Public Policy, Public Opinion, and Consent for Organ Donation

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Introduction

Medical advances in transplantation techniques have driven an exponential increase in the demand for transplantable organs.[1,2] Unfortunately, policy efforts to bolster the organ supply have been less than effective, failing to provide a stopgap for ever-increasing numbers of patients who await organ transplantation. The number of registrations on waiting lists exceeded 65,245 in early 1999, a 325% increase over the 20,000 that existed 11 years earlier in 1988. Regrettably, more than 4,000 patients die each year while awaiting transplantation.[3]

To address this problem, a number of legislative and policy solutions have either been proposed or implemented. These have had varying success in increasing organ supply. Current policies establish the families of deceased patients as surrogate decisionmakers with regard to the donation of the patients' organs. Other proposed policies, such as Mandated Choice and Presumed Consent, require that people prospectively make a decision regarding organ donation in an effort to eliminate surrogate decisionmakers at the time of death. Inherent in all these laws and policies is a system of consent that operates on voluntarism and altruism. By contrast, proposals that would use financial incentives to stimulate donation would seem to be a rebuke of this system. Examples of these proposals include financial assistance for funeral expenses paid to families who donate and reduced rates for health insurance for people who consent to donate a priori.

With few exceptions, most policies have failed to consider the role of preexisting attitudes of the public regarding donation and transplantation and how the donor request process affects decision outcomes. Consideration of how the attitudes of families, patients, and healthcare providers shape the manner in which the subject of organ donation is raised and ultimately decided may better inform future policy efforts.

To help in understanding how families respond to requests for donation we conducted a study of organ procurement.[4] Data were collected from more than 600 family members who had been asked to donate organs from approximately 400 patients in nine acute-care hospitals in two states. In addition to examining the organ donation process, we examined the attitudes and beliefs of families and their healthcare providers with respect to various policies and incentives to increase the number of organ donors. The interviews have provided us with

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insight into how the respective attitudes of healthcare providers and patient families may influence families' ultimate decisions with respect to organ donation. This paper considers a variety of different policies, both extant and proposed, and examines data that can inform us about public opinion of each.

Required Request

Required Request laws were designed to bolster the supply of transplantable organs. These laws require that hospitals develop and implement policies to ensure that healthcare providers (HCPs) approach all families of donor-eligible patients about organ donation once brain death is determined. Since 1984, 50 states, the District of Columbia, and the federal government have adopted such legislation, as has the Joint Commission on the Accreditation of Health Care Organizations (JCAHO), which requires such protocols in hospitals.[5,6] Required Request operates under the assumption that surrogate consent for organ donation is low because few eligible are asked. Therefore, consent would increase if HCPs would simply approach more families of donor-eligible patients and ask them to donate. This assumption ignores two very important elements: the manner in which the HCPs approach families, and whether families actually know the wishes of family members concerning donation.

Between 1991 and 1994 we conducted a study of Required Request policies in 23 hospitals. This study found that HCP compliance with such policies was already high but that healthcare providers were not entirely accurate in their conception of their responsibilities under the law.[7] Our present study has corroborated these findings, with 85% of HCPs asking donor-eligible families to donate organs.[8] However, only 56.0% of healthcare providers were aware of the existence of state laws with respect to requesting organ donation, 36.4% were unsure, and 7.7% of physicians categorically denied that such laws existed. Furthermore, their attitudes toward such laws were not entirely favorable: 46.8% of physicians favored the law in its entirety such that an organ donation request must be made without exception, 33.6% would agree to a law that allowed for exceptions, and 12.1% would oppose all laws that required them to approach families about organ donation. Under Required Request, it has been demonstrated that consent to organ donation is obtained in no more than half of cases.[9]

Routine Notification

In addition to Required Request, hospitals are now required to abide by the mandate of Routine Notification (sometimes called Required Referral). These policies obligate that a hospital representative report all deaths to a local organ procurement organization (OPO) so as to determine patient eligibility for organ donation. Hospitals are now in the process of implementing this regulation. The purpose of routine notification is to try to increase OPO involvement in the request process, compliance with required request, and improvement of the request process. Implementation most commonly entails one of two strategies: HCPs report all deaths to the OPO and then approach families of donor-eligible patients to request donation or the request for donation is performed by the OPO representative directly, thus eliminating the HCP from the request process entirely. Pennsylvania legislated this policy in 1994, and the Health Care

