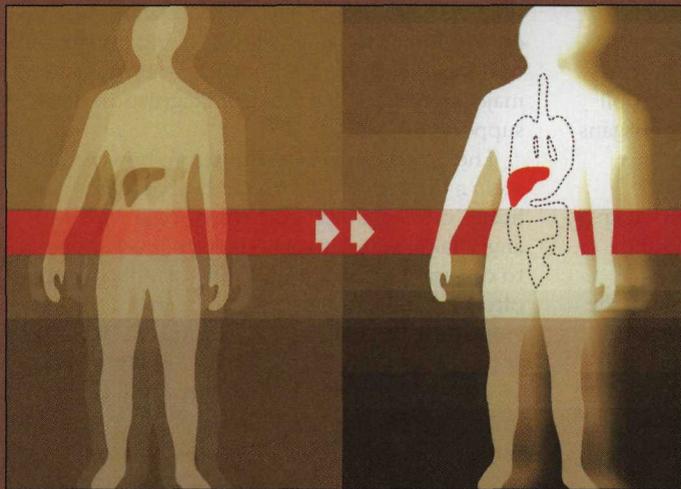


DEFENDING THE DONOR'S DECISION



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An Analysis of the Ethical Issues
Related to First-Person
Declarations of Organ Donation



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From the first successful organ transplants from deceased donors in the 1960s, the demand has been far greater than the available supply. Various possible solutions to this shortage have been suggested, including the legal right of a person to donate her or his organs posthumously. In the past several years, legislation has been passed affirming that the previously made declaration of a person to donate any medically suitable organs cannot be overridden by a family member upon the death of the patient.

Despite the passage of such laws, conflict between the wishes of the deceased and the surviving family can often leave medical personnel caught in the middle of an emotionally charged event. Reviewing some of the key ethical principles at stake in such a situation may help members of the ministry be better prepared to care of patients, family members and staff. Despite unambiguous laws supporting such a right in the United States, it is still a common practice for family members to be granted the power to override the previously made declaration of the deceased to donate any medically suitable organs. This article examines the arguments on both sides of this issue, and makes recommendations for improving the process of registering first-person organ donors to better support the ethical principle of informed consent.

The past several years have brought heightened attention to the issue of organ donation. Amidst various calls for systemic reform seeking to increase the number of organs available for transplant, the President's Council on Bioethics devoted its June and September 2006 sessions to the ethical issues inherent in donation and allocation policies. Likewise, the recent release of the Institute of Medicine report "Organ Donation: Opportunities for Action" in May 2006 suggests a high level of national interest.

A person cannot donate organs sustaining her or his life (the "dead donor" rule); thus, transplantable organs come primarily from the deceased.* Currently, two pathways exist for a person to be declared dead. The first and more common method is the cardio-pulmonary criteria. In 1968, an ad hoc Harvard committee recommended a process by which death could also be

*The issues around informed consent for *living* donors are also significant but beyond the scope of this paper. For the sake of simplicity, organ donation in the remainder of this paper refers only to donation after the declaration of death (whether by neurological or cardio-pulmonary criteria).

declared by neurological criteria. This concept was ratified in 1981 by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, contributing to the creation of the Uniform Determination of Death Act in 1986. The acceptance of death by neurological criteria greatly increased the number of organs available for transplant; however, as few as 15 to 20 percent of medically suitable organs are recovered each year.¹

One significant reason for the failure to recover more medically suitable organs relates to the difficulty in seeking permission to recover organs for transplant from family members, who have just experienced the sudden and oftentimes violent death of their loved one. The first laws and policies that sought to increase the number of organs available for transplant required health care providers to speak to the family of the newly deceased to request permission to pursue organ donation whenever it was medically indicated. Although this policy (known as Required Request) has helped to address the shortage, the fact remains that such moments are often filled with an intense grief that makes truly informed decision-making difficult.

