

What Body Parts Do We Owe Each Other?

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Abstract The American experience in organ transplantation illuminates the attitudes and practices that underlie the ongoing failure to establish a national health insurance system. In both spheres, the public makes a sharp divide between the well-being of intimates and the well-being of strangers. Private and public duties remain distinct; obligations recognized on a personal level do not expand public commitments. As a result, individuals must shift for themselves, whether they require an organ donor or a doctor. In the world of transplantation as in the world of health care more generally, we are all on our own.

Keywords Organ · Transplantation · Donation · National health care

No consideration of what we owe each other would be complete without reckoning with the field of health care. Whatever the specific rankings of social obligations, the provision of health services is certainly among the most important of them, the equal of education, housing, and employment. And yet, the USA stands almost alone among industrialized countries in not implementing national health insurance. Some provisions have been made for seniors (through Medicare) and for children of low income families (through SCHIP). But despite periodic statements by political candidates, corporate heads, and labor union leaders, and

findings by epidemiologists and health policy analysts of the detrimental effects of fragmented care, there is little reason to anticipate that national health insurance will soon be enacted.

The literature that analyzes why this is so is extensive and, for the most part, without sharp divisions. While policy prescriptions, such as a single payer, provoke intense controversy, different diagnoses of the roots of the failure supplement each other. Some analysts emphasize political dynamics, ranging from the strength of Southern Democrats in the New Deal era to the lobbying efforts of the AMA in the post-World War II decades. Others focus on vested corporate interests, including the strength of insurance companies whose Harry and Louise ads helped to defeat the Clinton health plan. Still others look to social explanations. Public opinion polls reveal that an overwhelming majority of Americans profess to favor a national health insurance program; but the percentage in favor drops as the cost and tax burden of the program is made more explicit. There is also evidence of a profound anxiety among those with health insurance that a national system that served everyone would intrude on their own privileges and limit their access to medical technologies.

The American experience with organ donation and transplantation helps explicate the attitudes that underlie the unwillingness to establish national health insurance. To put the question into the framework of social obligations, what do we owe each other in terms of body parts? In a 2005 Gallup poll conducted for the Division of Transplantation of the Health Resources and Services Administration, the overwhelming majority “strongly support the donation of organs for transplants.” However, when asked about the likelihood that they themselves will donate after death, only 39% (in 1993) and 51% (in 2005) said they were “very likely” to do so. Moreover, in practice, the rates of cadaveric donation are low (under 50% of eligible cases)

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and have not increased significantly over time. Here, as with national health insurance, support for the general idea does not translate into actual behavior.

There is, however, one feature of organ donation that seems to depart from this rule, and that is the willingness to serve as a living donor, in particular, a kidney donor. The public rhetoric that describes this act invokes the term “altruism,” and labels the donor a “hero.” Such terms in ordinary use suggest someone who is contributing to the common good and acting selflessly without regard to the status of the person in need. It is an attitude, which if generalized would promote a commitment to national health care. But as we shall see, among living organ donors, there is a sharp divide between meeting the needs of intimates and meeting the needs of strangers. Private and public duties remain very separate. Obligations recognized on a personal level do not help to expand public commitments.

The beginning point for much of the literature on organ donation is the notable shortage of body parts. The surgical techniques required for successful transplants are well-established and widely available. So are the effective regimens that prevent the body from rejecting the transplanted organ as a foreign part. In the great majority of kidney recipients, the organ will be fully functional 5 years after the transplant. The barrier to transplantation is the availability of an organ. Seventy thousand patients are on the national waiting list for a kidney; even with dialysis widely available, several hundred die each year for want of an organ. From the perspective of would-be recipients, the question of what we owe in body parts is a matter of life and death.

