6.2.2 Directed Donation of Organs for Transplantation

Efforts to increase the supply of organs available for transplant can serve the interests of individual patients and the public and are in keeping with physicians' obligations to promote the welfare of their patients and to support access to care. Although public solicitations for directed donation—that is, for donation to a specific patient—may benefit individual patients, such solicitations have the potential to adversely affect the equitable distribution of organs among patients in need, the efficacy of the transplant system, and trust in the overall system.

Donation of needed organs to specified recipients has long been permitted in organ transplantation. However, solicitation of organs from potential donors who have no pre-existing relationship with the intended recipient remains controversial. Directed donation policies that produce a net gain of organs for transplantation and do not unreasonably disadvantage other transplant candidates are ethically acceptable.

Physicians who participate in soliciting directed donation of organs for transplantation on behalf of their patients should:

(a) Support ongoing collection of empirical data to monitor the effects of solicitation of directed donations on the availability of organs for transplantation.

(b) Support the development of evidence-based policies for solicitation of directed donation.

(c) Ensure that solicitations do not include potentially coercive inducements. Donors should receive no payment beyond reimbursement for travel, lodging, lost wages, and the medical care associated with donation.

(d) Ensure that prospective donors are fully evaluated for medical and psychosocial suitability by health care professionals who are not part of the transplant team, regardless of any relationship, or lack of relationship, between prospective donor and transplant candidate.

(e) Refuse to participate in any transplant that he or she believes to be ethically improper and respect the decisions of other health care professionals should they choose not to participate on ethical or moral grounds.

AMA Principles of Medical Ethics: VII,VIII,IX

Background report(s):

CEJA Report 3-A-16 Modernized *Code of Medical Ethics*

CEJA Report 3-A-06 Solicitation of the public for directed donation of organs for transplantation

6.2.2 Directed Donation of Organs for Transplantation

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Donation of needed organs to specified recipients has long been permitted in organ transplantation. However, solicitation of organs from potential donors who have no pre-existing relationship with the intended recipient remains controversial. Directed donation policies that produce a net gain of organs for transplantation and do not unreasonably disadvantage other transplant candidates are ethically acceptable.

Physicians who participate in soliciting directed donation of organs for transplantation on behalf of their patients should: [new content identifies primary audience for guidance]

(a) Support ongoing collection of empirical data to monitor the effects of solicitation of directed donations on the availability of organs for transplantation.

(b) Support the development of evidence-based policies for solicitation of directed donation.

(c) *Ensure that solicitations do not include potentially coercive inducements.* Donors should receive no payment beyond reimbursement for travel, lodging, lost wages, and the medical care associated with donation. *[new content reiterates underlying ethical concern]*

(d) Ensure that prospective donors are fully evaluated for medical and psychosocial suitability *by health care professionals who are not part of the transplant team, regardless of any relationship, or lack of relationship, between prospective donor and transplant candidate. [new content consistent with 6.1.1, 6.1.2]*

(e) Refuse to participate in any transplant that he or she believes to be ethically improper and respect the decisions of other health care professionals should they choose not to participate on ethical or moral grounds.

AMA Principles of Medical Ethics: VII,VIII,IX

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 3-A-06

Subject: Solicitation of the Public for Directed Donation of Organs for Transplantation

Presented by: Priscilla Ray, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws (Joseph H. Reichman, MD, Chair)

INTRODUCTION

Recent public appeals for organ donors have received considerable attention and stimulated concern regarding the appropriateness of directed donation by a previously unknown person, that is, by a stranger.[1, 2, 3, 4] In 2004, Todd Krampitz received a new liver donated by the family of a deceased donor, as a result of the media coverage generated by his advertising campaign on a billboard and the personal website www.toddneedsaliver.com.[5] More recently, Rob Smitty donated a kidney to John Hickey after learning information about Mr. Hickey and his need for an organ transplant through a posted profile on the commercial website www.matchingdonors.com.[6]

The significant disparity between the large number of people in the United States awaiting an organ transplant and the much smaller number of suitable organs available for transplantation has left many transplant candidates desperate for ways to increase their chance of receiving a life-saving organ.[7] Through attempts to publicize their stories of need, individuals such as Krampitz and Hickey who are waiting for an organ through the national waiting list are seeking a directed donation to them, thus bypassing the national distribution algorithm. However, what may advantage one individual may have serious albeit unintended ramifications for others also awaiting an organ.

