LIVE KIDNEY DONATION (KL LENTINE, SECTION EDITOR)

Managing the Psychosocial and Financial Consequences of Living Donation

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Abstract There has been dramatic growth in the last decade in the literature on psychosocial and financial impacts of living organ donation. With this growth has come recognition that these impacts must be considered when educating prospective donors about the donation process and when planning donor follow-up care after donation. Our review highlights recent studies that provide new information on the nature of psychosocial and financial outcomes in living donors, with special attention to studies examining unrelated donors (i.e., those with no biologic or longstanding emotional connection to the transplant patient), given that these individuals represent a growing segment of the living donor population. Limitations and gaps in available evidence are noted. We also discuss recent recommendations for post-donation

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monitoring of donors' psychosocial and financial outcomes, and we consider advances in evidence regarding interventions and prevention strategies to minimize any adverse psychosocial and financial impacts of living donation.

Keywords Living donors \cdot Kidney donors \cdot Liver donors \cdot Psychosocial outcomes \cdot Financial outcomes \cdot Health-related quality of life

Introduction

The psychosocial and financial consequences of living organ donation have received greater attention in recent years than at any point in the history of living donation. Although there continue to be gaps in our understanding of these consequences, there is increasing recognition that they matter to donors, and deserve attention and care from transplant professionals as well. Moreover, psychosocial outcomes, as well as financial considerations and burden on donors have moved front and center as both the U.S. and worldwide transplant communities work to maximize donor safety and minimize adverse impacts on donors. Thus, not only have researchers sought to provide data to fully delineate specific psychosocial and financial consequences of donation, but consensus conferences and work groups have considered these issues with an eye toward the development of guidelines and national policy regarding the evaluation and selection of living donors, and the follow-up monitoring and care that they require $[1, 2^{\bullet}]$, 3, 4]. In the U.S., policies governing living donor kidney transplantation have been expanded to delineate psychosocial issues that must be considered in donor selection, and to specify the psychosocial and financial risks that must be described to potential donors when gaining their informed consent [5].

In the present review, we highlight recent advances pertinent to the management of living donor psychosocial and financial outcomes, as well as comment on critical limitations and gaps in available information. A prerequisite for optimal management is an understanding of the range of observed outcomes. Thus, we consider important recent studies that provide new information on the nature of psychosocial and financial outcomes across the population of living donors. We specifically highlight recent studies examining these outcomes within a segment of the living donor population that is increasing in size: unrelated donors (i.e., those with no biologic or longstanding emotional connection to the transplant patient), including individuals who donate anonymously or through kidney paired donation programs. We then discuss recent recommendations for post-donation monitoring of donors and changes in U.S. national policy regarding donor follow-up that have implications for the optimal management of donor psychosocial and financial outcomes. Finally, we consider advances and gaps in evidence regarding the effectiveness of management strategies.

The nature and Risk Factors for Psychosocial and Financial Outcomes

Psychosocial Outcomes

Psychosocial outcomes encompass specific reactions to the donation experience (e.g., positive feelings about the experience or oneself as a person, as well as negative reactions such as regret at having donated). Psychosocial outcomes also include elements of health-related quality of life (HRQOL), i.e., patients' well-being as impacted by any medical condition or treatment [6]. In donors, this includes (a) somatic symptoms and perceptions of physical well-being; (b) psychological symptoms and well-being; and (c) social well-being and functioning in relationships with the transplant recipient, other family members, and friends.

Recent reviews of the literature on these outcomes in living kidney and liver donors have shown that, on average, donors have positive feelings about the donation experience, show little to no regret at having donated, and have high levels of HRQOL both before and after donation [7–10]. Their mean HRQOL levels generally exceed those of the general population [7–10]. But it is equally clear that relying on averages does not tell the whole story. Sizable proportions of the living donor population experience psychosocial difficulties after donation. For example, as summarized in one review [8], elevated psychological distress and/or diagnosable psychiatric disorders have been documented in about one in every four living donors, including incident cases in individuals with no pre-donation history of disorder. Up to one-third of donors report that their health is fair to poor or markedly worse since

donation, with persistent fatigue and pain being relatively common complaints.

