Organ Donors and Nondonors

An American Dilemma

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The principal motive for organ donation in the United States remains altruism. Surveys suggest that if the life-threatening and critical shortage of cadaveric donor organs were appropriately understood by the public, an altruistic response would lead to increased donation. However, despite intense educational efforts appealing to altruism, cadaveric organ donation has not increased substantially while the number of patients in need of a life-saving organ has grown markedly. To understand why organ donation has not increased, a telephone survey and focus group sessions of volunteers who were either for or against donation (donors and nondonors, respectively) were reviewed. The focus group nondonors demonstrated a remarkable lack of trust in the fairness of organ allocation and in the success of transplantation; indeed, this mistrust extended to the entire medical profession. The donors in the focus groups, on the other hand, believed that the system worked equitably, although their knowledge about organ donation and transplantation was equivalent to that of nondonors. For organ donation to increase, efforts must be directed toward those who are not convinced that donation is for the common welfare. One way to increase organ donation is for physicians to educate their patients better regarding the equity and success of transplantation. *Arch Intern Med. 1996;156:2419-2424*

Medicine in general and transplantation in particular rely heavily on the public trust that equity and fairness are sought in scarce resource allocation. Maintaining trust is crucial because in the United States the supply of cadaveric organs for transplantation depends entirely on altruistic donations. Currently, however, there is a serious organ shortage that remains intractable despite the best current efforts at public education and despite expanding the potential number of donors by broadening criteria for cadaveric organ donation.[1-4] Meanwhile, the number of potential recipients increases steadily, causing inordinately long waiting times during which a significant number of potential recipients die. Although a fair allocation system based on medical need, biological constraints, and principles of justice is in place, negative perceptions about organ recovery and equal access to transplantable organs is widespread, especially among minority populations.[4-8] Reversal of these attitudes is central to overcoming the resistance of some members of the population to positively view organ donation and transplantation.[9] While the United Network for Organ Sharing (UNOS), the National Kidney Foundation (NKF), and other organizations have worked diligently to correct this problem, the support of physicians and health care workers in the community appears crucial in the attempt to reverse negative attitudes that ultimately threaten patient lives.

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MAGNITUDE OF THE PROBLEM

As of January 17, 1996, more than 44 167 Americans awaited organ transplantation.[10] While the majority of them (71%) awaited cadaveric kidney transplants, 13 010 persons awaited lifesaving organs such as

livers, hearts, and lungs. The total number of transplantations performed in the calendar year 1994 included 10 622 kidney and 6710 liver, heart, and lung transplants. In 1994, 3097 patients died waiting for an organ transplant. This brings the number of patients who have died while awaiting organ transplantation to a total of 16 009 since January 1, 1988, shortly after UNOS began monitoring mortality statistics.

Organ donation has increased slightly over the last several years. Discounting live organ donation (kidney and occasional segmental liver or lung), the numbers of cadaveric donors year to year from 1991 through 1994 have been 4528, 4521, 4862, and 5100, respectively.[10] During this period, use of the "expanded donor" has accounted for much of this growth. While expanded or nontraditional donors include the donor older than 55 years, the term is also applied to donors who demonstrate unstable cardiovascular function, infection, and medical conditions such as hypertension and diabetes mellitus.[1,3,11,12] Therefore, the small increase in organ donors has occurred not because of more frequent permission to recover organs, but because of broader donor criteria applied to individuals who are now considered potential organ donors. The current factual aspects of organ donation and allocation identify a progressive shortfall in lifesaving organs despite increased demand. This is occurring when, in fact, excellent potential donors with lifesaving organs are lost to the system frequently because families refuse to allow organ donation.[4,13] The reasons that families give or refuse to give permission for organ recovery or participate in the societal endeavor of donation are explored in the present study.

MATERIALS AND METHODS

In 1994, members of the UNOS Ad Hoc Donations Committee and the NKF Council on Transplantation began to compile and review data from 2 major sources. The first, a 1992 survey commissioned by UNOS and the NKF, sought to address public attitudes about organ donation and transplantation.[14] The telephone survey was conducted by the Southeastern Institute of Research, Richmond, Va, and measured key factors regarding motivation to donate organs (**Table 1** and **Table 2**). Important points of the survey included the view by 90% of those willing to donate that the family would honor their wish and that organ donation was consistent with their religious beliefs. Further, willing donors did not fear early termination of life-support methods "before they were really dead" to obtain organs. Most donor respondents felt the system of organ allocation was generally fair. Finally, more than 60% of all respondents believed that the government is the least appropriate source of information and that a US government promotion of organ donation would make no difference.