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Finance Administration (HCFA) has established a Routine Notification requirement for all federally subsidized healthcare facilities.[10] Compliance with this regulation was required by August 1, 1999. Theoretically, Routine Notification will increase the identification of donor-eligible patients, trigger more requests for organs, and thus increase consent for organ donation. So far, this policy has provided only marginal benefit over Required Request alone. In our previous study, conducted in Pennsylvania prior to 1994, we reported that 86.5% of families of donor-eligible patients were approached. The current study, which collected data from 1994 to 1998, has documented a request rate of 87.1% in Pennsylvania, a change of +0.6%. Additionally, we observed a donation rate of 40.9% prior to 1994 and a rate of 43.3% after implementation of Routine Notification.

An underlying assumption in Routine Referral policies is that OPO representatives are likely to be more effective in obtaining consent for organ donation from patients' families if they assume responsibility for the initial request. This is not surprising, based on our present study that found that patients' families exhibited a pronounced preference as to who should first approach them regarding organ donation: 44.8% of respondents believed this initial request should be made by the physician, whereas 9.3% believed that the OPO representative should initially approach families about donation. Table 1 delineates the approach preferences of families and the reasons for those preferences.[11] The most common reasons are that the person who knows the patient's condition best or who has spent the most time with the family should approach first, followed by the person who has the most experience discussing organ donation.

Table 1. Families' Preference: First to Approach about Organ Donation

Who should be the first person to ask about donation?	Percentage of total
Physician	44.8
Clergy/social worker/counselor	11.6
More than one clinician mentioned	11.0
OPO representative	9.3
Nurse	7.6
Someone who is trained or experienced	3.5
Clinician who has the best rapport with the family	2.9
Any clinician involved in caring for the patient	1.2
Someone with no ulterior motive/conflict of interest	0.6
Reasons given for which clinician should be first to ask about donation	**Percentage of total**
Knows the most about the patient's condition	18.0
Has the most experience with talking with families about organ donation	16.9
Spent the most time with the family/best relationship	16.3
Whoever is easiest for family to talk to	7.6
No conflict of interest	5.8
Physician in charge of the patient's case should ask first	4.7
Better to have hospital staff than OPO first ask	3.5
Has the most contact with the patient	2.9

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Mandated Choice

Mandated Choice would require all individuals to predesignate and document their wishes with respect to organ donation, thus eliminating the need for surrogate family decisionmakers at the time of death. Individuals could be required to make a decision when they apply for a driver's license or a state identification card or upon admission to hospital. Decisions would be documented on an individual's driver's license or state ID card or in a statewide computer database. Despite an endorsement by the American Medical Association, experiments with Mandated Choice in the state of Texas have been counterproductive, with at least 80% of individuals refusing to designate themselves as organ donors with a concomitant reduction in organ procurement (personal communication, Teresa Shafer, LifeGift, Fort Worth, Texas, August 18, 1995). The Texas legislature has now repealed this law.

Whereas this system may maximize individual autonomy, it significantly discounts a prevailing apprehension among the American public with respect to limiting the decisionmaking authority of their families, especially in situations where they might be incapable of making such decisions for themselves. Our present study found that only 43.2% of families agreed with the concept of Mandated Choice (see Table 2), which indicates that most Americans want family consent to remain an important element of organ procurement and donation.

Inherent in the policy of Mandated Choice is a presumption that the public trusts healthcare providers to treat all patients equally, regardless of their predesignated donation decision. This discounts the fears of some individuals that doctors will not institute every life-saving intervention for persons who are predesignated donors. In fact, 24.6% of families interviewed in our present study expressed a concern that if doctors know that they are willing to donate organs, they won't do as much to save their lives (see Table 2).