One significant reason for the failure to recover more medically suitable organs relates to the difficulty in seeking permission to recover organs for transplant from family members, who have just experienced the sudden and oftentimes violent death of their loved one.

Acknowledging this, various initiatives are being considered that would increase the number of organs available for transplant "while at the same time eliminating the delicate task of requesting organs from family members moments after a loved one has died."² Options being considered include the re-introduction of Donation after Cardiac Death (also known as Non-Heart-Beating Organ Donation), routine salvaging of organs,³ presumed consent (everyone is presumed to be an organ donor unless they have opted-out of the system),⁴ the use of financial and other incentives,⁵ required response (everyone must make a decision which is binding upon his/her death)⁶ and First-Person Organ Donation, the opt-in program that

is the focus of this article.

Stated simply, First-Person Declarations of Organ Donation intends to increase the number of organs available for transplant "while at the same time eliminating the delicate task of requesting organs from family members' moments after a loved one has died."⁷ But even set within this practical context, one important rationale for supporting First-Person Declarations of Organ Donation is grounded in the concept that persons who have declared their intent to have any medically suitable organs donated at the time of death should have that declaration honored, without the possibility of being overturned by a family member. At the present time, the vast majority of states have enacted legislation that supports this right.⁸

The presence of such legislation, however, can seem a distant comfort to medical providers and health care administrators when faced with an angry family member who is strenuously opposed to donation. As recently as 2001, families were often given the opportunity to overturn the previously made decision of the deceased. In a 2001 survey, only 8 percent of Organ Procurement Organizations (OPOs) indicated a willingness to proceed with organ donation in the face of objection by the next-of-kin.⁹ While such a concession is much less likely now, we must ask if there are ethically valid reasons to support such a concession? Or should the autonomous and legally binding declaration of the donor be honored despite any opposition?

Those who argue in favor of irreversible First-Person Declarations of Organ Donation ground their arguments in several ways. The principles of autonomy and altruism/beneficence are often considered, especially in light of communitarian or even utilitarian ethics.

Perhaps the strongest argument in favor of donor designation rests on the principle of autonomy. Dr. Roy Reeves envisions a scenario where:

You could die with an organ donor card in every pocket, and another one pasted on your forehead, and still no one would touch you if your [family] said no. When this occurs, a donor of life-saving organs is then no longer a donor.¹⁰

Given how important the principle of autonomy has become for the medical community and how strongly it reflects widespread public support in America for the right of a person to exercise control over his or her own body, one might ask if a family member arguing to reverse the informed decision of the deceased could reasonably be allowed to do so.

Even those who fear placing too much empha-

sis on autonomy suggest that donor declarations should be protected on communitarian or even utilitarian grounds. "The communitarian view holds that individuals have a moral duty to help others when the cost to the individual of helping is very low."¹¹ When the decision to donate organs is understood as an appropriate response to a societal obligation, then the reasons for overturning such a decision would have to be equal or greater in weight to the life-saving benefit offered. Considering this from a more utilitarian perspective, the consent of 500 additional kidney donors alone would save more than \$30 million in costs associated with dialysis, according to the American Medical Association in 1994. When we as a community have agreed to universally fund a medical expense, it seems reasonable to expect members of that same community to contribute in ways that help control that cost when the personal impact is minimal.

The process of organ donation offers a tremendous benefit to society with little to no negative impact on the individual donor, and that such a process seems consistent with the principle of autonomy and beneficence. Having said that, some people muster persuasive arguments for allowing family members to overturn the deceased's decision to donate.

Professors Rebecca Dresser and Peter Lawler of the President's Council on Bioethics have emphasized that declaring oneself to be an organ donor is actually a "fairly trivial exercise of altruism."¹² As Professor Lawler recently said, "Giving up my dead kidney is the weakest act of generosity I will ever perform in my life. If I buy you a soda, I will have done more [in terms of a cost to myself]. That would be more generous."¹³

Arguments such as these frame organ donation as a beneficent act and often suggest that overturning such a decision denies the deceased of her or his final opportunity to engage in an act of charity at a low (or even negligible) cost to the deceased.