Given the shortage of cadaveric organs and the well-documented superiority of transplantation to dialysis in terms of morbidity, mortality, and quality of life, kidney transplant teams and would-be recipients are increasingly turning to living donors. No sooner is a patient diagnosed with end stage renal disease than team members will inquire whether there is a spouse, child, relative, or friend who might make a donation. They will explain that from the perspective of the donor, the long-term risks of living with one kidney are minimal; some discomfort and a period of recuperation will follow the procedure, but now that laparoscopic rather than open field surgery has become standard, recovery is quick and the resulting scar will be tiny. From the perspective of the recipient, there will be no waiting period (which now averages 2 to 3 years), the organ retrieved will be optimal, and an immediate transplant will obviate the need to go on dialysis. Not surprisingly, then, about half of all kidney transplants in 2006 used organs removed from living donors, and the percentage will almost certainly increase in the future.

Because organ donation, particularly from living donors, is not familiar territory to many policy analysts, it may be

tempting to dismiss the inquiry as arcane. At the conference at which this paper was first presented, one of the commentators, Deborah Stone, initially expressed just such a sentiment. But she immediately corrected herself, recalling how her grandmother would express a keen desire for a particular outcome by declaring: “I would give my right arm if only....” Metaphor has now met reality. Would you give your right arm, or more specifically your left kidney, so that someone could undergo a transplant?

Although it may not be obvious, there is to be found a readiness to give one another some parts of our bodies. A particularly poignant but telling case in point came in the immediate aftermath of the calamity at the World Trade Center on 9/11. No sooner did the news of the disaster spread than New York residents began to line up at hospitals to donate blood. One way to express solidarity with the victims and to fulfill what was seen as a public duty was to donate blood to a stranger at a time of calamity. The fact that hospitals had ample supplies on hand for the emergency and, within a day, were requesting that people stop lining up to donate only adds weight to the finding.

Drawing conclusions on owed body parts from this incident must be carefully qualified. For one, the example involved blood, one of the easiest bodily substances to donate. For another, 9/11 was truly an extraordinary moment, a direct attack on US soil that outrivaled Pearl Harbor in the number of deaths. In more ordinary times, many hospitals face shortages in their blood supplies. For still another, the practice of blood donation is much more deeply rooted in the culture than organ donation. So cautiously put, we do owe each other blood in times of national disaster. But do we owe other body parts and in ordinary times? And to whom do we owe it? Immediate kin? Extended family members? Neighbors and friends? Associates? Strangers?

The counterpart of the easy case of a stranger donating blood in times of emergency is of a parent donating a kidney to his or her child or spouse. Teams report that in these circumstances, agreement to donate is immediately forthcoming, even before they have had a chance to explain the risks. Hence, both in blood to strangers and organs to immediate family, a strong sense of obligation dictate action. But how far does this obligation extend? What is it that we owe (beyond blood and solid organs) and to whom do we owe it?

To answer the question, it is first necessary to calculate the degree of risk involved. Donating blood is low risk, as is the donation of sperm and bone marrow (although bone marrow donation may cause temporary discomfort). The risk of negative outcomes with kidney donation is moderate; the surgery is done under anesthesia, post-operative complications do occur, and the long-term effects, that is, over 15 years, are still unknown. In the case of egg

donation, again risk is moderate because of the need to use powerful drugs to hyperstimulate the production of the eggs as well as to retrieve them. By comparison, the risks of donating a portion of one's liver are high (although the liver will regenerate, the surgical removal of a section is very complex and donors have died in the process). The same holds true for donating a lobe of a lung.

It would be difficult to make the case that any duty is owed by any one of us to donate a body part to non-family members when the risk of the procedure or the outcome is moderate or high. One might opt to make the donation but there are no grounds for establishing a moral obligation to do so. Evidence for this proposition comes from a variety of sources.

First, these judgments underlie transplant teams' decisions on how intensively to investigate donors' motives. (Between 2004 and 2005, we and members of our research team conducted an intensive investigation of the decision making process around living organ donation following transplant teams, donors, and would be recipients. Our investigation had IRB approval. We attended meetings of an East Coast based transplant team and interviewed a sample of donors and would be recipients. The Robert Wood Johnson Foundation's Health Policy Investigator Awards funded the project.) When the would-be donor is close kin to the recipient, the teams ask only a few perfunctory questions and then proceed to the workup. Let a mother want to donate to her child or a husband to his wife, and the oversight exercised is minimal. This is not the case when the relationship is more distant.

