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Expanding Organ Donor Options and Financial Resources

Cheryl L. Jacobs

Allowing for nontraditional donors will help patients on the waiting list throughout the country, potentially expand a given center's transplant program and raise public consciousness regarding the donor shortage.

Since the 1960s, transplant centers nationwide have been actively pursued by volunteers who wish to donate a kidney (and, later, sometimes part of a liver) to a waiting candidate unknown to them. Most of these would-be volunteers are initially denied the majority of centers and referred to the few centers in the United States that currently consider such offers seriously. However, the still prevalent practice of automatically turning down so-called altruistic strangers (as was frequently done prior to the mid-1980s with prospective non-biological donors) is likely to become less frequent. Centers are increasingly exploring and developing appropriate standards by which to fairly evaluate such volunteers and match them with recipients. Allowing for untraditional donors will help patients on the waiting list throughout the country, increasing the number of transplants while raising public consciousness regarding the donor shortage.

This innovative donor pool source of unsolicited volunteers is being pushed from the outside in. Medical professionals need to respond with respect to this generous gesture. Some transplant centers may continue to refer these volunteers elsewhere, hopefully in a gracious manner. Others may cautiously proceed. Still others may more actively welcome this previously untapped source.

Donation to a complete stranger is presently referred to as **nondirected donation**, in that the volunteer has not directed his or her organ to a particular recipient. In contrast, **directed donation** involves an identified recipient for whom the organ is specifically intended.¹ Nondirected donation may occur in several ways. Volunteer donors may be considered for a specific transplant center's waiting list (*center-specific*) or they may be considered for a shared regional list among local hospitals (*re-*

gional consortium). A 3rd possibility may occur in which a volunteer may donate to the regional cadaver list so that his or her incompatible recipient may move to the front of the queue of the cadaver list (*list paired exchange*). Several centers across the country have performed such transplants.

The transplant community is now attempting to formulate an ethical process for safe, uniform, equitable distribution of nondirected organs. This is a serious undertaking. The nondirected donor must be medically suitable and undergo a comprehensive psychosocial evaluation. His or her competence, motivation, and psychological and social well-being must be carefully addressed to ensure an informed decision-making process.² An individual must thoroughly comprehend the risks and benefits to himself or herself and the recipient.

Individual transplant centers or regional organizations should develop and distribute adequate donor education materials and outreach plans to reach all donor types. Altruistic volunteers are inclined to pursue such information, seeking out innovative surgical techniques that will allow donation to remain safe and perhaps even easier in the future. They may target centers that promote laparoscopic donation or other surgical methods that expedite recovery. The option of nondirected donation should at least be referenced as an alternative performed in some regions or programs of the country. This new patient population of nondirected donors is inspiring the transplant community to refine and standardize existing (or non-existent) donor services, ultimately benefiting other prospective living donors, whether related genetically or emotionally.

Now that nondirected donation is increasingly being considered and embraced, the financial con-

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A study on living related donation... found that 24% of family members did not volunteer to donate to a loved one because of the potential financial hardship that would follow.

sequences of living donations have emerged as a crucial concern. Historically, living related donors and their families have been reluctant to raise concerns about financial costs associated with donation. How, some ask, could they worry about money or time away from work when a loved one's life is at risk? One study on living related donation by Knotts et al. found that 24% of family members did not volunteer to donate to a loved one because of the potential financial hardship that would follow.³ Other studies have indicated that about one-fourth of kidney donors find that donating increases financial stress.^{4,5} Many transplant candidates hesitate to ask family members to donate because of the financial burden the request may create. This has changed with the quicker recovery experienced from laparoscopic nephrectomies. Transplant centers must inform nondirected donors that they will absorb any donor-related expenses, despite the gift of an organ to a stranger in need. Volunteers are, understandably, likely to question why they must pay to donate a desperately needed organ—a sacrifice that not only may save a recipient's life but also enhances efforts to increase the number of transplants. Centers will need to become more creative in response to financial concerns, for example, by developing in-house program assistance grants or applying to external sources for aid.

Nondirected donors living in a different city from the transplant center also incur the costs of travel, accommodations, and meals while away from home. These costs are high, especially because such donors are seen at initial evaluation and must return later for the actual surgery. In addition, working donors may experience a loss of income during their recovery if sick leave or vacation benefits are not available from their employer (as may be the case with smaller-scale employers or donors who work part time).

In recent years, the transplant community's focus on financial concerns has led the federal government to recognize the potential hardships created for all donors and to work toward reducing financial disincentives related to donation. The Organ Donor Leave Act, signed by President Bill Clinton in 1999, permits federal employees who serve as organ donors 30 days of paid leave, without affecting existing benefits. Similarly, several states (Wiscon-

sin and Maryland) have passed legislation allowing state employees the same leave. Other states (DE, MN, NY, VA, and TX) are attempting to pass similar legislation. Ultimately, the goal may be to have all larger-scale employers support some degree of paid leave—as is the case, to varying degrees, with bone marrow donors in some states. The overall positive fiscal benefits to all employers is that recipients rehabilitated by a living donor transplant can return to gainful employment, thus contributing positively to the nation's overall economy.

In early 2001, U.S. Secretary of Health and Human Services Tommy Thompson proposed an initiative that would allocate monies for state and program grants to assist with donor-related education, travel, and expenses to decrease financial disincentives to living donation.

On the national scale, as well as within individual transplant centers, extreme care must be taken to ensure that all possible points related to nondirected donation are thoroughly discussed and evaluated by everyone concerned. Meetings, locally and nationally, have been organized to deliberate the evaluation process, ethical and psychosocial considerations, costs, and other logistics. Transplant centers need to offer nondirected donors thoughtful, reasonable support that will honor their gesture and make it safely and fairly available to as many prospective recipients as possible.

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