The 1992 UNOS-NKF survey confirmed several major points elicited from the American public in 2 similar surveys, each of which sought information about public attitudes on organ donation and transplantation. The earliest survey, commissioned by UNOS and published in 1991,[15] indicated that the public generally supported organ donation and believed that alternative methods to increase organ donation were somewhat appropriate. The Partnership for Organ Donation,[16] which contracted with the Gallup Organization, published results disclosing that among 6127 persons polled, the vast majority supported organ donation. The UNOS-NKF survey was encouraging as regards support not only for organ donation but also for alternative methods, particularly financial incentives, which may motivate some individuals to consider organ donation. The 3 well-designed, professionally conducted, and scientifically analyzed surveys had uniformly disclosed public support for organ donation. Each had been widely distributed. These data and the topics broached in the surveys were further analyzed as they arose in focus group settings.

The second source of information consisted of focus group responses elicited from volunteers recruited for 2-hour sessions in 5 cities. The focus groups included individuals who were paid a modest stipend and who were assigned to a donor or nondonor group according to whether they answered the question, "Are you an organ donor?" affirmatively or negatively. The focus groups were then exclusively either persons who perceived themselves as being organ donors or persons who perceived themselves as not being donors. In 2 cities, Boston, Mass, and Atlanta, Ga, the nondonor focus group was composed exclusively of African Americans. The reason for this was to allay any reluctance that a nondonor might have as regards speaking in a racially mixed group. This strategy was undertaken in part because of the disadvantaged position of the African-American community as regards its underrepresentation in organ donation.[5-7,9,17] Examples of questions asked in the focus groups are summarized in **Table 3**. The 12 videotaped sessions were reviewed by the Southeastern Institute of Research (which reported to UNOS and the NKF), the UNOS Ad Hoc Donations Committee, and us.

Table 1. Public Attitudes About Organ Donation: Alternative Motives to Donate Organs*

	Percentage of 1203 Respondents	
Response	Implied Consent	Compensation
Yes	38	48
No	55	42
Do not know	7	10

*Adapted from Bowden and Hull.[14]

A total of 102 persons participated in focus groups in the cities of Boston, Atlanta, Kansas City, Kan, Phoenix, Ariz, and Seattle, Wash. There were 51 donors and 51 nondonors ranging in age from 18 to 64 years. There were equal numbers within each group having annual household incomes over and under $30 000. Efforts were made to recruit nondonors who were similar in age, race, and gender to those in the donor groups who were recruited first. It was not always possible to match the demographic mix of donor and nondonor focus groups, a circumstance that was predictable from the prior survey data.

Focus groups were led by a professional representative of the Southeastern Institute of Research skilled in this task. Questions were designed to be nonleading and to elicit conversation that would disclose knowledge and attitudes about organ donation and transplantation. Participants were encouraged to ex-

Table 2. Public Interest in Compensation Alternatives for Organ Donation

Incentive	Percentage Very or Somewhat Interested						
		Age, y			Annual Household Income, $		
	Total (N=1203)	18-24 (n=410)	25-54 (n=496)	≥55 (n=296)	<20 000 (n=582)	20 000-49 000 (n=372)	≥50 000 (n=165)
Preferred donor status	59	70	58	52	55	62	66
$2000 Payment only toward funeral expenses of deceased	54	67	57	35	53	60	52
$2000 Payment to donor family's favorite charity	52	65	54	33	49	57	50
Limited life insurance policy	46	63	43	34	47	46	46
$2000 Payment to the family of the deceased	35	53	35	19	36	39	30

pand on their own answers as well as to respond to the comments of others. All participants knew the sessions were videotaped by cameras located behind a 1-way mirror.

RESULTS

General Issues

From the focus group videotapes, it was apparent that neither donor nor nondonor individuals had much specific knowledge of organ donation and transplantation in America. Members from donor and nondonor groups seemed to understand that some system of organ recovery and allocation was in place and that there was a waiting list for organs. Both groups totally distrusted government involvement, and both groups were tremendously influenced by the mass media. The more sensational and potentially inaccurate a mass media story might have been, the better all tended to remember it.

In general, donors appeared somewhat more sophisticated and usually were positive and self-assured. They were willing to participate in the broadest aspects of organ donation and transplantation and tended to indicate that details regarding the structure and function of various organizations were not important to them. Donors seemed highly motivated, a bit more medically sophisticated, and were willing contributors in the groups.