Recent reviews have also identified key gaps in evidence concerning psychosocial outcomes [10, 11•]. For example, most studies focus on the early months and years postdonation with little consideration of longer-term outcomes. In addition, there is limited information on risk factors for poor outcomes. Several recent reports have provided new information on both issues. These studies, described in Table 1, are noteworthy in coming from several different countries, and assessing large living kidney and liver donor cohorts that include individuals who donated as many as 48 years earlier. Several of the reports not only compared donor HRQOL outcomes to normative data (i.e., national samples selected to be representative of the general population and used in the initial psychometric validation of the HRQOL instrument in question) but also drew comparison data from other community-based surveys [12., 16.] or constructed a comparison group of non-donors who were demographically and medically similar to donors [15•]. The studies' findings suggest that, on average, very favorable donor psychosocial outcomes are observed even many years post-donation, relative to normative or other comparative samples. However, like the relatively large literature on short-term HRQOL outcomes, these long-term follow-up reports also identify subgroups of donors with impaired physical, psychological, and social HRQOL. Rates of impairment in HRQOL domains (as defined based on study-specific thresholds) range from 5 % to 20 % across the studies in Table 1.

Such impairment rates are seen in samples followed up many years post-donation might arguably reflect the base rates of these problems that would be seen in any community-based population and, hence, would be unrelated to donation. It is, therefore, interesting to note the range of donation-related predictors and correlates of HROOL outcomes that were identified across these reports, as shown in Table 1. The most consistent correlates of poor HRQOL at follow-up were greater BMI at donation (a risk factor for impaired physical HRQOL), and donors' reports that they had negative psychological outcomes early post-donation or had longer recovery times. Donors' early post-donation reactions were assessed only retrospectively at follow-up. Thus, their recall may have been colored by current HRQOL rather pinpointing important risk factors for follow-up HRQOL. However, the BMI assessments were obtained from medical records from the time of donation. These findings suggest that BMI may be a central factor to consider during donors' medical evaluation not only due to its increasing prevalence in donors and potential impact on medical outcomes [17] but due to its role in increasing risk for poor psychosocial outcomes. The mechanism by which BMI may affect psychosocial outcomes remains unknown, but it has been suggested to stem from its impact on risk for surgical complications and other post-donation health



Table 1 Summary of recent studies examining long-term psychosocial outcomes in living donors

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Authors, Country	Sample	Comparison data	Descriptive data on outcomes	Predictors or correlates of outcomes*	Factors not associated with outcomes
Gross et al., USA [12••]	N=2455 kidney donors from 3 sites. Response rate: 36 % of those eligible (70 % of those contacted). Mean= 17 years post-donation (range, 5–48)	a) U.S. normative data b) Community- residing respondents from a national health survey	Mean SF=36 HRQOL subscale scores exceeded normative levels and were similar to mean levels in the national health survey sample 14 % to 20 % of donors scored below normative means on the SF-36 subscales; 9 % were considered to show impaired physical component HRQOL scores and 9 % showed impaired mental component scores 73 % felt health was unaffected by donation, 16 % reported a positive effect, 11 % reported a negative effect	Impaired physical component HRQOL: From medical records: non-white ethnicity, greater BMI, less education, pre-donation psychiatric history, donor not a first degree relative of recipient From follow-up survey: recollections of longer recovery time, longer time to resume daily activities; recovery longer than expected; depressed post-donation, felt ignored post-donation; less social support post-donation; medical complications post-donation Impaired mental component HRQOL: From medical records: younger age at donation; less education, pre-donation psychiatric history From follow-up survey: recollections of longer recovery time, longer time to resume daily activities, depressed post-donation, felt ignored post-donation; less social support post-donation, lower comfort with decision to donate, managing at follow-up less education at follow-up	Medical record measures of pre- donation history of depression or anxiety, employed at donation, gender, type of sugical procedure, recipient graft loss or death
Takada et al., Japan [13••]	N=578 liver donors from one site. Response rate: 58 % of those eligible. Mean=7 years post-donation (SD 3), range 1–15.	Japanese normative data	Mean SF-36 subscales and component scores were at or above normative levels	Lower mean physical component HRQOL: From medical records: older age at donation From follow-up survey: recollections of longer recovery time, more current comorbidities Lower mean mental component HRQOL: From follow-up survey: recent time off from work due to donation, more current comorbidities Lower mean role function component HRQOL: From follow-up survey: recollections of longer recovery time, more hospital visits due to donation-related symptoms, more current comorbidities.	Medical record measures of occurrence/ severity of post-donation complications, rehospitalization, gender, relationship to recipient, recipient death
de Groot et al., The Nether- lands [14•]	N=316 kidney donors from one site. Response rate: 74 %. Mean=5.1 years (SD 3.2) post-donation (range .9-13.5)	Dutch normative data	Mean SF-36 HRQOL subscales and physical component score were significantly higher than normative levels; mental component score was similar to normative level 11.5 % had impaired physical component HRQOL; 17.5 % had impaired mental component HRQOL	Impaired physical component HRQOL: From medical records: higher BMI, smoked at time of donation From follow-up survey: more current fatigue, less current social participation Impaired mental component HRQOL: From follow-up survey: recollections that they expected more negative health consequences of donation, had more current fatigue, less current social participation	Medical record measures of kidney function and blood pressure preand post-donation, cardiovascular events predonation; measures from follow-up survey on expected changes in donor-recipient relationship, measures of personal growth
Clemens et al., Canada [15•]	N=203 kidney donors from 9 sites in 3 countries. Response rate: 48 % of those eligible and contacted. Mean=7 years (SD 6) post-donation (median, 5.5, IRQ, 4–8).	a) Canadian normative data b) Demographically similar non- donors nominated by donors	Mean SF-36 HRQOL subscales and component scores were similar to or higher than normative levels No significant differences between donor and non-donor samples in SF-36 HRQOL subscales and component scores, 15D HRQOL score, or overall rating of health	(None)	Medical record measures of type of nephrectomy, time since donation, whether the recipient had an adverse outcome (all examined for mental health HRQOL only)



