

CHAPTER 9

ORGAN TRANSPLANTATION

RONALD MUNSON

IN 1954 the first successful kidney transplant was performed by Joseph Murray at the Harvard Medical School's Peter Bent Brigham Hospital (Merrill *et al.* 1956). At that moment, we entered a new age.

We had acquired, after decades of work by a small number of researchers, the power to snatch someone out of the grasp of death by replacing a vital organ. Since 1954 researchers have consolidated and extended that power. Improvements in surgical techniques, crossmatching tissues, experience in medical management, and, above all, the advent of Cyclosporin and other powerful immunosuppressive drugs have elevated transplantation to the category of standard therapy.

Kidney transplants offered a preferable alternative to dialysis by the late 1970s, and the list of organs that can be transplanted with significant success has now expanded to include the heart, liver, lungs, intestines, and pancreas. Corneas, bone, bone marrow, blood, cells, blood vessels, heart valves, and skin are also transplanted, but because they are not functional wholes, they are not considered organs. Discussions of organ transplants are thus typically restricted to what are known as *solid*, or *vital*, organs.

A SUCCESS—WITHIN LIMITS

Each year about 50,000 Americans have their lives extended by receiving new organs. (Statistics are from United Network for Organ Sharing 2004 unless otherwise cited;

EBSCO Publishing : eBook Collection (EBSCOhost) - printed on 12/18/2011 10:12 AM via MANCHESTER

COLLEGE

9781429470780 ; Steinbock, Bonnie.; Oxford Handbook of Bioethics

Account: s8481805

transplant and waiting-list numbers are estimates from 2003 data.) This is a number equal to the combined enrollments, graduate and undergraduate, of Columbia, Harvard, and Princeton universities. The number is particularly striking because three decades ago virtually all those now saved by transplants would have died. No matter how healthy the rest of a person's body, without a functioning kidney, liver, or heart, death is the outcome.

Yet transplants are not perfect fixes. Completely successful transplants would give people replacement organs without turning them into patients who must be treated with powerful immunosuppressive drugs for the rest of their lives. The drugs have disagreeable side effects, make recipients prone to infections, and increase their risk of cancer and other diseases. Chronic rejection remains a constant threat, and an organ that has functioned well for five or six years may, suddenly and unaccountably, be attacked by the recipient's immune system and damaged so severely it has to be removed.

A perfect transplant would restore a patient to health, be a one-time, long-term fix, and as free of negative consequences for the recipient as changing batteries is for a flashlight. Stem-cell technology may make this possible by engineering organs to be genetically identical with the ones they replace (Munson 2002, ch. 10). Yet while we wait for this marvelous future, transplants, though far from perfect, save lives right now.

A SHORTAGE

Every year nearly 10,000 people on the United States' United Network for Organ Sharing (UNOS) national waiting list die without getting the organ they need to survive. They depart quietly, with little public notice. Yet the total of their deaths is roughly equivalent to *three times* the number of people who died in the 11 September 2001 terrorist attack on the World Trade Center.

Almost 100,000 people are on the waiting list at any given time. Some are not as sick as others and, with medical help, are able to wait for months or even years. Those who are lucky may get a needed organ within weeks or a few days. But waiting is not always rewarded, and not everyone who needs an organ, no matter how desperately, receives one.

The waiting list is growing at a rapid rate. A new name was added every eighteen minutes in 1998, every sixteen minutes in 1999, every fourteen minutes in 2001, and by 2005 it may be every ten minutes. Given our aging population, the list will grow longer at an increasing rate, and even now more names are put on the list than are removed from it.

The need for organs is constant, pressing, and escalating. It may already be greater than can be met, even assuming complete efficiency in recovering organs from those recently dead (Evans 1989: 15). No more than 15,000 brain-dead potential donors are available annually, and even if the current average of 3.6 organs were recovered from each, this would amount to only 54,000 organs—less than half the number needed now. What makes the situation more desperate is that nothing like this number is actually recovered; hardly more than 50 per cent of those asked to donate the organs of a deceased family member agree to do so.

Every organ transplanted may translate into a life extended. Thus, the failure of the present system of altruistic donations to secure enough organs to meet even current needs has produced recommendations for making the system more efficient. It has also led to more radical proposals to recover organs by ‘presuming’ consent and to supplement voluntarism with some sort of market scheme to reward donors or donor families. Then, too, animal organs, organs grown from stem cells, or artificial devices might ultimately eliminate or severely reduce the need for donor organs (Munson 2002, chs. 9–11). Such prospects are at best long-term, however.

The ethical and social issues raised by transplants are so interrelated that the thread of any problem eventually leads to the whole tangled ball. I will, however, limit discussion to topics involving living donors in the United States. This restriction is not dictated solely by space constraints. Rather, the rise in the number of living donors gives a particular urgency to questions about informed consent, donor protection, and recipient needs. How we resolve conflicts of interest, address issues of consent, and define the scope of autonomy will shape the policies and practices that determine whether donors are protected and whether lives are lost or saved.

LIVING-DONOR TRANSPLANTS

The most effective measure to reduce the shortage of the organs in greatest demand, kidneys and livers, is to increase the number of living donors (Spital 1989, 2001). Although several attempts were made during the 1940s and 1950s to transplant a kidney taken from a patient’s mother or father, all efforts failed until 1954 when Joseph Murray took a kidney from Ronald Merrick and transplanted it into his identical-twin brother Richard (Munson 2002: 125–9). A series of sixty successful twin transplants followed (Tilney 1986), but it was not until the advent of effective immunosuppressive drugs and crossmatching tissues that using kidneys from unrelated donors became feasible.

Kidneys are no longer the only vital organ that—at least in part—can be donated by a living person. People can donate a liver lobe, lung lobe, or pancreas segment.

I will additionally restrict this chapter by focusing on issues associated with the living donors of kidneys and livers. Not only do these organs jointly constitute 80 per cent of all transplants; the ethical issues concerning donors are basically the same for other organs.

Sixty per cent of all transplants are of kidneys. More than 14,000 of the 23,000 organs transplanted in 2001 (the latest year with complete figures) were kidneys. With 50,000 people waiting for a kidney transplant, the kidney is the organ with the highest demand and shortest supply.

Liver transplants number about 5,000 a year, some 20 per cent of all transplants. Nearly 20,000 people are on the waiting list for a liver, making it the organ with the second highest demand and the second lowest supply. Only about 10 per cent of liver transplants use lobes contributed by living donors, but this number will likely increase as the surgical techniques involved become standardized and spread to more transplant centers. Pressure to increase living-donor liver transplants comes from the fact that there is no effective way to replace the liver's function (unlike that of the kidney and the heart) for even a few days or weeks.

The number of living donors increased by a factor of 2.5 during the period 1992–2000. Living donors constitute 52 per cent of all kidney donors, but they contribute only 40 per cent (6,000) of transplanted kidneys, because they can donate only one kidney. Most strikingly, the number of unrelated donors has reached 1,600, ten times the 1966 figure. The importance of living donors can be appreciated by the fact that if only one of every 3,000 people became a kidney donor, the kidney shortage would be solved.

Easing the organ shortage is not the only reason for valuing living donors. Transplant surgery can be planned; organs are disconnected from their blood supply for a shorter time and thus remain in good condition; recipients may spend little or no time on the waiting list or undergoing dialysis, so their health does not deteriorate; organs from a living donor will be healthy and undamaged; and good immunological compatibility between donor and recipient can often be arranged. Also, when cancerous liver nodules prompt a transplant, the patient needs a new liver before the cancer metastasizes. A living donor can save the patient from a long wait for a deceased-donor liver and thus perhaps from developing metastatic disease.

Kidney recipients benefit significantly from a living-donor organ. The one-year survival with a deceased-donor kidney is 94 per cent, but with a living-donor kidney, survival rises to 98 per cent. Five-year survival increases from 80 to 90 per cent.

Liver recipients do not gain as much. Those getting a deceased-donor liver do slightly better (86 v. 85 per cent) during the first year. Yet by the fifth year the situation is reversed, with living-donor recipients significantly surviving longer (86 v. 73 per cent). These figures may change as living-donor transplants become routine and more frequently performed.

