Options for Increasing Organ Donation: The Potential Role of Financial Incentives, Standardized Hospital Procedures, and Public Education to Promote Family Discussion

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RIGHT NOW, MORE THAN 37,000 AMERICANS ARE waiting for an organ transplant to restore their good health (United Network for Organ Sharing 1994). Sadly, with their hopes for a medical miracle left unfulfilled, nine of these people will die today, and another nine every day this year. A shortage of organs exists despite the fact that there are more than enough potential organ donors to meet current needs. State and federal laws that require hospital personnel to make requests for organ and tissue donations have not closed the gap (Caplan et al. 1991).

Ultimately, the scarcity of organs leads to public skepticism about the integrity and fairness of the nation's organ distribution system. Most recently, the public's concerns were underscored by allegations of preferential treatment for Governor Robert P. Casey of Pennsylvania, who received a heart–liver transplant at Pittsburgh's Presbyterian University Hospital (Colburn 1993). The fear is that these concerns will decrease the public's willingness to donate (Caplan 1992).

The continuing shortage of organs for transplant, coupled with a growing pessimism among medical professionals about the failure of education efforts to "sell" the public on organ donation, is inspiring in-

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creasingly radical and controversial proposals to meet the need for suitable organs. These include the genetic engineering of animals to produce human-compatible organs for xenotransplantation (Bishop 1993); encouraging condemned prisoners to donate their organs following execution (Kevorkian 1991); expanding the "definition" of death to include anencephalic newborns or patients in an irreversible vegetative state (Youngner 1990; Caplan 1992); and using so-called "no-heartbeat donors," which involves disconnecting terminally ill or severely brain-damaged patients from life-support systems so that organs can be removed after the heart stops beating (Youngner and Arnold 1993).

Less exotic, but perhaps no less radical, is the growing call to establish financial incentives for organ donation (Barnett, Blair, and Kaserman 1992). The buying or selling of organs is expressly prohibited by the National Organ Transplant Act of 1984, on the premise that "the human body and its parts cannot be the subject of commercial transactions" (World Health Organization 1991). This fundamental premise is now being called into question by those who promote a "market solution" to the organ shortage.

We have strong reservations about this proposal, for three reasons: First, the buying and selling of human organs raises profound moral difficulties. Beyond that, the offer of financial incentives may undermine the altruistic impulses that now drive most donation decisions.

Second, the findings of a recent national opinion survey suggest that such incentives would have very little influence on donation rates. The vast majority of survey respondents say that incentives would have *no impact* on their decision. A few respondents say that incentives would make donation more likely, but others say it would make donation less likely.

Third, we believe this proposal may distract the transplant community from effective and far less controversial measures for ending the organ shortage, including the standardization of hospital procedures to ensure a more humane and effective request process, as well as refocused public education efforts that encourage family discussion about organ donation.

Boosting Donations through Financial Incentives

A variety of financial incentives have been proposed to motivate families to agree more often to organ donation. Altruism, the proponents of

these proposals argue, was given a chance to work but has failed to meet the growing demand for organs.

Peters (1991), for example, has proposed that families be offered a $1,000 "death benefit" in return for their permission to use a loved one's organs. Similar ideas have included payment of the donor's burial costs, discounts on estate taxes, and extra insurance payments if a donation is made (Kittur et al. 1991; Khanna 1992).

Labeling these proposals as "morally dubious" and "destructive," Pellegrino (1991) notes that, because the family does not have proprietary rights over a relative's corpse, the decision to donate should reflect the deceased person's wishes and values, not the family's. In his view, the offer of incentives would serve to elevate the family's interests above those of the deceased. He even expresses concern that the incentives would come to be seen as an "entitlement," which could tempt families (or even physicians) to withdraw or withhold treatment sooner than they otherwise would.

Keyserlingk (1990) rejects incentives on the grounds that the human dignity of potential donors must take precedence over the need for more "efficient" organ procurement. In a similar vein, Dossetor and Manickavel (1991) assert that making the human body an "object of trade" would help erode respect for persons. An additional worry is that the commercialization of organ removal would open the door to a thriving black market and other abuses (Kittur et al. 1991; Pellegrino 1991).

