The Failure to Give: Reducing Barriers to Organ Donation

ABSTRACT. Moral frameworks for evaluating non-donation strategies to increase the supply of cadaveric human organs for transplantation and ways to overcome barriers to organ donation are explored. Organ transplantation is a very complex area, because the human body evokes various beliefs, symbols, sentiments, and emotions as well as various rituals and social practices. From a rationalistic standpoint, some policies to increase the supply of transplantable organs may appear to be quite defensible but then turn out to be ineffective and perhaps even counterproductive because of inadequate attention to these rich and complex features of human body parts. Excessively rationalistic policies neglect deep beliefs, symbols, sentiments, and emotions and the like, and that deficiency marks many actual and proposed policies. In addition, policies are often too individualistic and too legalistic.

MOST ETHICAL ANALYSES of possible ways to increase the supply of cadaveric human organs for transplantation focus on the gift of life through organ donation. I will focus on moral frameworks for evaluating non-donation strategies and ways to overcome barriers to organ donation. My starting point is the persistent, chronic shortage of organs for transplantation, and the relative stagnation of cadaveric organ donation for the last several years, at least in the United States.

The stagnation in organ procurement in the U.S. has resulted in part from a decline in the potential donor pool, especially because of the success of seat-belt laws, and the limited growth that has occurred in procurement is the result, to a great extent, of changes in the criteria for donor eligibility—e.g., accepting organs from older donors.

In discussing the failure to give and ways to overcome this failure, I will make two assumptions: (1) that we need to increase the supply of
organs in order to save lives and/or to enhance the quality of life and (2) that our societal efforts to increase the supply of transplantable organs should remain within certain ethical boundaries. Each of these assumptions is somewhat controversial: the first, because of challenges to organ transplantation in general as an overvalued enterprise relative to its benefits and its costs; the second, because of uncertainties about the appropriate ethical boundaries. I will ignore the controversy about the first assumption and only address the second through indirect efforts to clarify what I believe to be important ethical constraints on societal efforts to increase the number of transplantable organs.

Organ transplantation is a very complex area, because the human body evokes various beliefs, symbols, sentiments, and emotions as well as various rituals and social practices. From a rationalistic standpoint, some policies to increase the supply of transplantable organs may appear to be quite defensible but then turn out to be ineffective and perhaps even counterproductive, because of inadequate attention to these rich and complex features of human body parts. Excessively rationalistic policies neglect deep beliefs, symbols, sentiments, and emotions and the like—these various psychosocial factors—and that deficiency marks many actual and proposed policies. In addition, policies are often too individualistic and too legalistic. Those are three charges I will level against several efforts in the U.S. to increase the number of available organs. Much of my argument will hinge on how one characterizes the failure to give or to donate organs.

A CASE OF ORGAN DONATION

I will focus on an actual case in order to identify different frameworks of moral discourse that affect how we view failures to donate (or, if that language is too strong, acts of non-donation):

In early June, 1995, a popular, athletic Texan in his twenties, who was undecided about what he wanted to be and do, died unexpectedly from an aneurysm. “In death,” as a sports section in a newspaper noted, “he gave half a dozen people their futures, among them a truck driver, a farm manager, a backwoods-resort operator and an American legend named Mickey Mantle” (Dallas Morning News 1995). All six operations occurred at about the same time at Baylor University Medical Center in Dallas.

Newspaper reporters later managed to identify the source of the organs, but, at the family’s request, they did not disclose his identity in their reports or to the recipients. His mother explained the family’s decision to donate: “Once his soul and spirit is gone, nothing is left. His body is of...
use to somebody else only in this way. It never even crossed my mind not to donate. To me, it’s the decent thing to do. It’s the thing we should do.” In addition, she noted, “We thought we might as well make something good come out of our tragedy.” Hence, as soon as the doctors asked her, she responded, “Yes, definitely.” She made this decision even though her son had never discussed organ donation with her. However, his Texas driver’s license indicated “donor” (Dallas Morning News 1995).

Contrast the mother’s comment about why she donated her son’s organs with various media reports about organ donation. With specific reference to this case, the media underlined the “sacrifice” of organ donors and praised their “heroic” actions. Others have called such cadaveric organ donations “extraordinary,” a term that could refer to their relative infrequency or to their exceptional normative status—that is, beyond duty and obligation.