BENEFITS TO RECIPIENTS, RISKS TO DONORS

Living donors reduce the organ shortage and directly benefit transplant recipients, but what are the consequences for the donor? Donors risk death, as well as temporary and permanent injuries. They undergo abdominal surgery, and, in addition to the accompanying pain, they risk infection, blood clots, and a damaging or fatal reaction to the anesthesia. Removing a donor kidney via laparoscopy, as is now becoming more common, may reduce pain and shorten recovery, but risks remain.

A UNOS survey of transplant centers and a twenty-plus-year follow-up study of living kidney donors show that the risk of dying from a kidney donation is 0.03 per cent (Najarian *et al.* 1992). (This is about 3 out of 10,000 donors or one donor death every four years.) Also, 56 kidney donors (as of 2004) have later required a kidney transplant themselves. Life-threatening or permanent complications occur in about a quarter of one per cent (0.23 per cent) of donors. No long-term difference between the longevity of donors and non-donors has been determined (Najarian *et al.* 1992; Park *et al.* 1996). Donors must also be prepared to alter their behavior (e.g. giving up contact sports) to reduce the chance of damaging their remaining kidney.

Living-donor liver transplants are relatively recent. The first was performed in 1987, when surgeons at Brazil's São Paulo Medical College transplanted the left lobe of a mother's liver into her 4-year-old child (Crouch and Elliot 1999: 276). The procedure was restricted to children for the next few years, then several centers began transplanting the right lobe of an adult donor into an adult recipient. About 1,000 living-donor liver transplants are now performed every year.

Because the number of cases is comparatively small and the procedure relatively recent, risks to liver donors are not yet well understood (Miller *et al.* 2001). The donor has 25–60 per cent of the liver removed (the left lobe for children and the larger right lobe for adults). The liver begins to grow back, but during the first several weeks the donor may develop liver failure so severe as to require a transplant. The gall bladder is removed when the lobe is removed, and bile leaks occur in 2–5 per cent of donors and may require additional surgery. Problems, major or minor, occur in 15–30 per cent of all donors. The mortality rate is estimated to be 0.2 per cent or 2 deaths per 1,000 donors. So far only two people are known to have died as a result of being liver-lobe donors.

The following case called the public's attention to the risks of becoming a donor and raised the question of what policies transplant centers ought to adopt with respect to living liver donors.

Case 1. Mike Hurewitz, a 57-year-old Albany, New York, journalist, died at Mount Sinai Hospital in New York City on 13 January 2002 following an operation to remove a lobe of his liver. Hurewitz was in good health when he volunteered to donate part of his liver to his younger brother Alan. Alan made a good recovery from the surgery and continues to do well.

Vickie Hurewitz, Mike's widow, sued the hospital and six physicians, alleging negligence and malpractice. She also claimed that her husband had not been properly informed about the risks of becoming a liver donor. She recommended that transplant centers declare a national moratorium on the procedure until its value and safety could be established.

Neither federal nor state laws specify who is eligible to become a living donor, how informed consent should be obtained from a donor, nor how a donor's interests should be protected. These are all matters determined by policies at transplant centers. Legislation, state or federal, will likely replace local rules soon, and this makes framing ethically justifiable procedures particularly pressing. We need to be sure that any new regulatory laws are grounded on sound moral reasoning.

SHOULD LIVING DONORS BE ALLOWED?

Thomas Starzl, who pioneered both kidney and liver transplants, argues against the use of living donors on the grounds that, in his experience, the weakest or least valued member of a family is targeted as the donor. Others in the family then manipulate the person into volunteering. Starzl's view can be generalized into the claim that the risk that the decisions of candidate donors will not be voluntary is too great to permit the practice of using living donors.

Surveys of donors provide no evidence that they believe their decisions were manipulated or coerced. The studies show that donors are motivated by a desire to help, take satisfaction in their role in benefiting another person, and experience an increase in self-esteem. They are pleased with their decision and would make the same one again. (See Riether and Mahler 1995: 338; Rhodes 1994: 78; Spital 1996: 376.)

Yet surveys necessarily reflect how donors feel after the fact. Surveys cannot prove that donor decisions were not compromised. After all, an unconsenting person shoved off the platform at a bungee jump may later report a good experience. Also, some donors may have been so subtly manipulated that they were never aware of the factors influencing their decisions.

Like Starzl, we tend to think of family members or the recipient doing the controlling. Siblings Sue and Tom look to their younger sister Beth to volunteer a lobe of her liver for their mother. Beth is unmarried, has no children, and works only part-time. She is not regarded by her siblings as worth as much as they

are, because they are married, employed, and have young children. Beth, in her siblings' and maybe her mother's view, seems to owe it to the family to become a donor. Many similar scenarios are possible (Dwyer and Vig 1995), and, as Fox and Swazey (1978) point out in their classic study, where living donors and families are concerned, the potential always exists for moral blackmail.

Less appreciated is that physicians, nurses, or others at transplant centers may unintentionally evoke guilt and so maneuver candidates into becoming donors. Candidates may be 'actively encouraged' (Spital 1996: 374) to become donors. This may involve something as simple as a nurse pointing out that 'If you donated a liver lobe, your mom could beat her cancer.' Or the encouragement may be a conversation with the patient's physician, who urges the necessity for quick action to save a loved one.

AUTONOMY AS THE BASIS

Living-donor transplants can be morally legitimate, if the donor's autonomy can be guaranteed. We act autonomously when our actions are the result of our own decisions, when they are self-determined. Autonomy is thus infringed when our behavior is coerced or manipulated.

Our society is committed to recognizing the determining power of the individual in making self-regarding decisions. We thus let people decide how to live their lives, including deciding which risks to take. Some people, knowing the facts about becoming a donor, may be willing to undergo suffering and risk their lives to help a sister, mother, friend, or even a complete stranger. Others, for a variety of reasons or no reason at all, may decide otherwise.

Autonomy, if it is to be exercised, must be protected, and that is the purpose of informed consent. Informed consent is a way to minimize the chance that, when it comes to decision making, people will be deceived, exploited, tricked, misled, duped, manipulated, or pressured so that their autonomy is violated. If a significant violation of autonomy occurs, the resulting decision is not, in a real sense, the individual's. Informed consent is thus a means of making sure that the agent of an action is also its true author.

For informed consent to be legitimate (valid, genuine, etc.), we require that adults be competent to make decisions—that their powers to understand not be compromised by drugs, mental confusion, disabilities, injury, or depression. We then demand that these competent people be provided with information relevant to the decision at hand and that the information be understandable and sufficient to allow them to weigh the character and consequences of the actions open to them. We require, finally, that people be protected from coercive forces, deception, situational pressures, or other factors that infringe on their autonomy and thus

take away some of their decision-making power. To emphasize the importance of this requirement, we often speak redundantly of consent that is ‘free and informed’.

Requiring informed consent is a way of making sure that people understand what they might be getting into if they become a living donor, a participant in a clinical trial, or merely a patient considering surgery. The function of informed consent is not to protect people from the consequences of their actions. Rather, it is to make sure that they can know (so far as anyone does) the nature and results (the potential risks and benefits) of each course of action open to them before they make their decision.

The generalized Starzl objection that people always risk being manipulated into becoming donors does not entail that using living donors is inherently wrong. Rather, it is a condemnation of any process of securing consent from a candidate that fails to guarantee the protection of the candidate’s autonomy. To be morally legitimate, any transplant program that permits living donors must meet the practical challenge of securing informed consent in a way that protects donor candidates from family and situational pressures and permits them to refuse consent (or withdraw it later) without suffering adverse personal consequences. (See ‘Summary: Rules Regulating Living Donors’ below for measures to protect autonomy.)