The principle of beneficence can be defined as the ethical obligation to do as much good as one is able, with consideration given to one's abilities

and any potential negative outcomes that would affect the agent or others. Although offering one's organs for donation has been heralded as a truly altruistic act, the medical reality is that there is almost no possible negative outcome for the agent to consider. If the organs are not transplanted, they will quickly deteriorate, and most likely be buried or cremated.

Thus, it can be stated with some confidence that the process of organ donation offers a tremendous benefit to society with little to no negative impact on the individual donor, and that such a process seems consistent with the principle of autonomy and beneficence. Having said that, some people muster persuasive arguments for allowing family members to overturn the deceased's decision to donate.

Those who argue against binding donor declarations cite the emotional impact on the family, the desire to maintain public trust in the medical profession, reasonable fears that poor publicity will result in even fewer organ donations, and the lack of a truly informed consent process for organ donation.

Although autonomy does stand as a strong principle in medical ethics, it may fail to acknowledge and allow for the very real emotional distress that a family might experience and with which it will have to live.¹⁴ Although inexperienced clergy might suggest "the body is just a shell," pastoral experience with the bereaved suggests that the "remains" are an important connection between the living and the newly deceased. One funeral home director tells the story of watching a family member who had just picked up the cremated ashes of her deceased spouse walk out to the car, open the trunk, and then hesitate. After considering the back seat as well, she opened the passenger door and gently belted in the jar holding her husband's remains. Clearly, the dead do not care ... but the dead do matter.¹⁵

Stories such as these suggest the family may have a greater stake in the disposition of the body than the law acknowledges. It would not be unreasonable for a family member to argue that the deceased would not have insisted upon organ donation if they knew how it would have distressed their family. It is true that family members are often angry, sometimes bitterly, with how the person distributed his or her material and financial assets, yet those decisions are not subject to review. While it may seem logical that a person should be able to give away her or his organs in the same way, without fear that such a decision will be overturned, the family of the deceased has traditionally had complete authority to dispose of

the body as it sees fit, even to the extent of ignoring pre-paid burial arrangements. Acknowledging the disposition of the body carries with it a higher emotional stake than the disposition of more worldly goods, it could be argued the family's wishes should have precedence.

A second reason articulated to allow a family to overturn a donor declaration is to maintain the public's trust in the medical profession. While pursuing organ donation can be legitimately described as supporting the autonomous and legal decision of the donor, "enforced organ donation" by the OPO could also be perceived as a state-sponsored invasion of privacy and bodily integrity.¹⁶ Additionally, angry family members might wonder if the treating physicians really did everything possible, or if their treatment plan was unduly influenced by the possibility of organ donation.

Perhaps the strongest reason articulated for overturning a decision to donate relates to concerns that the consent process is not a truly informed one.

This desire to maintain the public's trust in the medical profession is related to the realistic fear that forcing the issue might result in a public relations backlash. Although the state laws appear sufficient to provide legal protection for the involved health care professionals and institutions, the true "risk" may be in the arena of public relations.¹⁷

Finally, perhaps the strongest reason articulated for overturning a decision to donate relates to concerns that the consent process is not a truly informed one. In the medical model, informed consent has traditionally relied on three essential conditions: the capacity of the decision-maker, an understanding of the risks, benefits and alternatives of a particular decision, and freedom from coercion or undue duress. Although capacity and freedom can be assumed in these situations, it is less clear that those making the declaration have the requisite knowledge of the risks, benefits, and alternatives. Certainly, the lengthy process by which a family member would give consent following death by neurological criteria cannot be compared to a simple "yes" or "no" while standing in line at a state's department of motor vehicles.

