

The Waiting Game

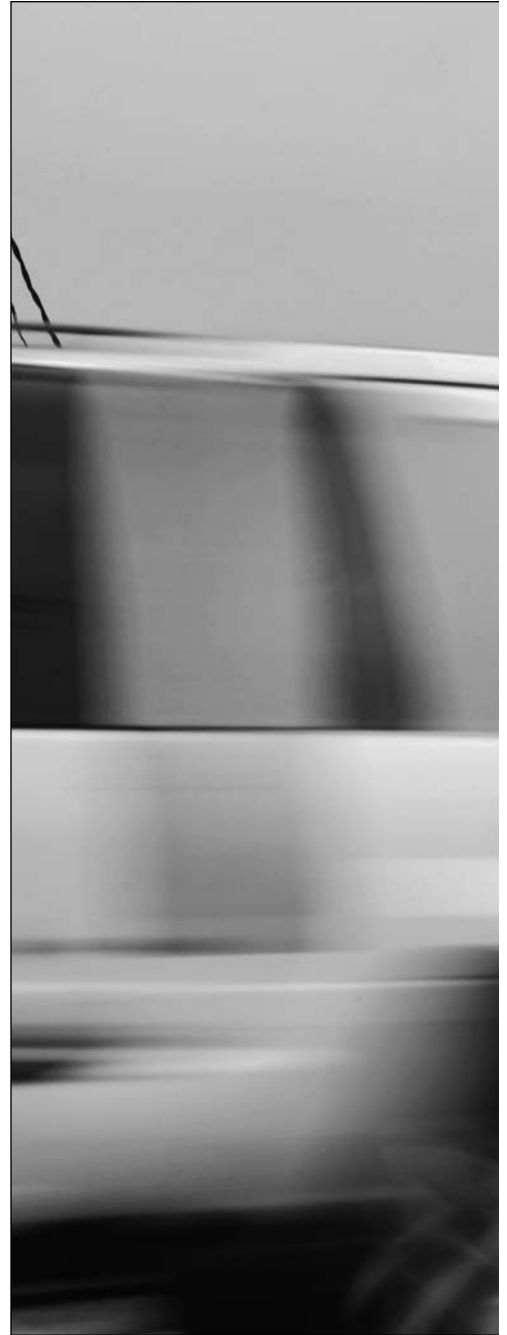
The struggle to find organ donors is more difficult
with a less-than-generous public policy

By Sally Satel

ON DECEMBER 23, 1954, RICHARD HERRICK GOT THE most remarkable Christmas present from his identical twin brother: a kidney. Doctors at Peter Bent Brigham Hospital in Boston performed the first successful kidney transplant on the twenty-four-year-old Coast Guard veteran. Today, a painting by Joel Babb commemorating the operating-room scene hangs in the Countway Library at Harvard Medical School.

I hope to receive the same gift. Mysteriously, after routine lab tests taken in August 2004, I learned that my own kidneys retired early.

I am one of about 91,000 people awaiting an organ, according to the United Network for Organ Sharing (UNOS), a national nonprofit that facilitates matching and placement of vital organs such as kidneys, hearts, livers, and lungs. Almost 65,000 of us are awaiting a kidney but only about a quarter will receive a transplant within the next year. The wait is four- to five-



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years long. Out of desperation, surgeons have begun using less healthy organs. Faced with a patient on the verge of death, they might transplant, for example, a virus-infected liver from a deceased intravenous drug abuser, as the *New York Times Magazine* reported last summer in a story titled “Will Any Organ Do?”

The need for kidneys, and organs in general, has long outstripped supply. The annual number of so-called cadaver kidneys – those made available at the time of death – has remained fairly stable at 2 to 3 percent growth a year for the last decade. Yet the number of people needing new kidneys increases by about 14 percent each year. Epidemiologists predict that by the year 2010, the wait on the UNOS list for a kidney will double to ten years.

Fortunately, the practice of living donation – wherein a healthy person, typically a relative or close friend, volunteers a kidney – has been growing. This is medically low-risk; a healthy person can function perfectly well with only a single kidney (sections of lung or liver can also be removed while the donor is alive but not, of course, a heart.). According to the Department of Health and Human Services, the number of living donors exceeded the number of cadaver donors every year since 2000. In 2004, for example, there were 6,647 living compared to 6,324 cadaver donors. But living donation at its current rate of growth cannot fill the gap between supply and demand. If this trend continues and waiting time for a kidney transplant extends to ten years or more, death on the waiting list will be far more common than transplantation.

