

EXECUTIVE SUMMARY

Psychosocial Aspects of Living Organ Donation

Prepared for the
Canadian Council for Donation and Transplantation
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Introduction

Maximizing the psychosocial status and well-being of donors, both before and after the transplant, is among the foremost goals of transplant centers that have living organ donation programs for kidney, liver, lung, intestine, or pancreas transplantation. The psychosocial issues that are currently of greatest concern in the context of living organ donation—e.g., prevention of psychological harm, ensuring that donors are fully informed and decide to donate without coercion, monitoring donor psychosocial outcomes—are intimately linked to the factors that historically served as barriers to use of organs from living donors. These barriers include an understandable aversion to the prospect of injuring one person (the potential donor) in order to save the life of another (the recipient); concern about the potential donor's motives and whether such an act of apparent altruism could reflect a lack of psychological stability; worry that potential donors may be unable to give truly informed consent or are coerced into donating; and apprehension about long-term, as-yet unidentified post-donation complications.¹⁻³

These long-time barriers to widespread use of living organ donation—and the resulting desire of transplant professionals to ensure that undesirable risks to donors are minimized—have led to a major focus in most transplant programs on pre-donation psychosocial evaluation of potential donors, as well as a growing post-donation research literature on post-donation psychosocial costs and benefits to living organ donors. We review the pre-donation evaluation issues that arise when considering the psychosocial eligibility of potential donors, as well as the post-donation data on donor psychosocial outcomes.

Pre-Donation Psychosocial Issues and the Psychosocial Evaluation of Potential Donors

In this section, we consider empirical data on (a) living donors' motives for donation, (b) the predominant ways in which donors arrive at the decision to donate, and (c) donors' psychological status and its relationship to their fitness as donors. We then offer guidelines for the content of the psychosocial evaluation of potential donors.

Donors' motives

Most donors are likely to be motivated by multiple factors. These include intrinsic factors (e.g., desires to relieve the suffering of another, or to act in accord with religious convictions) and extrinsic factors (e.g., social pressures or perceived norms) that may operate simultaneously. The particular combination of motivational forces will also differ depending on whether and how the donor is related to the recipient. Among living related donors, it has long been assumed that family members or emotional partners are motivated primarily by the prospect of saving the life of a loved one.⁴ Such motives are indeed the most commonly expressed feelings, as noted in a variety of studies over the past 30 years. For example, in a series of early studies, Simmons et al.⁵ found that 83% of living related kidney donors cited "helping to save the recipient's life" as the primary reason for donating. However, 78% also felt that the donation would make their own lives more worthwhile. In addition, other motives were frequently and simultaneously present, including a desire to donate due to guilt for past actions (25%), fear of disapproval if a potential donor did not donate (14%), and a desire to acquiesce to either direct or subtle family pressure to donate (43%). Subsequent studies have repeatedly documented similar distributions of key motives, with a desire to help the recipient being most common.⁶⁻¹⁴ Among nondirected living donors (individuals donating to unrelated patients whom the donors did not select)(NDLDs), recent studies have also found a preponderance of altruistic/humanitarian motives, in combination with beliefs that the donor's self-worth would be increased, and feelings of moral and religious obligation or identity.¹⁵⁻¹⁷ In general, the predominant motives expressed by living donors are similar to those expressed by other types of medical and social volunteers.^{18,19}

Donors' decision-making

Donors' motives contribute directly to their decisions to donate, but the process by which they reach those decisions is not uniform and is influenced by factors such as their relationship to the recipient. Most studies of donor decision-making have focused on the rapidity with which individuals decided to become potential donors. Decision-making swiftness may indicate the type of decision being made. There appear to be two decision-making approaches that capture the strategies used by most living donors to make their decisions.³² "Moral" decision-making involves awareness that one's actions can affect another; ascription of responsibility to oneself; acceptance of the social/moral norm governing the behavior; and taking action consistent with that norm.⁵ Because moral decision-making does not involve weighting the costs and benefits of a given behavior but, instead, is based on perceived norms governing that behavior, it is likely to lead to nondeliberative, instantaneous decisions.⁵ In contrast, "rational" decision-making includes multiple steps that focus on gathering relevant information, evaluating alternatives, selecting an alternative, and implementing the decision. Under this strategy, the decision-making process involves deliberation and therefore will not be swift.

Overwhelmingly, the empirical data on living donors' decision-making yields support for "moral," nondeliberative, instantaneous decision-making.^{5,7,9,13,20-28} This approach to making decisions is often of concern to transplant professionals, who want to ensure that potential donors have carefully (and perhaps deliberately) weighed the risks and benefits of the donation. Yet it is important to realize that rapid decision-making does not mean that donors necessarily fail to understand the risks and benefits or other issues involved. Moreover, deliberative decision-making has been found linked to other factors (e.g., ambivalence about the donation, discussed below) that are themselves strongly associated with poorer post-donation psychosocial outcomes.