This report explores some of the ethical issues arising from various approaches to connecting transplant candidates with potential organ donors, both deceased and living. It considers the impact of public appeals on donors, recipients, and other relevant parties, as well as on the values underlying the current system.

* Reports of the Council on Ethical and Judicial Affairs are assigned to the reference committee on Constitution and Bylaws. They may be adopted, not adopted, or referred. A report may not be amended, except to clarify the meaning of the report and only with the concurrence of the Council.

BACKGROUND

The Current Allocation System for Organs

The United Network for Organ Sharing (UNOS) administers the system for allocation of organs from deceased donors on behalf of the Organ Procurement and Transplantation Network (OPTN). The system aims to ensure an optimal balance between equity and efficacy.[8] Specifically, it seeks to provide balance between equitable allocation of organs to transplant candidates and allocation according to appropriate medical criteria.[9, 10] The allocation of organs from deceased donors follows algorithms developed by the OPTN/UNOS by broadly based, representative committees, using a process that is open, seeks broad public input, and is publicly transparent. The system for allocating organs to transplant candidates on various organ waiting lists has always allowed an important exception: the decedent or authorized decision maker may direct a medically suitable organ to a specific named individual or transplant center.[11]

Donations from living donors are not regulated in the same way that organs from deceased donors are; no nationwide system controls allocation of living donor organs.[10] In part, this is because most living donors come forward out of a desire to help a specific transplant candidate, even if there are other wait-listed individuals who have greater medical need or are a better biological match and who might also benefit from the donated organ.[12] Individual transplant centers make their own rules for accepting living donors and allocating their organs.

Living Donation

In recent years, the number of living kidney donors has exceeded the number of deceased donors. In addition, according to OPTN/UNOS, transplants from unrelated living donors have increased significantly.[13] In 2004, for example, most living kidney donors were biologically related to the recipient of their kidneys, but more than 30 percent were biologically unrelated (mostly spouses or friends).[12] The increase in biologically unrelated donors has been attributed to various factors, some medical and some cultural: grafts from biologically unrelated living donors have higher long-term survival rates than those from deceased donors, transplant centers are increasingly willing to perform transplants between donors and recipients who are not related, and innovative strategies have aimed at increasing the number of transplantable organs, including from living donors.[14]

It is uncommon for a living donor and recipient to have no previous personal relationship, but the frequency of such transplants is increasing as new approaches are used to connect potential donors with transplant candidates. OPTN/UNOS data for 2004 indicate that there were 87 Good Samaritan donations, 27 direct-paired donations[1], and 16 list-paired exchanges.[2,14] OPTN/UNOS has not tracked living directed donation, so no national statistical data are available.[14]

[1] In a direct-paired donation, for example, ABO incompatible donor-recipient pair Y and incompatible pair Z are recombined to make compatible pairs, donor-Y with recipient-Z and donor-Z with recipient-Y.

[2] In a list-paired exchange, a patient waiting for a transplant receives priority status for a deceased donor organ in exchange for a living donation into the general organ pool on his or her behalf.

CONCERNS

Solicitation of the public for an organ to be directed to a particular candidate has the potential to increase the number of available organs and thereby alleviate the disparity between supply and demand. However, if the current system's attempt to achieve an optimal balance between equity and efficacy is to be preserved, the effect of public solicitation on achieving this goal merits consideration.

The Code Of Medical Ethics

In it recent report, "Transplantation of Organs from Living Donors," the Council recognized that variations in donation and allocation schemes for transplantable organs from living donors required further study, and concluded this: "ultimately, only variations that produce a net gain of organs in the organ pool and do not unreasonably disadvantage others on the waiting list are ethically acceptable."[15]

With regard to how organs from deceased donors should be allocated, the AMA's *Code of Medical Ethics* has had clear policy since 1993: allocation should follow "ethically appropriate criteria relating to medical need"—the same criteria that guide allocation of scarce resources.[16] Moreover, it specifically excludes the use of non-medical criteria, such as "ability to pay, age, social worth, perceived obstacles to treatment, patient contribution to illness, or past use of resources should not be considered."[16] However, it does not exclude directed donation of organs. Similarly, directed donation has never been prohibited by national policy. [16]

The AMA's *Principles of Medical Ethics* articulates physicians' responsibility to contribute to the improvement of the community (Principle VII), the physicians' paramount responsibility to their patients (VIII), and physicians' obligation to support access to medical care for all (Principle IX).[17] These Principles and the aforementioned standards from the Code should guide deliberation on the moral permissibility of public solicitation of directed donation.

