Internet Organ Solicitation, Explained

Mark E. Williams

The growth of internet-based communications and the increasing demand for living organ donors are resulting in more use of Web sites for organ solicitation. Web resources have the capacity to improve public awareness about both organ donations and transplant outcomes. Rules for organ donation and fair allocation must follow legal principles regarding organ solicitation. Categories of internet recipient/donor matching services include "clearing house," "membership," and "individual" sites. All these raise ethical concerns related to the individual recipient/donor relationship and to the current system of organ allocation. However, a lack of rules and regulations regarding internet solicitation exists. Several pragmatic steps are proposed.

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R ising demand for Internet use has led to dramatic growth of Web-based communication in our society. Web-based communication is used by more than 200 million adults in the United States, which gave birth to both the Internet and the Web browser, and where computers are nearly universally available. In an unfortunate parallel, the demand for kidney transplants has also grown dramatically, as evidenced by recent United Network for Organ Sharing (UNOS) data. The waiting list for kidney transplants has grown to nearly 90,000 individuals, and the average waiting time has increased to 1,199 days. The list will be joined by 40,000 individuals this year. Over half of listed patients will die as their hopes for a transplant run out. The waiting list is growing at five times the rate of kidney donations.

Living-donation rates in the U.S. have recently increased to the extent that living kidney donation is the predominant form of kidney donation (Fig 1).¹ About 7,000 people became living kidney donors in the U.S. in 2004. About one third of the living donors are genetically unrelated to the recipient (Fig 2), which includes a spectrum of donor-recipient relationships, from spouse to friend to anonymous donors. A small segment, but one that shows growth potential, is the nonspouse, unrelated-donor group, a cohort that has dem-

mented,² but currently, dozens of such cases are known, and the number of Web sites used for solicitation continues to grow. The result is an intensifying debate about the role of the

Background

With kidney transplants now increasingly performed between individuals who are genetically dissimilar, the relationship between living kidney donors and transplant recipients has become more diverse. Historically, living donors have shared some genetic or emotional relationship with the organ recipient.3 Data on the source of kidney-transplant donations were reviewed in the New England Journal of Medicine recently.4 Categories of living donors include directed donations to a family member, loved one, or friend ("contingent" donations); nondirected living donations ("anonymous" donations); live-donor paired exchanges (which involves two living donors and two simultaneous transplants); and directed donations to a named stranger. The last may in some cases have a basis of religion,

onstrated 20-fold growth over the past 10 years and now totals twice as many donations

as from spouses. Living donations might be

further increased through more active pursuit

of organ donors, including those solicited

demand and transplant demand—have re-

cently intersected because of organ solicita-

tion and donor-matching services on the In-

ternet. In 1997, cases of directed organ

donations by absolute strangers were docu-

Those two very different trends— Internet

through media such as the Internet.

Internet in kidney-organ solicitation.

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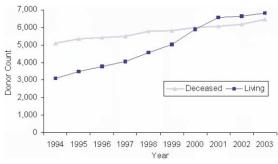


Figure 1. Deceased and living donors. (Reprinted with permission from Davis CL, Delmonico FL: Living-donor kidney transplantation: A review of the current practices for the live donor. J Am Soc Nephrol 16:2098-2110, 2005.

ethnicity, or other personal characteristic that forms the donor-recipient relationship.

The role of the Internet in personal health continues to expand, with a growing number of Web sites offering a wide range of information sources, online chat rooms, and forums to consumers. The number of health-related Internet sites is growing exponentially. The positive effects of the Internet, including prescription medication information, clinical trials results, telemonitoring, and rapid patientphysician communication, have empowered patients to take a more active role in improving and maintaining their health. With regard to organ transplants, the number of persons who access the Internet specifically about transplantation has grown. Web resources have the capacity to improve public awareness about both organ donation and transplant outcomes. Organ-donation registries, for example, have been used in some states to increase public awareness of the need for organ donations and to allow individuals to indicate their intention to donate. Visitors to an organ-donation Web site were more likely to join a registry, as shown by one study. Free and commercial Web sites provide opportunities in which recipient and donor may initiate a relationship. Such information technology may help speed the rates of organ donation.7 However, accreditation of Internet health sites⁸ and guidelines for Internet use by patients are lacking.⁹

Helped by information on the Internet, those in need of organs are joining a grassroots movement of donor solicitation with increasing frequency. A number of options exist for self-advertising by potential recipients in cyberspace. In fact, the movement is similar to recent trends toward self-representation by individuals within the legal system ("pro se" representation).

Legal Background

Rules for organ donation and fair allocation are based on a well-known legal background that the renal-care provider should know. The current controversies regarding organ solicitation, while ethically complex, must take into account this legal background. Important existing legal principles include the following:

- 1. Buying and selling human organs is strictly prohibited by law in the United States. The landmark National Organ Transplant Act (NOTA), ¹⁰ passed in 1984, forbids "any person (to) knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in a human transplantation if the transfer affects interstate commerce."
- 2. It is against the law to benefit financially from organ donation. Of note, removal of certain financial disincentives for live kidney donors is in effect for some. The Organ Donor Leave Act permits federal employees to take paid leave toward donating an organ, a policy being adopted by some states and businesses. "Reasonable payments" are also permitted to cover ex-

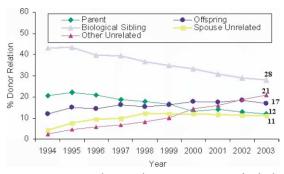


Figure 2. Living donor relation to recipient for kidney, 1994 to 2003. In 2003, 11% of living donors fall under another relationship to donor group. (Reprinted with permission from Davis CL, Delmonico FL: Living-donor kidney transplantation: A review of the current practices for the live donor. J Am Soc Nephrol 16:2098-2110, 2005.

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