Nondonors appeared suspicious and distrustful. There were negative comments regarding their lifelong linkage with organized medicine and the community in general. Negative feelings were brought out regarding nearly every aspect of every question. For example, at the conclusion of one discussion, a nondonor participant made a point of asking the moderator whether she was a potential donor and had signed a donor card. After the moderator responded affirmatively, another member of the nondonor group said, "I am not signing that card!" in a confrontational and defiant tone.

In 2 of the nondonor focus groups, individuals asserted that organ donation is not uppermost in their thoughts. Nondonors also felt pessimistic that any donated organ would go to minority recipients or to the poor, and nondonors tended to focus on the failures of organ donation and transplantation as well as the pain and suffering of the recipient. Nondonors felt that it was important to go to the grave "whole" and tended not to want to participate in the signing of donor cards.

Mistrust of Medicine

A striking finding in the nondonor focus groups was a profound mistrust of the medical community. Participants raised questions such as "what happened to the Hippocratic oath" in response to comments from others that physicians will work hard to obtain organs only if recipients have money. One participant even commented about trusting lawyers more than physicians, implying that while lawyers were not trusted, physicians were trusted even less. Such negative comments seemed to reflect long-held attitudes regarding organized medicine and the community in general. The source of this mistrust is probably complex and may be related to socioeconomic conditions that foster disenfranchisement.

Perceptions Regarding Organ Allocation

While members from donor and nondonor groups believed that an organ recovery and allocation system as well as a waiting list for organs existed, neither group had any idea of the specifics as to who controls, administers, or distributes transplantable organs. Nonetheless, donors generally trusted the system. They felt that the organs were probably distributed equitably according to medical and biological priorities.

In contrast, nondonors exuded pessimism. Their comments were frequently of the following nature: "a wealthy person will get the kidney"; "it won't be done equitably"; "you'll be passed over"; or "you're a minority." There were occasional balanced comments from some nondonor participants stating that organs are distributed by computer matching (for tissue compatibility), but statements about fairness were met by negative comments such as "doctors program the computer" and "is it [the computer list] categorized by race?" Thus, although some nondonors knew a bit about the allocation system, their general mistrust of the system was greater than their confidence in it.

Perceptions of Transplantation Outcomes

Donors generally believed that organ transplantation was an effective method in treating life-threatening end-stage organ failure. The nondo-

Table 3. Sample Questions for Focus Group Participants

- When you hear the words organ transplants what comes to mind? What comes to mind when you hear the words organ donation?
- How did you first learn about organ transplants? Organ donation?
- What organs are in most demand for transplants? Which are transplanted most often?
- Do you know if there are ever shortages of organs for the people who need transplants? Which organs? How do you hear about these shortages?
- How successful are organ transplants? Are patients able to lead normal, successful lives after receiving transplants?
- Where do the organs come from?
- Who decides who gets the available organs?
- How have you indicated your wishes about donating?
- For those who have not completely made up your minds, what concerns do you have that prevent you from making a final decision? Are there questions that you have not had answered?
- For those of you who do not want to donate your organs, what are the reasons that you think people decide not to donate or to donate?
- How do you feel about assumed consent? Financial incentives? Government-sponsored programs?
- Are you aware of any other ethnic or religious group that might have special concerns about organ transplants? Do you have any religious concerns?
- What do you think needs to be done to increase organ donations?

nors tended to focus on failures of organ transplantation as well as on the pain and suffering of the recipients. A most telling occurrence in a nondonor focus group occurred in response to a question regarding the efficacy of transplantation. A middle-aged nondonor man stated that he had a golfing partner who was a heart transplant recipient; he assured the group that his golfing partner had normal cardiac function and led a normal life. Nonetheless, throughout the remainder of this session, the efficacy of transplantation was called into question by many of the participants. In addition, the man who initially explained that his friend was a transplant recipient joined the group as one who doubted that transplantation surgery was successful. This striking example of focus group dynamics as well as an ingrained negative opinion of nondonors regarding organ recovery and transplantation may indicate that certain members of the population will simply not accept efforts of the larger community to treat patients and save lives through transplantation.

Brain Death

Donors were more knowledgeable and consequently comfortable with the concept of brain death. Several nondonor participants voiced concern that physicians may terminate life support prematurely if a patient had signed a donor card, and others agreed with this possibility. Lack of knowledge appeared in the form of questions such as "don't your organs die when you die?" Thus, there was a considerable ambivalence in the minds of nondonors regarding the events after death and, perhaps tied to this, a fear that life support would be compromised if a donor card was signed.

