Sounding Board

Ethical Incentives — Not Payment — for Organ Donation

THE therapeutic promise of transplanting organs from cadaveric donors, as envisioned by the pioneers of transplantation,[1] has never been realized because the demand for cadaveric organs has far exceeded the supply. The waiting list for organ transplants continues to grow, and in 2000, nearly 5000 patients were removed from the list because of death.[2] Consequently, many patients with end-stage organ failure are no longer relying solely on the waiting list. Instead, they are turning to spouses, friends, or strangers as possible donors — a medically acceptable alternative because advances in immunosuppression have eliminated the requirement of a genetic match for successful organ transplantation.[3] In many U.S. transplantation centers, the number of kidneys transplanted from living donors has surpassed the number obtained from cadavers.[2]

Although organs from living donors can be transplanted safely, concern about the protection and well-being of such donors has prompted the transplantation community to develop a consensus statement emphasizing that a living donor should be competent, willing to donate an organ, and free of coercion.[4] In addition, the new reliance on organs from living donors has increased the risk of donation for financial reasons, particularly in the case of a genetically unrelated donor. Until now, organ donation has relied on the voluntarism and altruism of uncompensated living donors and of uncompensated family members of cadaveric donors.

Proposals to increase the current supply of cadaveric organ donation have included a policy of presumed consent, which would allow health professionals to override family members' objections to donation after a patient's death unless the patient had formally indicated a preference not to donate organs,[5-8] and mandated choice, which would require all citizens to register their preference with regard to organ donation.[9,10] Neither proposal has been tested or demonstrated to be effective in the United States. Such strategies run counter to the expectation of autonomy on the part of most families and health care professionals and are unlikely to win widespread support.

Cultural values embodied in the National Organ Transplant Act make it illegal for "any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation."[11] Though the purchase of organs is explicitly unlawful in the United States (as it is in virtually all other countries), the shortage of cadaveric organs has led to a worldwide black market for organs from living donors, and patients with sufficient means can travel to distant locations in order to purchase kidneys for transplantation.[12,13]

The Market for Transplantable Tissues and Organs

Market forces influence the development of new drugs and procedures, access to health care, and the specific treatment options offered to individual patients. Nevertheless, an important purpose of the National Organ Transplant Act was to prohibit the assignment of a monetary value to an organ for transplantation, thus preventing commercialization and ensuring some level of equity in access to organs. This objective has been undermined by the development of a market for transplantable tissues.[14] Unlike solid organs, which are transplanted immediately, tissues such as bone and skin are now routinely stored for months after they have been altruistically donated by grieving families. The ways in which these tissues are handled make it possible to turn them into commodities, and for-profit companies have become important processors and distributors of such tissues. This aspect of American transplantation practice has circumvented the intention of the National Organ Transplant Act and makes the future of altruistic organ donation uncertain.

The standard of uncompensated donation of organs from living donors is also being eroded by the opportunity to obtain organs outside the United States. Since a close genetic match is no longer needed to ensure success, Americans (and others) are purchasing kidneys from strangers in China, Peru, and the Philippines.[12,15,16] The current federal law presents no obstacle to these patients in returning to the United States for post-transplantation care, further undercutting the objective of the National Organ Transplant Act.[17]

Finally, the principles underlying the act are also challenged by the increased frequency in the United States of kidney donation by persons unrelated to the recipients (20 percent of living kidney donors), increasing the possibility of the illegal purchase of kidneys by recipients and illegal profit by donors and making it more difficult for transplantation centers to prevent such transactions. Affluent patients from other countries have allegedly paid at least $200,000 to undergo transplantation at U.S. centers as part of a package prearranged outside the United States that included compensation of unrelated donors, who were coached by international brokers not to disclose the monetary agreements.[18]

New Congressional Legislation

Congress apparently considers the National Organ Transplant Act, as it pertains to organ donation, ei-

ther obsolete or in need of reinterpretation. In 2001, during the first session of the 107th Congress, several new legislative proposals were submitted for consideration.[19-25] Some of these bills promote organ donation through the establishment of donor registries and by providing formal recognition of donors through the presentation of commemorative medals. Other bills offer tax credits to persons who donate their organs.[26,27] In the current session of the 107th Congress, Senators William Frist (R-Tenn.) and Christopher Dodd (D-Conn.) have introduced legislation that removes a potential barrier to donation by living donors.[28] Their bill provides for the reimbursement of travel and subsistence expenses incurred as a result of such donation. The legislation was carefully worded to exclude the use of the word "payment." We suggest that new legislation designed to increase the supply of organs include a range of measures that reward altruism and preserve the ethical principles underlying the National Organ Transplant Act.