Table 2. Families' Attitudes toward Mandated Choice, Presumed Consent, and Financial Incentives

Attitude	Agree (Percentage of total)
Mandated Choice:	
If someone had a donor card, then hospitals shouldn't have to ask the family's permission to procure organs	43.2
Presumed Consent:	
We should have a law that says that everyone will be an organ donor unless they specifically say no	22.5
Financial Incentives:	
Families who agree to donate should be given money to pay for funeral expenses	31.6
The government should provide money to families who agree to donate organs	22.2
People who have signed a donor card should receive an organ transplant before others do	25.4

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Mandated Choice policies also assume that OPOs and hospitals are willing to discount families' preferences regarding organ donation. Owing to the litigious nature of our society as a whole, and the medical profession specifically, it is unclear how willing OPOs and hospitals would be to overrule families' decisions with regard to organ donation even if they should conflict with patients' wishes.

Presumed Consent

A different approach to enhancing the supply of transplantable organs would be to assume that all individuals are willing to become organ donors unless they specifically document their refusal to donate. Presumed Consent policies require that individuals take proactive, explicit, and legally sanctioned measures to register their refusal. These policies are in place in 15 European countries, including Austria, Belgium, and France. Although these policies would appear to dramatically increase the donor pool in the many European countries that have adopted a policy of Presumed Consent, there have been few appreciable gains in the availability of transplantable organs.[12,13] In addition, many believe that enacting presumed consent policies in the United States is premature for a variety of reasons. The attitudes of the general public are not clear and therefore, there is little evidence that the concept of presumed consent would be embraced in the United States. The one serious attempt in the Pennsylvania legislature to pass a presumed consent measure failed.[14] Also, because there is a perception among healthcare providers that this would not be acceptable to the general public, hospitals and physicians might be unwilling to remove organs without family consent, which has been the case in France.

A variety of objections have been raised regarding Presumed Consent policies. Presumed Consent assumes that the general public is well informed on the issue of organ donation and furthermore assumes that individuals will be proactive in documenting their refusal. Of greater concern is the possibility that presumed consent may increase a sense of distrust in the medical profession and, ultimately, persuade people who were initially in favor of donation to document their refusal. It is also of concern that the economically disadvantaged and ethnic minorities—precisely the people most likely to object to organ donation—will not be able to adequately avail themselves of an "opt-out" system. Families in the present study were generally against Presumed Consent, with only 22.5% agreeing that such a system should be implemented (see Table 2).

Financial Incentives

The aforementioned policies were designed to increase the supply of transplantable organs while continuing to operate under the principles of voluntarism and altruism. Some proposals under consideration would diverge fundamentally from these principles by offering a financial incentive for those who consent to organ donation. Many variations on this scheme have been suggested or implemented, including offering funeral benefits or cash payments and utilizing futures markets. Although these proposals are designed to meet the ever-growing demand for transplantable organs, they raise critical

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legal and ethical issues. Offering financial incentives for organ donation challenges the limits of the 1984 National Organ Transplant Act, which forbids " . . . any person knowingly to acquire, receive, or otherwise transfer any human organ for valuable consideration for use in a human transplantation if the transfer affects interstate commerce."[15]

The state of Pennsylvania is now in the process of conducting a pilot of a "voluntary incentive" in the form of a funeral benefit to the families of organ donors. This incentive continues to rely on the surrogate decisionmaking authority of donor-eligible patients' families. Although this incentive may be appealing to some families, others may not appreciate the offer. When asked how they would have felt about being offered a funeral expense incentive, 23.8% of families surveyed in our present study found this proposal offensive or insulting whereas 25% did not. However, 20.3% stated they would have appreciated the offer. Additionally, 17.4% felt that organ donation should not involve the selling of organs or be a business transaction, perhaps reflecting the adherence to a more altruistic model of organ donation. Of note, among families who refused to donate, 92.5% stated that they would *not* have been persuaded to donate were such an offer to have been made to them. Table 3 examines family attitudes with respect to funeral expense incentives.

Another financial incentive for organ donation would be to dispense a lump sum payment to the named personal or charitable beneficiaries of organ donors from whom organs are actually procured. This proposal removes the burden of decisionmaking from families whereby people prospectively make a decision to donate their organs. However, as with Mandated Choice and Presumed Consent, lump sum payment systems rely on proactive, legal documentation of organ donation decisions. This raises numerous logistical issues regarding appropriate documentation of donation decisions and access to this documentation. Additionally, lump sum payments raise ethical issues regarding coercion. A specified amount may be an incentive to one individual and coercive to another. Under the lump sum system, socioeconomically disadvantaged persons may be coerced into decisions to be organ donors, where otherwise they would refuse. However, because the proposed payment is disbursed after death, coercion may be eliminated. Despite the theoretical appeal of lump sum payments to increase donation, few families (22.2%) in the present study believed this system should exist, which suggests that perhaps the general public would not be receptive to a lump sum payment system (see Table 3).