I will raise a few questions about this case and then examine two frameworks of moral discourse that are often used to evaluate such cases. First, what criteria must be met before we can appropriately refer to someone as a donor? As obvious as this question sounds, it is far from obvious. By the term “donor,” we sometimes refer to the decision maker about donation—i.e., the one who decides to donate organs—and sometimes to the cadaveric source of the organs. Obviously, the two may be the same. However, the decision maker may not be the source of the organs, and the source may never have been competent to make a decision about donation—perhaps an anencephalic newborn, a child, or a mentally retarded person—or, if competent, may never have made a decision to donate. For instance, a dead child may be the source of organs, the one who provides organs, but cannot be the donor, that is, the one who makes the donation. Furthermore, someone who sells his or her human biological materials is not a donor, but a vendor or seller. For a long time, I have protested the promiscuous use of the terms “donor,” “donation,” “giver,” and “gift.” Their loose usage inappropriately extends a moral aura that is overrated but nonetheless important; hence, we need to be more precise in our language.

Second, who was the donor in this case? From the brief report in the newspapers, it appears that the mother viewed herself as the donor—i.e., the decision maker—and her son as the source or provider of the organs. She said: “It never even crossed my mind not to donate.” However, in view of the fact that the young man had checked “donor” on his driver’s license, he could have legitimately been viewed as the decision maker about donation. By signing a document of gift, he was the donor as well.
as the source, and, from one standpoint, his mother then merely conveyed or expressed his wishes. She simply implemented his prior donation.

Even if the young man had never indicated his decision to donate, his mother still could have argued that donation is what he would have wanted because of his fundamental values and commitments. She could even have appealed to his specific recent actions as indicative of those values and commitments. A week before his death this young man, a former lifeguard, was at a lake when a swimmer attempting to reach an island started to go under; he swam out a long distance and pulled the floundering swimmer safely to shore. Thus, his mother perhaps could have constructed his willingness to donate from the way he lived—she could have taken his recent heroic rescue as indicative of the kind of moral character that would seek to save others, even at some risk.

Third, it is not surprising that the mother and newspaper reports viewed her as actual “donor”—i.e., decision maker about the donation—of her dead son’s organs, in view of the laws and social practices that have evolved in the U.S. The legal structure for organ donation appears in state versions of the Uniform Anatomical Gift Act, as formulated in the late 1960s and then rapidly adopted by all 50 states and the District of Columbia. Within that “gift” framework, competent individuals can determine what will be done with their organs after their deaths. In the absence of a valid expression of the decedent’s prior wishes, the family can decide whether to donate his or her organs.

As a matter of social practice, the default mechanism of the family has become the primary mechanism—individuals rarely sign donor cards, organ procurement teams rarely find them, and, in occasional cases of conflict between the decedent’s expressed wish to donate and the family’s opposition, procurement teams generally yield to the family for mistaken legal reasons and understandable ethical reasons. The legal concerns are misplaced because the Uniform Anatomical Gift Act, as implemented by the states, provides immunity from criminal and civil liability for good faith actions on the basis of a signed document of gift. The moral concerns focus on harm to the grieving family and, ultimately, on risks to organ donation as a result of bad publicity.

In the U.S., then, the transfer of solid organs generally occurs through express donation by the individual or by the family. The law is primarily individualistic while social practice is primarily communitarian, that is, it views the deceased individual as part of a family. One ethical and practical problem is bringing the two together for educational and other purposes.
Social practices around the world are more similar than different, regardless of their specific legal context (Prottas 1994). Whether the legal structure is express donation or presumed donation, procurement teams still generally consult family members. Debates persist about whether these practices reflect moral wisdom or professional bias and thus whether they should be maintained or altered.

In this context, we should not neglect the moral and practical importance of not blocking donations in the U.S. Even if the individual while alive did not explicitly or expressly donate, it is important that he or she not block donation by the family by saying “no.” Checking “no” on the donor card blocks any subsequent action by the family, while in practice the family may block the decedent’s “yes” because, as previously noted, procurement teams rarely override the family’s rejection of donation. (Even though some state laws are being changed to emphasize the legal priority of the decedent’s express decision to donate, even against familial objections, it is too early to determine how they will work out in practice.) Not blocking donation can itself express benevolence or altruism. It is passive benevolence or passive altruism that does not assert one’s legal or social-practice rights. For example, when an individual has expressly indicated his/her wish to donate, it is morally important that the family not take advantage of social practice and block the donative transfer. There is good reason to affirm in law, as the amended UAGA proposes and some state laws now affirm, the primacy of an individual’s decision over the family’s decision, but practical difficulties may limit enforcement (National Conference 1987).