Table 1 (continued)	ınuea)				
Authors, Country	Sample	Comparison data	Descriptive data on outcomes	Predictors or correlates of outcomes*	Factors not associated with outcomes
Mjøen et al., Norway [16•]	N=1508 kidney donors Community-residing from national registry. respondents from Response rate: 76 % of one county in those eligible. Mean= 12.7 years post-donation (range, 1.1-42.9).	Community-residing respondents from one county in Norway	Mean SF-36 HRQOL subscales and component scores were significantly higher than the comparison group 6.8 % felt donation was detrimental to health; 5.4 % felt donation led to conflicts with friends or family; 5.4 % doubted they would donate again if they could	Lower mean SF-36 subscale and component scores: From follow-up survey: greater doubt at follow-up about whether the donor would have donated if he/she had a chance to reconsider.	

Impaired HRQOL signifies HRQOL that was below a study-identified threshold (scores less than .5 standard deviation below the normative mean); lower mean HRQOL indicates that HRQOL was Abbreviations: SD, standard deviation; IQR, interquartile range; SF-36, short-form 36 measure; HRQOL, health-related quality of life; BMI, body mass index examined as a continuous variable

All studies used cross-sectional retrospective designs

problems [12••, 14•]. Additional work directly examining such mechanisms would be important for developing strategies to mitigate any psychosocial impacts of BMI in donors.

Among other risk factors considered in the recent studies, it is noteworthy that the studies failed to find that recipient status (i.e., whether the recipient suffered graft loss or death) was related to donor long-term HRQOL outcomes. The occurrence of early post-donation donor complications was inconsistently associated with HRQOL, as was the donor's relationship to the recipient, although the vast majority of donors in these studies were first-degree relatives of their recipients.

Although these recent reports expand our understanding of the nature and correlates of long-term HRQOL, their generalizability may be limited because response rates were in some cases relatively low (see Table 1), and there were often important differences between follow-up survey responders and nonresponders. In addition, there are important differences between donors who donated even five years ago (much less 30 to 40 years ago) and today's donors in demographics, medical characteristics, and relationship to transplant recipients. For example, current donors in the U.S. include a much higher proportion of ethnic minorities, have more medical comorbidities at donation, and are less likely to be closely emotionally or biologically related to their recipients than are the donors described in the recent long-term follow-up studies [2•, 11•]. Because of the changing composition of the donor population, both short-term and long-term psychosocial outcomes and their risk factors require ongoing assessment. Furthermore, rather than relying on making comparisons of donors to normative data (which were collected largely during the psychometric development of the HRQOL instruments), it would be important for studies to routinely incorporate relevant comparison groups selected specifically to enable better identification of unique impacts of donation on HRQOL. Work by Clemens et al. [15•] in Table 1 presents one example of an attempt to construct a comparison group of individuals who would be expected to be similar to donors in major respects but who did not undergo donation.

