Published in final edited form as:

Adv Chronic Kidney Dis. 2012 July ; 19(4): 237–243. doi:10.1053/j.ackd.2012.04.006.

Psychosocial and Socioeconomic Issues Facing the Living Kidney Donor

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Abstract

At the 2010 Conference on Living Kidney Donor Follow-up, a workgroup was convened to comment on the state of the evidence in four broad areas: (a) health-related quality of life postdonation; (b) donors' financial and economic concerns; (c) outcomes issues specific to newer areas of donation, namely kidney exchange and anonymous (directed and nondirected) donation; and (d) the role of informed consent in relation to postdonation psychosocial outcomes. The workgroup sought to offer recommendations regarding research priorities for the next decade, and data collection strategies to accomplish the needed research. The workgroup concluded that there has been little consideration of the nature or predictors of any long-term psychosocial outcomes in living donors. In some areas (e.g., kidney exchange and anonymous donation) there is very limited information on outcomes even in the early aftermath of donation. Across all four psychosocial areas, prospective studies are needed that follow donors in order to examine the course of development and/or resolution of any donation-related difficulties. The formation of a national registry to routinely collect psychosocial follow-up data may be an efficient strategy to monitor donor outcomes in both the short-and long-term years after donation.

Keywords

living kidney donation; psychosocial outcomes; financial outcomes; quality of life; informed consent

From the inception of living donor kidney transplantation in the United States, careful consideration has been given not only to medical outcomes but to the psychosocial well-being of living donors. Significant accomplishments have been made in documenting psychosocial outcomes in the early months and years after donation and this has contributed, in turn, to the development of consensus recommendations for the content and process of the psychosocial evaluation and informed consent of prospective living donors (1–5). The consensus recommendations have themselves led to the development of guidelines and

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The authors have no conflicts of interest or financial disclosures to report.

national policy regarding evaluation of prospective donors as well as required follow-up of these individuals during the first several years postdonation (6–8).

As the United States and worldwide transplant communities continue their efforts to promote the safety of living donor kidney transplantation, it is important to now expand research on postdonation follow-up and outcomes to encompass donor psychosocial outcomes that either have received relatively little attention to date or have been examined primarily in the early years postdonation. Moreover, given the array of psychosocial issues that might be considered, it is essential to develop a research agenda that targets the issues meriting greatest attention in the next decade. To this end, a workgroup was convened at the 2010 Conference on Living Kidney Donor Follow-up to consider the available evidence and to delineate research questions of highest priority in four broad areas: health-related quality of life (HRQOL) postdonation; financial and economic concerns among donors; outcomes issues specific to newer areas of donation, namely kidney exchange and anonymous (directed and nondirected) donation; and the role of informed consent in relation to postdonation psychosocial outcomes.

Workgroup members are listed in Table 1. They were asked to:

- a. comment on the state of the evidence in each of these four areas, including the gaps in knowledge within each.
- b. offer recommendations regarding research priorities for each area, and
- c. generate a set of data collection strategies likely to have the best chance of enabling high-quality follow-up and psychosocial outcomes data to be collected from large, representative samples of donors in the United States.

As the backdrop to considering these issues, workgroup members delineated what they saw as the major reasons for following donors postdonation and for assessing their psychosocial outcomes not only in the short-term but in the long-term years as well. As summarized in Table 2, the rationale for collecting such data lies in the need to fully prepare individuals and families considering living donation, as well as to develop educational and other interventions both before and after donation in order to promote good psychosocial outcomes. Indeed, failure to determine (or to take steps to ensure) that donor psychosocial outcomes in both the short- and long-term are positive is likely to adversely affect the transplant community's ability to support the ongoing need for living donor transplantation in the face of continued organ shortages.

Evidence to date on psychosocial outcomes

Workgroup discussion focused on brief summaries of background evidence prepared by individual workgroup members (listed below), followed by delineation of major gaps in the evidence.