Such a review of the various arguments put forth both in support of and against the protec-

tion of donor designation makes it clear that several different values are at stake in these situations. On the one hand, organ donation is seen as a valuable gift to save or improve the life of another. This is experienced most clearly when the donor had previously made an informed decision which is supported by his/her remaining family. Conversely, U.S. law has a long tradition of allowing family members to determine the final disposition of the body. The recent modification to this tradition in support of organ donation carries several risks, including emotional distress to the family and loss of public confidence in the medical profession operating within this system. They can be phrased the following ways:

- Saving lives through organ donation is a good thing, especially when made possible through the beneficent actions of a donor.
- The medical model approaches organ donation as a risky surgical procedure that requires the provision of a great deal of information before consent can be accepted.
- The supraordinate value of the average OPO is to take care of families. While organ donation is valued, the comfort level of the family is seen in actual practice as a higher good.¹⁸
- Therefore, honoring the needs of a grieving family is more important than honoring the autonomous decision of a donor to bequeath any medically suitable organs.

Is there a process we might develop which would find a middle ground amongst these value statements in order to improve both the number of organs being recovered and the emotional experience of the family? Meyer and Martin have suggested that such a model could be developed in a way that understands the consent process for organ donation through a legacy paradigm rather than a medical model,¹⁹ using existing best practices to minimize the distress felt by certain family members and increasing public faith in the process of organ donation.

In the medical model, a patient is asked to assess the risks, benefits, and alternatives of a particular procedure in order to determine if that procedure is likely to provide an acceptable improvement in their quality of life. In the case of organ donation, however, the "patient" has already been declared dead, leaving no possibility of discomfort, pain, or other medical complications. The only possible negative consequence lies in the emotional distress of family members, who may be distressed at what could be perceived as a violation of bodily integrity. On the other hand, the benefits for the donor include a sense of altruism while living, and the opportunity to

save or improve the lives of many others upon her or his death. Although preservation of bodily integrity is often cited by families as a reason for declining organ donation, this does not seem sufficient to override the autonomous decision of the donor, who had expressed a willingness to have such bodily integrity violated for the possibility of a greater good. Additionally, organ donation does not preclude the possibility of an open casket, allowing family and friends that moment of closure without any visible evidence of the procedures necessary to donate the organs.

The intent of the donor, rather than the extent of the medical procedures necessary to accomplish that goal, becomes paramount. This is comparable to the moral responsibility of an estate executor to fulfill the directives regarding disposition of material possessions as stated in the last will and testament.

In moving from a medical model to a legacy paradigm, the revised system would be guided by three affirmative statements.

1. Organ donation is a beneficent action with little to no negative impact upon the donor.
2. First-person declarations of intent to donate will be respected as ethically and legally binding in order to promote personal autonomy and save the maximum number of lives.
3. Caring for the family of the donor is an important element of health care, but that responsibility is secondary to honoring the declaration of the organ donor. A commitment to following established best practices that decouple the declaration of death from any discussion around organ donation and to strengthening donor registry processes will be pursued.

Members of the ministry may wish to consult the work of Drs. Alexander Tartaglia and Diane Dodd-McCue for a review of the best practices developed to care for the families and staff of neurologically devastated patients. In my experience serving with Dr. Tartaglia in this capacity, protocols such as assigning a staff person with advanced training in the psycho-behavioral arts to be with the family, clearly explaining the possibility of death by neurological criteria early in the treatment process, clearly explaining the definitive nature of brain death testing prior to the beginning of such testing, and drawing a clear separation in roles between those engaged in treating and testing the patient and the explanation of organ donation by an OPO representative were all found to decrease the emotional distress of the family. This latter protocol, often referred to as decoupling, is particularly important to maintain the public trust in the medical profession.

These three affirmative statements are not meant to dismiss the emotional distress that may be felt by certain family members. They do suggest, however, that the emotional distress that may be felt by certain families can best be addressed by pastoral professionals as a response to sudden and unexpected death. A recent study shows nearly half of all new drivers declaring their intent to be organ donors,²⁰ up from 33 percent in 1992, and 16 percent in 1985 (Dennis et al. 1993). Such studies reflect a positive change in our culture's acceptance of organ donation.