INHERENT COERCION

Some bioethicists suggest that where the life of a patient is a stake, someone strongly emotionally attached to the patient is not free to decide to become a donor. The attachment plus the patient’s grave condition (it is suggested) make the situation inherently coercive for the potential donor. Caplan, in commenting on liver-lobe transplants when a parent is confronting the potential death of a child, asks, ‘Does anyone really think parents can say “No” when the option is certain death for their own son or daughter?’ Annas echoes this opinion: ‘The parents basically can’t say no’ (both quoted in Crouch and Elliott 1999: 276). If ‘The parents can’t say no’ is construed to mean something like ‘The parents dare not say no, because they will be berated as bad parents’, the argument has merit. Our society expects parents to make sacrifices for their children, and this includes enduring suffering and, if required, running the risk of injury and death. We do not admire a father who refuses to be a liver-lobe donor and so fails to give his child the chance to live. Yet we also acknowledge that it would be wrong for us to violate his autonomy by forcing him to become a donor.

Given our commitment to respecting autonomy, the most we can do is present the father with the option of becoming a donor and spell out its benefits and

risks. Indeed, given the role of informed consent in preserving autonomy, we must make it possible for the father to refuse to be a donor without suffering rebuke. Even if we feel disapproval, we must avoid pressuring the parent into making a positive decision. (Whether the parent may later regret his decision is not our concern.) Expressing autonomy is not necessarily doing what others think is right, but exercising control over one's actions.

Crouch and Elliott (1999: 277) suggest, alternatively, that the 'can't say no' of Caplan and Annas may be construed as invoking a certain notion of moral agency according to which agents are completely free only when they have no ties to others and so every decision considers only the agent's interests. The authors rightly reject this notion, pointing out that the only people who fit such a description are sociopaths. Moral and emotional commitments, they write, 'are not constraints on freedom, but are rather part of ordinary human life' (Crouch and Elliott 1999: 278). I take this to mean that acting for the sake of someone we love does not make us less free. Deciding to act out of love is not a constraint on autonomy but an expression of it, and the Caplan–Annas claim rests on an error.

'Can't say no', in a third interpretation, may be taken to mean 'For anyone emotionally attached to the patient, no option other than becoming a donor is worth considering.' Under this construal, when a transplant offers the best chance of saving the patient's life, the volunteer donor is not interested in other possibilities. He knows at once what he wants to do and is ready to make an immediate decision. 'Can't say no' means, in effect, 'Doesn't want to say no', and if this is what Caplan and Annas are claiming, I find it unobjectionable. (The volunteer must be informed of risks and options and given a chance to consider them, of course, for otherwise his consent is not informed.)

It is a mistake to believe, though, as Caplan and Annas may be asserting, that when a decision must be made in a stressful situation in which we care very much about the outcome, the decision is necessarily compromised. This confuses the external pressure that illegitimately influences a decision (family expectations, for example) with the pressure inherent in a situation that requires making a decision. Calling both 'coercive' obscures the crucial difference. Being forced to decide is not the same as being forced to decide a certain way.

Buying a house is stressful for most people, and while we use laws to shield customers from being coerced into buying the house they are considering, we have no way to shield them from the need to make the decision to buy that house, another house, or no house at all. Similarly, while we can use the consent process to protect parents or others from being pressured into becoming donors, we cannot protect them from the need to make the decision in an inherently stressful situation. They are coerced (by the situation) into having to make a decision, but the decision whether to become a donor is not necessarily (and should not be) coerced.

HEROIC DONORS

Because autonomy is the justifying foundation for using living donors, discussions of the practice usually focus on ways of making sure that candidates are free to decide if they want to take the risks. (See e.g. Gutmann and Land 1999: 516.) But what are we to say when volunteers insist on becoming donors against medical advice? Is it acceptable for a physician to reject a candidate who demands to become a donor because the risks would be greater than usual for donors? The case below illustrates how the question arises.

Case 2: Donald Astrid's wife died from a pulmonary embolism in childbirth, and his newborn daughter was diagnosed with biliary atresia. Surgery to bypass the child's bile ducts by attaching a loop of intestine to her liver failed, and without an immediate liver transplant, she would die.

Astrid is assessed as a donor at Bayshore Transplant Center and found medically unacceptable. He has a heart arrhythmia, diagnosed and treated with drugs for three years, that puts him at a higher than usual risk of suffering a stroke or dying during the surgery. Astrid insists on becoming a donor, despite the outcome of the assessment and against the recommendation of his physician.

Spital refers to people like Astrid as 'heroic volunteers' and argues that if a physician had to accept a volunteer 'against his best judgment', this would mean the volunteer 'has an absolute right to donate', because the volunteer's wishes 'would be determinative'. The physician would have to do the transplant, 'even though he considers donation to be dangerous and ill-advised' (Spital 2001: 193).

Spital's talk about an 'absolute right' is difficult to interpret in the absence of a definition. What Spital appears to mean is: If A has an absolute right to do D, we must permit A to do D whatever the circumstances or consequences. But it is unreasonable to believe that a heroic volunteer is asserting anything so strong. A volunteer who insists on donating against the 'best judgment' of his physician is merely rejecting the advice of his physician. He is not claiming that no consideration will alter his decision and that he must be allowed to do D just because that is what he wants to do. He would, presumably, drop his demand if he learned that his blood type is incompatible with his child's so that if his child received a lobe of his liver, the child would die. It is, furthermore, doubtful that anyone holds that we have any absolute rights in the sense Spital seems to mean.

Spital's argument seems beside the point, in any case. The real issue arises when we ask who is entitled to make the final decision about whether a volunteer can become a donor. Spital sees the autonomy of the heroic volunteer as conflicting with the autonomy of the physician who must carry out the volunteer's wishes. Thus, 'the physician must agree with the volunteer that the potential benefits of

the procedure are worth the risks, as is true for any medical procedure' (Spital 2001: 193).

Potential benefits have to be worth the risks, Spital says. But whose benefits and whose risks is Spital talking about? The potential *medical* benefits of being a donor are never worth the risks. Indeed, the donor suffers medical harms. By contrast, the potential medical benefits of being the recipient of a healthy organ are *always* worth the risks, because without it the recipient will either die (in cases like Astrid's daughter) or experience additional suffering. The benefit the donor achieves has to be something other than medical.

The physician, on Spital's view, must then have to balance the risk and non-medical benefit of the donor against the benefit of the recipient. But this means that the physician is put in the position of deciding whether she is willing for the volunteer to take the risks. The result is that, in making it her decision, she is denying the volunteer the opportunity to decide how much risk he is willing to take for the benefit he seeks. Rather than the physician's exercising her autonomy, as Spital suggests, she is exercising paternalistic power over the volunteer.

It would be wrong for a physician to agree to kill even a willing volunteer for the sake of obtaining an organ for a recipient, even if the transplanted organ would save the recipient's life. (Removing vital organs and thereby causing death would violate the dead-donor rule, which is the moral and social cornerstone of the practice of organ transplantation. While it is possible to challenge the rule on the ground that perhaps six lives might be saved by sacrificing one willing subject, it is not clear that rejecting the rule and permitting this would allow more lives to be saved. Indeed, the entire enterprise might collapse. I assume here, without argument, the legitimacy and utility of the rule.) Short of this extreme, however, the donation decision ought to be the volunteer's. The physician should, of course, advise the volunteer of the risks to his health and life. It would even be appropriate for the physician to warn the heroic volunteer against becoming a donor on the grounds that he will be taking a greater than usual risk.

Ultimately, though, the physician must let the volunteer decide whether he wants to put his life on the line. The physician may, as is the case with all medical treatment, exercise her autonomy by refusing to accept the heroic volunteer as a patient, but it is not clear, given her role as a physician, how she could justify her refusal.

Spital offers what can be taken as an attempt to address this issue. 'Physicians are responsible for the welfare of their patients, and should act in their best interests . . .', he writes. But the problem with this view, as with the initial one, is that because transplant surgery *always* causes harm to the donor, it can never be in the best medical interest of anyone to become a donor. This can be the case only if 'best medical interest' is understood to include a commitment to the welfare of the recipient. While this was the position taken by Justice Counihan (see below) in the

first of the twin-transplant cases, this construal of 'medical' seems arbitrary and no more than a dodge to permit causing medical harm.