Second, the same perspective on duties owed emerges in the decisions rendered by state courts. Particularly in the early days of transplantation, the cases that arose on organ donation often involved parents wanting permission for their minor child to donate an organ to a sibling. The classic incident occurred in 1954 when Joseph Murray, a surgeon at Boston's Peter Bent Brigham Hospital who would later win a Nobel Prize for his work, wanted to transplant a kidney from one identical twin child to another. (At a time when anti-rejection drugs were primitive, the only way to insure that the body would not reject a transplanted organ as a foreign body was to use one from an identical twin.) Murray asked the Massachusetts court to prospectively approve the transplant, declaring that if he acted on his own, he could be accused of committing the felony of maiming: he had operated on a perfectly healthy child and removed a functioning kidney. The court approved the donation, ruling that the procedure was in the best interest of the *donating* twin; were his sibling to die, he would later fault himself, and others, for not allowing him to save his brother's life. The court's reliance on the best interest standard, not an easy one to satisfy, reflects a social consensus on the duty of intimates to take moderate risks

for each other, even when they are minors and it is parents who are making the decision for them.

To contextualize the duty to supply body parts more broadly, let us examine the various policy options that have been proposed to reduce the shortage in organs. These include: (1) Emphasize and fund prevention programs to reduce demand; for example, promoting better diet and weight loss that would reduce the prevalence of diabetes and hypertension, and thus lower the rates of end stage kidney disease. (2) Use the power of government to increase the supply of organs, namely, by enacting presumed consent legislation. (3) Allow the sale of organs on the assumption that a market in organs would increase the supply. (4) Leave it to individuals to obtain their own organs, whether through social networks or Internet advertisements.

Taking these options in turn, it is apparent that the forces driving transplant will not be counterbalanced by efforts at prevention. Surgical teams are motivated to do transplants by reason of training, outlook, and financial returns to themselves, their departments, and their hospitals. They are not and will not be the leaders of a movement to promote prevention. Indeed, given the data on the efficacy of transplant, neither surgeons nor patient groups will allow expenditures for prevention to limit transplant programs. All the while, since rates of diabetes and hypertension are increasing for minorities and low income groups, the lack of access to health care makes a strategy of prevention even less feasible.

Nor is federal policy likely to affect organ supply. The government did put into place a Required Request regulation: hospitals are mandated to ask surviving kin of medically appropriate deceased patients whether they will consent to donation. But Required Request has had almost no impact on cadaveric donation rates. One intervention that would have positive results would be legislation providing for presumed consent for cadaveric organ removal. Under such a system, everyone is considered a potential donor except those who have formally opted out of the program. As implemented in Belgium, presumed consent has dramatically expanded the supply of cadaveric organs. Some individuals and groups have opted out, most notably the orthodox Jewish community of Antwerp, but they represent a small minority of the citizens.

The likelihood of presumed consent being enacted in the USA is very low. Resistance comes from transplant teams who are apprehensive about being labeled as organ snatchers by unhappy families; from civil libertarians who object to the by-passing of informed consent on an individual by individual basis; by pro-choice advocates who are loathe to make the government the de facto "owner" of body parts which might serve as a precedent for anti-abortion legislation; by conservatives who see this as

an egregious example of “big government;” and by minority spokespeople who contend that under such a system persons of color would become suppliers of body parts to more affluent members. Whatever the source of the objection, the idea of community responsibility to provide organs for transplantation is unacceptable to a variety of constituencies.

The third option, a market in organs, is presently illegal in the USA and is universally condemned by transplant societies in Western Europe and the USA. Over the past 5 years, numerous articles and books from bioethicists and economists have proposed such a market, insisting that selling a kidney would benefit the life chances of the poor donor; that prohibitions on sale are paternalistic, depriving the would-be sellers of their rights; and that a market in organs would increase organ supply. Since we do not acknowledge that we owe each other body parts, we should adopt a market solution.

