Patients, Families, and Organ Donation: Who Should Decide?

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ALTHOUGH STUDIES SUGGEST THAT BETWEEN 69 AND 75 percent of adults in the United States would be willing to become organ donors (Gallup Organization 1993), half of the families that are asked to consider donation after a relative has died do not give their consent to the procedure (Siminoff, Arnold, Caplan, et al. 1995; DeJong, Franz, Wolfe, et al. 1998). Thus, there is a significant discrepancy between individuals' willingness to donate organs and their families' willingness to give consent. The ramifications of this discrepancy are most noticeable when the family's reluctance to donate a loved one's organs conflicts with the patient's *known* wishes.

Typically, when the wishes of a competent adult patient conflict with those of the patient's family, the patient's wishes take precedence. This scenario is not the norm, however, when the issue involves donating organs or tissue. Although a variety of mechanisms exist through which a person may express the wish to be a donor, organs or tissue will normally not be procured unless the *family* of that person also agrees to donation. This protocol is taught to most organ-procurement coordinators and constitutes a problem that is cited extensively in the literature (Peters 1986; Gibson 1996; Kluge 1997). A study by the United Network for Organ Sharing (UNOS) in 1998 found that 35 of 36 organ procurement

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organizations (OPOs) *will not* recover organs or tissue from a patient *with a signed donor card* against family wishes (Wright 1998).

Recently, the Center for Organ Recovery and Education (CORE), an OPO operating in regions of New York, Pennsylvania, and West Virginia, adopted a controversial policy of acting on the documented wishes of individuals to donate, independent of family consent (Center for Organ Recovery and Education 1998). In practice, the policy adopted by CORE is carried out by *informing* families (rather than by seeking their *consent*) that the deceased patient documented a wish to donate and that this wish will be honored. Should the family still oppose donation, CORE's policy is to redouble its efforts to educate the family while still continuing to move ahead with organ procurement in accord with the patient's documented wishes. However, CORE has discovered that families rarely oppose donation when they are *informed* about it, rather than when they are asked to consent (B. A. Broznick, May 12, 1999: personal communication by telephone with M.P.A.). CORE implemented this controversial new policy to increase organ donation, in accord with its mission to comply with Pennsylvania Act 102 (1994), which explicitly upholds the validity of a properly executed donor card, Pennsylvania driver's license, or living will indicating a wish to donate without reference to family consent. At this time, CORE is the only OPO to have adopted such a policy (Brian A. Broznick, CEO of CORE, May 12, 1999: personal communication by telephone with M.P.A.; Snowbeck 1999).

To be sure, changing organ-procurement practice to one that respects a patient's documented wish to donate, which has been made without reference to the family's consent, will not solve the organ shortage. It is hard to measure the degree to which this approach (of informing, rather than seeking consent) has increased donations; however, its successful application in even a single instance could save several lives in the present context of extreme organ shortage. Indeed, it is estimated that nine patients *per day* die before a suitable heart, liver, or lung becomes available for transplantation (Gallup Organization 1993; Gortmaker, Beasley, Brigham, et al. 1996). Each organ donor represents up to seven lives saved (two lungs; one heart, pancreas, and liver; and two kidneys), and if tissue is counted, the number benefiting from an individual's decision to donate is even greater. Given the fact that the demand for organs currently far outstrips the supply, the refusal to consent to the procurement of organs that were designated for donation means that

several avoidable deaths will occur: a most profound effect on potential recipients and their families and friends.

The practice adopted by CORE, however, is controversial, and it is worth considering whether it is morally appropriate. Among the concerns it raises are the effect of this practice on grieving families, public opinion concerning organ transplantation programs, and liability. We will examine the issues raised by the CORE practice of procuring organs, independent of family consent, from individuals who have documented a wish to donate. Although we agree that respect for grieving families is important, we conclude that this respect must be balanced against the rights of patients. Ultimately, we will argue that the practice adopted by CORE is not only justified, but morally required.