'Best interest', as understood by the heroic volunteer, may include a commitment to the welfare of the recipient, despite the fact that the volunteer's medical best interest will not be served. Thus, Astrid's concept of his best interest will include doing whatever he can to save the life of his daughter. He will not find it acceptable, then, for a physician to refuse to let him become a donor because the physician does not consider it in his best interest. Why should the physician's concept of the volunteer's best interest always trump the volunteer's concept? Why should the volunteer's decision about the risk he is willing to take be supplanted by the physician's decision? Spital offers no answer to these questions.

Spital accepts the notion that a heroic volunteer rejected as a donor by one physician may legitimately find another who will accept him. This concession is enough to permit, in principle, heroic donors to take whatever risks they consider appropriate to further their concept of their best interest. But 'in principle' does not necessarily translate into 'in fact'. What if a heroic volunteer cannot find any physician willing to accept him as a donor?

We are then back in the position that Spital characterized as a conflict between the autonomy of the would-be donor and the autonomy of the physician. The donor cannot act to promote his understanding of his best interest (e.g. saving the life of his child) without the participation of the physician, while the physician believes she should not act, because it would not serve what she considers the best interest of the patient.

Once again, I hold that the patient's concept of his best interest should trump the physician's. The physician has a duty to inform the volunteer that he would be taking a greater than usual risk, but the decision about whether to take it should ultimately be the donor's, not the physician's. This would be no more than a case of acting against medical advice, something long acknowledged to fall within the scope of patient autonomy. While the physician may regret the patient's decision, refusing to abide by it would amount to a violation of the patient's autonomy for paternalistic reasons.

I also hold that, where living donors are concerned, an appropriate understanding of what it means for the physician to be committed to promoting the interest of the volunteer-patient makes clear that there is no conflict between the autonomy of the volunteer-patient and the physician. Ordinarily, the physician's commitment to promoting the best interest of the patient is understood as limited to the diagnosis and management of disease in the medical context. But the practice of using living donors requires extending the notion of 'best interest' beyond that context. The volunteer's best interest must include his non-medical wants and values. Thus, the physician's commitment to promote the volunteer-patient's best interest is a commitment to promote the broadened notion, the one that includes

the volunteer–patient’s decisions about what is important and what risks he is willing to run to secure ends he values.

A physician *qua* physician must act for the sake of the patient’s best interest, and, given the practice of using living donors, this means accepting the broadened notion of best interest as determined by the volunteer–patient. The physician, therefore, has an obligation to accept a heroic volunteer as a donor, even though the volunteer acts against medical advice. Because the physician *qua* physician is acting in the best interest of the volunteer, the physician’s autonomy is not in conflict with the volunteer’s. It would be in conflict only if ‘best interest’ is understood by the physician as limited to the medical best interest.

Even if this argument is correct, finding a physician willing to operate on a willing heroic volunteer may remain a practical problem. This is not, however, a circumstance unique to transplant ethics. During the early years of the AIDS epidemic, some physicians refused to treat HIV-positive patients. While physicians lack moral grounds for refusing to accept heroic volunteers, given the circumstances in which transplants take place, the volunteers may not be permitted realize their intention to become donors.

STRANGERS AS DONORS

The initial basis for accepting living donors was a broadly construed concept of ‘medical interest’ (the sort of construal Spital needs to make his argument work). The purpose of medical treatment is to benefit the patient, but when surgeons remove an organ from a living donor, only the recipient appears to benefit. How then can physicians justify causing harm to a healthy person for the sake of someone else?

Surgeons at Boston’s Brigham Hospital grappled with this question in 1957 at the dawn of kidney transplantation. Leonard Marsden, a 17-year-old, eagerly consented to donate a kidney to his identical twin, Leon. The surgeons then hesitated, questioning whether by subjecting Leonard to surgery they would be providing him with any benefit. Hoping to clear the way, the twins’ parents petitioned the Massachusetts Supreme Judicial Court to rule on the question. Justice E. A. Counihan, after hearing testimony about the brothers, decided that if the transplant were not done and Leon died, Leonard would suffer an emotional disturbance that would adversely affect his health and well-being (Curran 1959: 893). The surgery would thus confer a ‘medical benefit’ on both brothers. Consequently, the surgeons would not be harming Leonard just to benefit Leon.

The judge’s insight was that benefit should not be understood too narrowly, even in the medical context. That the benefit for Leonard should be viewed as ‘medical’ was never persuasive. Without much discussion, as the frequency

of kidney transplants increased, centers began to construe Coughlin's 'medical benefit' as equivalent to the donor's having an 'emotional relation' to the recipient. Thus, donors were limited by most centers to parents, spouses, siblings, or other blood relatives. In the 1980s and 1990s, however, as transplants became safer and deceased-donor organs scarcer, centers expanded the notion of 'emotional relation' and started accepting friends of recipients as donors.

While some centers still adhere to such a policy, others have decided to accept also 'altruistic strangers' or 'Good Samaritan donors' (see Case 3 below). The transplant community, even when dealing with family donors, has always stressed altruism as a reason for becoming a donor, and some recent writers have claimed altruism as the sole basis for organ donation. This has occasioned a debate about how the altruism of family and friends ('intimates') compares with that of strangers. At stake is thought to be how much risk each group ought to be permitted to take.

Ross and co-authors (Ross *et al.* 2002: 426) argue that intimates cannot be purely altruistic, because, given their sense of duties and obligations, they are both other-regarding and self-serving. Thus, intimates should be permitted to run higher risks than strangers, because intimates both act out of duty and do not identify their interest as being completely different from that of a recipient. Daar (2002) shows, however, that this conclusion depends on accepting the authors' definition of an altruistic act as 'one motivated primarily or solely by respect and concern for the preferences and needs of others, freely chosen rather than done out of a duty or obligation' (Ross *et al.* 2002: 426). Daar argues persuasively that, even if we accept the definition, 'altruism does not negate every element of self-interest' and even strangers may have their own sense of intimacy and duty (Daar 2002: 424). Each potential donor, Daar holds, should be treated as an individual person and his or her acceptability based on such considerations as the level of risk, not on intimacy or degree of altruism.

While Daar's rejection of the Ross position is warranted, the debate itself rests on a misconception. Altruism may be a motive for organ donation and serve as an explanation for why people become donors, but it is not the moral basis for allowing living donors. Altruism is a value, but it is neither a duty nor an ethical principle, and it is a mistake to look to it to justify donation policies. Rather, it is our commitment to the autonomy of the individual, protected by the process of informed consent, that makes the use of living donors morally legitimate.

Volunteers are given the opportunity to become informed and protected from pressures. They are given the chance to deliberate, with the opportunity to change their minds later, and then allowed to decide whether they wish to become donors. Perhaps some, maybe even the vast majority, will be moved by the wish to benefit others. But a misanthrope who wants to become a donor is as acceptable as an philanthropic superstar, so long as the process of informed consent is followed.

While we may be curious about people's motives (and may want to appeal to them to increase the number of donors), it is not motives that determine whether

the selection of volunteers is legitimate. When the conditions of informed consent are satisfied, living donors, whether strangers or intimates, can reasonably be viewed as promoting their own interest. They are exercising their autonomy in deciding what is important to them and what they are willing to risk to secure it. They are deciding how they want to shape their lives.

The assertion that altruism, rather than autonomy, is the basis for organ donation is a way of blocking what some see as an unacceptable consequence of allowing unrelated donors. The major objection to using such donors is that the practice may encourage the commercialization of transplantation (Kaplan and Polise 2000: 520). A mother is not likely to sell a kidney to her son, but a stranger might sell hers to the same person. Commercialization, which entails self-interest, is inherently incompatible with altruism. Thus, if altruism were required to legitimize donation, the very possibility of commercialization would be ruled out.

Yet even if compelling reasons could be given against commercializing organ procurement, merely asserting that altruism must always be the basis for donation is not persuasive. We need an argument to show that there is something about selling organs that is morally different from selling cars or blood plasma.