Psychological status of potential donors

Potential donors' psychological stability has been one of the areas of greatest concern for transplant programs that allow living donation. Concerns have been particularly high in the context of unrelated donation (either directed to a specific patient, or NDL): the willingness or desire to donate to a stranger has been historically viewed with suspicion and as likely to reflect significant psychopathology.^{1,4,29,30} There is no doubt that some potential donors will be psychologically poor candidates to serve as donors, and anecdotal examples have been described in the popular press and in commentaries on this topic.^{3,31} However, a growing number of studies that have examined the psychiatric status of potential donors (both related and unrelated) also suggest that the great majority of individuals who come forward as potential donors do not suffer from mental illness.^{9,15,17,30,32-35}

Psychosocial evaluation of potential living donors

Although there is uniform recognition that psychosocial evaluation of potential donors is critical,³⁶⁻³⁸ there are no widely adopted standards for the content of the evaluation. Table 1 lists seven components of psychosocial status and functioning that should be evaluated in individuals who are considering (and being considered) as potential organ donors. In many ways, the depth, value and purpose of the complete psychosocial evaluation of donors are analogous to those of the similarly extensive evaluation of candidates to receive organ transplants. In both situations, ultimate goals are to ensure that the individuals are psychologically and psychosocially likely to come through the transplant experience well, and to have fewer long-term costs (if any) than benefits. In the context of candidates for organ transplantation, we have argued strongly that the psychosocial evaluation should be used not necessarily to rule out someone as an organ recipient.³⁸ For the donor, we also argue that it should not be used primarily as a "veto" tool. Instead, it should be used to identify areas in which interventions might be offered that could enhance potential donors' well-being and hence their ability and suitability to serve as donors. Our position is consistent with others' recommendations on this issue.³⁷

Post-Donation Psychosocial Outcomes

Because post-donation psychosocial outcomes are critical to the balancing of potential risks and benefits of living organ donation, a growing research literature has sought to document the full range of potential psychosocial consequences to the donor in both the short- and long-term after donation.

Descriptive information on psychosocial and quality of life (QOL) outcomes

Since 1966, there have been at least 42 independent investigations of kidney donors' psychosocial outcomes, 15 studies of living liver donors, and one report noting QOL outcomes in living lung donors (references available upon request). Studies vary dramatically in sample size from as few as 7 to well over 500 donors. Altogether, over 4,800 kidney donors and over 500 liver donors have been surveyed across these studies. Most studies employed retrospective followup designs, in which donors were re-contacted at some point after the donation. Followup periods range from 1 week to 34 years after donation, with most in the range of 1 to 10 years.

Key results from this literature are summarized in Figures 1-3. Figures 1 and 2 show, for kidney and liver donors respectively, a series of 9 psychosocial outcomes that have been examined in a relatively large number of investigations. For example, 13 studies of kidney donors (Figure 1) and 4 studies of liver donors (Figure 2) have reported the percentages of donors who came to regret having donated. Among kidney donors, from 0% to 10% have been found to regret their donation, with a median of 3% across all studies. Similarly low percentages are reported across the studies of liver donors. The figures show that large percentages of donors have reported positive feelings about the donation (e.g., feelings of being a better person for having donated, and feelings that their lives are more worthwhile). In contrast, percentages of respondents who have reported feelings of psychological distress (e.g., depression or anxiety) are relatively low: with the exception of an early report on 7 kidney donors that described all of them as experiencing high distress, studies show low distress rates that are similar to or lower than those observed in the general population.

In addition, Figures 1 and 2 show that relatively low percentages of donors feel that their physical health is worse as the result of the donation or report that they are worried about their health. Low percentages of donors report that their relationship with either the recipient or with their spouses or families have been negatively affected. Instead the majority report that these relationships are unchanged or improved. One area of concern is the percentage of donors who have reported financial hardship due to the donation: while it is encouraging that the percentages constitute a minority of donors, it remains unfortunate that a median across studies of almost one quarter of donors have reported such difficulties.

Data on donors' perceptions of broad domains of QOL are shown in Figure 3, which includes all studies to date that have used the SF-36 survey⁴⁰ or its derivatives in examining these areas. On this measure, a higher score in each domain indicates better QOL. Normative data from the general U.S. population⁴⁰ are shown in Figure 3 for comparison purposes. In all studies, donors' perceptions of their physical functional, psychological, and social well-being were found to be either nonsignificantly different from or significantly better than levels reported in the general population.

In sum, the empirical data strongly indicate that psychosocial and QOL outcomes for donors are good to excellent in a broad range of areas. Yet, some donors—albeit a minority—do report costs, including psychological distress, worries about their health, and/or financial hardship. Thus, it becomes critical to identify key risk factors for these poorer outcomes so that steps can be taken (either pre- or post-donation) to further reduce their occurrence.