Patient–Family Conflict: The Context

Organ procurement occurs at a time of tremendous stress and grief for families. Family members are living, feeling people who are undergoing a deep loss. The spouse, child, parent, or friend of a recently deceased person often reacts to the loss with feelings of regret for all the things not done and time not spent with their loved one; they need to express their sense of bereavement, both symbolically (through ritual) and through action. Gary Sproat, a chaplain for 18 years in acute-care hospitals who helped to develop a protocol for Acute Bereavement Services (ABS) at the University of Nebraska Hospital in Omaha, describes the feelings that are common to families when a loved one has died:

One of the core philosophies in the development of ABS was the conviction that grief and loss come at a time when we move from a world that makes a fair amount of sense to a time of total disorientation, when everything seems to have fallen apart. It is as if one of the supporting pillars has been pulled out from underneath our world and we are trying to put Humpty Dumpty back together again. (Sproat 1999)

Part of the grieving process for families of a deceased person involves the disposition of the body after death. The rituals of funeral and burial allow families to express their loss and to demonstrate their respect for the deceased person. No one wishes to exacerbate their grief by initiating procedures that “mutilate” the loved one’s body. Excluding family

members from participation in the decision to take organs from the body might well amplify their sense of loss.

Indeed, health care professionals commonly voice this concern when they face the prospect of procuring organs without family consent. Health care professionals have described the difficulty of sharing a family's grief and have indicated their reluctance to add another burden to the family's stressful situation. The clinical reality is that the family's suffering is both real and tangible, and sensitivity to their grief is a profoundly important part of ethical, humane health care practice.

That sensitivity, however, must be balanced against respect for the rights of patients. There are times when respect for the known wishes of a patient simply *must* take precedence over family wishes. This emerges most clearly when we consider the family's role in surrogate decision making and the application of advance directives. A surrogate's foremost responsibility is to identify what the patient would have wanted if she were able to make decisions for herself (this is known as the "substituted judgment standard"). This responsibility holds even when the patient is not expected to recover, such as when a patient is in a persistent vegetative state. For example, the famous case of Nancy Cruzan revolved around "clear and convincing evidence" of *the patient's wishes concerning life support*, despite clear *family wishes* to discontinue life support¹ (LeBlang 1999). It is only when the wishes of a patient are not known, and we are unable reasonably to predict what her wishes would have been, that we revert to other decision procedures (Aulisio 1999).

Advance directives provide another good example of a patient's wishes taking precedence over those of the family. An advance directive allows a patient to refuse life-sustaining treatment in certain situations and/or to appoint a person of her choice to make health care decisions on her behalf, regardless of family preferences. Consider the following case:

A 52-year-old gentleman has a severe stroke and develops pneumonia and generalized infection. It is not known whether he will recover cognition from the stroke. The stroke will result in a chronic deficit of unknown severity, and the patient has the potential to completely recover from the infections. Using a standardized, validated prognostication system, his likelihood of hospital survival is 25 percent. A living will states that if he has a terminal illness or coma from which he cannot recover, then he refuses life-sustaining treatments, and

¹*Cruzan v. Director, Missouri Dept. of Health* (1990).

authorizes withdrawal of any life-sustaining treatments already being implemented.

This type of scenario is common. The family participates in the decision to implement an advance directive by determining whether the patient's current circumstances apply to the conditions of the directive. Although it is unlikely that the patient described here will recover, his *actual* outcome is unpredictable. The living will provides a clear indication of what the patient wants in a particular situation. However, because it is not always certain that the applicable situation has occurred, the clinicians and the family must do their best to interpret the patient's intent and extrapolate an action plan. Thus, in this case, the advance directive is less a directive and more a form of guidance. The importance of this distinction should not be overlooked: the document is neither definitive nor directly applicable because of the inherent uncertainty. Were the directive clearly applicable, it would take precedence over family wishes.

By contrast, a donor directive by a patient is both definitive and directly applicable. The assumed conditional clause ("If I am dead...") in a directive for organ donation is not uncertain. The medical state of the donor is death: he or she is not "probably" dead or "likely to be" dead. Therefore, subsequent instruction must be applied unless it is illegal, impossible, or unethical. Similarly, the directive ("I consent to organ donation") is not ambiguous and requires no interpretation about intent or meaning. Because there is no uncertainty about intent, diagnosis, or instruction in the scenario of organ donation from a dead potential donor, it is a more powerful document than an advance directive.

The lack of uncertainty about intent is bolstered by public beliefs concerning the goals of documenting one's wish to donate. A 1985 study of public attitudes toward consent for organ donation (Corlett 1985) divided respondents into two groups:

1. "donors": defined as those who had signed their driver's license
2. "nondonors": those who had not

Half of the "donors" believed that their signed driver's license "represented a legal document and that family had no say in the matter." *All respondents* who were donors indicated that the signed driver's license *should be* treated as a legal document. Indeed, many expressed outrage

upon learning that their signed donor cards could be overridden by their families.