The argument most often presented by pro-market advocates is that prohibiting a market in organs violates the best interests of would-be sellers. However, from what is known about outcomes in third world countries (particularly India and the Philippines), it has little basis in fact. (Since sale is illegal in developed countries, no comparable information is available.) Organ sellers do not escape poverty—within a year or two they are back in debt. Worse yet, their employment opportunities decline. They are discriminated against by employers, who fear that the surgery has weakened them. And evidence suggests that some sellers have, in fact, become compromised in their ability to hold certain jobs, like packers or longshoremen, which require heavy lifting.

Nor is it certain that allowing the sale of organs would increase supply. The market may crowd out altruism, leading to a decline. A school of behavioral economists has imaginatively, if not definitively, argued that putting a price on a behavior may produce less effective results than voluntary actions. In one classic example, when a day care center began to fine latecomers, instead of relying on a cooperative spirit, the incidence of lateness increased. Even after the fine was revoked, lateness persisted. As Uri Gneezy put it: “Extrinsic motivation might change the perception of the activity and destroy the intrinsic motivation to perform it when no apparent reward apart from the activity itself is expected.” Furthermore, it also suggests that once pay is introduced, there may be no going back: “Once a commodity, always a commodity.” Logic, too, suggests the limits of a market. Would family members want to run even the small risk of injury from donation if they could purchase an organ?

It is the reliance on individual organ donation that represents current policy. Responsibility has been left in the private realm. Data on the relationship between donor and

recipient makes clear how it has been fulfilled. In 2005, there were 6,563 living kidney donors: 68.4% of them involved donations from parent to child, child to parent, sibling to sibling, and spouse to spouse. Other relatives made up 7.6% of the total, and friends, neighbors, and other unrelated persons, 21.5%.

Thus, donors primarily come from the immediate family. No data exists on how many and how often family members turned down a request for donation; all that can be said is that successful recipients draw on family connections. Apparently, we do not bowl alone—we bowl with our families. Family obligations are owed and, from the perspective of those in the winner’s circle, paid.

In one-quarter of the cases, recipients were the beneficiaries of relationships with neighbors or associates; donation is not confined to the family. Because the data on unrelated donors is aggregated and numerical, the nature of the relationship between donor and recipient is not known. However, as a starting assumption, it is likely that recipients drew on social capital, successfully turning to neighbors, workplace partners, church members, and the like. (We did attempt to correlate states with high social capital scores as tallied by Robert Putnam with rates of organ donation but no relationship was found.) It is not possible to chart how often employees donated to employers, patients to doctors, parishioners to clergy, or whether donation reversed lines of power and prestige.

Two additional observations clarify how private values have superseded public values in organ donation. First, transplant policy, as established by the United Network of Organ Sharing (UNOS), allows for “directed donation,” whereby the donor specifies the recipient. (Blatant discriminatory practices by category are not allowed; donors may not say that a person of color may not get their organ). Theoretically, UNOS might have ruled that families have the right to give their donation to kin but all others must put their donated organ into a common pool, to be allocated on the basis of such criteria as length of time on the waiting list or degree of illness. This has not been done. The argument favoring the existing policy is that directed donation increases the supply of organs. But at the same time, directed donation confines the donation process to the private realm and does not encourage a public solution.

Second, even efforts to obtain a kidney that are not limited to immediate acquaintances more often emphasize personal worth and obligations rather than the public good. Would-be recipients are increasingly turning to the Internet, an innovative but highly controversial choice. There are numerous web sites that now serve as an outlet for requests for organs, resembling the web sites for dating and for open adoption. Barry Wellman has called this decreased reliance on a single group “networked individualism.” He posits, “Rather than relying on a single community for social

capital, individuals must actively seek out a variety of appropriate people and resources for different situations.” The Internet has provided the “material support” for this type of behavior, making it easier for people to connect without living nearby and without knowing each other well.