Donor declarations must be respected as ethically and legally binding in order to promote personal autonomy and save the maximum number of lives. One recent study of family satisfaction with their organ donation decision showed that 21 percent of families who had declined organ donation had changed their minds as the grief receded.²¹ Given the immense good that can be done through organ donation, it would be unsettling for the personal intent of the donor to be overturned by a family in the midst of substantial and unexpected grief.²²

Donor declarations must be respected as ethically and legally binding in order to promote personal autonomy and save the maximum number of lives.

Caring for the family of the donor can best be accomplished by following established best practices that decouple the declaration of death from any discussion around organ donation and by strengthening donor registry processes. The principle of decoupling is particularly important to maintain the public trust in the medical profession.

The major issue that remains is to increase the confidence of the American public in the moral authority and ethical grounding of the consent process. It has been suggested that a lower level of informed consent can be ethically justified within the paradigm shift from a medical to a legacy model.²³ However, the question may still be reasonably asked if the current system seeking first-person organ donation provides the minimal level of information necessary to establish donor intent. In other words, did the person making the declaration have sufficient information to make such a choice?²⁴

At this time, most states have partnered with the department of motor vehicles as the primary

gateway for recording donor designations. The level of information available at this time is inconsistent, ranging from a presumption that one would have researched the issue at a prior time to pamphlets or looping videos. Several states, including Illinois and Maryland, send letters of appreciation *with additional information* to those who have registered as organ donors. This material includes information on how to update one's preferences and suggestions as to how to celebrate this decision with one's family. Preparing one's family in such a way has been shown to significantly decrease family distress at the time of donation.²⁵

To go a step further, annual contact with those who have registered would offer the opportunity to record a pattern of affirming the intent to donate. At the time of death, the family would be assured of a decision made and affirmed over time, with adequate information having been provided to both the donor and her or his family. This is consistent with the approach of the Advance Medical Directive Registry, which provides an opportunity for its directive to be affirmed or updated each year.

Thus, the creation of a national registry of First-Person Declarations of Organ Donors, protected from the possibility of his or her decision to donate being reversed by grieving family members, offers us an opportunity to increase the number of organs available for transplant while simultaneously affirming the great value we place on the principle of autonomy.

There is one element of the current process which begs for correction in light of this principle. In Virginia, visitors to the department of motor vehicles are asked if they wish to be listed as organ donors. Those who respond in the affirmation have their decision recorded and enshrined in the database of the OPO until such time as that decision may become operationally relevant.

On the other hand, a similar process is not available for those who wish to register their desire *not* to become an organ donor. "It may be determined that if a positive designation ... constitutes a binding advance directive, then the negative designation should be clearly and consistently [upheld] as well ... That is, 'yes' means yes, then 'no' means no."²⁶

Although such a proposal may strike fear in the hearts of organ donation proponents fearful of uninformed negatives, it is the strongest possible affirmation of the power of the autonomous decision and would undoubtedly encourage improvements to ensure a more informed process of deci-

sion-making.

Given the difficult nature of medical situations where organ donation becomes a possibility, complicated by the highly emotional environment, a general lack of understanding of death by neurological criteria amongst both physicians and families, and the difficulty experienced by many when trying to provide an environment in the midst of this chaos where such a decision could be considered,²⁷ it is not surprising that support for First-Person Declarations of Organ Donation appears to be growing.

Each year, roughly 12,000 patients are declared dead by neurological criteria.²⁸ While tragic, each such death paradoxically holds the capacity to save seven other lives and greatly increase the quality of life for many others.* The concept of legally-protected First-Person Declarations of Organ Donation offers an ethically acceptable process for increasing the availability of organs for transplant. With modifications intended to strengthen the principle of autonomy and the practice of informed consent, First-Person Declarations of Organ Donation can earn the same standing in the ethical world that it holds in the legal arena. ■

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