There is still another concern. Could the offer of incentives serve to undermine the altruistic impulses that drive most donations, thus exacerbating the shortage (Belk 1990; Dossetor and Manickavel 1991; Prottas 1992)? Caplan underscores the fragility of public support for organ donation and transplantation:

> The values of altruism and autonomy—the foundations of organ procurement—rest on the presumption that organs which are given freely, voluntarily, and altruistically will be distributed in a fair and impartial manner to those in need. Any policies, practices, or activities that suggest otherwise imperil the entire enterprise of organ donation and, thus, transplantation. (1992, 160)

O'Neill (1993) acknowledges that donor families do have an "expectation of reciprocity," but this is typically expressed by requests for information about the recipients and the outcome of the donation rather than for any kind of monetary payment.

Taking a contrary point of view, Peters (1991) argues that the transplant community's insistence that organ donation be altruistically motivated imposes a value system on people who may think about donation in completely different terms. Moreover, he implies, there is hypocrisy in not giving donors something of tangible value when the medical establishment uses those organs to generate income. Barnett, Blair, and Kaserman (1992, 373) concur, stating that "defenders of the current system are effectively sacrificing patients' lives in order to indulge their own penchant for altruistic behavior (by others)."

Because of their overriding concern about the immorality of offering any form of compensation for body parts, most health care professionals remain in favor of the current altruism-based system (Guttmann and Guttmann 1992). A recent survey found that majorities from several professional groups are opposed to the offer of financial incentives to encourage families to donate: hospital chaplains (79 percent), critical care nurses (79 percent), neurosurgeons (78 percent), organ procurement coordinators (53 percent), and hospital social workers (70 percent) (Altshuler and Evanisko 1992).

Will Financial Incentives Work?

Putting this controversy aside, we also need to consider the practical question of whether such incentives would increase donation rates. In general, evidence on this point is lacking. Until recently, opinion surveys focused on what the public thinks about financial incentives without addressing the more important question of whether such incentives would actually change donation rates.

A survey on this issue was reported in 1991 by the United Network for Organ Sharing (UNOS). Fully 52 percent of U.S. adults said that some form of financial or nonfinancial compensation should be offered in an effort to increase the number of organs for donation (Kittur et al. 1991). A UNOS poll conducted two years later in collaboration with the National Kidney Foundation (NKF) found that 48 percent of respondents supported compensation (United Network for Organ Sharing 1993).

According to the NKF/UNOS poll, 59 percent of U.S. adults were "somewhat" or "very interested" in gaining "preferred donor status" through donation. By this proposal, those agreeing to donate organs would receive higher priority should they or members of their family require a transplant in the future.

Respondents were "somewhat" or "very interested" in other proposals as follows:

1. a $2,000 payment toward funeral expenses (54 percent)
2. a $2,000 payment to the donor family's favorite charity (52 percent)
3. a limited life insurance policy (46 percent)
4. a $2,000 payment to the family (35 percent).

Based on these findings, NKF and UNOS have argued that the use of financial incentives deserves another look (NKF/UNOS Poll 1993). In contrast, other surveys have found public hostility toward the offer of incentives. For example, Prottas (1992) reported that 78 percent of U.S. adults who responded to his survey rejected the idea that families of donors ought to be paid for granting permission.

The real issue, however, is whether the offer of such incentives would actually change behavior and increase donation rates. Under the sponsorship of the Partnership for Organ Donation, the Harvard School of Public Health, and 17 organ procurement organizations (OPOs), the Gallup Organization conducted a national survey in late 1992 of 6,127 U.S. adults to explore this issue, among others. (A description of the survey methodology is available upon request. The 95 percent confidence interval associated with a total sample this large is ± 1.3 percent.)

The survey included two questions about the likely impact of financial incentives on behavioral intentions. These questions were introduced by the following statement:

> Some people believe that families who donate organs should receive some sort of financial incentive such as assistance in paying funeral expenses, a cash award to the donor's estate, or a cash award to a charity of the family's choice.

The first question asked whether such financial incentives would make the respondents more or less likely to donate their own organs, or if it would have no effect. The next question asked about the impact of financial incentives on donation of a family member's organs.

Fully 78 percent of the respondents said that financial incentives would have no effect on their likelihood of donating a family member's organs. While 12 percent said that incentives would make them more

likely to donate, 5 percent said that incentives would make them less likely. Similar results were found concerning the donation of the respondents' own organs.

If the offer of financial incentives is intended to make those who oppose organ donation more likely to donate, this policy is likely to yield disappointing results. Among respondents who said they were unlikely to donate their organs, only 6 percent said incentives would make them more likely to donate, whereas 9 percent said incentives would make them even less likely. In regard to donating a family member's organs, 10 percent of this group said incentives would make donation more likely, whereas 8 percent said that incentives would make it less likely.