The practice of requiring family consent in order to procure organs when the patient has documented a wish to donate is inconsistent, then, with the way we approach conflict between patient and family wishes in other areas (most notably advance directives). This should cause us to stop and ask whether there is a defining characteristic of organ donation that sets it apart from other types of health care and determines that the wishes of the family should supersede those of the patient. We will argue, in the following sections, that the most common reasons given for respecting the wishes of the family, rather than the expressed wishes of the patient concerning organ donation (respect for grieving families, the strength of preferences after death, and concerns about liability), do not justify the practice of *overriding a patient's documented wish* to donate by requiring the family's consent.

Respect for Grieving Families

Perhaps the most commonly given reason for not procuring organs independent of family consent, despite the patient's documented wish to donate, is that this practice would show a lack of respect for the grieving family (Wright 1998). The concern is that organ procurement without family consent would be considered "ghoulish," that procurement agencies would be viewed as "organ vultures," and, therefore, the net effect on organ donation would be a decline in the number of donors. Klassen and Klassen (1996), for example, argue that the family's role in the decision to donate is vital—even if the patient's wishes to donate are known:

The unfortunate reality of cadaveric organ donation is that it is the family, not the deceased patient, who comes home from the hospital; talks to their friends, neighbors, and community about their experience at the hospital; and shapes public opinion about organ donation among those they know. Can the transplantation community afford to go against the wishes of the family for its own apparent gain, even if it is legally entitled to? (Klassen and Klassen 1996, 71–2)

This argument is based on a belief that the general population would view procurement of organs, even when the patient has indicated a desire to donate, as ghastly, unless the family has consented. Such a belief,

however, is not supported in the empirical literature. Indeed, the small accumulation of empirical data on public attitudes in this context suggests just the opposite. As far back as the mid-1980s, a study by Maninen and Evans (1985) reported that more than 70 percent of the respondents to a survey indicated that family objection to organ donation should not override the wishes written on a donor card (only 16 percent thought it should; 12 percent responded "don't know"). A study published by Corlett (1985) found that even nondonors surveyed firmly agreed that donor cards should be legally binding and the family barred from overriding these written indications of intent. The results of these two studies suggest that public attitudes do not support the practice of families overriding patients' own wishes concerning donation.

More important, however, it is unclear that requiring family consent for organ donation when the patient's wishes are already known is the best way to respect the grieving family. In Corlett's study of public attitudes toward donation, referred to above, respondents offered several reasons for their opinion that donor cards should take precedence over family wishes, including the belief that "one should be master of one's own body," and the facilitation of quick recovery of organs. Perhaps the most interesting answer, however, was that "the whole point of signing a donor card is to relieve the family of the burden of this decision." This argument suggests that asking the family for consent when an organ donor card has been signed *actually places an undue, and unnecessary, burden on the family.*

A good analogy to consider is that of presenting decisions concerning withdrawal of ventilator support to the family of a brain-dead patient. As chaplain Sproat (1999) describes this situation, it can impose a tremendous (and inappropriate) burden:

In frequently working with potential organ donor situations, I have seen the dilemmas that can unintentionally be posed for family when considering a diagnosis of brain death. Too often, when a family member is informed of the diagnosis of brain death, someone in the family will ask, "What do we do now?" and the response will be something like, "We recommend shutting off the ventilator and 'letting them die'" or "When we turn off the machines he/she will die very quickly." If we really mean what we have told them (that the patient is dead), then we should not be talking about allowing the patient to die or letting the patient die.... We can inadvertently place a heavy emotional burden on families by suggesting they have a decision to make.

It has been our experience that the burden of decision-making during traumatic times, such as when family members have to play the role of surrogates in making end-of-life choices, can be profound. Family members in this context sometimes find it liberating to recognize that their role is to help others identify what their loved one would have wanted, rather than having to decide themselves whether or not to “give up” on their loved one (Aulisio 1999). Ironically, asking for consent to organ donation from family members when the patient’s wishes are already known may accomplish the opposite effect: it places the burden of decision-making squarely on the shoulders of the grieving. The experience of chaplain Sproat seems to support this observation:

We find ourselves caught between the commitment to be loyal to what a parent, or spouse, or patient, has asked of us and not wanting to let go of deep emotional ties and reliance upon parent, or spouse, or patient. The feelings we experience at these times are not intellectual feelings; they are feelings that tie us in knots internally.... Family members, and staff, are almost always in some tension between competing values and feelings, between holding on too long and letting go too soon. (Sproat 1999)

