

Psychosocial care of living kidney donors

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Author: Emma van Hardeveld, Allison Tong

GUIDELINES

No recommendations possible based on Level I or II evidence

SUGGESTIONS FOR CLINICAL CARE

(Suggestions are based on Level III and IV evidence)

- A formal psychosocial assessment should be a mandatory part of the pre-transplant workup process.
- Semi-structured interview guides (for preoperative and postoperative psychosocial assessments) are useful for focussing the discussion on relevant and critical issues while allowing open discussion.
- Education and assessment of potential donors is essential to identify 'high-risk' donors.
- Donors should be followed-up for psychological care post-donation.
- Donors with poor recipient outcomes should have extensive psychological support available.
- A formal multidisciplinary approach should be taken in the event of negative recipient outcome.

IMPLEMENTATION AND AUDIT

Living kidney donors should undergo psychosocial assessment and have access to psychosocial care before and after the transplant surgery.

BACKGROUND

Living kidney donor transplantation leads to better outcomes for the transplant recipient; however, there is increasing concern about the safety and wellbeing of live kidney donors.¹ Live donors are not only at risk of physical adverse events including infection and loss of renal function in the remaining kidney but they may also experience psychosocial problems including anxiety, depression, regret and financial hardship.^{2,3}

The psychosocial evaluation of donors (pre- and post-transplant) is widely advocated;⁴ however, there is a paucity of data on the process and content of psychosocial evaluations. For example, there are no set standards regarding who should conduct psychosocial evaluations (physician, psychiatrist, psychologist, medical social worker), whether evaluations should be mandatory, at what stage of the

work-up evaluations should be conducted, at what time interval repeat evaluations should be performed and what criteria need to be met.

A limited number of studies and evaluation tools have suggested that the live donor psychosocial evaluation should include an assessment of: the donor's ability to give informed consent, donor motivation, relationship between donor and recipient, donor/spouse agreement, information needs, mental status, coping and personality style, emotional and behavioural issues that may impact on donation, and social and financial support.⁴⁻⁷

The objective of this guideline is to assess and summarize the evidence on psychosocial care for living donors.

SEARCH STRATEGY

Databases searched: MeSH terms and text words for kidney transplantation were combined with MeSH terms and text words for living donors and MeSH terms and text words for social psychology and support. The search was conducted in Medline (1955 to September Week 1, 2006).

Date of searches: 9 September 2006.

Update search:

Databases searched: MeSH terms and text words for kidney transplantation were combined with MeSH terms and text words for living donor and combined with MeSH terms and text words for open and laparoscopic nephrectomy. The search was carried out in Medline (1966 – March Week 1, 2009). The Cochrane Renal Group Trials Register was also searched for trials not indexed in Medline.

Date of searches: 9 March 2009.

WHAT IS THE EVIDENCE?

There are no randomized controlled trials (RCTs) on this topic. Most studies have used questionnaires, in-depth interviews and focus groups to explore living kidney donor perspectives, psychosocial needs and support. Most studies were retrospective and sent questionnaires to living donors after surgery.

A recent systematic review assessed and synthesized 51 questionnaire studies that examined the psychosocial

functioning of living kidney donors after transplantation ($n = 5139$).⁸ The authors extracted data on donor social function, self-concept, body image, psychological wellbeing, and quality of life. Most donor-recipient relationships, donor-partner relationships, and family relationships remained unchanged or improved. Many donors reported an increase in their self-esteem. The majority of donors were happy, while some experienced negative emotions including feeling ignored, unappreciated, abandoned and disappointed. There was variation in depressive symptoms in donors across studies. Most donors reported stress, which was related to the surgery, recovery, physical postoperative state, employment, worry about future health problems, and recipient health. Scores for donor quality of life varied across studies. The majority of donors would donate again.

Studies to date have found that the majority of donors view kidney donation as a positive experience and did not regret their decision to donate.^{2,3,9-14} Positive outcomes for living donors included improvements in the donor-recipient relationship, donor self-esteem, and social recognition.^{2,3,10,15} Studies have also consistently found that a small proportion of donors (<10%) regretted their decision to donate or would not donate again.^{2,3,9,11,12} The proportion of donors who felt pressure to donate their kidney varied across studies. The major concerns of donors related to postoperative pain (with some donors reporting the surgery as the most painful experience ever encountered), length of recovery, recipient wellbeing, health, employment issues, financial problems, health risks and lifestyle restrictions.^{2,3,9,10,12,14-20} Also, some donors perceived a lack of psychological support and felt they should receive more attention, appreciation and follow-up care from health care providers.^{12,15,20,21}

While the percentage of donors experiencing negative psychosocial outcomes is small compared with those viewing it as a positive experience, all living donors should have access to psychosocial care to minimize the risk of negative outcomes such as relationship problems, depression, anxiety and financial problems.