Another limitation that the studies in Table 1 share with previous literature is the almost exclusive focus on generic HRQOL measures, rather than consideration of donation-specific HRQOL measures or in-depth measurement of certain domains of well-being that may be more relevant to unique issues and concerns faced by donors. For example, it has been suggested that diagnosable depression, anxiety and other negative psychological reactions may be important sequelae of living donation that often go unrecognized [7, 12••]. Recent work by Lentine and colleagues [18••] is, therefore, notable because it considered both the prevalence and correlates of depressive disorders in a national sample of kidney donors, based on an analysis of billing claims of a private health insurer. From the start of insurance benefits (at a median of 4.9 years post-donation) to one year later, Lentine et al.



found that 4.2 % of their cohort of 4650 donors experienced diagnosed depression and 11.5 % had experienced depression by five years later. Although depression was less common in these donors than in age-matched and gender-matched general insurance beneficiaries, the risk of depression was significantly elevated among donors who were female, white, or required reoperation after initial donation surgery. Among non-spousal unrelated donors, recipient death or graft failure more than doubled the risk of depression. Recipient outcomes did not increase related donors' depression risk.

Finally, a recent synthesis of qualitative studies examining kidney donors' reactions to the donation experience helps to round out the picture of the wide-ranging impact of donation on donors' lives. Across 26 studies, Tong et al. [19] concluded that several themes dominated donors' views of their experience (Table 2). Each theme included a mixture of both negatives and positives, reflecting losses and difficulties as well as personal benefits. This mixture illustrates the complexity of the reactions that donors may have.

Financial Impacts

The financial impacts of donation encompass out-of-pocket costs; lost wages or loss of employment; difficulties in obtaining or retaining health and life insurance; and hardships that may be more difficult to assess empirically (e.g., financial hardship, reflecting the ability to absorb costs). The impacts may extend to the donor's family. The degree of impact ranges across a spectrum from the severely negative consequences experienced by organ vendors in countries where vending and trafficking continue to prevail, to the burden experienced by donors in countries where the organ transplantation system is highly regulated and is designed to prevent coercion of donors and promote their health and safety.

Organ vending and trafficking have been repeatedly shown to have not only extremely high physical and psychological costs for vendors, but also socioeconomic costs [9, 20]. A recent qualitative study vividly captures these costs in Bangladeshi kidney donors, calling such activity a form of bioterrorism that leaves impoverished persons in significantly worsened circumstances than before donation [21]. There is an international consensus that this type of activity should be prohibited [22].

In countries with strict standards to protect donor safety, where prospective donors are carefully evaluated to determine that they have no expectation of remuneration, there unfortunately also continue to be some significant financial burdens associated with living donation. A small literature has accrued within the last ten years, mostly from North America, and focused on living kidney donors, showing that (a) concerns about the financial impact of donation affect the pursuit of living donor transplantation by transplant candidates, potential donors, and transplant programs, and (b) significant proportions of donors report costs and financial hardship attributable to donation and recovery from surgery. For example, twothirds of kidney transplant candidates report concerns about such effects on potential living donors [23], and more than one-third of living donor kidney and liver transplant programs reported that prospective donors themselves declined the option of donation due to reservations about finances and insurability [24]. At donation, 18 % to 25 % of kidney donors are uninsured [25, 26]. After donation, up to almost one-quarter of kidney donors report financial hardships attributable to donation [16•, 27, 28•]. Although Clemens et al. [15•] recently found no differences in employment rates between kidney donors and non-donor comparison group members, implying no impact of donation on employment per se, living donation exerts other costs. For example, 25 % to 30 % of employed kidney donors do not have sufficient medical leave and/or vacation time to cover their surgical recovery [27, 28•]. In

Table 2 Results from systematic analysis of qualitative studies of kidney donors' reactions to the donation experience

Elements of the experience	Major themes describing donors' experiences		
	Renegotiating one's identity	Renegotiating roles	Renegotiating relationships
Negative elements	 Feelings of fear and vulnerability Having a sense of loss Depression Guilt 	 Fears about being able to resume previous activities Problems fulfilling multiple simultaneous roles (e.g., being a donor as well as a parent, caregiver, etc.) 	Feeling neglected Feeling proprietorial concern and worry about the recipient
Positive elements	 Gaining a new appreciation of life Personal growth Enhanced self-worth 	 Feeling like a better person or hero Being seen by others as a hero 	Strengthened bonds with the recipientStrengthened bonds with family and friends

(Adapted from: 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) [19].



addition, 2 % to 9 % of kidney donors report problems getting health, life, or disability insurance after donation and nearly 12 % report stress regarding future health insurability [27, 29]. In liver donors, a study from Germany reported that 3 % were denied life insurance due to their donation [30].