Clearly, the system is in bad shape. And this is largely because of a misplaced faith in altruism.

The system expects people (or their loved ones) to give a body part and receive nothing in return. In fact, it is against the law to receive money or anything of value in exchange for an organ, a principle set down in 1984 by the National Organ Transplantation Act. Violators face fines of up to \$50,000 and felony prison terms of up to five years. “Organ transplantation is built upon altruism and public trust. If anything shakes that trust, then everyone loses,” says the UNOS web site. But so many have lost already: eighteen people die each day while waiting for an organ and, without changes, the situation is virtually guaranteed to worsen.



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Without a doubt, some people are capable of supreme acts of generosity. In fact, among the roughly 6,650 living donors mentioned earlier a small number gave their kidneys to a stranger. These admirable souls either called a hospital to offer an organ or sought potential recipients via advertisement.

But reliance on generosity makes for woeful public health policy. The distance between opinion and practice is often considerable. Surveys generally find that over 80 percent of respondents approve of the idea of organ donation at death. Yet fewer of them (about 60 percent) say they would permit their own organs to be taken after death, and only 30 to 40 percent of those surveyed actually designate themselves donors on their driver's licenses or on state-run donor registries.

Another problem is the relatively small number of deaths that are “eligible” to participate in donation. About 13,000 to 15,000 individuals die in hospital in a manner that permits their organs to remain healthy enough for transplantation. Optimally, a single body could yield two kidneys, one liver, one heart, one pancreas, and two lungs and save seven lives. Thus, if every family gave permission, this would be a vast improvement over the status quo. Yet even assuming a maximum yield of 30,000 kidneys annually (up to two for each of

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the 15,000 deceased individuals), barely half of the nation's need would be met.

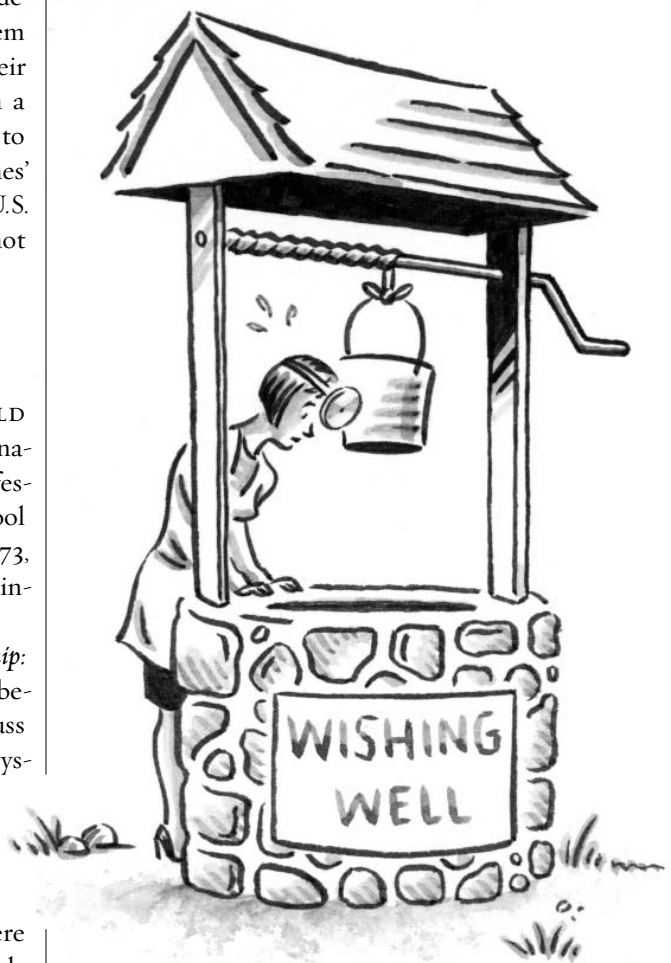
To make matters worse, only half of all eligible deaths result in donation, according to a 2003 report from the Department of Health and Human Services. Despite the law, as set forth in the 1964 Uniform Anatomical Gift Act, which grants immunity to any health organization that honors the deceased's wish to donate, hospitals continue to ask families' permission – and about half the time families do not consent to remove their loved one's organs, sometimes even reversing the deceased's expressed desire to donate. The problem of family refusal – in essence, the reversal of their loved one's altruism – has been deemed such a problem that Australia passed a law in 2004 to prevent families from overriding their loved ones' expressed wishes. Forty-three states in the U.S. have similar laws but, unfortunately, they are not enforced.