Moral and Psychological Barriers to Donation

Religious beliefs were considered to be a source of reluctance to donate despite the fact that virtually all major organized Western religions support postmortem organ donation to save lives. The nondonor groups shed some interesting insights into this paradox, although some participants were uncertain if their religion had definitive views on donation. However, they felt that it was important to go to the grave whole. Some participants were more explicit. They felt that although their religion favored donation, their personal moral beliefs were against it. Some even felt that by donating organs for transplantation they "may change destiny . . . like Frankenstein." In contrast, objections like these were seldom voiced by donors.

Alternative Methods to Increase Donation

In view of ethical, legal, and political issues, it was deemed important to obtain some opinion about alternative methods to increase donation. In the 1992 UNOS-NKF survey,[14] findings were encouraging as regards general support for organ donation and positive responses about alternative methods, particularly financial incentives, to increase organ donation. Many in both donor and nondonor groups felt as though preferred status (families having donated a loved one's organs would receive preferential care if subsequent need for an organ arose) was a reasonable incentive. Education and dissemination of information about donation and transplantation were generally thought more important then several alternative methods. There was nearly universal agreement that implied consent (presumed consent) should not be tried. The use of financial incentives was not markedly opposed (some accepted the idea of funeral expense reimbursement), although there was not strong support either. In general, methods to increase organ donation had not been well thought out by either donors or nondonors indicating, perhaps, that the assumption of altruism as an immutable motive in organ donation may be in question.

COMMENT

Universal access to health care is a current societal goal in the United States. In organ transplantation, however, universal access is hampered by the shortage of cadaveric donor organs. This shortage has not improved substantially by broadening the criteria for potential donors and with intense efforts to educate the public about the organ shortage. The number of potential recipients, on the other hand, has increased steadily. A most complex issue is organ recovery from minority populations and their access to available organs. Although a fair allocation system based on medical need, biological constraints, and principles of justice is extant, negative perceptions about organ recovery and equal access to transplantable organs is widespread. There is considerable resistance of some to view organ donation and transplantation positively.

Organ donation in the United States depends entirely on public altruism. It has become apparent, however, that many lives are lost in the face of a large number of suit-

able potential donors whose organs are not recovered because families refuse permission for organ recovery.[4,13] This is occurring when the success of organ transplantation is undisputed: 76% to 94% of liver, heart, pancreas, and kidney recipients are alive, most with the initial organ functioning, 1 year following the transplant operation.[1,3,18] Information regarding public attitudes about organ donation and transplantation has been adequately gathered in surveys showing broad support for this type of care.[14-16,19,20] Nearly half of potential donor families approached to give consent for organ recovery, however, refuse to permit this lifesaving measure.[4]

The 1992 UNOS-NKF survey addressed organ donation quantitatively.[14] This survey was subject to the problems of similar instruments when they are applied to delicate issues such as organ donation. Surveys provide quantitative data, but cannot explore attitudes in depth since they seldom address important issues that may follow survey questions. The response to an impersonal telephone survey may be different from a response to the same issues that are explored by a group of people. Consider, for example, the question, "Would you favor financial incentives to increase organ donation?" In telephone surveys, more people favor than disfavor financial incentives. On the other hand, in focus groups, participants are reluctant about reaching a positive conclusion regarding this or other methods to motivate those considering organ donation. Thus, if strategies to improve organ donation are adopted by relying on survey findings, policies could be based on erroneous interpretations of public attitudes. The consequences of such error could be disastrous if the impact on organ donation were negative.

From the various surveys and particularly the focus groups, it appears as though the public has a number of perceptions that exist regardless of the realities of organ donation and transplantation medicine. Clearly, those who are willing to donate probably are participants not just in organ donation and transplantation, but in the broader society as well. Their perceptions of transplantation as successful, as generally equitable, and as another aspect of the society in which one places trust seem fairly firm. Many perceptions of nondonors, however, are skewed negatively as shown not only in the focus group setting but in survey instruments as well.[4,6,14,16,19,20]

A critical factor influencing attitudes about transplantation is the attention that organ donation and transplantation receive in the mass media, especially television. There have been a number of sensational reports that appear to have had a considerable negative impact on the attitudes of the public to organ donation. The recent controversy surrounding the Mickey Mantle liver transplant is an example. The UNOS independent review of the circumstances in this case found that organ allocation was administered properly and according to established policy. That is, there was no consideration given to wealth, citizenship, or celebrity status, and there was no indication that undue influence played a part in that transplant. Nonetheless, negative impressions left on an uneducated public by a news media cadre posing prejudiciously leading questions are difficult to overcome, even with truthful answers. It is crucial that health care professionals, knowledgeable about transplantation, educate and inform the public and mass media representatives of the positive aspects of organ donation and transplantation. Closer liaisons between the transplant and news media communities must be forged if appropriately informed decisions are ultimately to be considered by families of potential donors.

