duty to the patient before him and the utilitarian imperative of enhancing survival benefit across the population of

patients needing transplants.

It is the eternal tradeoff that comes with medical rationing: individual versus societal benefit. Who will be saved? This question recalls the classic quandary of lifeboat ethics that famously confronted the physicians who developed chronic dialysis in the early 1960s.

## RATIONING AND ITS DISCONTENTS

**E**FFECTIVE DIALYSIS BEGAN during World War ii, but the technology could be used only in patients with temporary damage to their kidneys. Ongoing dialysis was not possible because of the difficulty of maintaining a connection between patients' veins and arteries and the artificial kidney, as the dialysis machine was once called. Glass tubing was used as the conduit for blood as it flowed into and out of the machine, but it would get blocked with clots from the vessel in which it was embedded. Doctors rotated the tubes after each dialysis session, but within a few weeks all viable vasculature would clot off. Unless the patient's renal failure reversed before then, he would die.

A breakthrough came on March 9, 1960, when a nephrologist at the University of Washington experimented with tubes made of a relatively new substance called Teflon. The non-stick surface of the Teflon allowed the tubes to remain in the patient's arm for months without clotting. "Suddenly, we took something that was 100 percent fatal and overnight turned it into 90 percent survival," said Dr. Belding Scribner, who pioneered the technique. And just as suddenly, the University of Washington Hospital was inundated with referrals for dialysis from physicians and patients across the country. Scribner secured private funding to underwrite an experimental dialysis program, the Seattle Artificial Kidney Center. It opened in January 1962 with a total of three treatment slots. But who among the dying should get them? Scribner argued that the job of choosing among medically eligible candidates ought to be shared by society.

Thus, a lay committee, known as the Admissions and Policy Committee of the Seattle Artificial Kidney Center at Swedish Hospital, was formed to decide nothing less than who would be allowed to live. The committee comprised seven volunteers — a lawyer, minister, housewife, state government official, labor leader, banker, and surgeon — and was among the earliest instances, if not the first, of physicians bringing nonprofessionals into the realm of clinical decision-making. Committee members insisted on remaining anonymous so that the medical staff, the public, and especially the applicant-patients would never know their identities.

The lay committee took its Solomonic charge seriously. "As human beings ourselves," the lawyer told a reporter, "we rejected the idea, instinctively, of classifying other human beings in pigeonholes, but we realized we had to narrow the field somehow." The committee did this by considering many factors, among them the applicant's income, sex, marital status, net worth, nature of occupation, extent of education, church attendance, number of dependents (more dependents conferred a better chance of being chosen), and potential for rehabilitation.

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*the modern era of medical innovation.*

Within five months of its founding, the lay committee was thrust into the public eye. The New York Times ran a front page story in May 1962: “Panel Holds Life-or-Death Vote in Allocating Artificial Kidney.” In November, Life, the 1960s’ most influential popular weekly magazine, ran a story by journalist Shana Alexander called “They Decide Who Lives, Who Dies: Medical Miracle Puts Moral Burden on a Small Community.” The exposé drew national attention to what was happening in Seattle. Alexander dubbed it the “Life or Death Committee,” and the accompanying photo spread depicted the members in silhouette, as if sitting in harsh judgment. In 1965, Edwin Newman narrated an nbc documentary about Seattle called “Who Shall Live?” Vocal physicians, social scientists, theologians, and legal scholars felt that the selection of dialysis recipients based upon determinations of human worth was an affront to the ideal of equality. The moral claim of each patient to treatment was equivalent, they argued. One much-cited essay in the UCLA Law Review bitinglly observed that “The Pacific Northwest is no place for a Henry David Thoreau with bad kidneys,” chiding the committee for ruling out creative nonconformists.

Allocation of dialysis was among the first tragic choices to arise in the modern era of medical innovation. Only on the battlefield had case-by-case triage ever been performed so explicitly. The scarcity of dialysis treatment generated layer upon layer of vexing questions. Who should receive life-saving care, who should choose, and on what principle? Some medical centers employed a first come, first served policy; a few shuttered their programs altogether so they would not have to choose. Most medical centers favored the utilitarian principle of maximizing outcome — in other words, choosing patients who would get more productive years out of dialysis. Inevitably, this ended up favoring the same patients who impressed selection committees as more conscientious, better educated, and more likely to be beneficiaries of the emotional and instrumental support that comes along with stable families.

Thus, throughout the 1960s and early ’70s, the tragic choice posed by dialysis was uneasily resolved in favor of handpicking patients. By 1972, however, pressure from advocates and physicians had become strong enough to move Congress to establish universal funding for dialysis. The Medicare End-Stage Renal Disease ( esrd) program, the new federal entitlement, offered virtually unfettered access to dialysis. Once the gate had swung open — admitting not only more patients who were good dialysis candidates (i.e., otherwise fairly healthy and cooperative) but also those with other medical and behavioral problems — enrollment and costs skyrocketed. More and more patients were kept alive on dialysis, and as advances in anti-rejection medication came about in the early 1980s, more people wanted kidney transplants, viewing dialysis as a bridge to surgery. With each passing year, the volume of candidates burgeoned and the amount of time spent waiting for a cadaver kidney increased. These dynamics were soon compounded by the aging of the U.S. population and the surge of diabetes (the most common single cause of renal failure). In 2004, the most recent year for which there are data, the esrd enrolled about 340,000 patients and cost over \$18 billion. Less than 1 percent of the Medicare population consumed more than 6 percent of Medicare expenditures that year.