It is important to note as well that the CORE policy of respecting donor preferences by *informing*, rather than *seeking consent from*, families does not ignore the grief of families. Although it is uncommon for the family to disagree with the donor designation when *informed*, it does occur, and CORE offers the support of coordinators and grief counselors to those donor families. The families are personally contacted by phone afterwards and are also told about donor family support groups. CORE has found that the few families who still opposed donation when informed of the wishes of their loved one have *all* come to understand, appreciate, and agree with the donation. Indeed, they have gone on to assist with community and health-care professional donor awareness activities (B. A. Brosnick, February 1, 2000: personal communication with M.A.D.).

Respect for grieving families has another important dimension, which we alluded to earlier: its effect on health care professionals. Klassen and Klassen have argued, for example, that “it is not uniformly accepted by caregivers that the patient’s choice should predominate over the family’s wishes once the patient has died. Therefore, overriding family wishes may not reduce stress on caregivers, but may actually increase it” (Klassen and Klassen 1996, 71). Indeed, we recognized and described the concern

of health care professionals about adding to the family's grief. However, this concern focuses on the family's grief and does not stem from a belief that the family's feelings about donation should supersede the patient's decision. A 1996 survey of health care professionals (Spielman and Verhulst 1996) found that 98 percent of respondents believed that a conflict between a deceased individual's expressed intent to donate and family refusal should be resolved in line with the individual's preference. Sixty-seven percent also *disagreed* with the proposition that when a person has expressed a desire to donate, the family's permission should be required. To the extent that it *removes the burden of decision-making* from families and thus reduces family stress at a difficult time, acknowledging the primacy of the patient's wish should also reduce the stress experienced by health care professionals.

Do Patients' Interests Die with Them?

Another argument for acceding to family wishes concerns the status, or strength, of a deceased person's interests. Autonomy rights are designed to protect the interests of individuals, allowing them to pursue interests that they find valuable. This recognition is derived from the notion that the person making a decision is the one who is most affected by it. When this is not true (such as when others may be harmed as a result of our decisions), one's autonomy rights are sharply circumscribed. The argument that family interests should prevail is based on the view that family interests will be most affected by procurement. Such an argument must presume either that: (a) the person who declared the wish to donate can have no interests in whether donation occurs because he is dead; or (b) the interests of the deceased individual have been so attenuated by death that they can be outweighed by the family's interests. Otherwise, the interests expressed by the individual will take precedence, no matter how strong the family's preferences.

The presumptions upon which this argument must be based are controversial at best. There are many examples where we continue to respect the wishes of a person, even after he loses the ability to appreciate this respect. For example, we recently encountered a case in which ventilator support was about to be withdrawn from a permanently comatose man. Before this was done, however, the family asked that he be transferred to a VA hospital, as he had repeatedly expressed a wish to die in this

setting. Despite the fact that the man could not *experience* being in the setting of a VA hospital, everyone involved in the case recognized that his interest in dying in a VA hospital remained. Interestingly, logistical considerations surrounding the transfer to a VA hospital precluded the family from being present when ventilator support was withdrawn. Despite their strong desire to attend and witness this event, even the family recognized that the interest of the patient should take precedence over their own preferences.

Philosopher Joel Feinberg has discussed at length the possibility of interests surviving death (Feinberg 1982). He considers that interests are “stakes” derived from, and linked to, a person’s wants and desires. In examining how these interests may be promoted or thwarted, Feinberg points to a distinction between *fulfillment* and *satisfaction* of a want or desire (Feinberg 1982, 84). Fulfillment consists in the object of the want simply coming into existence. Satisfaction, on the other hand, consists in the pleasant experience of contentment or gratification that occurs when a want is fulfilled. Feinberg argues that an interest is defined better in terms of the *objective fulfillment of wants* than the *subjective satisfaction of wants* because the latter condition is highly contingent and unreliable. For example, fulfilled wants often fail to satisfy. Although the failure may be due to the want being ill advised or poorly thought out, this is not always the case. The fulfillment of a want can leave a person feeling only fatigue, sadness, or an affective blankness, even when that want is based on logical reasoning that can withstand retrospective scrutiny. In addition, a want can be thwarted without an accompanying feeling of frustration or disappointment. It is in this way that death itself can be understood as thwarting an individual’s interests, even though he or she experiences no pain after death.

