

Follow-Up of the Living Kidney Donor

By Sindhu Chandran

Transplantation from a living kidney donor provides the best outcomes in recipients with end stage renal disease. However, our knowledge regarding the effects of kidney donation on long-term mental and physical health of the living donor remains incomplete. Published data are largely derived from single-center retrospective studies in young, healthy, and mostly white populations (1), whereas donors in today's environment are increasingly older, larger, racially diverse, and medically complex (2).

We also suffer from a paucity of information on the psychological and socioeconomic consequences of donation, including the long-term health-related quality of life, financial consequences of donation, and potential issues unique to participation in exchange programs or altruistic donation. Since 1999, transplant centers have been required to submit donor follow-up data at 6 and 12 months to the Organ Procurement and Transplantation Network (OPTN), and in 2008 a 24-month follow-up was added. Unfortunately, nationally collected United Network for Organ Sharing (UNOS) living donor follow-up data are often incomplete (3) and do not allow meaningful interpretations of safety and outcomes.

Why do we need better living donor follow-up? Potential donors, particularly if they are nontraditional, need accurate outcomes information on which to base informed consent. Programs need this information to provide reliable counseling during the evaluation process as well as to assess and improve center performance. Surveillance of the donor may also identify individual problems allowing for early intervention.

What are the barriers to living donor follow-up?

A survey of transplant centers in the United States (4) found that the most commonly reported barrier was donors not wanting to return to the program, cited by 87 percent of programs. Out-of-date contact information (73 percent) was next, followed by lack of program (54 percent) or donor (49 percent) reimbursement for follow-up costs.

How can we improve the follow-up of living kidney donors? Ideally, longitudinal prospective cohort studies would be conducted to answer our questions regarding donor health. These studies would follow and compare clinical outcomes in donors to a control group of similarly screened and examined individuals who did not donate. However, since kidney donors are generally healthy and have low event rates, the long duration of follow-up needed makes it difficult to recruit subjects and sustain funding for such studies. Retrospective cohort studies are more efficient in terms of time and cost, but limited by response bias and low inclusion rates of minorities. Linkage of UNOS donor registration forms to large databases such as the U.S. Renal Data System or health insurance databases can allow us to track major events, but not all outcomes.

It has been argued that a national donor follow-up registry would achieve a greater degree of follow-up, obtain data on a larger and more diverse donor population, and permit the examination of a broader range of health outcomes (5). The recommendations of a living donor follow-up conference included mandating more complete data collection by transplant centers in the immediate postdonation period, setting up a system of incentives and penalties that would moti-

vate transplant center compliance with the standards, and delegating lifelong follow-up of the living kidney donor to a separate third-party organization that would be responsible for maintaining the registry and for any costs of follow-up (3). Obtaining comprehensive knowledge of the outcomes of donation is critical to providing safe and ethical care to our living kidney donors and building community trust in the system of living kidney donation. ●

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