Donor HRQOL

Zeeshan Butt, Mary Amanda Dew

HRQOL in donors, as in other populations, is best conceptualized within the World Health Organization perspective that health is “not merely the absence of disease or infirmity” (9). HRQOL accordingly is a multidimensional concept that encompasses an individual's physical, emotional, and social well-being, as impacted by any medical condition or treatment (9–11). Pre-donation psychosocial and medical evaluations are intended to preclude donation by individuals with significant physical, emotional, or social liabilities, and those unwilling or unable to give informed consent for donation. This evaluation

process results in donors who are generally very healthy before donation. In fact, pre-donation assessments of kidney donors' HRQOL across multiple dimensions show uniform and extremely high levels of well-being, relative to normative or comparison group levels (e.g., 12–14). Literature reviews have shown that, on average, donors' HRQOL remains high and shows little change from pre- to postdonation in terms of perceived health, psychological status, and social functioning (15,16). A recent report suggests that their HRQOL, on average, exceeds that of the general population, even many years postdonation (17). But relying on averages can obscure additional findings that sizable minorities of donors experience psychosocial difficulties postdonation. For example, as summarized in a recent review (18), significant psychological distress and/or diagnosable depression and anxiety disorder have been documented in kidney donors, typically at a rate of about 1 in every 4 donors. Donors have also reported the development or worsening of interpersonal difficulties within their families. Up to one third of donors report that their health is fair to poor or markedly worse since donation, with symptoms of fatigue and enduring pain being particularly common (18).

Key shortcomings in the postdonation HRQOL literature identified during discussion by workgroup members included the limited durations of followup (1 year or less after surgery in the bulk of research), a predominance of cross-sectional rather than longitudinal or prospective study designs, and relatively small convenience samples (n 's < 100). Few studies include comparison groups whose HRQOL might serve as benchmarks for donors' HRQOL.

Importantly, the HRQOL assessments themselves remain limited. Much of the existing literature relies on generic HRQOL assessments rather than the use of HRQOL measures specific to the living donor population. A narrow range of potential predictors of donor HRQOL have been considered, with little attempt to examine how HRQOL outcomes are influenced by such factors as donor motives and psychological history, donor ethnicity or cultural background, or donors' social network and supports. Several potentially important areas of HRQOL outcomes have received little consideration, including issues such as time to return to work or daily responsibilities, or bidirectional effects between donor and recipient HRQOL outcomes. Whether HRQOL early postdonation itself affects risk for later-term HRQOL deficits is unknown. Little consideration has been given to whether there are identifiable subgroups of donors who may require more intensive short and/or long-term monitoring in order to implement psychological or other psychosocial interventions in a timely manner. Intervention development and evaluation is extremely rare.

Donor financial and socioeconomic concerns

James R. Rodrigue, Cheryl L. Jacobs

Concerns about financial and economic costs of donation affect the pursuit of living donor kidney transplantation by transplant candidates, potential living donors, and transplant programs. For instance, approximately two-thirds of transplant candidates report concerns about pursuing living donor transplantation because of the potential financial and economic impact on the donor (19). More than one-third of living donor transplant centers have reported that potential donors in their centers declined the option of donation due to concerns about finances and insurability (20). In a recent survey of U.S. kidney transplant programs, 15% reported that they do not accept donor candidates without health insurance and 42% viewed the lack of health insurance as a relative contraindication to donation (21).

Concerns by patients, prospective donors, and centers are not unfounded. The literature shows that donors incur many direct and indirect costs related to donation (22), and 4% to 23% of donors have reported financial hardships attributable to donation and recovery from

surgery (23,24). From 25% to 30% of employed donors do not have ample medical leave and/or vacation time to adequately cover their surgical recovery (23,24). About 18% of donors do not have health insurance at the time of donation (25). Although several studies indicate that insurance companies in the U.S. state that kidney donation would not affect an individual's ability to obtain or retain health and life insurance (26,27), other reports find that 2% to 9% of donors reported problems getting health, life, or disability insurance after donation (24,27). Nearly 12% of donors report stress over future health insurability (27).

Workgroup members agreed that a key shortcoming of the literature on financial and socioeconomic concerns is that the body of empirical work remains very small. The few available data come primarily from retrospective reports of donors, often years after surgery, and they rely on the recall of historically incurred costs. Prospective data are extremely rare, and methods used to assess both direct and indirect costs associated with donation vary considerably. For these reasons, we have insufficient information regarding the prevalence of donor difficulties in obtaining/retaining health and life insurance, the full array of donor and donor family costs associated with donation, and whether financial issues and costs vary across types of donation (e.g., related vs. unrelated donation, directed vs. nondirected donation). Little is known not only about whether donors experience unexpected costs, but their extent of any financial hardship (ability to absorb costs), financial burden and hardship among their family members, and whether financial issues affect donor ability or willingness to obtain follow-up health monitoring and care for any donation-related complications. It remains unclear how many donors file short- or long-term disability claims, or the extent to which transplant centers absorb donors' postdonation medical costs.