Table 3. Families' Attitudes about Funeral Expense Incentive

If someone offered to pay for some of the funeral expenses if you donated, how would you have reacted? ($N = 172$)	Percentage of total
Would have been offended/insulted	23.8
Would not have been offended/insulted	25.0
Would have appreciated the offer	20.3
Organ donation should not involve the selling of organs or be a business transaction	17.4
Other people may appreciate the offer	16.9
Financial help for funeral expenses should not be offered	8.7

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A more complex payment system could utilize futures markets, whereby organ donors are provided with some presumably extendable benefit in return for future rights to their organs. Such benefits can be monetary, such as reductions in life and health insurance premiums. More viable is a system of reciprocity, which would establish a preference to individuals awaiting transplant who have stated and maintained a prior willingness to donate their own organs. Futures-market systems may be a greater incentive for donation than lump sum payments, as the patient willing to become an organ donor may enjoy benefits directly. However, futures-market systems would require the development and maintenance of a bureaucracy capable of accurately managing such a system. These proposals also challenge individuals to reevaluate and change their attitudes about preferential treatment, a notably contentious issue for the general public. In our present study, only 25.4% of families surveyed agreed that individuals with a signed donor card should receive preferential treatment were they awaiting transplant.

Regardless of the incentive involved, many bioethicists have expressed grave concerns regarding the use of financial incentives of any kind. Not least among these reservations is a fear that payment for organs may foster coercion of the socioeconomically disadvantaged. More fundamentally, some have decried such policies for their erosion of principles of voluntariness and altruism.[16] An additional ethical concern is that the system commodifies (by definition) body parts. Finally, it may lead to a black market for organs. The findings of our present study indicate that families who have been surrogate decisionmakers regarding organ donation are generally against policies that remove surrogate family decisionmakers and include financial incentives.

Families' Attitudes toward Organ Donation and Transplantation

Strong public support for organ donation seems at odds with current real consent rates. However, the evaluation of attitudes through the use of public opinion polls is superficial considering the emotionally charged situations in which consent decisions occur. If more detailed data were considered, less extreme solutions might be under discussion. Information from families who have been surrogate decisionmakers provides us with valuable data to guide proposed policies designed to increase donations. All families enrolled in our study were asked to indicate whether or not they agreed with various attitude statements. For some of these statements, significant to highly significant differences were observed in the relative rate of agreement among families who donated versus those who refused donation.

Among donor families, 70.2% believed that organ donation helps families to grieve, as opposed to a rate of agreement of 42.0% among families refusing donation ($p < 0.001$). This difference indicates that the majority of families who donated their loved ones' organs received some benefit from the donation. The surrogates' decision to donate, albeit an altruistic gesture, resulted in some reciprocal benefit to the families. This insight may assist policymakers as they attempt to shift from donation incentives that rely on altruism to those that acknowledge a certain degree of reciprocity inherent in donation decisions. When asked if rich or famous people who need transplants were more likely than others to get them, 68.5% of donor families agreed, as compared to 77.1%

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of families refusing donation ($p < 0.05$). Thus, nondonor families have less trust in an equitable organ distribution system than donor families. Table 4 presents significant differences in attitudes between donor and nondonor families.

Overall agreement with several other attitude statements were of note. Of all families surveyed, 38.4% agreed that when families donate they should be able to ask that the organs go to a particular person. It appears that people are willing to trust that the current distribution system is equitable in distributing organs to those with the greatest need. Of interest, 50.2% said they would be willing to pay higher premiums to be sure everyone who needed a transplant received one.