Gill et al. [31••] recently sought to quantify donor financial burden more precisely. They used census tract data on median household income levels to estimate donor (and recipient) income in a large series of living donor transplants captured in the U.S. Renal Data System. Using a conservative estimate that a kidney donor's direct out-of-pocket expenses total approximately \$5000 [32], they showed that this cost is greater than one month's income for 76 % of donors. They also demonstrated that most recipients have modest median household incomes that are similar to their donors' income levels. Thus, recipients would likely have limited ability to help their donors cover even those expenses that recipients are allowed to cover under the U.S. National Organ Transplantation Act, including out-of-pocket costs and lost wages.

Other recent studies have focused on identifying segments of the donor population at greatest risk for financial burdens. McGrath et al. [33] show in a detailed qualitative report that Australian kidney donors from rural settings incur greater costs for travel and accommodations, loss of income due to missed work, and costs of testing, since testing at local facilities may not be covered by the transplant program or recipient insurance. Similar issues are likely to arise in other countries. In particular, financial and logistical burdens to donors are among the most often-cited factors believed to hamper follow-up care of living donors in the U.S. [34, 35••]

The risks of financial impacts both pre-donation and postdonation are magnified in ethnic/racial minority donors. Purnell et al. [36] summarized recent evidence, reviewing the socioeconomic barriers and impacts that arise at the stages of kidney donor identification, evaluation, and donation in the U.S. For example, the fact that ethic minority donors are less likely to have health insurance at donation sets the stage for a cascade of potential financial hardships should donors develop ongoing health problems, miss additional work, and accrue other costs in the wake of donation. Given that ethnic minorities comprise a disproportionately large percentage of kidney transplant candidates, it is imperative that barriers such as donor access to health insurance not serve to preclude donors from helping patients in need [25, 26]. Rather, policy-based initiatives are needed to ensure that these generous individuals have healthcare coverage for the long-term post-donation [26].

Because the literature on financial impacts in living donation remains small and largely limited to North American cohorts, it is not known whether the findings are generalizable. Additionally, the data largely come from donors' retrospective reports, requiring accurate recall of historically incurred costs [11•]. There has been almost no consideration of

financial impacts in liver donors, or financial burden and hardship among donors' family members. Finally, although it is presumed that financial issues will affect donor ability or willingness to obtain follow-up health monitoring and care, there remains little direct evidence demonstrating this [37].

Special Psychosocial and Financial Issues in Unrelated Donors

The small literature to date provides somewhat mixed evidence on whether unrelated donors' psychosocial or financial outcomes differ from those in related donors. Gore et al. [38] recently examined census tract data for a national cohort of U.S. kidney donors and found that unrelated donors had higher socioeconomic status than did related donors. This suggests that unrelated donors might have a greater financial "cushion" for donation. Rodrigue et al. [28•] collected followup survey data from a sample of nondirected and directed anonymous kidney donors and a comparison group of related donors to examine financial as well as psychosocial outcomes. The two groups reported similar levels of psychological benefits and health consequences of donation. They did not differ in perceived financial consequences, HRQOL, or satisfaction with having donated. Massey et al. [39] obtained similar survey findings. However, both reports provide some evidence that anonymous donors may be more likely than other donors to experience negative reactions from others regarding their decision to donate, and these reactions may cause donors distress.

In the only prospective study to date, Timmerman et al. [40•] found that psychological symptoms increased from predonation to post-donation in a sample of nondirected anonymous donors, particularly in the areas of depression, anxiety, somatization, hostility, and sleep problems. The increases were larger among donors with longer follow-up times. The authors suggest that the changes might represent natural fluctuations in symptoms, a hypothesis that would require the inclusion of a comparison group (e.g., related donors or nondonors) followed longitudinally in order to be tested. Finally, one small report of kidney exchange participants found no evidence that these individuals needed additional psychosocial services or practical or emotional support after donation [41]. No studies have compared outcomes in unrelated vs. related liver donors.