Today, 35 years after the establishment of esrd, we have come full circle. Once we were rationing dialysis, and now we are rationing kidneys. The details have changed, but the basic challenge of assigning scarce resources has not.

### **A SHORTAGE OF ALTRUISM**

**U**NDER THE 1984 National Organ Transplant Act, anyone who offers or receives something of material value in exchange for an organ can be charged with a felony.

The ban's rationale was twofold: to prevent lurid scenarios in which desperately poor people auctioned off their spare parts to the wealthy and to ensure that citizens had equal access to the organs collected. "The prisoner in California gets the heart transplant because he needs it and is first on the list. It's blind to whether you're a saint or a sinner or a celebrity. That's key to maintaining the public trust," said Mark Fox, former head of the unos ethics committee.

But the trust is already damaged because of the death toll over which unos presides. The equity that unos seeks to preserve is "degenerating into an equal opportunity to die waiting," nephrologist Benjamin Hippen told the President's Council on Bioethics last year. The dire shortage of organs today is striking evidence of the fact that altruism is not sufficient to produce enough organs. In 2006, there were 7,180 deceased donors (yielding an average of 1.5 kidneys each) and 6,242 living donors (mainly family and friends). At the end of that year, the 67,000 candidates remaining dwarfed the number of available organs.

A cohort of physicians and economists has sought for at least two decades to persuade the transplant establishment to apply incentives to increase the organ supply. Many creative arrangements — from tax credits to tuition vouchers for children to charitable contributions in the donor's name — should be given a trial, they urge, to see whether new practices could compensate for the limits of altruism. Over the past few years, their voices have grown more insistent. In 2003, the American Medical Association testified in favor of a House bill that proposed pilot studies of incentives for harvesting the organs of deceased donors. At the 2006 World Transplant Congress in Boston, Dr. Richard Fine, president of the American Society of Transplantation, asked his colleagues: "Is it wrong for an individual who wishes to utilize part of his body for the benefit of another [to] be provided with financial compensation that could obliterate a life of destitution for the individual and his family?"

At the 2007 annual meeting of the American Society of Transplant Surgeons in January, a straw poll revealed that 80 to 85 percent of participants were in favor of studying incentives for living and deceased donors, according to society president Dr. Arthur Matas of the University of Minnesota. The public is receptive as well. A 2007 national Gallup Poll on attitudes toward donation of organs after death found that incentives would encourage more respondents to donate than would be discouraged from doing so, though the majority said their decision would remain unchanged. Most striking, among the 18- to 34-year-old age group, 34 percent said they would be more likely to donate, 6 percent said they would be less likely to do so; the rest were unchanged.

### **THE MORAL IMPERATIVE TO INNOVATE**

**P**ARADOXICALLY, THE CURRENT system, which is based on an altruism-or-else policy, undermines respect for individual autonomy, one of the most dearly held values in bioethics. Why shouldn't donors be able to receive some form of reward for giving up a kidney to save a life, especially if the act of compensating them encourages others to do the same? To be sure, the idea of combining organ donation with material gain can make people queasy. Yet the mix of financial and humanitarian motives is commonplace. No one objects, for example, to a tax credit for charitable contributions — a financial incentive to complement the “pure” motive of giving to others. The great teachers who enlighten us and the doctors who heal us inspire no less gratitude because they are paid. A salaried firefighter who saves a child trapped in a burning building is no less heroic in our eyes. Motives for giving an organ should not be the issue. More important than whether a kidney is given freely or for material gain is that it will increase the supply of kidneys to ameliorate suffering.

How could incentives work? A plan first offered in the late 1980s proposed to register a would-be donor today in return for the possibility of a much larger payment to his estate should his organ be used at his death. A major advantage of such a forward-looking approach is that the decision-making burden is taken off family members at a painful time — when they are sitting in the emergency room learning that someone they love is now brain-dead. The drawback to this plan, however, is that deceased donors alone cannot meet the need for kidneys because very few Americans who die, perhaps <<span class="text30">13,000 a year (or less than 1 percent of all deaths), possess organs healthy enough for transplanting. Thus, even if every American participated in a futures arrangement, the need for thousands of kidneys would go unmet.

Of course, the organs from deceased donors obtained through a futures mechanism would be a most welcome contribution to the pool, but in order to enhance supply more quickly and more robustly, living donors need to be recruited as well. Not only can a person live a healthy life with one kidney, but the long-term risk to the donor is negligible, and short-term risks are comparable to surgical intervention in general (about 3 deaths in 10,000). Moreover, a kidney from a living donor lasts longer than one from a cadaver, thereby keeping young and middle-aged recipients from getting back in the queue for a second organ sooner than they otherwise might have to.