THE DOCTRINE THAT ALTRUISM SHOULD count as the sole legitimate impulse behind donation can be traced to Richard M. Titmuss, professor of Social Administration at the London School of Economics. From 1950 until his death in 1973, Titmuss wrote about class inequality and was instrumental in shaping the British welfare state.

In 1971 Titmuss published *The Gift Relationship: From Human Blood to Social Policy*, which rapidly became a best-seller in the U.S. In the book, Titmuss compared the efficiency of the U.K. and U.S. systems of blood procurement. He concluded that the free giving of blood within the National Health Service was a more efficient way to collect and distribute blood than the practices of the American system, which were partly commercialized. First, blood in the U.S. obtained from paid donors was more likely to be contaminated – given that prostitutes, drug addicts, and others at high risk for transmitted diseases were among the donor groups. Second, Titmuss claimed, the idea that people would give

their own blood away with no expectation of reciprocity encouraged a sense of community.

On the first claim, Titmuss was partially correct. When organizations such as the Red Cross collected from addicts and prostitutes, the blood obtained was indeed more likely to be tainted with hepatitis. But it turned out that this could be avoided by setting up collecting sites in middle-class neighborhoods where most people in the vicinity had homes and jobs. Nor was free blood guaranteed to be cleaner: when AIDS appeared in



the early 80s, most of the infected blood came from gay men, a socially conscious group who volunteered blood regularly. In any case, today blood is tested for HIV and hepatitis B and C, and contamination is rare, whether blood is paid for or not.



Titmuss's second claim, however – that altruistic acts are among the most sensitive indicators of the quality of human relationships and values in a society – is alive and well. As a faithful socialist and member of the Fabian society, Titmuss believed capitalism to be morally bankrupt. He wrote that blood donors were “taking part in the creation of a greater good transcending the good of self-love. To ‘love’ themselves they recognized the need to ‘love’ strangers. By contrast, one of the functions of atomistic private market systems is to ‘free’ men from any sense of obligation to or for other men regardless of the consequences to others who cannot reciprocate.”

Money allegedly taints transactions because of the risk that the giver has been coerced into giving against his will, been exploited into treating his body like an object, or has been forced into violating his own moral commitments. Also, a free market supposedly suppresses charity – an argument disputed by the health of American philanthropy.

The current U.S. transplant “community” similarly sees the market as incompatible with fairness. To maintain the equal distribution of scarce organs, the argument goes, the community (e.g., UNOS) must exercise total control. According to Mark Fox, head of the UNOS ethics committee: “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.” On the contrary, depending upon how heinous the crime, it is just as likely that this kind of aggressive equity undermines trust. When rationing is necessary, one would imagine the public prefers to think of authorities as wise stewards of scarce resources, not radical egalitarians. In any event, public trust is already badly damaged because of the long waits and daily death toll over which UNOS presides.

“Almost everyone agrees that an incentive program would encourage more donation than would

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a purely altruistic approach,” says Adam Kolber of the University of San Diego Law School. “It is as if the institution of organ donation is being used as a means to further another goal, not specifically related to organ donation.”

What Kolber is referring to are the Titmussian ideals of community connectedness, egalitarianism, and a general collectivist mentality – all geared toward preserving control over distribution of a scarce resource – paired with a fear of markets, competition, and self-interest. The problem is that the system itself may be the cause of the shortage it is charged with regulating. As nephrologist Benjamin Hippen has observed, the human cost is a system “degenerat[ing] into an equal opportunity to die on the waiting list.”

Finally, a system based on altruism-or-else fails to accommodate one of the most widely held values in the bioethics canon: autonomy. Individual freedom is enhanced when options are increased. This includes the freedom to refuse remuneration. Indeed, if such arrangements ever become possible by federal law, then we will know who the truly altruistic donors are. They will be the ones who choose to give their organs, or those of a loved one, for nothing of value in return.

Today, Titmuss’s ideological offspring populate bioethics committees and medical schools. They regard our current system of “detached generosity,” in the words of University of Chicago legal scholar and economist Richard A. Epstein, as an exemplar of resource redistribution. Even if it falls short of its public health goal, at least it symbolizes the ideal of social equality. In the end, however, the cost of pursuing Titmuss’s vision of a noble act is to deny other people their very lives – a consequence that is almost surely true, given well-established economic principles, and one that professionals should at least have the chance to put to the test.

