

Decision making and psychosocial outcomes among living kidney donors: a pilot study

With an increasing number of available kidney transplant donors comes greater demand for systematic screening of prospective donors to ensure the integrity of the donor's decision and to minimize the risk of a poor postoperative outcome. The present study was intended to explore psychosocial outcomes after kidney donation, aspects of donors' decision making, and donors' experience of the transplantation process. It was hoped that this pilot study would inform the design of a large-scale longitudinal prospective investigation of psychosocial outcomes of kidney donation. In this cross-sectional, retrospective investigation, all patients who had received psychosocial screening before their kidney donation were approached. Seventeen of 43 previous kidney donors responded to a postal questionnaire. Donors' health-related quality of life was higher than population norms on all dimensions. Most participants reported involving someone else in the decision-making process. Donors indicated high levels of satisfaction with virtually all aspects of the donation process. The generalizability of the findings in the context of the limitations of the present pilot study is discussed and specific suggestions for the design of future studies are provided. (*Progress in Transplantation*. 2010;20:53-57)

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Recent legislative changes¹ permitting consideration of kidneys from nonrelated donors have led to an increase in the number of living donor transplantations. With this change comes a greater need for the development of thorough screening procedures of prospective donors in order to promote fully informed consent and optimize the safety of donors. Donors' postoperative quality of life has been widely studied with a general, albeit tentative, consensus that donors' quality of life is at least equivalent, if not better than that of controls.² Beyond investigating health-related quality of life, little investigation of outcomes relating to psychosocial well-being has been done. Some concern about donors' well-being has been expressed,³ with donors seemingly having an increased likelihood of developing psychological morbidity.⁴ Such information regarding the true extent of risk is required for fully informed consent and the evaluation of prospective donors for the presence of risk factors.

The importance of donors' process of decision making is beginning to be recognized as a crucial determinant in predicting risk of adverse psychosocial outcome.⁵

Investigation of this process may reveal the extent and impact of overt and/or covert coercion on both the decision-making process and psychosocial well-being after donation. In the present study, we used standardized instruments to gather preliminary data about how individuals decide to become living kidney donors and how they experience their care and postoperative recovery. An aim of this pilot investigation is to determine the feasibility of obtaining information of this type and the potential value of doing so.

Method

A convenience sample of living kidney donors participated in the study. All kidney donors who had been assessed by the Glasgow Liaison Psychiatry Service were eligible for inclusion in the study. The study was sponsored by National Health Services Research and Development, and ethical approval was obtained from the local research ethics committee. All participants had to provide consent. Patients' demographic information was extracted from medical records. Donors were sent a packet containing information sheets about

the present study, the consent form, outcome measures for completion, and a stamped, addressed envelope to return the documents.

Outcomes

The Donor Decision Control Scale is a 3-item 5-point Likert scale indicating the extent to which donors involved a family member or members in the decision to donate. Level 1 is a decision made independently by the donor; level 2 is a decision made by the donor after consulting with a family member(s); level 3 is a shared decision made by both the donor and a family member(s); level 4 is the donor relying on a family member(s) to make the decision after consulting with the donor; level 5 is the donor relying on a family member(s) to make the decision that the donor will donate. The test-retest reliability for this scale in a prospective study⁶ of donor decision making and outcomes was 0.76.

Health-related quality of life with both physical and mental status dimensions was measured by using the SF-36, a 36-item multiple choice and Likert scale instrument.⁷ The SF-36 measures 8 health concepts: physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality, social functioning, role limitations due to personal or emotional problems, and mental health. Higher scores indicate better health-related quality of life. Normative data have been established for a sample from the United Kingdom; reliability has been reported as 0.92 for the physical status dimension and 0.89 for the mental status dimension. The test-retest reliability for an interval of 2 weeks was 0.89 for the physical status dimension and 0.80 for the mental status dimension.⁸

The Living Donor Survey was used to measure attitude toward living kidney donation, satisfaction with donation education, hospital care, and care after discharge. This instrument comprises 55 multiple choice items and Likert scale questions.⁹ In a study⁷ of donors' decision making and outcomes, the internal consistency (Cronbach α) of the dimension that measured attitude to living donation was .75.

Results

Forty-three persons were identified as having attended the Glasgow Liaison Psychiatry Service for psychological screening for a prospective kidney donation. Nineteen (44.2%) of them consented to participation and returned the survey. Two of the respondents were excluded from the study because they had eventually not donated. The demographic data for the final sample (N=17) are summarized in Table 1. One participant did not return a full data set. Absence of data will be made clear throughout reporting as appropriate. The majority (82.3%) of the donors were biologically related to the recipients. Thirteen (76.5%) of the donors were in some form of employment. Four

(25%) of 16 participants lived within one of Scotland's most deprived areas.