We examined the first 100 patient profiles on www.matchingdonors.com between February 2005 and March 2006 to analyze the nature of the appeal. The would-be recipients of a kidney, like those seeking a social relationship or to participate in an open adoption, must establish their worthiness. We found that in the great majority of cases, would-be kidney recipients invoked family values. The plea for a donation took the form of the recipient being able to have more time with children and grandchildren and to have the opportunity to watch them grow up. (Occasionally, an Internet appeal will mention the fact that there is no one in the family circle available to donate but most often the issue is passed over without explanation.)

In a minority of cases, an appeal was made to values of work: with a transplant the would-be recipient would be able to work. This formulation based on the premise that the recipient will repay society for the investment made. In fact, invoking this frame has many precedents. Transplant teams take great pride in announcing how many of their recipients go back to work, not only using employment as an index of success (he was well enough to rejoin the labor force) but as a justification for transplant (yes, it is expensive but the recipient is now contributing to the common weal and paying taxes). Moreover, when dialysis machines were in short supply and “who shall live committees,” as in Seattle, had to decide priorities, they gave preference not only to family but to work status. Dialysis went first to the married over the unmarried, to parents over non-parents, and, as well, to the employed over the unemployed.

However important the place of work in Internet appeals, family values predominate. Reframed in our terms, this orientation suggests a recognition that family members owe each other organs, and when for some reason the family tie fails and strangers must be solicited, the appeal deemed most effective is to family values. The donor may be a stranger but his or her generosity will enable the recipient to fulfill family duties.

To turn the question around and ask what are the rewards expected by non-family donors, interviews with them suggest that a major consideration is the possibility of establishing a close personal relationship with the recipient. If I give you my kidney, I become kin to you, and you have obligations of kinship back to me. Many commentators are concerned that organ donation from strangers carries an implicit expectation of monetary rewards. But the more dominant consideration may well be personal. Donors may expect to become organ brothers with the recipient, a

modern day counterpart to blood brothers. The blood brothers mingled their blood in a symbolic exchange. The donor and recipient make a very real exchange, becoming brothers through their body parts.

The policy implications of organ donation practices help us to better understand the failure to achieve universal access to health care. First, transplant policies have not attempted to establish a system that would better promote equity. Rather than enact or even seriously debate presumed consent, policymakers have preferred to allow individual decision-making to dominate the donation process. Although individual preference could be protected in an opt-out system, policy continues to rely on opt-in. It is true that organ sale, with its potential for exploitation, remains illegal. But beyond this important exclusion, community values have not shaped policy.

Second, public policy has made no effort to compensate for the privileges that belong to patients with more resources. Although the power of Internet advertising to attract donors is still uncertain, not everyone is able to access the web and make appeals to a broad public. Even donation from relatives and friends disproportionately favors recipients with assets and privilege. They are the ones who can take time off from work, garner the necessary assistance, and, perhaps, be in a psychological frame that allows for the taking of risks.

Third, in this arena as almost everywhere else in American health care, technology overwhelms prevention. It is not always appreciated that the USA has national health insurance for end stage renal disease under which the government pays for dialysis and transplant. However, there is no coverage for programs that would attempt to reduce hypertension or diabetes, which are among the leading causes of kidney failure. Federal funds reimburse dialysis centers, both for-profit and not-for-profit, and academic medical centers that carry out transplants; but the purse strings are held much tighter when primary care or community clinics attempt to provide preventive services. Americans are most comfortable investing in medical technology, both because of a suspicion that public programs are open to fraud and because those who control the technology, be they investors in dialysis machines or chiefs of transplant teams, are more effective in communicating their needs and securing their support.

The message that pervades donation for transplant, like the message that pervades the politics of health insurance, can be summed up in a phrase: shift for yourself. Do not count on the selflessness of others. Make your own arrangements; draw as you can on family and personal connections, take advantage of a privileged access to communication tools. In transplantation, as in health care, citizens are essentially on their own. To take transplantation policies as an index of future health policies, Americans are

moving further away from recognizing communal obligations. They are narrowing, rather than expanding, definitions of what we owe each other.

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