For years, creative physicians and ethicists, as well as frustrated patients, have tried to change the system to increase the number of organs. Unfortunately, the transplant “community” has rejected practically every suggestion and fledgling



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effort, charging innovators with violations of equality and altruism.

In 2003 Alex Crionas, a young man on dialysis living in Orange City, Florida, started his own web site to attract potential donors. Fortunately, Crionas met a young man at a party who decided to donate a kidney to him; this man had never seen Crionas’s web site. The young man passed the medical qualifications but, as the date for surgery neared, the Tampa-based transplant center refused to perform the surgery because of the existence of Crionas’s web site, even though the two did not meet that way. The center went further, noted the *Tampa Tribune*, which reported the story, and refused to accept, a priori, any living donor for Mr. Crionas because of his web site. According to Dr. Douglas W. Hanto, head of the ethics committee at the American Society of Transplant Surgeons, such brokered transplants would “undermine trust in the whole system.” Dr. Hanto’s group even asked its members to boycott privately arranged transplants.

This is absurd. The UNOS “system” to which Dr. Hanto refers is for dead donors. The web site is for living donation. Not only are these different pools of donors, but a live donation also takes the

recipient out of the cadaver waiting pool and thus benefits people on the list because they can move up. As well, sites like MatchingDonors.com and other public efforts raise awareness: a person who might never have thought of donating could, after seeing the site, decide to. Again, the more organs offered, the quicker people are taken off the UNOS list, to the benefit of all.

On his web site (selflessact.net), Mr. Crionas elaborates: "To the person needing an organ, the whole world is his family. Why should he wait to be called off a list when he can take the initiative to expand his circle of friends, his family, among whom an altruistic donor may be found?" He also posts letters from the organizations that blocked his transplant: the American Society of Transplant Surgeons ("transplant community should discourage such 'directed donation' [made through] Internet stories") and Lifelink Healthcare Institute of Florida ("[we are] strongly opposed to the solicitation of organs through web sites").

In the end, happily, Mr. Crionas found a different center to perform his surgery. But his poignant letter reveals the grave limitations of our transplant policy and the callous paternalism of those in control. Deviation is interpreted as a sign of selfishness, a violation of the altruistic code. "I see patients increasingly willing to take things into their own hands," Dr. Hanto of the American Society of Transplant Surgeons told a reporter disapprovingly. Side-stepping a broken system does not "undermine the trust" in it, as UNOS says; circumvention is symptomatic of the system's dysfunction. In the case of Mr. Crionas, his resourcefulness was an attempt to enlarge on potential public altruism.

I had my own brush with the transplant establishment when I turned to MatchingDonors.com, a web site created to help link potential donors and recipients. The site lists about 2,700 potential donors and 120 possible recipients, and it claims to have brokered thirteen transplants, with about twenty more recipient-donor pairs matched and



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awaiting surgery. The site charges organ seekers several hundred dollars for a listing. There is no charge for donors and fees are waived for seekers if necessary.

I went to the web site because friends who said they would look into donation either turned out to have disqualifying medical problems or spouses who objected, or they grew scared. Once you "meet" a donor on the web site, the process follows the standard months-long screening process, with physicians at a transplant center determining whether he or she is medically and psychologically eligible to proceed with the surgery.

What could be a more dramatic enactment of generosity than giving an organ to a stranger? Yet when I wrote about the experience in the *New York Times*, Dr. David Steinberg, director of medical ethics at Lahey Clinic Medical Center in Burlington, Massachusetts, voiced the incomprehensible complaint: "It is not unreasonable to ask whether it is ethical for people to go on dialysis or die while Dr. Satel gets a kidney that, perhaps more appropriately should have gone to [someone on the UNOS list]." This is the same illogical point raised by Dr. Hanto: How can receipt of a living kidney disadvantage someone waiting for a cadaver organ? Besides, I am on the UNOS list (because it is possible no live donor will come through for me), and if I receive a living donation, then my name will be removed and the next person will advance.



Patrick Garrity, left, agreed to donate a kidney to Alex Crionas, right. But Lifelink of Florida denied the transplant because Crionas had put up a web site asking for a donor.

Other critics fret about whether the web site process is unfair, as some prospective recipients could write more compelling “ads” to attract more donors. (For the record, my notice was two sentences long, including only my age, place of residence, profession, and blood type, and within a week I received a number of inquiries.) Arthur Caplan, bioethicist at the University of Pennsylvania, observed of online matching, “Not everyone has the means to use the Internet.” What Caplan is saying, then, is that the ethical conduct of anyone in need of a transplant is to be passive and resigned to his fate at the hands of a grossly inefficient system.