FRAMEWORKS OF MORAL DISCOURSE ABOUT ORGAN DONATION

Two frameworks of moral discourse appear in discussions of the Texas mother’s act of donation (and other such cases): morality of aspiration and morality of duty; supererogation and obligation; ideal and right; praiseworthiness and blameworthiness. The paired categories are not totally separate; the lines between them are not always clear; and we move back and forth between them. The mother’s framework, which stressed that her action was “the decent thing to do . . . the thing we should do,” appears to be one of obligation, duty, and right action. By contrast, commentators often used the language of aspiration, supererogation, ideals, and good actions to describe and praise acts of donation of cadaveric organs. These two frameworks of moral discourse produce different descriptions of and responses to non-donation or the failure to donate.
Within a morality of aspiration or supererogation, the failure to donate does not produce guilt—although it might produce shame if an agent has committed himself/herself to living up to certain ideals. Others may not be indignant or complain about the agent’s failure to donate. Instead, when donation does occur, praise and gratitude are appropriate responses. By contrast, within a morality of duty or obligation, the failure to donate does, or should, produce a feeling of guilt; others may be indignant and complain; and praise and gratitude are inappropriate—after all, the donor just did his or her duty.

Both patterns of moral discourse play significant roles in our social-moral practices relating to organ donation. It is tempting to say that one perspective is internal, not only to individuals but also to families, as in the case of the Texas mother—and perhaps to a small community, such as a religious community—while the other is external, the perspective that observers and spectators must take, as in the case of reporters, legislators, courts, and society at large.

But could we establish an obligation of beneficence, or obligatory beneficence, versus ideal or supererogatory beneficence? In *Principles of Biomedical Ethics*, Tom Beauchamp and I describe a continuum between obligation and supererogation, with few bright lines to separate them. We note that it is “extremely difficult to pin down and discharge obligations of beneficence. We bounce back and forth between viewing actions as charitable and as obligatory; and we sometimes feel guilty for not doing more, at the same time doubting that we are obligated to do more” (Beauchamp and Childress 1994, p. 268). “Strongly recommended” is possible intermediate language. A framework of obligation may include both general beneficence and specific beneficence, and specific beneficence may include both a duty to rescue and role-related beneficence. If there is a duty to donate cadaveric organs, it largely falls under the duty to rescue.

It is plausible to argue from liberal, secular premises for such a (moral) duty of rescue: Apart from special moral relationships, such as contracts, a person D has a determinate obligation of beneficence toward person R if and only if each of the following conditions is satisfied (assuming that D is aware of the relevant factors). (D stands for potential donor, while R stands for potential recipient.)

1. R is at risk of significant loss or damage to life or health or some other major interest;
2. D’s action is needed (singly or in concert with others) to prevent this loss or damage;
(3) D’s action (singly or in concern with others) has a high probability of preventing that loss or damage;
(4) D’s action would not present significant risks, costs, or burdens to D [or to others];
(5) the benefit that R can be expected to gain outweighs any harms, costs, or burdens that D is likely to incur [or that others are likely to incur as a result].

We could increase the stringency of D’s obligation by increasing the benefit, that is, by increasing the probability and magnitude of a positive outcome for R (conditions 1-3), with impact on the fifth condition. We could also decrease the risk, cost, or burden to D (condition 4), again with an impact on the fifth condition.

Both moral frameworks are important: (1) cadaveric organ donation as supererogatory, and (2) cadaveric organ donation as obligatory. Nevertheless, the moral discourse of the larger society, apart from particular communities, must, I believe, remain within the framework of heroic, even sacrificial action, that earns societal praise and gratitude.

A strong obligation to donate cadaveric organs also emerges in Judaism and Christianity, among other religious traditions, and it converges with a duty to rescue in liberal, secular morality. However, this “overlapping consensus” does not provide a warrant for society to accept an enforceable legal obligation to donate. As I will argue, in this context, the society should primarily express community, not impose community.