PAYING LIVING DONORS

The idea of paying donors or selling organs has been denounced by the transplant community, politicians, and religious leaders since the early 1980s (Munson 2002: 98–110), coincidental with the time that transplants were becoming successful. The United States National Organ Transplantation Act of 1984 makes buying and selling organs, whether from living or deceased donors, illegal, as do the laws of Great Britain, all European countries, China, India, Russia, Mexico, and South Africa. The World Health Organization condemns paying for organs under any circumstance (World Health Organization 1991), and, although trade in transplant organs takes place in parts of Asia, the Middle East, and South America, it is illicit (Cameron and Hoffenberg 1999: 727).

The world ban on organ sales has been defended over the decades by a number of ethicists, lawyers, and transplant professionals who have generated a laundry list of objections to paying donors. (I shall limit discussion to living donors of kidneys; selling organs from deceased donors raises different issues.) Prominent and recurrent objections include: a paid donor loses the psychological benefits that reward an altruistic donor; paid donation reduces altruism in society; the quality of donated kidneys will decline; the donor may suffer harm and become a burden to society; paying donors may reduce the number of donations from deceased donors; organ selling puts the human body in the same moral category as slavery; organ selling involves putting a price on the priceless; paying for organs exploits the poor;

organ selling treats the human body as a commodity and thus violates our respect for persons. (See Phadke and Anandh 2002; Radcliffe-Richards *et al.* 1998; Russo and Brown 2003, for a review of objections.)

Most of these complaints are about institutionalizing the buying and selling of transplant organs—that is, making organs goods in the market economy. Such objections are, for the most, consequentialist, and while the numerous issues raised are important, they go beyond the scope of this chapter. The question logically prior to the market and consequentialist issues is whether there is something about paying kidney donors that makes it inherently wrong.

I claim there is not. If the autonomy of the individual is the basis for recognizing that, when the conditions of informed consent are met, donating a kidney to someone is a morally legitimate act, it must also be morally legitimate for the individual to be paid for donating the kidney. Either act follows as a result of a decision made freely by the person. In the first case, the individual decides to be altruistic, in the second case, she decides she wants money.

Individuals may be said to own (or, at a minimum, have legitimate control over) their bodies in substantially the same sense in which they own their diamonds. Thus, in the way that individuals are free either to sell or give away one of their diamonds, they are free either to sell or give away parts of their bodies. Altruism might move someone to donate a diamond to a charity or to donate a kidney to a stranger; or he might decide to sell both. (I consider someone's selling his own organ and being paid to be an organ donor as equivalent.)

While differences between diamonds and body parts are numerous, I suggest that none is morally relevant with respect to the matter of getting paid to become an organ donor. Once we have agreed that autonomy is the ground for legitimizing an individual's decision to donate a kidney, we must also acknowledge it as legitimizing his decision to sell a kidney.

But what if someone wants to sell both his kidneys? Or his heart, liver, or lungs? While we may agree that, as their owner, he may dispose of his organs in any way that he sees fit, this does not mean that we are free to remove them or to buy them. We are constrained by the fact that by taking both his kidneys or his vital organs, we would be killing him. We would (to put the point another way) be violating the dead-donor rule, which requires us to establish that a donor is dead before any organ needed to sustain his life is removed. It is *prima facie* wrong to kill someone, even if he wants us to, and even if we could use his organs to save several lives.

The most common defense of the claim that selling a kidney is morally wrong in itself is based on the Kantian view that it does not show respect for one's humanity. Selling a kidney expresses disrespect for oneself and, as a consequence, disrespect for what it means to be human (Morelli 1999: 320). Gill and Sade (2002: 26) reject this complaint, justifiably, on the ground that it is not persuasive to consider one's humanity as dependent on one of one's kidneys. One's humanity may be viewed, more reasonably, as dependent on one's rationality and one's capacity to follow

self-given laws (autonomy) dependent on it. Selling a kidney thus has no destructive effects on one's humanity. Hence, it cannot express disrespect for all humanity.

A second and similar Kantian-type objection is that it is wrong to sell kidneys because human beings are not property, and, as Cohen says, to sell them 'and those bits and pieces integral to them is to violate that which is essential to them' (Cohen 2002: 28). While Cohen is right that to sell human beings violates their inherent worth, she wrongly assumes that the 'bits and pieces' of their bodies are likewise of inherent worth. If 'integral' means 'essential' or 'indispensable', a kidney fails to meet the description. Unlike selling oneself into slavery, selling one's kidney will have no consequences on one's capacity for self-governance. Indeed, Cohen's argument appears to be a case of the fallacy of division.

Gill and Sade (2002: 25) point out that even if the Kantian argument that selling one's kidney violates the categorical imperative, because it involves treating oneself as a means only, were correct, it would not follow that paying a donor should be against the law. We do not base our laws on the Kantian duty to respect humanity by respecting oneself. The laws we make aim, rather, at protecting the (non-Kantian) autonomy of individuals. We protect their freedom to make personal decisions about self-regarding acts, and, if the decision they make is to follow their understanding of a rational moral law (Kantian autonomy), they are free to do that as well. No one need sell a kidney.

The transplant community is now in the process of rethinking its long-time condemnation of paying donors (Joralemon 2001; Cameron and Hoffenberg 1999: 724–5). The initial impetus for disapproval, in my opinion, was the fear of alienating the public by associating transplants with money and the unseemly business of trading in body parts. The community was afraid that a loss of public approval, due to bad associations, would result in a decline in the number of people donating their organs at death. Without donated organs, the entire transplant enterprise would then collapse. To sustain the system, the community has always stressed altruism and downplayed the commercial aspects of transplantation. That hospitals, surgeons, coordinators, laboratories, transport services, and organ procurement organizations make money from transplants is not a shameful truth, yet it is rarely mentioned in public. Inspiring stories of transplant miracles are the preferred sort of publicity.

Yet now that the organ shortage is desperate and the public is more familiar with transplants (and perhaps more tolerant of commerce), some are saying that we need to reconsider the issue of paying donors. Extolling altruism has not produced nearly enough donors, so thousands of people are dying who might be saved. (The situation is especially critical in countries that cannot afford to buy and maintain the dialysis equipment required to sustain the lives of thousands in kidney failure.) Many do not find the arguments against paying donors compelling and believe that we could devise mechanisms to protect consent and prevent the exploitation of the

poor and disadvantaged. Because so many lives are at stake, the resolution of this issue is of more than academic concern.

PROTECTING THE DONOR: PROMISES UNKEPT

Protecting a living donor must be understood as involving more than securing informed consent and guaranteeing the volunteer's autonomy at the time of decision making. The following case points to a problem that needs solving.

Case 3: Arielle Dove was so moved by the selfless acts displayed in the aftermath of the 9/11 terrorist attacks that she decided to donate a kidney to a stranger (Meckler: 2003). She located a living-donor web site and arranged for one of hers to be removed and transplanted into someone she had never met.

After the surgery her life took a turn for the worse. More than a year later she still had episodes of vomiting and felt dizzy and listless. She was also very angry. The man who received her kidney assured her he would pay for her expenses not covered by his insurance. But he didn't keep his promise. 'I volunteered to put my life on the line, and I guess I've given up my good health for this, and nobody seems to care,' she said. 'It's really hard not to cry.'

Living donors may develop long-term medical problems, may not be able to work for weeks or months, may require a liver or kidney transplant themselves, may run up medical bills not covered by their insurance or a recipient's. Who is going to pay for the donor's post-transplant expenses? Will it be the recipient? The transplant center? Or will the donor herself have to find some way? These are among the questions that need to be settled before a potential donor becomes an actual one. Yet often the questions are neither asked nor answered.

No one, as matters stand, is committed to looking out for the longer-term interest of the donor. Some donors complain that once they have had a kidney or liver lobe removed and are out of the hospital, transplant centers no longer take any interest in their welfare. Promises that the donors thought were made are not kept, and their future health problems are not recognized as possibly related to the surgery or the loss of an organ. To make sure that the practice of using living donors functions in a morally legitimate way requires that we introduce into general practice three measures to protect the welfare of donors and future donors.

1. *Living-donor advocate: medical.* Some transplant centers provide donors with a medical advocate, and this should be required of all centers that accept living donors. (This is also a recommendation of United States Department of Health and Human Services Advisory Committee on Organ Transplantation 2002: 3.) A medical advocate should be a physician with expertise in transplantation who is not

involved in the care of a potential recipient. An advocate should assist a candidate donor in understanding the process, risks, and benefits of becoming a donor and help the candidate frame appropriate questions and gather information relevant to making a decision. The advocate should, in general, take the measures needed to guarantee that consent is free and informed.