ETHICAL INCENTIVES TO INCREASE ORGAN DONATION

The motives of living donors and the motives of families of deceased donors are complex and not necessarily purely altruistic.[29] Families of deceased donors often regard organ donation as a way of giving meaning to the death or of allowing the person to "live on" in others.[29] Spouses and siblings who act as living donors experience the personal reward of seeing that the recipient's well-being is restored. Because organ donation is voluntary and valuable, it should be considered a charitable gift. Society could explicitly thank organ donors for their gift, as is done with other charitable contributions, without jeopardizing its altruistic basis. New federal legislation should embrace ethically acceptable ways to encourage such charitable donation of organs, some of which are outlined here.

Donor Medal of Honor

Organ-procurement organizations have ceremonies that recognize organ donation by family members of deceased persons. A donor medal of honor enacted by Congress would express appreciation on behalf of the American people to living donors and the families of deceased donors.[20,24]

Reimbursement for Funeral Expenses

The majority of the members of an ethics panel recently convened by the American Society of Transplant Surgeons has supported a proposed program in Pennsylvania that provides partial reimbursement for funeral expenses for a deceased donor.[30] The intentionally small reimbursement ($300) is meant to emphasize that the purpose of the program is to express appreciation for the donation, not to provide payment for it.

We suggest that Congress establish a pilot program of reimbursement for funeral expenses in order to determine whether such an approach would increase organ donation and be effective without offending those who would have donated organs in the absence of such an incentive.[31,32] We oppose a tax credit of $10,000 for cadaveric donation, as one bill proposes,[27] and we also oppose a tax refund of $2,500 for the donation of an organ from a living or deceased person, as another bill proposes[26]; both measures place an arbitrary monetary value on an organ and in reality are merely forms of payment.

Some will argue that there is no difference between reimbursement for funeral expenses and a tax credit because both are payments for cadaveric organs. We disagree. Reimbursement for funeral expenses is intended as an expression of society's appreciation for the donation, and it is consistent with the provision for reimbursement of the expenses of donation after the declaration of death.

Organ Exchanges

Until recently, many persons who wished to donate an organ to a spouse or another family member were unable to do so because of incompatible blood types or other immunologic barriers. A program of paired kidney exchange addresses this problem by permitting an exchange of organs from two living donors[33] or from one living donor and one deceased donor. In the latter approach, recently introduced in New England, a living donor whose intended recipient is incompatible donates an organ to a compatible patient on the waiting list for a cadaveric organ, in exchange for priority in the allocation of a cadaveric organ to the donor's intended recipient. Thus, two transplantations are performed in circumstances that would otherwise have permitted neither. Although such exchanges could open the door to paid sponsorship of donors, the same prohibition against the payment of a compatible, unrelated donor should be applied to organ exchanges.

Medical Leave for Organ Donation

Currently, organ donors risk loss of wages or even loss of employment because of the time away from work that is required for donation.[34] Congress has enacted legislation that provides a 30-day paid medical leave for all federal and some state employees who donate an organ for transplantation.[35] However, no one should have to incur a personal expense for donating an organ. The American Society of Transplantation is organizing a national effort to encourage hospitals with transplantation services to provide paid medical leave for employees who become organ donors. New federal legislation, while emphasizing that monetary enrichment should not be the result of or reason for donation, could make paid medical leave available to a

larger number of would-be donors, much as the Health Insurance Portability and Accountability Act of 1996 mandated health insurance coverage for the majority of workers in the United States.[36]

Ensuring Access to Organs for Previous Donors

The vast majority of living donors do well. Since 1988, when the United Network for Organ Sharing established its data base, however, end-stage renal disease has developed in 56 persons who had previously donated a kidney; these donors were subsequently placed on the waiting list for a cadaveric organ.[37] Despite the additional allocation points prior kidney donors receive, the wait for a cadaveric kidney may still be several years.[38] The health and well-being of living donors should be monitored in a follow-up registry in order to document medical problems associated with donation that occur over the ensuing years.[4] The need for a transplant in a previous kidney donor should constitute the highest priority in the allocation of organs.