Predictors of living donor psychosocial and QOL outcomes

There has been only limited work to date that has attempted to identify robust predictors or correlates of donor psychosocial outcomes. The evidence regarding most potential predictors/correlates is inconsistent. Studies of the following factors are as likely to find evidence that refutes their importance as they are to find evidence that supports them: recipient death or graft loss;^{6,24,34,41-47} donor medical

complications,^{34,41,42,46,48,49} donor history of mood or other psychiatric problems,^{34,44,50-53} and poor donor relationships with recipient or family.^{48,50-52} However, a few factors emerge as consistently important predictors: related donors who are not first degree relatives,^{44,53} donors who are more ambivalent before donation,^{52,53} and “black sheep” donors (e.g., who donated in order to compensate for or repair past wrongs, or to restore their position in the family⁵) may be at higher risk for poorer post-donation psychosocial outcomes.^{52,53} Pre-donation ambivalence has been found to be a powerful predictor of poorer outcomes in unrelated bone marrow donors as well.⁵⁴ Ambivalence before living organ donation has long been recognized clinically as prognostic of poor outcomes, and detection of high levels of ambivalence in prospective living organ donors are generally taken to indicate that the donation must either not be undertaken, or must be postponed pending further discussion, education, or counseling.^{3,36,55} The empirical data^{5,54} support these clinical decisions.

Conclusions and Issues for the Future

Living organ donation is becoming increasingly prevalent. Despite the lack of uniform protocols to evaluate the psychosocial status and background of potential donors, there is wide recognition that such evaluation is critical in order to ensure that donor outcomes in both the short-term and long-term years post-donation remain favorable. We suggest that such evaluations continue to move in the direction of comprehensiveness, and that they be viewed as opportunities not so much to rule potential donors out as to enhance individuals’ eventual suitability as donors. Of course there will be individuals who will be identified during this process as poor candidates to serve as donors, and these individuals need to have a clear understanding of why it is in their best interests that they not donate. The psychosocial evaluation process will help to increase this understanding. Clinical and empirical evidence suggests that these individuals will themselves often be ambivalent about donating, are likely to have deliberated extensively about the donation (rather than reaching a more rapid decision), and may sometimes have psychiatric illnesses that preclude the possibility of donation. Yet, empirical data also show that most potential donors should not be regarded with undue suspicion regarding their motives or psychological stability, and such findings should be reassuring to transplant teams.

With regard to post-donation donor outcomes, studies show that there are clearly both psychosocial benefits and costs—although most donors experience the former rather than the latter. But the fact that some individuals do have poorer post-donation outcomes points to the need to incorporate routine psychosocial followup into donor medical care after surgery. This is not currently standard practice.^{56,57} Indeed, a common donor complaint has been the lack of post-surgical followup care.^{24,26,58,59}

A variety of additional issues require clinical and empirical attention in the future. These include the need to document psychosocial outcomes in understudied groups including, for example, lung donors. In addition, there has been little direct comparison of donor psychosocial outcomes according to type of donation (e.g., kidney vs. liver), type of donor-recipient relationship (e.g., genetic vs. emotional; related vs. NDL), or even according to basic demographic characteristics. For example, do older and younger donors differ in their psychosocial outcomes? Are there ethnic group differences? Are there unique concerns that certain subgroups bring to the donation experience that increase their likelihood of better vs. poorer outcomes? Findings regarding these issues will, in turn, allow the process by which potential donors are evaluated, educated, and counseled before donation to become more useful and more likely to ensure positive donor psychosocial outcomes.

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Table 1. Core components of pre-donation psychosocial evaluation of living organ donors

Component	Areas addressed
Motivation for donation	Reasons for donation; how decision to donate was made; evidence of coercion/inducement; expectations; ambivalence about donation
Relationship between donor and recipient	Nature of relationship (biological, emotional, unrelated directed, or unrelated nondirected); if related, quality of the relationship
Attitudes of significant others toward the donation	Support, pressure, and/or opposition by family, friends; availability of emotional and practical assistance during recovery
Knowledge about the surgery and recovery	Understanding of risks of surgery, possible complications, expected recovery and recuperation time; understanding of basic insurance issues
Work- and/or school-related issues	Arrangements made with employer or school; financial resources
Mental health history and current status	Psychiatric disorders (mood disorders, anxiety disorders, psychosis, suicidal ideation and/or attempts); personality disorders; Substance use history (symptoms of abuse and/or dependence; quantity and frequency of current use of alcohol and other substances); cognitive ability, and competence and capability to make informed decisions
Psychosocial history and current status	Marital status and relationship stability, living arrangements; religious beliefs and orientation; community or religious activities; concurrent stressors (work-related, home-related, other); strategies used to cope with health-related and other life stressors