If a volunteer becomes a donor, the advocate should then be responsible for making sure that the medical interest of the donor is served. This means not only seeing to it that the donor–patient receives appropriate hospital care, but making sure that she receives whatever follow-up care she needs. The advocate should serve as the donor’s medical advisor and champion, though not as her physician.

2. *Living-donor advocate: legal.* The Dove case illustrates, taking Dove at her word, what can happen to a donor when commitments made to her are only an informal understanding. A properly written consent document spells out the potential risks and benefits to the donor, alternatives to donation, and the opportunity to withdraw consent, but its usefulness is limited.

It serves the dual purposes of informing the volunteer and offering partial proof that a donor’s choice was appropriately informed and risks were voluntarily undertaken. This (among other things) helps protect centers and physicians from lawsuits and professional censure, but the document, other than informing, provides little help to the donor. The center or the recipient’s insurer may agree to provide the donor with medical care that is immediately associated with the surgery, but if the donor loses income due to the hospitalization, will the money be reimbursed? And if the donor develops medical problems six months or a year later, will she be provided with free care? If, as Dove alleges happened to her, the recipient agrees to pay for costs not covered by insurance, then fails or refuses to do so, what remedy does the donor have?

What the donor requires to protect her interest is a legally enforceable agreement—a contract—with the transplant center and with the recipient. The donor needs a legal advocate, as well as a medical one. The advocate should be an attorney whose fees are paid by the center, the recipient, or the recipient’s insurer, but whose client is the donor.

The legal advocate, with the medical advocate, should consult with the potential donor as part of the consent process. The advocates should go over the consent document with the candidate, and the legal advocate should be available to offer advice before the volunteer makes the consent decision. (A potential donor may refuse legal advice or act against it.)

Either as part of the consent document or in an additional document, commitments made to the donor with respect to such matters as financial compensation for time lost while hospitalized, the assumption of responsibility for health-care costs of the donor for donation-related problems, how a dispute about whether a complaint is donation-related should be resolved, and the limits of assumed responsibility should be addressed.

The legal advisor should consult with the donor after the donation is completed and the donor hospitalized. If either advocate questions whether the kind or quality of care promised is being delivered, then the attorney should advise the donor about the availability of appropriate legal remedies.

Physicians and centers, fearing unwarranted litigation, are not likely to welcome legal advocates into the donation process. Yet donors put themselves at risk, and they deserve to be assured that guarantees made to them have the status of a legally enforceable contract.

The addition of a legal advocate will add to the cost of a transplant. Quite apart from protecting the interests of donors, however, the knowledge that a legal advocate will be assigned to each donor may make becoming a living donor an acceptable option for many more people. This opens the possibility of saving more lives than can be saved at present.

3. *Living-donor registry.* Data about living donors are mostly from kidney donors. Even here, the data are for the most part confined to statistics about operative mortality and survival (Park *et al.* 1996). Liver-lobe donation is sufficiently untried that even the mortality rate associated with it is uncertain. Data for lung-lobe and pancreas-segment donors are similarly sparse.

The long-term effects of becoming a living donor of any organ or organ-part have been little studied (Najarian *et al.* 1992). Thus, the information needed by donor candidates is not as good as it should be. Perhaps better information would do little to change the decisions parents make to donate to their children, but it might have a significant impact on others, particularly on those who want to deliberate before making a decision about donating an organ to a stranger. Because the liver regenerates, data showing that harmful results are rare over the long term would likely increase the number of living liver donors.

Also, if donors develop serious medical problems years later that are shown to be donation-related, we need to decide how to compensate the donors and establish who has responsibility for doing so. Further, if some problems are serious and occur often, we need to decide whether our commitment to individual autonomy requires transplant centers to accept donors who are likely to develop diseases that will compel us to spend considerable public resources for treatment.

Such considerations show that because we allow living donors, establishing a national living-donor registry is a compelling need. (For a similar recommendation, see United States Department of Health and Human Services Advisory Committee on Organ Transplantation 2002: 3.) The registry would keep track of donors and collect and preserve medical information about them over the years. The registry could take the form of a database operated and financed either by a federal agency or by an organization like UNOS, which works under a federal contract. Computers and the Internet make it possible for hospitals, transplant centers, and physicians to supply the information needed at relatively little cost. That the time has come

to establish such a registry is a belief widely shared in the transplant community (Ochs 2002).

DONORS OF LAST RESORT

A basic rule of donor selection is that children and others incapable of consenting ought to be donors of last resort. Those able to consent are (by definition) capable of looking out for their welfare, but those incapable of doing so are open to exploitation. Hence, we have a duty to protect them.

When primarily living donors were employed in the 1950s–1970s, whether it was legitimate to use a child as a donor was often a life-or-death issue. The situation has eased but not disappeared. Kidneys remain in short supply, and children benefit from being removed from dialysis as soon as possible. Thus, families continue to be pressured by circumstances to make wrenching decisions about risking the health and safety of one child to benefit another. The scope of the problem may also be increasing. While now only adults are accepted as liver-lobe donors, when the transplants become better established, children and other ‘incompetents’ may become regarded as potential donors for siblings or other family members.

Circumstances in which a child might be the only available liver-lobe donor for a sibling are easy to imagine. The surviving parent, for example, might not have a blood type compatible with that of the child in need. Or the parent might be too ill to become a donor. More distant relatives, if any, might fail to qualify as donors or might refuse. The child’s sacrifice could be all that stands between her sibling and death.

Important Interest at Stake

The fundamental requirement to be met in justifying a child’s becoming an organ donor, I suggest, is that the child must have something important at stake in the use made of the organ. (I will refer to children here, yet most considerations apply also to incompetent adults.) Becoming a donor must be in the child’s best interest, and this may require that the child suffer surgical injury and run some risk of death. The child’s best interest can be understood as the child’s having a significant stake in the welfare of the organ’s intended recipient. (As mentioned above, Leonard Marsden, with respect to his brother’s welfare, had at stake something affecting his own ‘health and physical well-being’.)

No matter how slight the risk, a child (or other incompetent person) cannot be required to donate an organ to help a stranger, even if the organ would save the stranger’s life. The child has no direct stake in the stranger’s welfare, and thus the donation would not serve the best interest of the child. By contrast, an intimate

who is not a relative may be of crucial importance to the child's welfare, as Anne Sullivan was to Helen Keller.

Reasonable Risk

It is appropriate to subject a child to some risk to protect her best interest. Thus, in cases where the life of a person important in the child's life is at stake, it is reasonable to put the child at risk for the benefit she may gain. We put children at risk for expected benefits in other medical contexts, even when their lives are not endangered—surgery to correct club foot, cleft palate, or amblyopia, for example.

What we know of risks at present indicates that it is sometimes justifiable to make children into kidney donors, but not liver-lobe or lung-lobe or pancreas-segment donors. We do not yet know enough about the effects and risks of such donations to subject children to them, even when a child has an important stake in the life of a recipient. The American Medical Association's Council on Ethical and Judicial Affairs puts the point tersely: 'Children should not be used for transplants that are considered experimental or non-standard' (American Medical Association 1996–7: 35).

Where the chances of death or suffering serious harm are considerable or unknown, we lack justification to put a child at risk, even to save the life of a person important to the child. We are free to decide to risk our own lives for anyone, because we are able to understand our alternatives and the consequences of our actions. Children cannot. Hence, when we decide for them, we must take the most conservative stance compatible with their interest.

Deciding About Donors of Last Resort

An asymmetry exists between those competent to consent and those who are not. Children are not competent to decide to become donors, but they are also not competent to decide *not* to become donors. (I will not address here issues of assent connected with older children.) A decision belonging to competent people belongs to someone else in the case of incompetent people.