Statements by Transplant-Related Organizations

The OPTN/UNOS Board of Directors is on record as opposing any attempt by an individual transplant candidate (or her/his representative) to solicit a deceased donor's organ(s), if doing so would place the transplant candidate ahead of others on the waiting list in a way that subverted the system's commitment to equity.[18] Counterbalancing the Board's concern is the possibility that directed donation may increase the number of organs available for transplantation, a significant goal of the organ donation and procurement system.

The American Society of Transplant Surgeons also has expressed its opposition to the solicitation of organs, both from potential living and deceased donors, if the intent is to direct the donation to a specific individual rather than to allocate it according to waiting list policies.[3] It does support, however, directed donation (by living and deceased donors) to family members, friends, and

individuals with whom a relationship exists through a community (e.g., school, place of worship, or place of employment), except when solicitation is involved.[3] It is not clear why an individual from a shared community, whom the transplant candidate does not know directly, is morally different, as a donor, from an individual from an unshared community.

Perceptions of Trust and Fairness of the Transplantation System

Another concern about public appeals that aim to connect a transplant candidate with a living or deceased donor is that such appeals might undermine trust in the allocation fairness upon which the current system has been built and depends.[3, 19] Individuals might be perceived as circumventing the accepted system when they obtain an organ transplant before others on the waiting list, despite less urgent need, shorter waiting times, or a less desirable organ-recipient match [19] However, transplant programs encourage transplant candidates to seek potential donors among relatives, friends, and colleagues, despite the subverting effect of such donation on the equity and fairness of the waiting list. Transplant-related organizations praise solicitation of donation from living friends and relatives; if they did the same for directed donation solicited from the public, perhaps trust in allocation fairness would be strengthened rather than threatened.

Actual or perceived preferential access to scarce life-saving resources has raised several concerns. First, perceived injustice in the national organ donation system might deter some from participating in the transplant enterprise in general.[9] The transplant community has invested great effort in developing the public's trust in the fairness of donation in order to minimize such perceptions.[5] However, at least some of the publicly perceived injustice of public appeals would disappear if solicitation were shown to generate more donations overall.

Second, resources that may be necessary for public appeals are not available to everyone.[10] Recent campaigns, for instance, have relied on billboard advertisements and personal or commercial websites; all of these services require at least modest financial resources.[7] Solicitation also is facilitated by practical knowledge, relationships with key individuals, social status, media appeal, and membership in certain communities.[19,20] Thus, condoning public solicitation may reinforce disparities in health care, because those without the means to advertise must wait and possibly be passed over for an organ that could otherwise have been theirs. [7] However, such an organ might not otherwise have been theirs because it might not have been donated at all if not solicited. How many organs are transplanted solely because they were solicited (that is, they would not have been donated without solicitation) is unknown. The concern about lack of resources to advertise should be lessened by the fact that websites such as www.matchingdonors.com have waived the listing charge for individuals who could not afford it.[21] Moreover, there is benefit to those on the waiting list who are below the recipient of an organ from directed donation when the recipient ahead of them moves off the list, thus advancing their positions by one rank.

Finally, solicitation might facilitate unacceptable discrimination if potential donors identify intended recipients to whom they will donate based on race, color, religion, national origin, sexual orientation, gender, ethnicity, age, religion, sexual preference, or any other basis that would

constitute invidious discrimination.[10, 22] Some, however, have suggested that directed donation on the basis of such criteria actually could help balance a system that already is discriminatory.[23] Currently, no mechanism exists to monitor such occurrences in order to better understand their impact.

Coercion and Inducements

Exploitation might occur if those seeking to obtain an organ through public appeals are subjected to demands for payment or other remuneration at the time of solicitation.[10] These payments would be unethical except for reimbursement for travel, lodging, lost wages, and the medical care associated with donation.[24] Indeed, because anyone can reply to a public solicitation, some potential donors may have ulterior motives such as gaining access to the recipient's personal information.[9, 10] Safeguards to monitor and prevent this kind of activity would be needed.

Coercive inducements could be minimized if organizations such as the OPTN/UNOS or transplant centers served as brokers between potential donors and transplant candidates. Anonymity, however, could not be fully protected if the potential donor were responding to a particular individual's media appeal, leaving open the possibility for future donor demands.[19] This possibility also would need to be monitored and prevented.