*Why shouldn't someone be rewarded for giving up a kidney to save another person's life?*

What kinds of incentives could be offered to individuals amenable to relinquishing a kidney while living? Perhaps the federal government could offer lifetime Medicare coverage. Not only would this be medically responsible; it could serve as an inducement to donate — not to mention saving taxpayer dollars by liberating patients from costly dialysis. If the promise of health insurance did not attract a sufficient pool of donors, other incentives could be offered as well. For example, the donor could choose from a menu of options including a deposit to a 401(k) retirement plan, tax credits, tuition vouchers for the donor's children, long-term nursing care, family health coverage, life and nonfatal injury insurance, a charitable contribution in the

donor's name, or cash payments stretched over time. Under this scheme, Medicare would underwrite the incentives in light of the fact that it already pays for dialysis treatment, which costs about \$ 66,650 per patient annually according to the United States Renal Data Service. Compare these expenses with the cost of a transplant operation — approximately \$75,000 in all for the one-time cost of the surgeries and hospital stays of the donor and recipient, plus the first year of follow-up medical care including medication. Thereafter, the cost of immunosuppressive drugs is about \$ 12,000 per year.<sup>4</sup>

An important concern accompanying any enrichment plan is the potential for exploiting donors — especially low-income donors who, as the critics reasonably claim, will be the most likely to find incentives attractive. This is why donor protection is the linchpin of any compensation model. Standard guidelines for physical and psychological screening, donor education, and informed consent could be formulated by a medical organization, such as the American Society of Transplant Surgeons, or another entity designated by the federal Department of Health and Human Services ( hhs). A “waiting period” of three to six months could be built in to ensure that the prospective donor has ample time to think through his commitment. Monitoring donor health post-transplant is important as well and should include annual physicals and laboratory tests for one to two years after donation.

Incentive arrangements could be overseen by hhs or an entity it designates. As is currently the case with cadaver organs, kidneys obtained from compensated donors would be matched with the next best candidate waiting on the national list. This would require revising the National Organ Transplant Act to lift the ban on valuable consideration so that experimental trials could be conducted. Alternatively, Congress might permit individual states to apply for a waiver from the ban in order to devise their own incentive systems.

Within such a framework, altruistic donation would proceed in parallel with a system that offers compensation. Any medical center or physician that objects to the practice of compensating donors can simply opt out of performing transplants that use such organs. Recipients on the list are free to turn down a paid-for organ and wait for one given altruistically. Choice for all — donors, recipients, and physicians — is enhanced, while lives are saved.

## A REPRIEVE

**T**HESE BROAD PROPOSALS and variants on them need considerable elaboration. There is no denying the political and practical challenges that come with introducing payment into a 20-year-old scheme built on the premise that generosity is the only legitimate motive for relinquishing an organ. Yet as death and suffering mount, constructing an incentive program to increase the supply of transplantable organs becomes a moral imperative.

We see again in 2007 how remarkable advances in transplant medicine have reintroduced the classic dilemma of equity versus utilitarianism that beset the medical profession in 1962 after the advent of dialysis therapy. To be sure, the world of health care is no stranger to rationing — simply determining what pharmaceuticals are to be covered by health plans is a form of rationing. But rarely has case-by-case access to treatment been as overt as it was in the early days of dialysis and is now in transplantation, though these days it is perhaps somewhat less

dramatic, as choices are not based explicitly upon patients' social characteristics.

Would incentives work? There is good reason to be optimistic, but pilot studies are required to test various models. Architects of any new plan must give serious consideration to principled reservations and practical concerns; but they must act nonetheless, taking small, cautious steps. One thing is certain: A larger pool of kidneys would offer a reprieve, at least a partial one, to those patients languishing on dialysis and to those given the tragic charge of deciding which lives will be saved.

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<sup>1</sup> Dr. Guthrie's story was reported in Alan Zarembo, "How old is too old for a transplant? Kidneys are scarce. Elderly patients may get fewer if rules change," *Los Angeles Times* (November 5, 2006).

<sup>2</sup> Paired exchanges are estimated to yield about 1,000 new kidneys per year, according to Dorry Segev, MD, Johns Hopkins School of Medicine (personal communication, May 16, 2007). Non-heart-beating decedents may yield as many as 7,000 new donors per year (at 1.5 kidneys per donor, plus other vital organs) from deaths that occur in hospitals, according to Jim Warren, editor of *Transplant News* (personal communication, April 12, 2007).

<sup>3</sup> Judith Graham, "Should age determine who gets a kidney transplant? Controversial proposal would put younger patients higher on waiting list," *Chicago Tribune* (February 9, 2007).

<sup>4</sup> Arthur J. Matas and Mark Schnitzler, "Payment for Living Donor (Vendor) Kidneys: A Cost-Effectiveness Analysis," *American Journal of Transplantation* 4 (February 2004).

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