Finally, research has not examined whether donors (and transplant programs) are aware of, have access to, and understand the full array of financial assistance programs or other resources that may be available to them. We have limited understanding of whether willingness to donate, donation rates and donor psychosocial outcomes are affected by factors such as the receipt of long-term donation-specific health insurance, employer acceptance and encouragement of the donor, and employer assistance (e.g., paid leave).

Psychosocial outcomes in new and developing areas of donation

Dianne LaPointe Rudow

Two areas showing rapid growth in living donor transplantation are kidney exchange (KE) programs, and donation by anonymous (directed and nondirected) donors. The literature on psychosocial issues in KE has focused primarily on (a) clinical, logistical and feasibility issues as new programs of matching and exchange are developed and mounted (28–30) and (b) delineation of psychological, behavioral, or ethical issues relevant to evaluating or obtaining informed consent from prospective donors for KE (3,31). One small study found no evidence that KE participants required additional psychosocial services or supports postdonation (32). However, there is little additional evidence on psychosocial outcomes in these individuals.

Empirical evidence on psychosocial outcomes in anonymous donors is also slim and has focused on elements to consider in the evaluation and informed consent of these donors (e.g., an increased emphasis on assessing motives for donation and expectations regarding meeting or developing a relationship with the recipient; issues to consider when these donors participate in KE programs)(3,31,33,34). In two small studies of anonymous donors, patterns of HRQOL outcomes appeared similar to those in other types of donors, namely, average HRQOL levels were similar or higher than normative levels, but significant minorities of donors reported psychological, somatic, interpersonal, and/or financial difficulties (23,35). These donors may also be likely to experience negative reactions by

others regarding the act of anonymous donation, and these reactions may promote elevated psychological distress (35).

Workgroup members agreed that the key gaps in literature on these issues include the small samples studied to date and the narrow range of psychosocial outcomes considered in KE donors as well as in anonymous donors. Whether outcomes in these groups differ systematically from those of other living kidney donors is unclear. In addition, for KE, it is not known whether specific elements of the exchange affect donor psychosocial outcomes (e.g., when a donor and his/her own transplant candidate differ markedly in age from a donor-candidate pair with whom they are exchanging kidneys, or when there are differences in the success of the transplants across the various recipients in the exchange). Whether such factors influence donor willingness to engage in postdonation medical follow-up and health monitoring is unknown. New strategies are being developed and tested for KE (e.g., the inclusion of anonymous nondirected donors, and the use of “bridge” donors who, at the end of a chain of exchanges, may wait for many months before donating to a prospective recipient). Whether the outcomes for these individuals in the short- and long-term after donation resemble outcomes among other KE donors or among donors not participating in KE is unknown.

For anonymous donors, there has been little empirical examination of factors influencing the decision to donate (e.g., their motives and the circumstances leading them to come forward for donation), and little consideration of these factors’ relationships to postdonation outcomes. Whether psychosocial outcomes differ between anonymous donors who want vs. do not want to have any relationship with the recipient is unknown. Finally, unique financial or economic issues arising for either KE donors or anonymous donors have not been investigated.

Informed consent in relation to postdonation psychosocial outcomes

Maryam Valapour, Linda Wright

Among the elements required in order for individuals to give informed consent to serve as living donors, two key conditions must be satisfied (36). First, they must understand the information they have received regarding the process, risks, and benefits of donation. Second, their decision to proceed with donation must be voluntary (i.e., made by their own free will). Understanding and voluntariness both exist along a continuum. Thus, even when the informed consent process is carefully executed and living donor transplant programs are confident that prospective donors’ understanding and voluntariness are sufficient to allow them to proceed with donation, there is still likely to be some degree of variability across donors in these areas. This variability may be linked to postdonation outcomes.

In the very small empirical literature on these issues, one survey found that, while over 90% of living kidney donors understood the effects of donation for the recipient, the donation process, and the short-term medical risks for donors, only 31% to 68% understood the long-term medical risks, or psychological or financial risks of donation (37). The few reports yield mixed findings as to whether donors’ perceptions of understanding (or their views of being adequately informed) are associated with willingness to donate again or with regret at having donated (37,38). Perceptions of inadequate understanding have, however, been linked to deteriorating social relationships, including separations and divorce in the aftermath of donation (38,39). A recent review suggested that postdonation feelings of being inadequately informed were also associated with HRQOL generally, and with psychological well-being in particular (40). Given work in other patient populations suggesting that inadequate understanding about a medical procedure is linked to greater anxiety about undergoing the procedure and more somatic symptoms in its aftermath (41–43), living

donors with lower levels of understanding may be at risk for heightened anxiety pre-donation, and they may have more worry about complications and long-term health effects post-donation.