Multivariate regression analyses established three independent predictors of greater responsiveness to financial incentives when considering donation of a family member's organs: young age, minority race/ethnicity, and low household income. These results are displayed in table 1. The fact that economically distressed people might be more likely to respond to financial incentives when considering organ donation compounds the moral complexities raised by this proposal. In some cases, the offer of incentives can be viewed as unfairly coercive.

Testing the Use of Financial Incentives

Ultimately, there is no way to resolve whether the use of financial incentives will help end the shortage of organs without subjecting the idea to a "market test." Will incentives increase the number of donors, or will they serve instead to undermine the public's altruistic motives and thereby make the shortage worse? Will the public tolerate the offer of incentives, or will they see it instead as morally repugnant? Will health care providers embrace this method, or will their discomfort with it lead to even lower donation rates (Altshuler and Evanisko 1992). These and other questions can only be answered with small, carefully evaluated pilot programs.

Such an opportunity is presented by the passage of Pennsylvania's new organ donor law in late 1994 (Eshleman 1994). Residents can now donate one dollar to a "Donor Awareness Trust Fund" when they obtain a driver's license or complete their state income tax form. By statute, up to 10 percent of the fund can be used to reimburse families of donors for hospital, medical, and funeral costs they incur, up to $3,000. Payments are made directly to service providers.

TABLE 1
Effect of Financial Incentives on the Likelihood of Donating a Family Member's Organs by Age, Race/Ethnicity, and Household Income

Effect	Variable				
	Age				
	18–24	25–34	35–44	45–54	55+
More likely	27%	16%	10%	10%	6%
Less likely	9	5	4	3	5
No effect	61	74	84	83	81
	Race/ethnicity				
	White		Black		Hispanic
More likely	11%		21%		17%
Less likely	5		8		8
No effect	80		62		66
	Household income				
	<$25K		$25K–<$45K		$45K+
More likely	15%		12%		9%
Less likely	5		5		3
No effect	73		81		86

Source: Gallup Survey 1992.

Evaluating the impact of pilot programs involving financial incentives will take time. Meanwhile, promising alternative strategies for increasing organ donation have emerged that should be acted on immediately.

Alternative Strategies for Increasing Organ Donation

The driving force behind the proposal to offer financial incentives for organ donation is frustration over the continuing shortage of organs. Fortunately, far less radical steps can be taken to increase the supply of organs. Perhaps the most important of these is a change in hospital pro-

cedures for approaching potential donor families. Another important step is public education to promote family discussion about organ donation, so that families facing a decision about whether to donate will know for sure what their loved one's wishes are. Both of these strategies are described more fully below.

Developing Standardized Hospital Procedures

Evidence continues to mount that U.S. hospitals can do much more to increase the number of organ donors. One recent study of medically suitable organ donors at 69 hospitals in four geographic regions of the United States found that donation occurred among only 33 percent of potential donors (Gortmaker et al. 1993a). Interestingly, there was no evidence from this study that donation rates varied by hospital unit characteristics or that transplant hospitals were different from other hospitals.

A review of the medical records indicated three key reasons for nondonation:

1. Potential donors were not identified or declared as brain dead in 10 percent of the reviewed cases.
2. Families were not asked about donation in 17 percent of the cases.
3. Families denied consent 36 percent of the time.

Two implications of this study are immediately evident. First, hospitals must have standardized procedures for identifying all potential donors and consistently declaring brain death. Second, these procedures must ensure that all families of potential donors are asked about donation. Hospitals can monitor their donation performance through regular reviews of medical records.

How families are approached with the donation request also needs standardization. There are three ways to improve this process (Partnership for Organ Donation 1991): First, the family should be approached in a private setting; requests made at the bedside, at a nursing station, or in a hallway with other people present are inappropriate.

Second, families should never be informed about their relative's brain death and then presented with the option to donate as part of the same conversation (Garrison et al. 1991). The point of having a "decoupled request" is to ensure that the family understands and accepts the fact of

brain death and is capable of making an informed decision about donation well before they are asked (Lee and Kissner 1986).

Third, a hospital-based health professional should be the first person to approach the family about donation, whereas the formal request of the family to make a decision is best handled by a coordinator from the regional organ procurement organization (OPO). If the physician who cared for the patient also made the donation request, this could create the appearance of a conflict of interest. Having someone else make the request also reinforces the fact that death has occurred and that new concerns need to be addressed.