An important question is whether recipient outcomes would differentially affect unrelated vs. related donors. On one hand, the lack of a close connection between unrelated donors and their recipients might lead to less distress in these donors in the event of recipient morbidity or death. Alternatively, given the lessened likelihood of ongoing contact with the recipient, unrelated donors may feel even more devastated at learning of a poor recipient outcome because this might be the only specific information they have about the recipient.



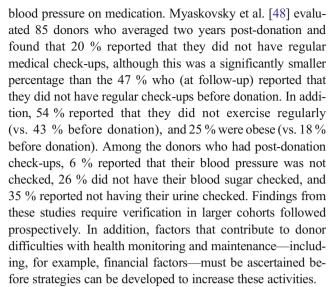
The findings in the Lentine et al. report $[18 \cdot \cdot]$ are consistent with this supposition.

Management of Psychosocial and Financial Outcomes

Requirements and Recommendations for Follow-up

The routine collection of follow-up data on donor outcomes is becoming more common in European and North American countries [5, 42]. To date, most efforts focus on donor clinical and laboratory data, although one psychosocial parameter (whether donors have returned to work) is collected in the U.S., and a range of HRQOL and psychosocial parameters are targeted for future collection in a European registry [42, 43]. In the U.S., the submission of follow-up information to the Organ Procurement and Transplantation Network is required through two years post-donation [5]. The level of missing data in the submitted forms renders them of little value [2•, 44•, 45], and donors with missing data are more likely to have the very characteristics that increase their risk for medical problems (e.g., older age and a history of hypertension in kidney donors) [44•]. With recent policy modifications, submitted forms information must be complete (i.e., without any missing information) for the majority of kidney donors [5]. Similar requirements may go into effect for liver donors [4]. The ability of living donor programs to obtain high rates of follow-up is a subject of debate. Recent surveys of living donor kidney and liver programs show that, while follow-up (a) is viewed as important for donor safety and well-being [35••] and (b) should be expanded to include more psychosocial outcomes [35...], programs perceive significant barriers to locating and evaluating donors [34, 35...]. Barriers include potential unwillingness among donors to participate in such evaluations [34, 35...]. Whether required follow-up constitutes yet another financial burden for donors is another concern [33, 34], although programs with high rates of follow-up generally subsidize at least some costs to donors [45].

The rationale for required follow-up stems from the transplant community's obligation to ensure donors' safety, as well as to provide data to inform future donors about the risks and benefits of donation. This is emphasized in both the education and informed consent of prospective donors, in which—consistent with consensus conference and expert recommendations [2•, 4, 46]—they are encouraged to have annual checkups and engage in other health promotion activities for the remainder of their lives. Yet, two recent cross-sectional follow-up studies suggest that many kidney donors do not engage in recommended activities [47, 48]. Doshi et al. [47] assessed 103 African American donors from two centers at an average of six years post-donation and found that 41 % were hypertensive; of these, over half (52 %) were not receiving treatment, and another 17 % had inadequately controlled



A recent consensus conference on the follow-up care of living kidney donors suggested that rather than requiring U.S. living donor programs to collect extensive medical or psychosocial follow-up data. Specific registries or long-term follow-up research efforts should be devoted to the collection of a full range of donor psychosocial and financial outcomes and their relationships with—or increased risk due to—other medical outcomes [2•, 11•]. This recommendation would address limitations in the evidence that we noted earlier, namely, that although subgroups of living donors may be at heightened risk for psychosocial and financial impacts of donation, we have very limited ability to identify such individuals prospectively. Moreover, there is a dearth of such information in liver donors or in the very small populations of other types of living donors (e.g., lung donors).