Few data are available concerning the impact of donor voluntariness on post-donation psychosocial outcomes. However, it is noteworthy that up to 40% of donors have reported that their decision to donate was not entirely voluntary and/or that they felt pressured by others or by the circumstances in making their decision (37,38,44). These reports, in turn, have been found to be associated with declining social relationships after donation (e.g., higher risk of separation and divorce)(38).

The workgroup agreed that little is known regarding donors' views of the informed consent process, what they retain post-donation from this process, and what factors they believe were or were not adequately addressed. How best to modify the informed consent process for newer types of donation (e.g., KE program participants and anonymous directed and nondirected donors) is unknown. With regard to understanding and voluntariness in particular, workgroup members agreed that prospective studies are critically needed to examine their impact on a full range of post-donation short- and long-term psychosocial outcomes. The extent to which understanding and voluntariness are themselves interrelated, and/or whether one or the other element is relatively more important for psychosocial outcomes is unknown. Finally, factors potentially affecting degree of understanding and voluntariness (e.g., demographic characteristics, levels of general and health literacy, how information for gaining informed consent was presented to prospective donors, transplant candidate characteristics such as medical urgency of transplant) should also be examined. The identification of critical factors could prompt the development of interventions to improve the informed consent process that might, in turn, improve post-donation psychosocial outcomes.

Recommendations for long-term donor follow-up research priorities

The workgroup weighed the needs for additional research in each of the four areas considered and then delineated the highest priority questions that should be considered in a research agenda going forward (Table 3). Given that resources to be devoted to collecting donor follow-up data are limited, the workgroup judged that answers to the questions listed in Table 3 would provide critical information on which to then build more targeted longitudinal, prospective, or intervention studies. The data resulting from the agenda listed in Table 3 might also suggest what areas of psychosocial outcomes should be routinely monitored during clinical follow-up in living donors during the years after donation, as well as what areas are seldom problematic and would not require routine monitoring by transplant programs.

Recommendations for strategies to collect long-term donor psychosocial follow-up data

The workgroup debated the issue of how best to ensure that national data on long-term psychosocial outcomes could be systematically collected. Given limited resources for data collection (no matter whether such funding comes from clinical programs or external grants), a key tradeoff exists between breadth vs. depth of data collection. For example, a large registry of living donors might enable repeated surveys from a representative population, but might not allow for an in-depth exploration of many research questions. That is because the types of studies that require intensive or lengthy questioning or qualitative assessments would be too burdensome and costly to conduct with large samples. In contrast, samples enrolled in order to exhaustively investigate multiple facets of an issue (e.g., very

detailed questioning about HRQOL or about individuals' exact understanding of all aspects of the informed consent process) are likely to provide important levels of detail about selected issues but may be more subject to participant selection biases, and may be relatively small and less generalizable.

Given these considerations, the workgroup suggested that a two-tier approach would be most realistic. This might include, for example, a national registry of donors who provide information on a limited set of variables, with data collection being accomplished by a single entity (e.g., by a contractor or by an organization focused on living donation). This is similar to the model adopted by the National Marrow Donor Program. Then, in addition to the national registry, voluntary subsamples of donors might be recruited to be assessed by expert researchers seeking to obtain more extensive data in order to address specific psychosocial issues. These expert researchers might either (a) collaborate and receive financial support for additional data collection efforts through the contractor and/or governmental agency responsible for the registry, or (b) seek external grants (e.g., the National Institutes of Health) in order to conduct the work. Advantages of this two-tier approach could include more complete outcomes ascertainment than what is currently obtained by U.S. transplant programs, who are charged with collecting follow-up data on donors. In addition, such an approach could lead to a significantly reduced burden on transplant programs since a separate entity would be responsible for data collection.

Conclusions

Examination and documentation of both short- and long-term psychosocial outcomes after living donor kidney transplantation is important in order to better educate and prepare prospective donors, accurately anticipate donors' postdonation needs, and provide timely interventions for donors. Although a growing literature has considered HRQOL and financial issues in the early months and years postdonation, there has been very limited consideration of the nature or predictors of these or other long-term psychosocial outcomes in living donors. In some areas (e.g., kidney exchange and anonymous donation) there are no data on long-term outcomes and limited information on outcomes even in the early aftermath of donation. Whether the informed consent process could be further improved in order to foster optimal postdonation outcomes also remains largely unknown. Across all of the areas of psychosocial outcomes considered by the workgroup, prospective studies are needed that follow donors in order to examine the course of development and/or resolution of any donation-related difficulties. The formation of a national registry to collect routine follow-up data may be an efficient strategy to monitor donor outcomes in both the short- and long-term years after donation. Additional research studying smaller samples of donors within the registry would allow for more in-depth evaluation of new psychosocial issues that might emerge as the practice of living donor kidney transplantation continues to evolve.