Education regarding organ donation and transplantation can be broadly divided into professional and public sectors. Both have enjoyed enormous activity over the past 10 to 15 years. Educational efforts have used virtually every medium and include local, regional, and national enterprises.[1-5,9,13-15,18,21] Currently, a national effort to educate the public is under way throughout the United States under the aegis of the Coalition on Donation and the Advertising Council, Richmond, Va. The goal of the Coalition is to ensure that every individual in the United States understands the need for organ and tissue donation and accepts donation as a fundamental human responsibility. Nonetheless, public and professional efforts have not produced explicit and measurable gains in the number of organs recovered. Further, education efforts have not reached many concerning such issues as brain death, organ recovery and allocation, and specifics regarding the efficacy of transplantation. Extensive public (and professional) education has probably held the line in cadaveric organ recovery, but has not demonstrably increased the number of donors. That is not to say that these efforts are wasted; one can only guess that organ donation would decrease were educational efforts not extant.

Considering results of surveys and focus groups, several conclusions and proposed remedies may be considered. Further surveys regarding public attitudes about organ donation and transplantation will not shed additional light; surveys disclose support for most donation and transplant endeavors. The mistrust of medicine by a substantial portion of focus group participants should give pause, although many persons with negative feelings about organ donation distrusted every organization, medical or otherwise. Organ allocation, a complex system made as fair as is possible, will only be made better by the recovery of more donor organs. Alternative methods to motivate and persuade reluctant potential donor families may be acceptable to some, but would not need to be considered if permission to recover transplantable organs increased significantly.

To positively affect current issues of the organ donation dilemma, the following proposals should be addressed in America:

First, public and professional education must be evaluated and improved with regard to several current problems. The attention that organ and tissue donation and transplantation receive in the mass media, schools, and places of worship is critical. Health care professionals, knowledgeable about transplantation, must educate our society as to the positive aspects of organ donation and transplantation so that a responsible and balanced view of the considerable benefits of organ donation exists.

Second, routine referral of all potential donors to appropriate and trained professionals is essential.[21] Minority requestors, who are sensitive to the cultural diversity of the public that they serve, need to be trained. These efforts have already improved organ donation in certain areas of the United States.[5,9]

Third, expansion of the organ donor pool must be evaluated. Potential kidney recipients should be encouraged to discuss living donor transplantation whenever possible. Relaxation of cadaveric donor criteria may increase organ supply and could include older donors, patients with short-term diabetes, patients with hypertension with normal renal function, and nonheartbeating donors. Short-term and long-term outcomes with nontraditional donor organs must be assessed.

Fourth, incentives to positively motivate individuals to consider organ donation should be studied in pilot programs. Financial incentives, directed donation, and preferred status for donor families should a need arise are all debatable, but should not be dismissed without data demonstrating measurable impact.[13,14,21-23] The question of directed organ donation is an issue that has been debated in recent years.[22,24,25] Perceptions regarding organ allocation by some nondonor-focus group participants suggest that a system permitting directed donation may be considered fair, addressing assertions that "a wealthy person will get the kidney," or "you're a minority," or the suspicion that waiting lists are "categorized by race." Should the donor family have the right to direct where the organs go? The view has been expressed that while this may be neither desirable nor ideal, all have a right to their opinions, and no organ should go unused.

Physicians have an opportunity to substantially improve results in the care of patients with life-threatening, end-stage organ failure amenable to transplantation. With current surgical and medical modalities, organ transplantation may save or significantly improve the lives of more than 20 000 patients annually. Those patients in need but unserved suffer an enormous yet needless risk to their lives. This risk would be markedly abated were all physicians to recognize their roles for patients requiring lifesaving organs. These roles include encouragement to all families that organ and tissue donation gives life to those in great need and that any of us may someday be in need of an organ or tissue transplant ourselves. Further, physicians can influence their colleagues, hospitals, institutions, and communities as to the utility, efficacy, and fairness of the donation and transplantation enterprise. Finally, physicians assume a large role in the care that patients expect everyday: that of empathetic, pragmatic, and competent advice to families faced with a decision to donate a loved one's organs or to seek lifesaving care by organ transplantation.

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