

Psychosocial Risks of Living Kidney Donation

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ISSUE

Psychosocial outcomes include donor (as well as family) reactions to the donation experience. These may reflect both positive and negative feelings about the experience. Psychosocial outcomes also include aspects of health-related quality of life (HRQOL), which typically includes (a) perceived physical symptoms, physical functional status, and general physical well-being; (b) psychological symptoms and overall emotional well-being; and (c) social well-being, including the ability to perform social roles at work and at home, and functioning in relationships with family, and friends.

DATA

A growing literature examining psychosocial outcomes shows that, on average, living kidney donors have positive feelings about the donation experience. They show little to no regret at having donated, would make the same decision again to donate, report a deep sense of fulfillment at having donated, and have very favorable levels of HRQOL both before and after donation. Their average HRQOL levels are uniformly found to be equal to or even more favorable than those of the general population and healthy non-donor comparison groups. Such favorable average HRQOL levels have been observed in donors in both the short-term (e.g., first few years) and long-term (even decades) post-donation.

However, findings about average levels may be insufficient for gauging risk in individual donors. Moreover, considering data focused on averages can mask equally compelling evidence that there are sizable proportions of the living kidney donor population that do experience psychosocial difficulties after donation. For example, looking across studies, up to one-third of donors report that their physical health is fair to poor, or much worse, since donation. Common complaints include persistent fatigue and pain. Donors have been frequently found to report worries about their current and/or future health as a result of donation. Donors' body image may undergo unfavorable changes.

With regard to emotional reactions, elevated emotional distress and/or psychiatric disorders have been found in about one-quarter of all donors. Such problems are found not only in donors with pre-donation histories of mental health problems, but also in donors with no pre-donation history. Symptoms of depression and anxiety are the most commonly reported types of distress in donors. There are anecdotal reports of donors having suicidal thoughts and committing suicide. However, it has been difficult to definitively link these outcomes to donation.

Concerning social functioning, while few studies have explored such outcomes post-donation, it appears that donation can increase interpersonal strains for some donors. Although most donors

report either no change or an improved relationship with the recipient, relationships with other family members, including the spouse, may worsen. The spousal relationship may be particularly vulnerable, with anecdotal evidence from some studies describing separations and divorces occurring after donation.

Who is at risk for poor psychosocial outcomes post-donation? There is only limited research on this question and findings have been inconsistent. It appears that donors, who—despite their decision to proceed with donation—harbor some remaining ambivalence about proceeding, are at increased risk for post-donation psychosocial problems. Donors who report longer recovery times post-donation as well as negative initial psychological reactions post-donation are at risk for poorer longer-term psychosocial outcomes. Several recent reports indicate that greater donor body mass index at donation increases risk for poor psychosocial outcomes, possibly via its more immediate impact on risk for surgical complications and other post-donation health problems. Finally, there is mixed evidence about whether recipient status (i.e., whether the recipient suffered graft loss or death) emerges as a major risk factor for poor donor psychosocial outcomes. Donors do experience grief after such bereavement. However, in the wake of graft loss or patient death, most donors state that they are buoyed by the fact that they did everything they could to help the recipient.

RECOMMENDATION

In conclusion, there is evidence that living kidney donors have, on average, highly positive average levels of psychosocial outcomes. However, a subset of donors is at risk for poor post-donation outcomes. Thus, health care providers should consider both routine questioning of donors at follow-up medical appointments and use of screening measures to detect donor distress or impairment. For example, generic HRQOL measures (e.g., the SF-36 or its shorter derivatives, SF-12 or SF-8) may be used and compared to norms in order to identify donors falling into the “impaired” range (generally indicated by scores 0.5 to 1.0 standard deviations below the normative means). Or, for specific domains such as mental health, brief screeners for depression and anxiety (e.g., the Patient Health Questionnaire-9; the Patient Health Questionnaire-2, the Generalized Anxiety Disorder-7) are available.

The articles below offer detailed reviews about the psychosocial risks of donation.

1. Clemens KK, Thiessen-Philbrook H, Parikh CR, et al. Psychosocial health of living kidney donors: a systematic review. *AmTransplant*. 2006;6:2965–77.
2. Dew MA, Myaskovsky L, Steel JL, DiMartini AF (2014). Managing the psychosocial and financial consequences of living donation. *Curr Transplant Reports*, 1(1), 24-34. PMID: PMC393819
3. Dew MA, Zuckoff A, DiMartini AF, et al. Prevention of poor psychosocial outcomes in living organ donors: from description to theory-driven intervention development and initial feasibility testing. *Prog Transplant*. 2012;22(3):280–92.
4. Timmerman L, Laging M, Timman R, et al. The impact of the donors' and recipients' medical complications on living kidney donors' mental health. *Transpl Int*. 2016 May;29(5):589-602. doi: 10.1111/tri.12760. Epub 2016 Mar 16.
5. Tong A, Chapman JR, Wong G, et al. The motivations and experiences of living kidney donors: a thematic synthesis. *Am J Kidney Dis*. 2012;60(1):15–26.
6. Wirken L, van Middendorp H, Hooghof CW, et al. The Course and Predictors of Health-Related Quality of Life in Living Kidney Donors: A Systematic Review and Meta-Analysis. *Am J Transplant*. 2015 Dec;15(12):3041-54. doi: 10.1111/ajt.13453. Epub 2015 Sep 28.

Note: The recommendations in these chapters are the opinions of the Living Donor Community of Practice of AST. They are not meant to be prescriptive and opinions by other groups or institutions may be equally valid.