Donor Insurance

The fact that there have been cases in which a kidney donor died immediately after donation or needed a kidney transplant at a later date serves as a reminder that nephrectomy is not a risk-free procedure. A recent survey of centers that are members of the Organ Procurement and Transplantation Network showed that at least two kidney donors had died from perioperative complications between January 1, 1999, and June 30, 2001, and that a third donor was in a persistent vegetative state.[39] Although a regional insurance plan for donors has been proposed,[40] a national plan should be enacted that provides life and disability insurance for all living donors, including a mechanism to ensure that they do not incur catastrophic medical expenses as a result of donation.

A REGULATED MARKET SYSTEM

Since the current system of altruistic organ donation has not met the demand for organs, some critics suggest that the way to resolve this problem is to turn to a market approach that would permit the sale of human organs.[41-44] However, the ethical principle that one should not sell one's body applies whether the market is regulated or left to the vicissitudes of capitalism.[45] A system regulated by a government agency (e.g., the Department of Health and Human Services) would probably not be the only source of organs for sale. In fact, the futility of trying to regulate payments to donors is suggested by worldwide experience. In the current global market, prices vary depending on the region and the social status and sex of the donor. For example, in Bombay, India, the current price for a woman's kidney is said to be $1,000; in Manila, the Philippines, the price for a man's kidney may be closer to $2,000; and in urban Latin America, a kidney can be sold for more than $10,000. Such are the payments allegedly made to the vendor; payments to the broker are an additional expense that can drive the cost of the organ even higher. Payments have allegedly exceeded $200,000 for arrangements in which the financial transaction occurred in another country and the transplantation was performed in the United States.[18]

Brokering in the United States according to market criteria of donor suitability would probably be no different. If the current prohibition against the sale of organs were rescinded, there would be little legal or ethical justification for preventing persons from bypassing the regulated system and using other means to obtain a better price for an organ from a more medically suitable donor. The Internet can be used to secure the best price for any commodity. A federally regulated system would have to outlaw Internet bidding and set a controlled price for certain types of donors or continuously modify the price.

INCENTIVES VERSUS PAYMENT

Why draw a line between incentives, such as reimbursement for funeral expenses or life and disability insurance, and actual payments, such as tax credits or even regulated organ sales? We recognize that some people may view the difference as symbolic, but in our view, the symbolism is very important. Symbols that are figurative representations of core social values and boundaries are both subtle and complex and do not always stand up to purely rational analysis. We bring a bottle of wine to the home of a friend who has invited us for dinner, not a $20 bill. The Red Cross gives T-shirts, food, and drinks to those who donate blood but would not give their cash equivalent. Despite the increasing encroachment of market forces into medicine, we believe that the symbol of altruism in organ donation continues to represent powerful notions about the use of human body parts.

The fundamental truths of our society, of life and liberty, are values that should not have a monetary price. These values are degraded when a poor person feels compelled to risk death for the sole purpose of obtaining monetary payment for a body part. Physicians, whose primary responsibility is to provide care, should not support this practice. Furthermore, our society places limits on individual autonomy when it comes to protection from harm. We do not endorse as public policy the sale of the human body through prostitution of any sort, despite the purported benefits of such a sale for both the buyer and the seller.

In the final analysis, we believe that a market system of organ donation fosters class distinctions (and exploitation), infringes on the inalienable values of life and liberty, and is therefore ethically unacceptable. In contrast, nonmonetary recognition of donation appeals to our notions of equity and, most impor-

tant, does not subvert the altruistic social good that must be preserved in a revised system of organ donation. We urge Congress to retain the prohibition, established by the National Organ Transplant Act, against payment for organs in the United States.

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Editor's note: Dr. Youngner serves on the Medical Board of Trustees of the Musculoskeletal Transplant Foundation, a nonprofit organization. He recently completed a project examining ethical issues in tissue banking that was supported by the Greenwall and Cleveland Foundations, not-for-profit tissue banks, and five for-profit companies: Osteotech, LifeCell, Synthes, DePuy/Acromed, and GenSci Scientific.

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