A recent study conducted in four OPO regions confirms the wisdom of these simple procedural steps (Gortmaker et al. 1993b). When donation requests were decoupled—that is, families were first informed about their relative's death and then offered the option to donate as part of a separate conversation—61 percent of families agreed to donate, compared with 44 percent when the request came immediately and was not decoupled. Consent was also more likely when donation was first mentioned by a health professional and the request for organ donation was then made by an OPO coordinator.

In sum, it is clear that not enough U.S. hospitals have instituted protocols to ensure an orderly process for working with potential donor families. It is just as clear that, if hospitals were to implement and enforce basic standards of care, this would contribute significantly to increasing the supply of organs for transplantation.

The question naturally arises as to why hospitals should devote time and resources to developing and implementing an organ donation protocol, given the relatively small number of potential donors each year. Clearly, hospitals that perform transplants have an obvious economic incentive to encourage on-site donations. Even at nontransplant hospitals, however, there are good reasons to adopt a standardized protocol.

First, improving the donation request process means providing more humane care to families. The "Bill of Rights for Donor Families" that was recently adopted by the National Kidney Foundation specifies a number of rights to which donor families are entitled (Corr and Nile 1994). These include the right to a full and careful explanation about the death of their loved one, the right to receive information in a manner that is suited to the family's needs and capabilities, and the right to make an informed, private, and uncoerced decision about donation.

Second, meeting the needs of the family is an essential component of

good medical practice. Standards issued by the Joint Commission on Accreditation of Health-Care Organizations (1992) reinforce this point, stating that the "mechanism" used to notify families of the option to donate should allow for "the use of discretion and sensitivity, as appropriate, to the circumstances, beliefs, and desires of the families of potential donors." The JCAHO is increasingly citing hospitals for lack of documentation about organ donation practices.

Third, there are sound economic reasons for implementing a standardized protocol. Maintaining good will between the family and the medical staff is essential to preserving the hospital's reputation in a competitive marketplace and reducing the risk of malpractice suits. Moreover, major transplant centers are not the only health care facilities that use organs and tissues. Nearly any hospital with an operating room has a need for donated human tissue.

More work is required to develop and evaluate a model protocol for the request process—that is, one that is both workable and cost effective—and to develop and evaluate staff training and monitoring procedures. Eventually, this effort should succeed. After all, the changes in practice being called for are not technical in nature, but center around the need for improved staff–patient communication. Moreover, surveys show that health care professionals support organ donation (Prottas and Batten 1986). What they need now is an established standard of practice to help families make an informed decision that best serves their needs.

Refocusing Public Education to Promote Family Discussion

Public education has a limited but vital role to play in increasing organ donation. As we have seen, what happens at the hospital is key. Potential donors have to be identified, and the families have to be approached in the right way. All public education can do is "help the process be successful once the process has begun" (Davis 1991, 92). The goal should be to dispose families favorably toward donation so that they will grant consent.

Public education to promote organ donation has focused traditionally on two messages: first, that organ donation is a good thing to do, and, second, that signing a donor card is what makes it possible to be a donor (Davis 1991). This effort has paid off in strong public support for organ

donation. The 1992 Gallup survey found that 69 percent of Americans said they would be likely to want their organs donated upon death.

But this support is not always translated into action. The same survey also revealed that only 28 percent had granted permission for organ donation on their driver's license or a signed donor card. This is so, even though 79 percent said they believe that a donor card must be signed before a person can become a donor. Meanwhile, the shortage of organs for transplantation continues to grow.

We first must acknowledge that getting more people to sign donor cards, by itself, will do little to close the donation gap. The reason is simple: Although donor cards have legal standing as a statement of the potential donor's wishes, in medical practice they have no standing whatsoever, owing to concerns about legal liability or bad publicity (Lee and Kissner 1986; Thukral and Cummins 1990). What doctors rely on instead are the wishes expressed by a patient's next of kin, whether that potential donor has a signed card or not.

Most Americans do not know this, and they therefore fail to understand the importance of telling their family what they would want done. Results of the Gallup survey underscore the importance of family discussion about organ donation. Among the 69 percent of respondents who said they are likely to donate, almost half (48 percent) had never communicated that wish to a member of their family. Among all respondents, only 29 percent said that a member of their family told them about their wish to donate or not to donate their organs after death.

This failure to communicate represents a significant barrier to donation. An overwhelming majority of people (93 percent) said they would be "somewhat" or "very likely" to donate a deceased family member's organs if he or she had expressed this wish prior to death. But in the absence of discussion, without knowing what the person's wishes would be, less than half (47 percent) would be likely to have a donation made. An earlier survey found similar results (Prottas and Batten 1991). The effect of knowing a family member's wishes on these statements of intention were consistently found across all key demographic variables (gender, age, race/ethnicity, education, and household income).