Searching for a donor via the Web is a symptom of the desperate need for more organs. Unfortunately, many bioethicists and physicians ob-

struct the kinds of innovation that could increase the number of organs donated.

Consider “presumed consent.” Also known as “opt out,” this approach is used in most European countries. It stipulates that individuals presumably agree to donate their organs at death unless they specifically decline to do so. In the U.S., the system of deceased organ donation operates on a voluntary system known as explicit consent, in which one is presumed *not* to want to donate in the absence of explicit instructions to the contrary.

In 1989 Spain adopted presumed consent and within a decade the number of donors more than doubled. After Austria passed a presumed consent law in 1982, its donation rate quadrupled, and by 1990 the number of kidney transplants performed was nearly equal to the number of people on the waiting list. In Belgium, an interesting natural experiment took place: the law passed in 1986 but some locales did not implement it. The city of Leuven did and within three years its donation



rate more than doubled. Meanwhile, Antwerp did not and donation rates remained flat. Though not all regions have seen such marked improvement with presumed consent, it is generally accepted that adopting a presumed consent policy could raise deceased donation rates by about 15 to 20 percent.

Nonetheless, transplant policy experts believe the policy has a poor chance of being accepted here, despite endorsement by the American Medical Association. The biggest concern of critics is that organs would be removed from people who, in life, might not have wanted to donate – that is, those who failed to indicate their objection out of simple negligence. One wonders, however, what Titmuss might have said: with an assumption of altruism built into the system, as is the case with presumed consent compared to opt-in, shouldn't we expect the bonded, "loving" community of citizens to want to make it their business to comply with the policy?

And wouldn't a sense of community be strength-

ened by a program like LifeSharers? It is a network of organ donors who agree to offer their organs first to other organ donors when they die. Participation is free and open to any one. LifeSharers works through a form of directed donation that is legal under state and federal law. Giving organs first to organ donors, the theory goes, will convince more people to register as organ donors. The program is too new at this point to be able to prove that it increases registered donors, but there is no denying that it promotes fairness (about 60% of the organs transplanted in the United States go to people who haven't agreed to donate their own organs when they die) and it actually rewards altruism. Yet Sheldon Zink, Director of the Program for Transplant Policy and Ethics at the University of Pennsylvania, finds fault. Touting the primacy of UNOS, she writes in the *American Journal of Bioethics* that organs "should go first to people that UNOS determines are most in need... [also] Lifesharers contradicts the concept of equity by denying anyone in need."

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Another potential solution to the organ shortage is remuneration of various kinds. This does not violate the integrity of the UNOS list, yet many consider it the buzzing third rail of transplant policy. Some tentative efforts to introduce controlled remuneration into the organ transplant system have been unsuccessful. In 2003, Representative Jim Greenwood, Republican of Pennsylvania, proposed to sponsor a handful of demonstration projects in which the government would pay for the purchase of life insurance policies payable to a living donor's designee. This modest proposal would have simply created a few pilot programs, but it was opposed by the National Kidney Foundation and the American College of Surgeons. (The American Medical Association, American Society of Transplant Surgeons and UNOS, however, did approve.) The state of Pennsylvania proposed the allowance of \$300 toward funeral expenses, but the bill failed, and Wisconsin recently passed a bill allowing live donors to subtract up to \$10,000 in costs (e.g., missed work, travel) from their taxable state income.

Also in 2003, a bold group of physicians, legal scholars, economists, and other concerned individuals formed the Ad Hoc Committee for Solving the Intractable Organ Shortage. With the most common reason for missed donation opportunities being refusal by the donor's family, the express purpose of the committee was to lobby Congress for pilot programs to test the effects of paying the relatives of post-mortem donors a modest sum – perhaps \$5,000 or \$10,000 – which the family could put toward the deceased's estate or give to charity. Tax credits and health insurance discounts were other options. Predictably, the idea was rejected by the National Kidney Foundation and, this time, by the American Society of Transplant Surgeons. "Any attempt to assign monetary value to the human body ... devaluates the very human life we seek to save," claimed Dr. Frank Delmonico of the National Kidney Foundation. The fear of such monetary transac-



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Some bioethicists fear that nonaltruistic arrangements debase human beings. They recoil from what they consider the "commodification of the body." Leon Kass, former head of the President's Council on Bioethics, says that receiving payment for an organ makes a donor or family barely different from one who sells a "pork belly," and comes "perilously close to selling out [one's] soul." Accepting money in exchange for an organ, he writes, "repels us, quite properly I would say, because we sense that the human body especially belongs in the category of things that defy or resist commensuration – like love or friendship or life itself." This strikes me as a poor analogy. Unlike one's personality or a set of ideas, which do indeed constitute selfhood, one's identity is not threatened by having a diseased kidney or replacing a defective body part with someone else's. We replace heart valves and fit amputees with artificial limbs all the time. We have well-established markets for semen, blood plasma, teeth, and human hair.