Interests that die with a person are only those that can no longer be helped or harmed by posthumous events, such as a self-regarding stake in personal enjoyment, the desire to become a self of a certain sort, or the desire for self-respect. Because a person often wants objects that are beyond his grasp or wishes for events that will occur outside his immediate experience and/or at some future time, his interests necessarily exceed his subjective experience and endure past the end of his biological life.

We believe it is this conception of interests that is presumed by the broader, political understanding of autonomy rights in our society. These rights are not contingent upon a subjective experience of satisfaction

arising from the exercise of autonomy. Often, our concern is to protect the right to take on responsibilities and commitments, which, although viewed as valuable, do not result in the experience of satisfaction. The case described above, of the family that went to such lengths to respect the patient's wish to die in a VA hospital, is but one illustrative example. Acceptance of Feinberg's argument would settle the issue of family consent for procurement when an individual has expressed a desire to donate owing to its thesis that the rights protecting the individual's interests will take precedence over family preferences.

Social attitudes toward disposition of property after death buttress this view of interests surviving death. David Peters (1986) has argued that the Uniform Anatomical Gift Act (UAGA) clearly favors the wish of a deceased patient to donate, rather than family objection to donation. Peters argues that this rests on a deeper idea that a person's body is her property. Understood as *property*, the individual has a *first right* of control over the disposition of her body, both before and after death, consistent with society's approach to the disposition of other forms of property after death. Although we find Peters' argument persuasive, even those who would not must account for societal attitudes toward disposition of property after death (in, for example, a will disposing of one's estate after death) if they are to argue that interests cannot survive death.

Liability

Finally, a more cynical (but pragmatic) answer to the question of why organs are not procured from patients who have documented their wish to donate in the face of family refusal lies in the anecdotal statements of organ-procurement coordinators: "Dead patients don't sue, but live families do." In fact, "fear of being sued" was cited as among the common reasons for ignoring a valid donor card and, instead, seeking consent from family (Wright 1998). This is perhaps the simplest reason to address.

Laws concerning organ donation in most states, as well as Canada, and the Model Uniform Anatomical Gift Act (which has been adopted in some form by all 50 states and the district of Columbia) explicitly recognize the priority of an individual's right to donate over family rights to refuse (Peters 1986; Spielman and Verhulst 1996; Wright 1998). Because the wishes of patients to donate are legally recognized as

superseding family wishes, there is little reason to fear liability for acting on a valid donor card.

Indeed, Peters (1986) has argued that any liability should arise from the opposite direction than from the one commonly feared. Peters argues that overriding a willing donor's documented wishes to donate should be grounds for legal action by potential recipients, given the legal status of gifts after death and the rights this bestows on recipients. He argues that, whereas before passage of the UAGA, case law was indecisive regarding whose wishes should take precedence in a conflict between an individual and the family concerning post-death disposition of the body, the Act has settled this conflict clearly in favor of the individual.

Conclusion

We have examined the issues raised by a policy, like the one adopted by CORE, in which organ procurement moves forward, independent of family consent, when a deceased patient has documented a wish to donate. Such a practice is consistent with society's approach to consent in other areas of health care. Although we agree that sensitivity to family wishes is important, we have argued that the leading reasons given for requiring the family to consent to organ donation (respect for grieving families, strength of preferences after death, and concerns about liability) do *not* justify a practice of overriding a deceased patient's documented wish to donate by *requiring* family consent. Indeed, we have argued that requiring family consent for donation when an individual has documented a wish to donate may not be the best way to respect grieving families.

Based on the lack of justification for overriding a deceased patient's documented wishes to donate, combined with the positive reasons to honor an individual's documented wish to donate (including the individual's autonomy rights and the compelling need for more organs for transplantation), we conclude that honoring the documented wishes of a deceased patient to donate, even when the family does not consent, is not only morally permissible, but morally required. We believe, therefore, that the CORE policy of honoring a patient's documented wish to donate, independent of family consent, should become the standard of practice for organ-procurement organizations throughout the country.

Perhaps the most important aspect of our recommended change in procurement practice, however, is its broader approach to increasing

organ donation. At a time when various controversial proposals are being drawn up to address the shortage of organs for transplantation, a simple mechanism is already available for increasing the number of organs obtained. This mechanism requires only that our procurement practices become consistent with current law and, critically, public opinion. Although this practice will not solve the organ shortage, until it is universally accepted even noncontroversial campaigns, such as state efforts to encourage individuals to fill out donor cards or indicate a desire to donate on their driver's licenses, will continue to be undermined.

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