According to the Gallup survey, there was no particular reason for the absence of family discussion, other than it had never occurred to people to talk about it. Of those likely donors who had not yet discussed their wishes with their family, 89 percent would be willing to do so.

A key, then, is to find ways to encourage family discussion about organ donation. All that is needed to make a difference is for families to have a single, memorable conversation. Families can benefit from the peace of mind that comes from knowing that plans are in place to help the family deal with what could be a profoundly difficult decision. And should that decision ever be faced, such a conversation would enkindle a determination to honor the loved one's wishes.

The donor card does have a role to play here, so long as the card is promoted as a *stimulus for family discussion*, not as an end unto itself (Davis 1991). The point is not to get people to sign donor cards but to tell their families what they want done. To facilitate this role, the standard donor card should be redesigned to include instructions to discuss one's intentions to donate with family members. Further, the card should call for at least one of the witnesses who sign it to be a family member.

Use of even the standard donor card might help stimulate family discussion. The Gallup survey showed that 82 percent of those who had granted permission for organ donation on their driver's license or a signed donor card had communicated their wishes to their families, compared with just 33 percent of those without such documentation. It must be recalled, however, that only 28 percent of the survey respondents had a signed donor card.

This redesigned donor card should also be promoted at times and places where people come together as a family. Unfortunately, in driver's license bureaus, one of the places where donor cards are most heavily promoted, people usually come alone, and they sometimes forget to talk later about their decision to sign a card.

Another opportunity to promote family discussion about organ donation is when people are preparing a living will or establishing health care powers of attorney, both of which require thinking in advance about the type of care they might want in a medical emergency. Considering the possibility of organ donation in this context makes sense, although current guidebooks to living wills and powers of attorney do not explicitly point this out (e.g., see Sabatino 1990).

Families may also need guidance on how to conduct a helpful discussion on organ donation. Key issues include how and when to bring up the subject; typical concerns about organ donation that might come up and how they can be answered; and the importance of respecting each family member's individual decision about organ donation.

Public education efforts are moving in this direction. For example, the Advertising Council, working with the Coalition on Donation, has carried out plans for a campaign to promote organ and tissue donation (Advertising Council 1993). A key message of this campaign has been that, once people are committed to becoming an organ donor, they should tell their families about their intentions.

There are limits to what a focus on family discussion can accomplish, if only because organ donation is not universally favored by the U.S. public. Moreover, many people who are favorably inclined toward donation remain somewhat ambivalent because of certain attitudes, beliefs, or fears they have (Shanteau and Harris 1990).

This is especially true in minority communities. The Gallup survey revealed that, compared to whites, African Americans and Hispanics were more likely to express concerns about the act of organ or tissue transplantation, plus a greater skepticism about the intentions of the medical establishment. These concerns cannot be glibly dismissed, but require serious attention through public education and a careful examination of the organ donation request process.

Conclusion

The shortage of organs and tissue suitable for donation is a profound crisis in U.S. health care, but it is also a crisis with a cure. This is not a matter of waiting for a new medical discovery, but of converting positive public attitudes, which already exist, into action.

Currently, there is little evidence that financial incentives would make an important difference in donation rates. Although some respondents on the Gallup survey said that incentives would increase the likelihood of their donation, others said incentives would make donation less likely.

Pilot programs to test the use of financial incentives are warranted, but such experiments must be approached cautiously, given the moral qualms this proposal might raise and the availability of other options for increasing organ donation. If put into place, such incentives would probably create controversy and intensive news media scrutiny, which could serve to undermine the altruistic basis on which most donations are currently made.

The idea that financial incentives or any other type of policy "quick fix" can bring the organ shortage to an end is alluring, but in the end the organ transplantation community is left with a lot of hard work to do. Most important is to standardize the procedures that are used by hospitals to identify potential organ donors, to declare brain death, and to approach families with a donation request. Institutional change is difficult, but recent evaluations show that the payoff in increased donation rates is well worth the effort.

As hospitals improve their procedures, public education can help prepare families to deal with the crisis of making a decision about donation. This year alone, up to 15,000 families may well be confronted with that decision. Unfortunately, only a small minority will have previously talked to their loved ones to learn their wishes about donation. Without knowing those wishes, many of these families will be likely to hold back. On the other hand, if they have discussed organ donation and know that their loved one wanted to be a donor, virtually all families, no matter what their personal views might be, will be willing to honor that request.

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