This asymmetry offers the potential for exploitation. Suppose Sue Crane needs a kidney transplant. High blood pressure eliminates her husband, Sam, as a donor, but their healthy 22-year-old son Bob, now in law school, has the same blood type and is a good antigen match. The Cranes's retarded 16-year-old son, Tom, is also a good match, however.

Bob is willing to be the donor, but he is the pride of the Crane family, and his parents do not want to interrupt his education and subject him to the risks of surgery. Tom is a constant source of difficulty. 'Now he has a chance to do something to help the family,' Sam says. Sam and Sue then instruct Bob to refuse

to volunteer when he is interviewed at the transplant center. Sam is medically unacceptable, Bob refuses, and no one else steps forward. Thus, Tom becomes the donor of last resort.

The duty to protect incompetent people from exploitation rests with whoever has the responsibility to decide what is in their best interest. The courts already decide for institutionalized and demonstrably incompetent adults. With respect to children, parents are the obvious candidates to make the decision, but two considerations rule them out. First, parents like the Cranes can conspire to sacrifice the weakest member of the family to protect a favored one. The person who needs the most protection thus becomes, ironically, the one who is the most vulnerable.

The situation is not improved if, as Ross (1993) recommends, the family as a whole is given the power to decide. While this could, as she says, promote intimate relations and allow the family to draw upon its own values, religious beliefs, and sense of itself, it leaves children with no protection from family pressures. Indeed, Ross's process of family decision making describes exactly the situation Starzl (1985) considered so inherently manipulative as to lead him to recommend against the use of even adults as living donors.

A second difficulty is that parents can be forced into a Sophie's-choice situation requiring them to help one child (or family member) only at the expense of another. This faces them with a conflict of interest, so that whatever decision they make will be suspect (even to themselves) and open to charges of unfairness and favoritism.

Decisions about accepting competent adult candidates as donors are now made by committees at transplant centers, and this same approach might be taken with children. Williams (1995: 499) advocates the use of ad hoc groups to make decisions about children as potential bone marrow donors and describes how, at a Honolulu hospital, a staff committee interviews children in an informal way and determines if they understand 'their role in the transplant procedure' and if their willingness to be a donor is 'free from duress and based on adequate information'. Depending on the judgment of the committee, a child is accepted or rejected as a donor. The committee process, Williams observes, is inexpensive, efficient, and offers a way to consider the best interest of a child.

Despite these virtues, a committee approach has drawbacks so serious as to make it unacceptable. First, committees work effectively only when children are old enough to grasp what is being asked of them and assent to it. This leaves open the question of how we should deal with younger children.

Committees are also limited in their powers to obtain data relevant to the decision they must make. If a family member withholds information or lies to the committee (claiming he has a close relationship with a child, for example), the committee can impose no sanctions and must make its decision on the basis of whatever data it can gather or surmise.

More is at stake, furthermore, for an organ donor than for a bone marrow donor. Harvesting bone marrow involves discomfort and the risk of infection, but

no significant danger is associated with it. Being a kidney donor requires extensive surgery, greater risk of infection, and a chance of dying or long-term effects. Because more is at stake for organ donors, more protection for vulnerable potential donors is required.

Decision of the Court

Williams's observation that court proceedings can be time consuming and costly is correct, but protecting people from serious exploitation is sufficiently important to warrant additional time and money. The courts, more than any other institution, are in the best position to guarantee that stringent criteria for a child's becoming a donor are satisfied and that the best interest of the child is served.

Courts of law, unlike committees, however constituted, operate within a tradition of protecting the rights of individuals by invoking a variety of procedural and substantive safeguards. Should a 6-year-old girl contribute a kidney to her teenage sister? A court can conduct discovery proceedings and gather relevant medical and personal information, using its subpoena powers if necessary, and thus put itself in the position of answering the question.

Experts can be called to offer opinions, and family members required to testify under oath. Rules of evidence, relevance, and proof can be brought to bear on the basic question. Most important, a court can appoint an attorney (a guardian *ad litem*) to represent the child to make sure everything recognized as relevant to her interest is brought forward for the court to consider.

Because courts have powers committees lack, committees are never able to delve so thoroughly into issues affecting the welfare of candidate donors. At the end of hearings, when the evidence and arguments for and against a child's becoming a donor have been presented, a court's deliberations offer the best chance of getting an independent and objective decision. A committee might have arrived at the same decision, but where protecting the vulnerable is concerned, process and safeguards matter.

The presiding judge of a Massachusetts court made this point forcefully in the 1977 *Saikewicz* decision:

We take a dim view of any attempt to shift the ultimate decision-making responsibility away from the duly established court... to any committee, panel, or group, ad hoc or permanent.... questions of life and death seem to us to require the process of detached but passionate investigation and decision that would form the ideals under which the judicial branch of government was created. Achieving this ideal is our responsibility... (*Superintendent of Belchertown State School, et al. v. Saikewicz*, 417)

I have argued, to recapitulate, that a child (or other incompetent person) may become an organ donor when: it is in the child's best interest; risk to the child is

reasonable; the child is the donor of last resort; a court of law, rather than parents or any sort of committee, is making the decision.

SUMMARY: RULES REGULATING LIVING DONORS

Perhaps the most useful way to summarize the above discussions is to state rules or guidelines. Yet because several important questions were not addressed and guidelines must always be interpreted, the following rules are not offered as either exhaustive or definitive.

1. A potential donor must be competent to make decisions. This includes being able to understand the nature and likelihood of the risks involved in becoming a donor.

2. A potential donor must be provided with information adequate for making the donation decision. The need to provide information about the nature and likelihood of risks and benefits is clear. Less obvious is the need to supply the candidate with information about the alternatives available to the potential recipient (e.g. dialysis, continued medical support, waiting for a deceased-donor organ, or waiting for another living donor).

3. Potential donors should not be solicited. A center may inform the patient and others that those who want to consider becoming donors should contact a designated person who is uninvolved with the patient. Russo and Brown endorse this rule (Russo and Brown 2003: 27), and Biller-Andorno and Schauenburg suggest that a volunteer should identify herself 'without any action on the part of the physician' (2001: 163).

4. A potential donor must be protected from pressures to volunteer. A willingness to become a donor ought to be considered a necessary condition for being a 'suitable' candidate. The assessment team should determine in a private interview if the candidate is willing. The candidate needs to be told that, no matter what he may have said to others nor what others may expect him to do, if he decides he is not willing to be a donor, this will remain confidential. If the candidate says he is unwilling, the assessment team will then declare him an 'unsuitable' candidate, with no details made public. This will protect the candidate from the anger, recriminations, or blame that might have been directed at him for publicly refusing to help the patient needing the transplant.

A candidate must also be permitted to change his mind about becoming a donor until the last moment before surgery. This may result in great inconvenience and disappointment and even put the intended recipient at greater risk than if no apparent donor had become available, but it would be a serious violation of an

individual's autonomy to remove one of his organs after he has withdrawn his consent.

5. Assessment of the suitability of a potential donor should not be done by physicians or others involved in the care of the potential recipient. This will eliminate the conflict of interest inherent in a relationship in which those caring for a patient needing a transplant also select a donor.

The assessment should be done by a team (e.g. hepatologist or nephrologist, psychiatrist or psychologist, social worker, etc.) able to determine whether the candidate is medically and psychologically suitable to become a donor. The assessment should also consider a potential donor's social and economic situation so that the candidate can be provided with information about the impact that becoming a donor might have on his or her life.

6. Potential donors should be provided with medical and legal advocates. Both advocates should advise a candidate before she makes a decision. If she decides to become a donor, the legal advocate should represent her interests in making contractual arrangements with the center and with the intended recipient. The medical and legal advocates should monitor her welfare after the transplant.

7. A registry should be established to gather longitudinal data about the health of living donors. The database in the United States could be operated by UNOS under a contract with the federal government. The information could be medically important to donors, and it would be relevant in informing potential donors about potential risks.

8. Donors incompetent to consent may become donors if it is in their best interest, the risk to them is reasonable, no other donors are available, and the decision permitting them to become donors is made by a court of law.

CONCLUSION

Organ transplants save thousands of lives every year, yet thousands more die because of the shortage of organs. While increasing the number of organs from deceased donors would be of considerable value, the best hope for saving the lives of tens of thousands of people who would otherwise die is to increase the number of living donors.