In the common law tradition, Good Samaritan laws tend to work this way. A few states in the U.S. do impose a legal obligation to act to rescue someone in trouble—usually a failure to do so is a misdemeanor punishable by a modest fine. However, most Good Samaritan laws do not obligate but rather facilitate actions. They facilitate beneficent actions by reducing risks or perceived risks. For example, they may reduce risks to the Good Samaritan by protecting him or her from legal liability for good faith actions. Such laws may point a direction for society’s interventions—through both policies and education—to increase cadaveric organ donation.

FACILITATING ORGAN DONATION

I will consider four main ways the society could facilitate cadaveric organ donation by making it more reasonable for individuals and/or families to choose to donate. The first two focus on the value of organs to rights-holders and to potential recipients; the second two focus on the risks and benefits of acts of donation. They are not mutually exclusive and may be combined in various ways.
First, we could try to increase the perceived value of donated organs to the potential recipients and the society. In principle this approach could be useful in both obligation and supererogation models. And it has been widely used, particularly through attention to the needs of potential transplant recipients, especially children, and to successful outcomes. In commenting on mandated choice, the American Medical Association Council on Judicial and Ethical Affairs stresses: “To be effective, information on the importance of organ donation and the success of organ transplantation must be provided when the donation decision is made” (AMA Council 1994, p. 812). Although such information is necessary, merely attempting to increase the perceived value of donated organs fails to address what is really crucial for many individual and familial decisions to donate, viz., the perceived risks, costs and burdens of acts of donation.

Second, we could try to reduce the perceived value of the organs to the initial rights holders. The mother who donated her son’s organs in Texas insisted that they had no value, except insofar as they could be useful to others. We might view organs as “spare parts” that will go to “waste” if not used in transplantation. Even though many might agree with this perspective, it is not clear that societal policies or educational efforts to devalue organs for rights holders apart from their donation are appropriate, in part because of the complex beliefs, sentiments, and rituals surrounding the body in various communities.

Third, we could attempt to reduce perceived risks, costs, and burdens of acts of donation. These risks, costs, and burdens—coupled with the organs’ value to potential recipients—all combine to support the judgment that cadaveric organ donation is heroic or sacrificial, perhaps even too heroic or too sacrificial. Furthermore, because of these risks, costs, and burdens, some individuals or families may not discharge their obligation to donate—if they accept that moral framework. After all, some level of risks, costs, and burdens can defeat an obligation of beneficence.

Various opinion polls suggest that individuals while alive do not undertake donative acts of completing documents of gift for various reasons, some of which include the burden of contemplating their own deaths and the sense of risk, for instance, in having life-sustaining procedures terminated prematurely or death declared prematurely (see Childress 1997). In view of such opinion polls, several analysts in the 1980s thought that the major bottleneck in organ procurement was professional unwillingness to ask families following a relative’s death, rather than familial unwillingness to donate. The problem, many supposed, was a shortage of
askers, not a shortage of donors (as decision makers). Families’ failures to give resulted from professionals’ failure to ask. Hence, Arthur Caplan (1984) proposed “required request” directed at the decedent’s next of kin. And many of us thought it would work. However, required request has failed to increase the supply of organs substantially even though it has perhaps prevented a decline in donations. In one study, Laura Siminoff and her colleagues discovered that now most families are asked. In her study, more than 70 percent of the families of organ-donor-eligible patients were asked, but only 46.5 percent agreed to donate organs (Siminoff, et al. 1995). We do not know exactly how they were approached. And, in general, we do not know much about why familial decision makers fail to donate in part because too much attention has focused on getting individuals to sign donor cards.

Even among families donating, “complaints about the lack of information on brain death, the cost of donation, the effect of donation on funeral arrangements, and health care providers’ insensitivity were relatively common” (Siminoff et al. 1995, p. 16). We need efforts to reduce all these negative effects. For instance, misunderstandings about so-called “brain death” are numerous and deep-seated, and they help to create and sustain distrust and mistrust because they increase agents’ sense that a decision to donate is highly risky—it may lead physicians and other health care professionals to declare a “donor” dead before he or she is “really” dead.

Fourth, we could try to increase the perceived benefits of acts of donation. Those who donate report both positive and negative outcomes, in terms of meaning and significance of the act of donation (see, e.g., Siminoff et al. 1995, p. 16). In the Texas case discussed earlier, the mother also noted: “I just can’t believe people don’t donate more. This was the best thing we could have ever done. Whoever the people are that got the organs, we’re just grateful to them to keep part of him alive in this way. We’re grateful they are living.”