We also found that agreement was significantly correlated with ethnicity for certain attitudes. Of White respondents, 20.2% agreed that the government should provide money to families that agree to donate. Non-White families were more favorable; 36.5% in agreement ($p < 0.01$). A similar difference in attitude was observed with respect to funeral expenses, with 48.1% of non-Whites agreeing that families of donors should be compensated, as opposed to 29.4% of Whites ($p < 0.01$). Most significantly, non-Whites were far more concerned that if doctors knew they were organ donors, they would do less to save their lives: 51.9% of non-Whites agreed as opposed to only 20.8% of Whites ($p < 0.001$). These differences demonstrate that there are some clear differences in the attitudes and beliefs between Whites and non-Whites with regards to incentives for donation and trust in the healthcare system. Different policies are likely to be received by various ethnic communities differently, and their impact on consent will not be homogenous. Such information should be considered by policymakers as they attempt to develop, market, and implement incentives for donation.

The success of any public policy designed to increase donation depends on how readily the general public accepts the premise behind that policy, as well as how the policy is implemented and marketed. Our data demonstrate that the general public's attitudes toward donation and transplantation powerfully impact surrogate decisionmaking regarding donation. Therefore, policymakers should be aware of the general public's attitudes regarding donation and transplantation, use this information to develop palatable and effective policies, and widely market these new policies.

Table 4. Significant Differences in Attitudes between Donor and Nondonor Families

	Agree (Percentage of total)	
Attitude	Donated	Refused
Organ donation helps families to grieve***	70.2	42.0
Organ donation makes something positive come out of death***	94.1	84.7
If my doctor told me I needed a transplant, I would want one**	84.5	75.2
Rich or famous people who need a transplant are more likely to get a transplant than others*	68.5	77.1
People who have organ transplants are able to lead full, productive lives**	81.1	69.4

*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$.

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Conclusions

As long as the indications for organ transplantation continue to expand, demand for transplantable organs can be expected to increase. Policymakers must move beyond the existing policies of Required Request and Routine Notification if the rate of consent to donation is to increase. Required Request is widely accepted, but many physicians wish to exercise discretion when approaching families about donation. Additionally, hospital healthcare providers' knowledge of policies and laws governing organ donation remains unacceptably low. Routine Notification will probably maximize the request rate but is unlikely to increase the consent *rate* for donation. This is because request rates are already high and requesters will now be asking for donation from individuals with an even lower propensity to donate. Also, we have not yet uncovered the optimal request process. Required Request and Routine Notification seem to best embody the aspects of altruism and familial involvement with which patients and families are most comfortable. If success is measured by number of organs procured, these policies are failures. If success is measured as opportunities to donate, they can be considered a success. However, these policies assume that the majority of families will consent to donate if donation is requested. Our findings dispute this assumption. Thus, these policies optimize requesting but not consent.

Families who donate the organs of loved ones seem to possess fundamentally different attitudes toward organ donation than those who refuse. Nevertheless, all families seem to favor systems driven by altruism more than ones driven by incentives. Furthermore, any system that allows usurpation of the family's role in the decisionmaking process was not favored. Again, we need to consider the particular ethos of autonomy coupled with a deep aversion to death. For this reason, Americans are reluctant to discuss death-related issues with their families (including wills and advance directives) and are distrustful of strangers deciding when they are dead. Many Americans are clearly most comfortable to know that family members will have a final say, even when they favor donation of their own organs at death. For this reason, Mandated Choice and Presumed Consent is not likely to win the favor of the American public, at least within the context of the existing healthcare system. Furthermore, Presumed Consent would need to be coupled with a more equitable system for accessing organ transplantation on the part of patients, especially extrarenal organs. A system that presumes an obligation from citizens (i.e., donating organs) should guarantee the corollary right to obtain an organ if needed (i.e., providing medical and financial access to transplantation and access to the expensive medications required to maintain that organ posttransplantation).

Our data suggest that the general public may not readily accept financial incentives to donation. It is notable that our data show that non–White Americans, most notably African Americans, are much more favorably disposed toward this idea. For this reason, and because of the critical shortage of African American donor organs, some form of financial incentives is worth exploring. Moving toward incentive systems will require a shift in the attitudes and beliefs about organ donation and transplantation. Further insight into how families avail or disabuse themselves of preconceived attitudes regarding organ donation promises to engage the most useful dialogue in further refining organ procurement efforts.

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