The autonomy of the individual legitimizes an individual's decision to become a living organ donor. This does not relieve transplant centers of the responsibility for seeing to it that donors are genuine volunteers and have the information they need to assess their risks and options. Measures are needed to protect the autonomy of the individual in deciding whether to become a donor, but additional measures are needed to protect the welfare of living donors. These include appointing donor advocates and maintaining a registry of living donors.

The prospect of saving so many thousands of lives requires us to take seriously the moral and the practical issues centering around the use of living donors. Yet we do not have time to discuss those issues indefinitely. The sooner some matters are settled, such as the moral legitimacy of paying donors, the more lives will be saved. The issues are urgent, for literally life and death are at stake.

REFERENCES

- AMERICAN MEDICAL ASSOCIATION, COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS (1996–7), 'The Use of Minors as Organ and Tissue Donors', in *Code of Medical Ethics: Current Opinions with Annotations* (Chicago: American Medical Association), 34–6.
- BILLER-ANDORNO, N., and SCHAUENBURG, H. (2001), 'It's Only Love? Some Pitfalls in Emotionally Related Organ Donation', *Journal of Medical Ethics*, 27: 162–4.
- ____ (2001), 'Who Shall Be Allowed to Give? Living Organ Donors and the Concept of Autonomy', *Theoretical Medicine*, 22: 351–68.
- CAMERON, J., and HOFFENBERG, R. (1999), 'The Ethics of Organ Transplantation Reconsidered: Paid Organ Donation and the Use of Executed Prisoners as Donors', *Kidney International*, 55: 724–32.
- COHEN, C. (2002), 'Public Policy and the Sale of Human Organs', *Kennedy Institute of Ethics Journal*, 12: 47–64.
- CROUCH, R., and ELLIOTT, C. (1999), 'Moral Agency and the Family: The Case of Living Related Organ Transplantation', *Cambridge Quarterly of Healthcare Ethics*, 8: 275–87.
- CURRAN, W. (1959), 'A Problem of Consent: Kidney Transplantation in Minors', *New York University Law Review*, 34: 891–8.
- DAAR, A. (2002), 'Strangers, Intimates, and Altruism in Organ Donation', *Transplantation*, 74: 424–6.
- DWYER, J., and VIG, E. (1995), 'Rethinking Transplantation Between Siblings', *Hastings Center Report*, 25: 7–12.
- EVANS, M. (1989), 'Organ Donations Should Not Be Restricted to Relatives', *Journal of Medical Ethics*, 15: 15–20.
- FOX, R., and SWAZEY, J. (1978), *The Courage to Fail: A Social View of Organ Transplants and Dialysis* (Chicago: University of Chicago Press).
- GILL, M., and SADE, R. (2002), 'Paying for Kidneys: The Case Against Prohibition', *Kennedy Institute of Ethics Journal*, 12: 17–45.
- GUTMANN, T., and LAND, W. (1999), 'Ethics Regarding Living-Donor Organ Transplantation', *Langenbeck's Archives of Surgery*, 384: 515–22.
- JORALEMON, D. (2001), 'Shifting Ethics: Debating the Incentive Question in Organ Transplantation', *Journal of Medical Ethics*, 27: 30–5.
- KAPLAN, B., and POLISE, K. (2000), 'In Defense of Altruistic Kidney Donation by Strangers', *Pediatric Nephrology*, 14: 518–22.
- LINDSAY, D. (2002), 'An Organ, Stem Cells, and Blood Are Precious Gifts of Life', *Online Washingtonian Community Service*, <<http://www.washingtonian.com/schools/savealife-give>>.
- MECKLER, L. (2003), 'The Dark Side of Organ Donation', *Associated Press*, <www.cbsnews.com/stories/2003/08/12/health>.

- MERRILL, J., MURRAY, J. E., HARRISON, J. H., GUILD, W. R. (1956), 'Successful Homotransplantation of the Human Kidney Between Identical Twins', *JAMA* 160: 277–82.
- MILLER, C., *et al.* (2001), 'One Hundred Nine Living Donor Liver Transplants in Adults and Children: A Single-Center Experience', *Annals of Surgery*, 234: 301–10.
- MORELLI, M. (1999), 'Commerce in Organs: A Kantian Critique', *Journal of Social Philosophy*, 30: 315–24.
- MUNSON, R. (2002), *Raising the Dead: Organ Transplants, Ethics and Society* (Oxford: Oxford University Press).
- NAJARIAN, J., CHAVERS, B. M., MCHUGH, L. E., and MATAS, A. J. (1992), 'Twenty Years or More of Follow-Up of Living Kidney Donors', *The Lancet*, 340: 807–10.
- OCHS, R. (2002), 'Live-Donor Procedures Carry Risks', *Newsday.com*, <<http://www.newsday.com/health/ny-hsmed1928302117aug1>>.
- PARK, K., *et al.* (1996), 'A 16-Year Experience with 1275 Primary Living Donor Transplants: Univariate and Multivariate Analysis and Risk Factors Affecting Graft Survival', *Transplantation Proceedings*, 28: 1578–9.
- PHADKE, K., and ANANDH, U. (2002), 'Ethics of Paid Organ Donation', *Pediatric Nephrology*, 17: 309–11.
- RADCLIFFE-RICHARDS, J., *et al.* (1998), 'The Case for Allowing Kidney Sales', *The Lancet*, 352: 1950–2.
- RHODES, R. (1994), 'A Review of Ethical Issues in Transplantation', *Mount Sinai Journal of Medicine*, 61: 77–82.
- RIETHER, A., and MAHLER, E. (1995), 'Organ Donation: Psychiatric, Social, and Ethical Considerations', *Psychosomatics*, 36: 336–43.
- ROSS, L. (1993), 'Moral Grounding for the Participation of Children as Organ Donors', *Journal of Law, Medicine, and Ethics*, 21: 251–7.
- GLANNON, W., JOSEPHSON, M. A., and THISTLETHWAITE, J. R., Jr. (2002), 'Should All Living Donors Be Treated Equally?', *Transplantation*, 74: 418–22.
- RUSSO, M., and BROWN, R. (2003), 'Ethical Issues in Living Donor Liver Transplantation', *Current Gastroenterology Reports*, 5: 26–30.
- SPITAL, A. (1989), 'Unconventional Living Kidney Donors: Attitudes and Use Among Transplant Centers', *Transplantation*, 48: 243–8.
- (1996), 'Do U.S. Transplant Centers Encourage Emotionally Related Kidney Donation?', *Transplantation*, 61: 374–7.
- (2001), 'Ethical Issues in Living Organ Donation: Donor Autonomy and Beyond', *American Journal of Kidney Diseases*, 38: 189–95.
- and SPITAL, M. (1990), 'The Ethics of Liver Transplantation from a Living Donor', *New England Journal of Medicine*, 322: 549–50.
- STARZL, T. (1985), 'Will Live Organ Donations No Longer Be Justified?', *Hastings Center Report*, 15: 5.
- Superintendent of Belchertown State School, et al. v. Saikewicz*, 370 NE 2d 417(MA), 1977.
- TILNEY, N. (1986), 'Renal Transplantation Between Identical Twins: A Review', *World Journal of Surgery*, 10: 381–8.
- UNITED NETWORK FOR ORGAN SHARING (2004), <<http://www.unos.org>>.
- UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES ADVISORY COMMITTEE ON ORGAN TRANSPLANTATION (2002), 'Organ Donation: Recommendations to the Secretary', <<http://www.organdonor.gov/acotrecs>>.

- WILLIAMS, R. (1995), 'Consent for Children as Organ Donors', *Hawaii Medical Journal*, 54: 498–500.
- WILLIAMS, S. (1986), 'Long-Term Renal Function in Kidney Donors: A Comparison of Donors and Their Siblings', *Annals of Internal Medicine*, 106: 1–8.
- WORLD HEALTH ORGANIZATION (1991), 'Guiding Principles on Human Organ Transplantation', *The Lancet*, 337: 1470–1.

EBSCOhost®