One barrier to proposals to increase the benefits of acts of donation to donors is that the dominant interpretation of the present system of organ procurement in the U.S. stresses its altruism and its voluntarism. Acts of transfer of organs are deemed to be altruistic, that is, purely other-directed, as well as voluntary. For example, in his excellent book, The Most Useful Gift, Jeffrey Prottas (1994, p. 50) writes: “the voluntary decision to donate must be based on altruistic motives; otherwise, it is not permitted.” That is an overstatement, however. Indeed, for cadaveric donors, there is no inquiry into motives, as long as it is clear that financial com-
pensation is not involved. Donors may have all sorts of mixed motives for donating—ranging from altruism, which is certainly important, to a sense of obligation, to a desire to find redemptive meaning in a tragic set of circumstances, to a hope that their loved one can live on in others, to a desire for praise, honor, fame, and so forth.

Once we recognize that motives are often, and perhaps usually, mixed and that the procurement system does not require pure altruism as the donor’s sole motivation, then we can begin to consider not only how the society could remove disincentives to donation, but also how it might provide incentives—i.e., additional motivating reasons—without replacing a moral sense of altruism or moral obligation. Honoring the act of donation and the donor/source of the organs has certainly been one way, for example, through letters from the Surgeon General or president or through public ceremonies to honor donor families.

One question that arises is whether, within moral constraints, we could find more meaningful and powerful incentives, perhaps even financial ones. I will not here examine arguments for a market in organs, which I have opposed elsewhere as ethically unacceptable as well as politically infeasible, at least in the short-run, because it is currently illegal. Although some proposals to provide financial incentives for organ donation stop short of a market in organs, they are mistakenly characterized as “paid donation.” Such proposals (1) fail to distinguish the logic of donation and the logic of sales, and/or (2) attempt to transfer the moral aura surrounding organ donation to sales.

No doubt, some proposals to provide financial incentives for organ donation are really ways to purchase organs. However, short of actually buying and selling organs, can financial incentives be used legitimately “as tools to improve the decision for donation”? Can they be used without blurring the line between donations and sales?

Providing some financial (and other incentives) has been labeled “rewarded gifting.” According to William F. May (1991, p. 181), if the reward is given only when the gift of the organ has been provided, then it is hard to see how the transfer differs from a sale—“the transaction differs very little from an outright sale” (with all the attendant problems). But a “very little” difference may still mark a significant boundary between donations and sales, particularly if the “reward” represents an expression of communal solidarity with and gratitude to the donor/source.

My starting point is Thomas Peter’s (1991) proposal of a pilot program to test the effects of providing a death benefit of $1,000 for recover-
able donations. In his proposal, the benefit is provided not for acts of donation but for organs actually recovered. Hence, this proposal does indeed appear to be equivalent to a purchase/sale. However, some possible modifications might be more compatible with socio-moral practices of donation. We could provide the death benefit as a tangible societal expression of gratitude for acts of donation, not only for recoverable organs. Thus, as a regular practice, the society could cover the organ source’s funeral expenses up to a certain level (say, $1,000) in order to express, quite concretely and tangibly, its gratitude for the act of donation, whether by the organ source while alive or by the family at the time of death, and to share in the disposition of the final remains, following the removal of donated organs. Such a practice of conveying gratitude would express communal solidarity with the deceased and the bereaved who donate or do not block donation.

I do not argue for this approach, even as a pilot experiment. I only want to suggest that, in principle, it could be developed in a way that would avoid sales/purchases along with some of the associated ethical problems. However, we should be quite cautious about tampering with policies and practices regarding organ donation, since it is probably more fragile than we often suspect. The wrong kinds of policies, and even the wrong kinds of experiments, could increase the failure to donate.

OTHER POSSIBLE DIRECTIONS IN POLICIES AND PRACTICES

My arguments about ways the society could make the act of cadaveric organ donation more reasonable for individuals and/or families—whether that act is deemed morally ideal or morally obligatory—suggest some other directions we should consider in our social policies and practices of organ procurement.

First, in addition to reducing perceived risks, costs, and burdens, we need in more general ways to reduce mistrust and distrust. These more general ways involve expressions of community toward, and solidarity with, individuals and families, so that individuals and families come to trust the overall system. Throughout I have stressed expressing rather than imposing community.