One participant did not complete the SF-36 adequately for inclusion. The health-related quality of life for the participants is summarized in Table 1. The majority (76.5%) of participants reported involving someone else in the decision-making process. All 10 married donors and 3 (42.9%) of the 7 unmarried donors involved a family member in their decision to donate. Of the married donors who involved someone in their decision to donate, all involved their spouse in the decision. The majority (64.7%) of participants believed that they had made their decision to donate independently. Two (11.8%) shared responsibility for their decision with another person. No participants believed that the decision for them to donate was made by someone else.

The key findings from the Living Donor Survey are presented in Table 2. The majority (93.8%) of participants considered the process of donation to have been explained "very clearly." Similarly, 68.8% and 75.0% of donors described being "very clearly" given general information and information about possible complications, respectively. All participants reported being "very clearly" informed of the risk of death associated with the procedure. The majority (62.5%) of donors considered the pain following surgery to have been "consistent with," "less," or "much less" than their expectations. The majority (56.3%) of participants had a hospital stay that was shorter in duration than they had expected. Most donors did not believe that their lives had been altered since donation with respect to hours worked (85.7%), social activity (93.8%), physical activity (75.0%), mood (81.3%), and sexual activity (86.7%). Most participants indicated they "strongly agree" with the use of living donors (80.0%) and that living donation should be a routine option (66.7%). The majority (64.3%) indicated that they would "strongly encourage" living donation.

The Living Donor Survey includes 2 open-ended questions to canvas patients about their opinion on how the donation process could be improved. Two donors suggested that having an opportunity to speak with previous donors might be helpful in facilitating understanding of the issues of donation. Four patients indicated their belief that donors should receive more information about the recovery process. Specifically, 2 of these patients conveyed a need for more information or support to facilitate muscular rehabilitation. Two participants suggested the process should be shorter in duration, that the workup "took longer than necessary."

Discussion

The present study was designed to assess the feasibility and utility of collecting data related to the psychosocial outcomes of kidney donation and donors'

Table 1 Participant characteristics (number of participants [%] for categorical data; median for ordinal data; mean \pm standard deviation for continuous data)

		Value
Sex, No. (%)	Male	9 (52.9)
	Female	8 (47.1)
Age, mean (SD), y		44.37 (11.62)
Time passed since donation, mean (SD), months		1.86 (0.97)
Ethnicity, No. (%)	White, Scottish	13 (76.5)
	White, other British	1 (5.9)
	Missing	3 (17.6)
Employment status, No. (%)	Full-time employment	11 (64.7)
	Part-time employment	2 (11.8)
	Retired	2 (11.8)
	Other	2 (11.8)
Relationship of recipient to donor, No. (%)	Spouse	3 (17.6)
	Son/daughter	3 (17.6)
	Parent	1 (5.9)
	Sibling	7 (41.2)
	Other relative	3 (17.6)
Marital status, No. (%)	Married	10 (58.8)
	Single	2 (11.8)
	Cohabiting	1 (5.9)
	Separated	1 (5.9)
	Divorced	2 (11.8)
	Widowed	1 (5.9)
Scottish Index of Multiple Deprivation rank, ^a median		2012.50
SF-36 score, ^a mean (SD)	Physical functioning	93.13 (15.04)
	Role, physical	94.53 (11.61)
	Bodily pain	84.72 (20.64)
	General health	83.13 (14.10)
	Vitality	71.48 (19.49)
	Social functioning	86.72 (19.62)
	Role, emotional	95.83 (12.91)
	Mental health	81.56 (12.07)

^a Only 16 of the 17 participants provided data for this item.

process of decision making. It was hoped that the results elicited from this investigation could be used to inform the design and application of a larger scale prospective study to investigate donors' psychosocial well-being.

The study relied on a historical convenience sample that offered a limited population from which to recruit. The response rate (~40%) was encouraging and suggests that patients are interested in participating in studies of this nature. The reasons for nonparticipation are unclear. However, it is perhaps reasonable to assume low motivation or interest to participate given the length of time elapsed since donation in some instances. It is anticipated that recruitment will be more successful if patients are informed of the study during their workup when the relevancy of such an investigation should be at its most obvious. Researchers in earlier studies that used prospective designs have reported excellent rates of recruitment and retention.¹⁰

Donor's health-related quality of life was a primary outcome measure of the current study. Consistent with previous research,¹¹ our results suggest higher levels of quality of life on all dimensions compared with population norms.¹² This cross-sectional finding is limited by the absence of data documenting the change in psychosocial well-being as the donation process progressed. Measures of aspects of psychosocial functioning, including health-related quality of life, before donation would permit meaningful comparison of scores in this regard. Data collected throughout the donation process would reveal any change in such outcomes and foster an understanding of the true impact of donation on variables of this nature. Additionally, it would allow scrutiny of the mechanisms underlying any change in this regard or facilitating adjustment to the surgery.