Management Strategies for Psychosocial and Financial Outcomes

Approaches to optimize donor psychosocial and financial outcomes come primarily from anecdotal accounts of and recommendations for clinical and educational activities. For example, based on their synthesis of qualitative studies of kidney donors' reactions to the donation experience, Tong et al. developed an educational summary that could be given to donors in order to better prepare them for what to expect emotionally from the donation experience [19, see supplemental materials]. This summary was subsequently revised and adapted as a pamphlet that might be routinely distributed by donor transplant programs [49]. Other recent reviews and recommendations focus on the content and nature of the informed consent process [50•], and the activities of the independent living donor advocate (ILDA) [51•, 52]. With respect to informed consent, findings that post-donation satisfaction and regret are related to perceptions of inadequate predonation information suggest possible deficiencies in the



manner and/or timing of the pre-donation education and informed consent process [50•, 53]. Concerning the ILDA, recommendations have been made that the ILDA's role be extended to encompass post-donation follow-up, particularly with potentially vulnerable subgroups of donors [52]. Thus, as suggested by the Lentine et al. findings [18••], increased vigilance for depressive disorders could be warranted in donors who had serious complications requiring reoperation and in unrelated donors whose recipients suffered death or graft failure. Findings noted earlier regarding BMI as a risk factor for poor physical HRQOL similarly suggest that obese donors may need heightened monitoring as well.

There have been no clinical trials testing the efficacy of increased post-donation monitoring for the identification and treatment of psychosocial problems in living donors. However, we recently developed and tested a brief telephone-based pre-donation intervention designed to prevent the development of such problems in kidney and liver donors [8, 54...]. The intervention utilized techniques from motivational interviewing (MI) [55] to target residual ambivalence (i.e., lingering hesitation and uncertainty) about donating. A literature spanning over 20 years has shown such ambivalence to be prevalent and to be a key risk factor for poor post-donation outcomes in several psychosocial domains, including somatic complaints, psychological distress, and interpersonal relationship strains [8, 56]. We compared prospective donors randomized to receive the MI intervention to those in an active comparison condition (health education) or receiving standard pre-donation care. By three months post-donation, MI participants reported fewer physical symptoms, lower rates of fatigue and pain, shorter recovery times, and fewer unexpected medical problems than other donors. They also had a lower rate of anxiety symptoms and fewer unexpected familyrelated problems. These promising findings from donors at a single center suggest that a broader test involving multiple living donor programs would be warranted as a next step in establishing intervention effectiveness.

We know of no formal tests of interventions to address the negative financial impacts of donation. A recent systematic review of public attitude studies showed a preference among members of the general public for reducing financial disincentives (i.e., removing donor-incurred burdens) as opposed to providing financial incentives for living donation [57]. Indeed, legislation adopted in some countries has sought to achieve this goal, leading to "natural experiments," in which data from before to after the legislative changes were examined in order to assess potential impact on donation rates. For example, Boulware et al. [58] found that rates of unrelated (but not related) donation increased from before to after enactment of U.S. federal and state legislation in the late 1990s supporting donors (including paid or unpaid leave for extended time periods and tax benefits). Most recently, Lavee et al. [59•] demonstrated that there has been a marked increase in living donation rates with the passage of new legislation in Israel. It, among other components, prioritizes organ allocation to individuals who are living donors, removes disincentives for anonymous living donation by mandating reimbursement for lost wages, some coverage for transportation costs, modest insurance reimbursements and social supportive services.

Conclusion

The recent literature is noteworthy for beginning to examine long-term psychosocial outcomes in living donors, and for advancing our understanding of specific areas of psychosocial outcomes that matter most for living donors. Most work considers only kidney donors. The range of identified risk factors for post-donation psychosocial difficulties also remains relatively limited. Identification is hampered by the focus on cross-sectional follow-up assessments as opposed to longitudinal or prospective investigations. However, at least for kidney donors, findings to date point to some identifiable subgroups of donors—e.g., unrelated donors—who may require more intensive short- and/or long-term monitoring in order to identify and manage post-donation psychosocial problems. Management strategies for post-donation psychosocial outcomes have largely gone untested, but promising findings in one small clinical trial suggest that empirical evaluation of strategies for prevention or post-donation intervention could be important in order to optimize the care offered to living donors. Finally, the financial impacts are becoming increasingly apparent, and may be larger and more pervasive than previously realized. While living donor transplant programs may be able to subsidize the costs to donors of required post-donation follow-up monitoring, it is likely that financial disincentives for donation will be successfully removed only via additional national legislation or other government-mandated sources of support.

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Compliance with Ethics Guidelines

Conflict of Interest Mary Amanda Dew, Larissa Myaskovsky, Jennifer L. Steel, and Andrea F. DiMartini declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.



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