As we note the importance of trust, we can also see some important connections between organ procurement and organ distribution. Recall the numerous cynical comments about how quickly Mickey Mantle received a liver transplant. It is important to assure the public that donated organs are used in fair as well as effective ways, without priority to pa-
patients who are rich, powerful, or famous. Many of the problems of public accountability in organ distribution appear at the point of admission to waiting lists rather than selection from waiting lists. Furthermore, the long and vitriolic debates about the United Network for Organ Sharing’s (UNOS’s) policies regarding liver allocation have aroused suspicions that allocation policies put transplant centers ahead of potential transplant recipients.

In addition, as the federal Task Force on Organ Transplantation (1986) argued more than 15 years ago, there are good reasons to eliminate ability to pay as a criterion for access to most transplants. Inability to pay is now rarely a problem for kidney transplantation because of the End-Stage Renal Disease Program of Medicare (but the limited coverage for post-transplant immunosuppressive medications does create problems of access). Inability to pay remains a major roadblock for patients needing other expensive transplants. The Task Force argued that it is unfair and even exploitative for the society to ask people, rich and poor alike, to donate organs if poor people would not have an opportunity to get on waiting lists if they needed a transplant. Hence, it is important to include all potential donors in the community of potential recipients.

Second, public education needs to be redirected in at least two ways. First, it must deal with some of the fundamental causes of distrust and mistrust, attitudes that are difficult to change. Those attitudes are reflected in various opinion polls, and they are more common among minorities, who view themselves as on the margins of the larger society and have less reason to trust it (see the summary in Childress 1997). One important part of public education that is both cognitive and attitudinal in nature concerns “brain death,” which, as previously noted, is widely misunderstood and which, as a result, generates mistrust.

Public education also needs to target individuals as members of families—or families including individuals. Too often public education has concentrated on the individual’s signed donor card as the desired outcome. However, the donor card expresses an individualistic, legalistic, and rationalistic approach to organ donation that downplays communities (families), practices, and non-rational aspects of decision making.

By contrast, and in line with several recent educational campaigns, individuals also should be encouraged to indicate their wishes to their families and to consider how they would make decisions about deceased family members. Donor cards can play a useful role in this process, especially if they are viewed as ways to stimulate familial conversation rather than as ways to effectively donate organs. These comments begin to suggest
why society should avoid some proposed changes in law or social practices as misguided.

For example, one widely discussed proposal is mandated choice. In my judgment, such a policy would be excessively individualistic, rationalistic, and legalistic. It would require individuals to state their preferences regarding organ donations in conjunction with some other state-mandated task, such as renewing a driver’s license or filing income tax forms. According to the American Medical Association (AMA) Council on Ethical and Judicial Affairs (1994, p. 809), “Requiring a decision regarding donation would overcome a major obstacle to organ donation—the reluctance of individuals to contemplate their own deaths and the disposition of their bodies after death—and individual autonomy would be protected and even enhanced.”

The Council claims that such a policy would be both right and effective, that is, would both respect autonomy and increase the supply of transplantable organs. However, their explanation displays the proposal’s deficiency: “Under mandated choice, individuals who feel this reluctance [to contemplate their own deaths and the disposition of their bodies after death] would have to confront it, thereby removing it as a barrier to donation” (AMA Council 1994, p. 809). In contrast to the Council’s claim, mandating choice, at least without other major changes of the kind I am proposing, would probably decrease, rather than increase, the supply of organs. If forced to choose, many individuals would probably check “no,” not because they oppose the donation of their organs after their deaths, but because they are afraid of being on record as donors of organs, with only the time of delivery to be determined. In saying “no,” they would block their family’s possible decision to donate.

In affirming that mandated choice is not only right but would also be effective, the Council appeals to “empirical evidence that mandated choice would be acceptable to the public and therefore effective in increasing the organ supply” (AMA Council 1994, p. 810). Putative empirical evidence is found in a survey in which 90 percent of the respondents indicated that they would support such a program of mandated choice. However, the Council’s inference confuses public acceptance of a program with individuals’ willingness to say “yes” if forced to make a choice. We do not have the evidence to support the claim that a legal mandate for individuals to make a decision about post-mortem organ donation will actually increase acts of donation. The factors that currently deter individuals and families from deciding to donate would also apply under mandated choice,
and they would prevent mandated choice from increasing organ donation. However, if those factors were corrected, as I am arguing they should be, then mandated choice would be unnecessary.