The mean time since donation in the present study was almost 2 years. It is therefore difficult to make

Table 2 Participants' satisfaction with kidney donation

Aspect evaluated	Response	% of 16 respondents
Explanation of donation process before surgery	Very clear	93.8
	Moderately clear	6.3
Pain after surgery	Much less than expected	12.5
	Less than expected	31.3
	As expected	18.8
	More than expected	31.3
	Much more than expected	6.3
Length of hospital stay	Many fewer days than expected	12.5
	Fewer days than expected	43.8
	As expected	37.5
	More days than expected	6.3
Medical complications after surgery	No	75.0
	Yes	25.0
Medical complications after discharge	No	86.7
	Yes	13.3
Donate again	Strongly agree	93.3
	Somewhat agree	6.7
Pressure was exerted by the transplant team	Strongly disagree	93.3
	Moderately disagree	6.7
Pressure was exerted by the recipient	Strongly disagree	93.3
	Moderately disagree	6.7

any assumptions about the effect of donation on quality of life because psychological adjustment could have occurred in the intervening period. What our results do perhaps indicate is that if donors do experience any difficulties after the procedure, most do not show problematic adjustment to these difficulties.

The majority of donors indicated they involved a family member or friend in their decision to donate, supporting previous reports.¹³ Although all such donors stressed that their final decision was made independently, it is not unreasonable to suppose some degree of conscious or unconscious influence of close family members, friends, or indeed the recipients themselves. Given such potential influence it would be prudent to encourage the involvement of identified sources of counsel and support within the workup of prospective donors. Such involvement could facilitate better understanding of the procedure and realistic expectations regarding outcome and postoperative recovery for both donor and family or friend. The measure used to assess the process of donor decision making was limited in both the quantity and quality of information elicited. There could be value in developing more sophisticated measures in an effort to establish some of the social cognitive components implicated in the decision-making process.

An attempt was made to assess the acceptability of the process of kidney donation from the donors' perspective. Generally, donors indicated high levels of satisfaction with all aspects of their contact with the

transplant team. The inclusion of 2 open-ended question permitted donors' reporting of aspects of the process that they believed could be enhanced. Comment was given to a broad range of topics; most commonly donors indicated the need for better quality information relating to the postoperative recovery process. Little previous research has addressed that issue. More substantial qualitative research designed to elicit feedback from patients about all aspects of the donation process could provide valuable insights into how services could be appropriately designed to meet the needs of this population.

Limitations

The current investigation used a convenience sample to pilot the use of methods designed to elicit information on the outcome of transplant donation. The number of donors who consented to the study was insufficient to derive any firm conclusions regarding the generalizability of the findings. The study was a retrospective pilot investigation that included persons who had donated up to 3 years earlier. This study provides useful information about long-term outcomes of kidney donation. However, retrospective recollection is recognized as unreliable and subject to recall bias.

The present study had a healthy response rate to postal questionnaires. However, this self-selecting group may be a potential source of bias. For example, those who experienced positive outcomes after donation may have been more likely to respond. A methodological

weakness is the absence of key characteristics of the donors who did not participate, which would have enabled between-groups comparison. Further, an absence of specific measures of psychological well-being denied the opportunity to describe the populations' adjustment in this regard and correlate outcomes to psychosocial characteristics.

Conclusions

It was hoped that the experience of this pilot investigation would both demonstrate the feasibility of working with this unique population and inform the design of a larger scale prospective investigation. Our results suggest that this population is both willing and able to report on a number of outcomes pertaining to the process of kidney donation.

Possibilities regarding the extension of this pilot investigation are numerous. Data regarding the psychosocial well-being of donors should be collected routinely throughout the donation process. Prospective collection of data before donation would allow the direct comparison of outcomes before and after donation. A variety of demographic and psychosocial variables could be considered as predictors of outcome. This might incorporate aspects of the decision-making process. However, further more substantial prospective studies are required to determine what these factors are and the true extent of their influence. Any findings in this regard would help in the development of evidence-based screening tools for the psychological assessment of prospective donors, which could meaningfully contribute to the identification of candidates at an increased risk of poor adjustment after donation.

Financial Disclosures

None reported.

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