Clinical Summary

- Examination of psychosocial outcomes after living kidney donation is important in order to educate prospective donors, anticipate donors' needs, and provide timely interventions for donors.
- Limited outcomes data are available, particularly in the long-term postdonation, in each of four broad areas: health-related quality of life, financial and economic issues, outcomes in newer areas of donation (kidney exchange, anonymous donation), and the role of informed consent in relation to outcomes.

- A workgroup was convened to develop a research agenda that targets the issues meriting greatest attention in these areas, and to propose optimal strategies for data collection.
- The resulting research agenda emphasizes the importance of prospective studies in order to examine the course of development and/or resolution of any donation-related difficulties.
- Data collection strategies should involve the development of registries (to routinely monitor psychosocial outcomes), as well as the completion of smaller substudies of registry participants (for in-depth examination of specific psychosocial issues as needed).

Acknowledgments

Preparation of this article was supported in part by Grant R21 NR011149 from the National Institute of Mental Health, Rockville, MD.

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Table 2

Rationale for assessing long-term psychosocial outcomes in living kidney donors

- To educate and help to improve the informed consent of prospective donors
- To improve the evaluation process and criteria used to approve individuals as donors
- To delineate outcomes that donors themselves consider to be important
- To document outcomes among donors participating in evolving programs such as kidney paired exchange and anonymous nondirected donation
- To accurately anticipate donors' long-term care needs
- To provide timely late-term interventions for donors
- To identify any additional psychosocial benefits of donation
- To further improve the donation experience so future donors, recipients, and families are not deterred from considering living donation

Table 3

Long-term follow-up of living kidney donors: Priorities for research in 4 key areas of postdonation psychosocial outcomes

Area of psychosocial outcome	Priority issues
HRQOL	<ul style="list-style-type: none"> Assess donation-specific HRQOL rather than using only generic HRQOL metrics that may not be relevant to donor concerns Assess not only typical HRQOL domains (physical, psychological, social) but behavioral outcomes (e.g., adherence to health maintenance recommendations) Determine if HRQOL early postdonation (first year) affects degree of risk for later-term difficulties (cascading events); examine who will have which trajectory of HRQOL benefit/harm across post-donation years Prospectively examine several classes of predonation factors effects' on HRQOL outcomes (e.g., motives for donation and other psychological factors; donor ethnicity/cultural background; donor-recipient relationship variables) Develop and evaluate the effectiveness of predonation intervention strategies to promote good postdonation psychosocial outcomes
Financial and socioeconomic concerns in donors	<ul style="list-style-type: none"> Prospectively examine the incidence/prevalence of a full range of financial consequences of donation, including new financial costs incurred, employment issues, health and life insurability, and associated family-related financial costs Examine whether financial/socioeconomic concerns and hardship affect long-term donor HRQOL outcomes, follow-up and healthcare maintenance
Issues in kidney exchange and anonymous (directed/nondirected) donors	<ul style="list-style-type: none"> Conduct large-sample studies of kidney exchange and anonymous donors to investigate a full range of psychosocial outcomes (e.g., HRQOL, financial) and their predictors. Compare donors in exchange programs, anonymous donors, and remaining types of donors on psychosocial outcomes and their predictors Examine whether the degree to which any relationship is developed with the recipient affects psychosocial outcomes (including adherence to health maintenance and follow-up requirements) Prospectively examine the impact of motives and other predonation factors on anonymous donors' psychosocial outcomes
Informed consent and its relationship to postdonation outcomes	<ul style="list-style-type: none"> Determine whether, in the long-term postdonation, donors feel the education and informed consent process gave them reasonable expectations for donation and its aftermath. Conduct prospective, large sample studies to assess associations of key elements of informed consent (level of understanding, voluntariness) with a full range of psychosocial outcomes (e.g., regret, multiple domains of HRQOL). Examine whether different modes of presentation of required elements of informed consent (e.g., risk information), as well as donor preferences for any additional information (e.g., regarding unique recipient risk factors) affect understanding, voluntariness, and postdonation psychosocial outcomes