Inaccurate or Inadequate Information

No simple verification is available for the accuracy of the stories put forward by individuals at either end of the recipient-donor connection. In the context of unregulated solicitations, potential donors could be swayed by incomplete or false information.[9, 10] Some of the commercial websites that aim to connect potential donors with transplant candidates do not include any information or only inadequate information about the risks of donation.[10] Individuals may volunteer as donors before carefully exploring and understanding the risks of donation;[25] this is likely to result only in temporary inconvenience to the potential donor, however, as all risks will be fully explained by the transplant team before any volunteer is accepted as a donor.

It is not inconceivable that a transplant candidate would misrepresent some information in an attempt to make a personal story more compelling to attract willing donors. Likewise, potential donors might not represent themselves accurately if their motivation for donation extended beyond altruism. Most such misrepresentations are likely to be corrected during the preliminary and preoperative evaluations and disclosures by the transplant team.

POTENTIAL TO INCREASE THE NUMBER OF ORGAN DONATIONS

A particular recipient's publicly told story could increase overall organ donation; by associating the story with the suffering of tens of thousands waitlisted individuals, public pleas for donor organs may bring about donations that would not otherwise have been made. Personal accounts can generate sympathy and action in a way that statistics and fact sheets cannot.[26] Moreover,

solicitations could well have the effect of increasing public awareness of the need for organ donation, potentially generating more donations in general.[27]

If public appeals result in higher donation rates, solicitation of organ donation could benefit everyone on the national waiting lists.[27] The potential effect of public solicitation on overall donation rates is unknown, as is the extent to which waitlisted individuals are disadvantaged as a result of solicitation.[28] Given these unknowns, it seems wise to generate information to answer these questions rather than make an uninformed judgment based on assumptions that may or may not be valid.

A justification for allowing individuals to direct their organs to family members and close friends is the special bond of these intimate relationships; the same bonds do not exist between people who have no prior relationship.[9] Some have argued that there is a prima facie obligation for family members to donate, and that a campaign that seeks to further the cause of one individual by reaching into a large community with many similarly suffering individuals is, on egalitarian grounds, unjust.[29] A different view of justice, however, has led others to argue that individuals in a free society may reach agreements with others, by right, without outside interference; thus, there is no warrant to prohibit public solicitation of organs.[30]

Currently, individual transplant centers have to determine how to allocate non-directed donations from living donors. Regardless of how a potential living donor and a transplant candidate came to be connected, the health care team must evaluate the suitability of the potential donor and the transplant candidate.[31] A physician should resist pressure to participate in a transplant that he or she believes to be ethically improper and should not pressure others to participate if they refuse on ethical or moral grounds.[32]

CONCLUSION

Although the effect of public solicitations for donor organs has yet to be fully established, physicians should support policies that can increase the quantity of available donor organs without unreasonably disadvantaging individuals already on transplant waiting lists. Physicians may also participate in the transplantation of publicly-solicited organs when appropriate ethical safeguards outlined in this report and its recommendations have been followed. Alternatively, physicians may refrain from participation in such transplantations on the basis of their own ethical or moral beliefs.

RECOMMENDATIONS

The Council on Ethical and Judicial Affairs recommends that the following be adopted and the remainder of this report be filed:

The obligation of physicians to hold their patients' interests paramount and to support access to medical care requires that maximizing the number of medically suitable solid organs for transplantation by ethical means should remain a priority of the medical profession. Donation of

organs to specified recipients has been permitted by donation policy since the beginning of organ transplantation. Although directed donation is permitted under current national policy, solicitation of organs from potential donors who have no preexisting relationship with the recipient is controversial. The Council offers the following guidelines regarding solicitation of organ donors.

(1) Solicitation of the public for organ donation on the organ supply or on transplant waiting lists has unknown effects. Policies should be based, as far as possible, on facts rather than assumptions, so physicians should support study of the current system and development of policy based on the results of such studies.

(2) Directed donation policies that produce a net gain of organs in the organ pool and do not unreasonably disadvantage others on the waiting list are ethically acceptable, as long as donors receive no payment beyond reimbursement for travel, lodging, lost wages, and the medical care associated with donation.

(3) The health care team must fully evaluate the medical and psychosocial suitability of all potential donors, regardless of the nature of the relationship between the potential donor and transplant candidate.

A physician should resist pressure to participate in a transplant that he or she believes to be ethically improper and should not pressure others to participate if they refuse on ethical or moral grounds.

(New HOD/CEJA Policy)

Fiscal Note: Staff cost estimated at less than $500 to implement

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