Proponents of mandated choice overemphasize a very individualistic, rationalistic, and legalistic version of autonomy. They fail to see how people might exercise their autonomy in various ways—for example, delegating the decision to their family or not blocking their family's subsequent decision may also be an exercise of autonomy and even altruistic in motivation.

According to the AMA Council (1994, p. 810), “The individual’s interest in controlling the disposition of his or her own body and property after death suggests that it is ethically preferable for the individual, rather than the family, to decide to donate organs” (emphasis added). The AMA Council (1994, p. 810) also indicates that this is what UAGA says: “The Uniform Anatomical Gift Act’s emphasis on individual autonomy and individual decision making would be protected and enhanced by a system of mandated choice, in which the donation decision would have to be confronted before death and would have to be made by the individual donor, not by a surrogate.”

These statements represent basic misconceptions and fundamental confusions. The UAGA only identifies rights holders and the rights they hold. It does not claim that it is ethically preferable for the individual to make an express decision about donation. A system in which individuals have the right to make their own decisions is, in my judgment, ethically preferable to any other system. However, such a system does not and need not embody an ideal of human autonomy that implies that it is ethically preferable for individuals to determine, let alone be required to determine, in an explicit way what will happen with their bodies after their deaths, rather than, for instance, delegating this decision to others.

CONCLUSION

In conclusion, a fundamental question concerns how organ procurement can affirm individuals, rationality, and law without being excessively individualistic (e.g., in neglecting individuals in their communities), excessively rationalistic (e.g., in neglecting various non-rational aspects of individual and familial decisions and policies that influence those decisions), and excessively legalistic (e.g., in assuming that law can make all the difference while neglecting social practices).

Drawing together various themes, I would characterize my approach as communitarian in several respects, but firmly individualistic in others.
A possible label would be liberal communitarian—it starts from and continues to affirm the UAGA’s emphasis on individuals’ rights to make their own decisions about donation. And it favors laws that would not allow the family to override the decedent’s prior express wish to donate, just as current laws and social practices do not allow the family to override the decedent’s prior express wish not to donate.

It is communitarian in that it recognizes the individual’s and/or family’s duty or obligation to rescue others through cadaveric organ donation under some circumstances, but that duty or obligation does not authorize claiming bodies and their parts against the decedent’s or family’s objections. It still appreciates the relevance for various purposes, including legislation, of a model of supererogation.

To hold that cadaveric organ donation is morally obligatory, at least in some circumstances, does not imply that we should evaluate failures to donate merely in terms of failures to discharge an obligation. We should still express community, rather than impose community through communal norms and sanctions for failures to donate. The society can make it easier and more reasonable for individuals and families to discharge an obligation (or live up to an ideal) of cadaveric organ donation in part by reducing actual and perceived risks, costs, and burdens of acts of donation.

My approach recognizes that individuals’ (and families’) willingness to donate generally presupposes their trust in the larger community, for example, in its criteria and procedures for determining death and for distributing donated organs. Also important is the society’s expression of communal solidarity in individual and familial suffering, in part through the provision of health care. Indeed, it is morally and practically problematic to request organ donation from people who have difficulty obtaining basic health care, much less expensive procedures such as organ transplants. What is utterly indispensable is the expression of community in several ways, rather than the imposition of communal norms and sanctions in demanding the provision of organs.

It is important to educate the public not only or even primarily as individuals who are invited to sign donor cards as putatively effective means for the post-mortem transfer of organs, but as individuals who are members of communities, particularly small communities of families, who should communicate their preferences regarding donation to other members of the family, who should engage in moral discourse with other family members about organ donation, who should discern the views of other family members about organ donation, and who should themselves con-
sider how to make decisions regarding other family members’ organs in the event of death. Nevertheless, my approach remains “liberal” in that it recognizes and prioritizes individuals’ legal and social rights to decide to donate or withhold their own organs after death, whether cadaveric organ donation is considered morally obligatory or ideal.

This paper has its origins in the André Hellegers Memorial Lecture at Georgetown University in 1995 and in the Alloway Lecture at the University of Toronto and the Canadian Bioethics Association in 1997. The author is indebted to these and other audiences for perceptive criticisms and helpful suggestions, but absolves them of any responsibility for the final product.

REFERENCES