Then there is the Titmussian objection that financial arrangements will mean the loss of a personal link. I, for one, welcome that. I prefer *not* to

know whose organ I have. Ideally, I would like to carry on the entire transaction via vending machine to keep it as impersonal as possible. If my fellow prospective recipients wish to develop a relationship with their donors, fine, but for me anonymity would be best. Why? I worry that my feelings of immense gratitude toward a donor would turn into a sense of constricting obligation.

Proof that my sentiments are not unusual resides in the existence of a modest literature devoted to “the tyranny of the gift.” The phrase was coined by sociologists Renee Fox and Judith Swazey. Referring specifically to an organ, they write, “the gift the recipient has received from the donor is so extraordinary that it is inherently unreciprocal.... As a consequence, the giver, the receiver, and their families may find themselves locked in a creditor-debtor vise that binds them one to another in a mutually fettering way.” I object to Fox

and Swazey’s portrayal of a vise-like entanglement as inevitable, but surely it can happen.

The “tyrannical” aspect also extends to donors, who may feel compelled to give, though not out of pure altruism. Imagine, for example, a person who doesn’t really want to donate, but feels a sense of obligation to do so lest his relative or friend be forced onto dialysis. Another person might donate in order to seem like a hero or gain attention or inflate her self-importance. Yet another might do so out of guilt. A paradoxical effect of such coerced altruism is that it exploits the emotions and generosity of potential donors.

In *Kidney for Sale by Owner: Human Organs, Transplantation and the Market*, bioethicist Mark J. Cherry argues incisively against the transplant establishment’s consensus that altruism is the only morally acceptable motive for donation. “The question is not whether selling organs has harmful



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elements, but whether on balance, the costs outweigh the benefits,” he writes. “Concerns support caution; they [should] not sustain prohibition.” For the record, most of those in favor of markets do not promote the ability of a prospective recipient to purchase directly from a living individual or the family of the deceased; instead, market proposals govern the purchase of organs by authorized firms for sale to transplant centers.

For virtually every procedural objection, Cherry suggests a solution. For example, worries that impoverished people will be financially coerced into selling their organs could be averted by only allowing people above a certain income level to participate in the organ market. (Though who is to say that the poor should not be allowed to make a rational decision to part with an organ – and liberate themselves from poverty in the process?)

Might the exchange of money be so off-putting to some potential donors, their families, or recipients that they would refuse to consider donation at all? Those people could still donate under the terms of our current system, but how many would forego the opportunity to give the money to a charity? Wouldn't that complement, rather than undermine, the altruistic impulse that motivated them in the first place? With pilot programs, we could study so many of these questions. If, in the very unlikely case, the incentives were no better in recruiting donors than the current system, we could return to business as usual.

What's more, a regulated market would likely suppress the international black market, which has produced horror stories of exploited donors and recipients alike. In my view, individuals should be able to use their own wealth to purchase organs, and public agencies and charitable organizations should be allowed to use their funds to supply organs to the needy within an organized structure that prevents corruption. As legal scholar Richard A. Epstein puts it: “We should all be far better off if altruism were confined to a more modest role: as a reason for private charity for those in need.”



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Most important, we need scientific data. Only Iran now has a regulated organ market, so there are few functioning models to study. Nonetheless, nearly all of the arguments against financial incentives are based on assumptions that can be resolved by empirical studies.

By emphasizing generosity as the only acceptable motive for donation, many bioethicists and physicians undermine their own cause, which is to alleviate individual suffering and improve public health. The system they defend is tied so tightly to a particular ideal of social justice that it ends up committing a greater moral failure, resisting developments that could increase available organs and thus save thousands of lives yearly.

Many transplant professionals have lost sight of one of the most important measures of ethical worth: Whether more good than harm results from the decisions they have imposed on us. The imperative to innovate and experiment is great because altruism alone cannot solve the problem. To expect as much is to hold a naive view of human nature; to accept as little is to stand by while many die. ❀

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