

Donation benefit to organ donor families: a current debate

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CME

ETHICS CME, Part 2 of 3

Target audience: All physicians

Learning objectives:

1. Explain presumed consent.
2. Describe the concept of a donation benefit.
3. Discuss the potential benefits and concerns regarding a donation benefit.
4. List 3 donation benefit options.

Faculty credentials/disclosure:

James A. Cutler, CPTC, is chief executive officer/president of Southwest Transplant Alliance. He has no significant financial relationships to disclose other than his employment. No unapproved/off-label uses of any product are addressed in the article.

Before beginning this activity, please read the instructions for CME on p. 241. This page also provides important information on the method of physician participation, estimated time to complete the educational activity, medium used for instruction, and dates of release and expiration. The quiz, evaluation form, and certification appear on pp. 241–243.

Since initiation of the Uniform Anatomical Gift Act in 1968, organ donation in the USA has been based upon a voluntary system of organ donation, with all states, territories, and districts adopting some form of the act. Subsequent federal legislation such as the National Organ Transplant Act (NOTA) has continued to refine this system. The basis of these laws was to provide the legal framework and to express public policy regarding organ donation and transplantation. The basic structure created by these laws includes a system of voluntary “altruistic” donation without benefit to the donor or the donor’s estate or family. Since initiation of NOTA, the number of patients waiting for an organ transplant, and those dying while waiting because of the inability of the current system to keep pace with demand, has grown exponentially. According to the United Network for Organ Sharing, the waiting list of patients eligible for an organ transplant has doubled every 4 to 5 years since 1986. With <6000 donations occurring after death (cadaveric organ donors), the current system is failing most of the almost 80,000 patients waiting for an organ transplant.

Since the early 1990s physicians and ethicists have recognized the deficiency of the current system and have explored other concepts for the organ donation structure in this country. The 2 most discussed alternative donation structures are pre-

sumed consent and financial incentives. The presumed consent model is an opt-out model, as opposed to the opt-in model currently in place in the USA. In other words, people would have to decide before death that they did not want to be an organ donor; otherwise they would automatically become a donor. Many countries in Europe and elsewhere use this model. In some jurisdictions in the USA, a limited version of this system exists for corneal donation for deaths that fall under the jurisdiction of the medical examiner or coroner. In those jurisdictions, the medical examiner or coroner gives permission for corneal donation without prior consent of the donor or the next of kin.

Perhaps the most commonly debated alternative system for organ donation is a system called financial incentive or donation benefit. For the purpose of this review, the term donation benefit will be used. The concept of donation benefit is that the estates or the families of patients who donate their organs after death receive some benefit as a result of having donated. Similar to benefits received by veterans or Social Security beneficiaries, the concept of a donation benefit can take many forms, but the most common forms suggested are for the donor’s surviving family to select one of the available benefit options that best meets their needs and beliefs. These potential benefits might include

1. An offset to funeral expenses, paid by the organ procurement organization that recovered the donated organs.
2. A charitable donation to a qualified nonprofit charity (501[c]3) in memory of the organ donor.
3. Higher priority and/or access on the waiting list for organ transplantation for the organ donor’s remaining family members, should they ever need an organ transplant.

It is not completely clear whether current law would allow such benefits to be offered. For example, NOTA precludes giving “valuable consideration” to organ donors. Most have interpreted this to mean that federal law would preclude benefits that involve a significant cost. Staff from the office of the Division of Transplantation within the Office of Special Programs for the Department of Health Resources and Services Administration, in personal communication with this author, indicated that the Department of Justice would need to review any such system to make a determination whether that system violated the NOTA

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provision. There is general agreement in the transplant community that any such system would probably violate the terms of NOTA, requiring either a modification or amendment of this 1984 federal law to allow for a system of donation benefit.

The proponents of donation benefit support the development of carefully controlled trials to determine whether donation benefit would substantially increase donation rates. Proponents generally cite the following 3 compelling reasons for the use of donation benefit:

1. It will increase the frequency at which the public donates, making more organs available and decreasing the number of deaths of patients on the waiting list and the amount of time patients have to wait for an organ transplant.
2. It provides recognition and demonstrates gratitude for the donation through a benefit to the organ donor's family.
3. It provides financial assistance for end-of-life expenses, in some cases for families who have no other financial means available to them.

Several concerns have been raised about such a system by opponents of donation benefit, including the following:

1. It is unclear how much such a system would diminish the number of patients who die waiting for an organ transplant or how much it would reduce the waiting time for an organ.
2. It could reduce or eliminate the altruism that is the basis of our current system and might discourage donations by those who donate now.
3. It makes a commodity of the human body or commodifies what otherwise was a gift.
4. It may reduce the medical efficacy of donated organs by creating a system in which, to obtain the donation benefit, people might not be truthful about underlying medical conditions that might make an organ unsuitable for transplant.

The first and main difficulty associated with the arguments for or against such a system is an almost complete absence of data. Other than limited retrospective studies of families who donated organs, no solid data exist to suggest that such a system would increase or decrease donation. There are no data to suggest that deaths on the waiting list would decrease nor that people who currently donate would not do so under such a system.

Considering that the most common reason for missed donation opportunities is denial of consent by the donor's family, the greatest opportunity to increase donation is in this area. Proponents of such a system argue that some resistant families and families who are neutral to the idea of donation most likely would be persuaded to donate through receipt of a donation benefit. Further argument is given to the fact that some rights of ownership of the body are already recognized. It is allowable for blood, reproductive material, and other tissues to be "sold" by the donor. No compelling reason that is backed by data has emerged for handling solid organs in a far different manner. Even in the issue of consent, the concept of giving away one's organs after

death implies ownership. Individuals cannot give away something they do not first own, any more than they can sell it.

In response to this debate, the Council on Ethical and Judicial Affairs of the American Medical Association, in a January 2001 report, revisited the issue of encouraging physicians to explore new alternatives in pursuit of ethical means to increase the supply of donated organs. Because of the absence of compelling evidence either for or against this issue, the council pointed to the American Medical Association's previously established ethical principles of the physician's obligation to patients, to improve the community, and to support access to care. The council recommended the following:

Physicians should encourage pilot programs that investigate the effects of financial incentives for cadaveric organ donation. Such pilot studies should be implemented only after certain considerations have been met. Prior to the implementation of pilot studies:

- There should be consultation and advice from the population in which the study is to take place.
- Objectives and strategies, as well as measurable outcomes and set time frames, should be clearly defined in written protocols.
- Such protocols should be publicly available and approved by appropriate oversight bodies, such as institutional review boards.

The issue of donation benefit is gaining momentum as more and more patients are denied access to organ transplants because of a shortage of donated organs. With almost 18 patients a day dying for lack of an adequate donation system, donation benefit may be a system that addresses this important area; however, significant concerns remain to be addressed.

Suggested reading

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