SUMMARY OF THE EVIDENCE

The study characteristics of the qualitative and questionnaires studies included in this guideline are provided in Table 1 in the Appendix.

Most studies on this topic were retrospective and used questionnaires to survey donors and potential donors. The majority of donors were satisfied with the donation process and did not regret their decision. However, several concerns frequently reported by donors related to surgical pain, recipient wellbeing (complications and side-effects), uncertainty about donor health, assessment of donor eligibility, poor follow-up care, lifestyle restrictions, financial impact and inadequate information.

WHAT DO THE OTHER GUIDELINES SAY?

Kidney Disease Outcomes Quality Initiative: No recommendation.

UK Renal Association: The doctor looking after the donor has a responsibility to inform donors of psychosocial issues around transplantation.

Canadian Society of Nephrology: No recommendation.

European Best Practice Guidelines: No recommendation.

Organ Procurement and Transplantation Network (OPTN):

The program has a responsibility to have available to the potential donor a donor team that consists of at least the following: physician/surgeon, transplant coordinator/nurse clinician, medical social worker, psychiatrist or psychologist, ethicist/clergy.

The donor team's function is to:

1. Educate the potential donor regarding the potential risks and benefits
2. Provide counselling and support regarding family, disability, intellectual, emotional or other pressures
3. Determine that the donor's decision is voluntary, without coercion
4. Provide opportunities for the donor to 'opt out' of the procedure without consequences.

Psychiatric and social screening: the dedicated mental health professional familiar with transplantation and living donation should evaluate the potential donor for:

1. Psychosocial history
2. Relationship between the donor and recipient and potential areas where undue pressure or coercion may be applied
3. Presence of psychiatric disorder
4. Existence of a financial incentive as motivation
5. Presence of physical or sexual abuse of the donor in the past or the presence of active substance abuse in the donor.

The Canadian Council for Donation and Transplantation:²²

Pre-donation psychosocial evaluation should be conducted by a clinical social worker (with the appropriate knowledge and skill set) who is independent of the intended recipient's care team.

A psychosocial evaluation should be based on a semi-structured tool. This tool should guide discussion while enabling the latitude necessary for individual variation.

The timing of the psychosocial evaluation should be left to the discretion of the living donor coordinator on the basis of the initial interview.

Suggested components of the evaluation include:

- An exploration of the motivation for organ donation (how the decision was made, evidence of coercion or inducement, expectations and ambivalence)
- The nature of the relationship between donor and recipient (strengths, past conflicts/ difficulties)
- Attitudes of significant others towards donation (availability of emotional and practical assistance)
- Knowledge and comprehension about the surgery and recovery
- Review of work- or school-related issues

- Mental health history and current status (psychiatric disorders, substance abuse, cognitive ability, competence, and capacity)
- Psychosocial history and current status (marital stress, living arrangements, religious beliefs and orientation, concurrent stressors, coping strategies).

SUGGESTIONS FOR FUTURE RESEARCH

1. Renal units could conduct a standard comprehensive psychosocial assessment, using a semi-structured questionnaire, during the postoperative clinical check up. The questionnaire should be evaluated.
2. Conduct large, prospective studies to assess the psychosocial implications of donation (including quality of life, depression, stress, financial support, donor relationships, information needs and social support).
3. Perform in-depth interviews to assess the experiences and needs of donors who had poor transplant outcomes (e.g. recipient graft failure)
4. Perform follow-up studies to compare and evaluate psychological care provided by different members of the health care team.
5. Conduct research focussing on implementation of psychosocial assessment pre-donation and preoperatively, as well as posttransplant.

CONFLICT OF INTEREST

Emma van Hardeveld and Allison Tong have no relevant financial affiliations that would cause a conflict of interest according to the conflict of interest statement set down by CARI.

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APPENDIX

Table 1 Characteristics of included qualitative and questionnaire studies

Study ID	n responded	Response rate	Study design	Setting	Participants (pre- or post-transplant, related or non-related)	Main findings (themes, questionnaire results)
Anderson <i>et al.</i> 2005 ¹⁶	12	100%	In-depth interview, face to face (phenomenology)	Norway	Post Tx, related	<ul style="list-style-type: none"> • Strong feelings of responsibility and obligation towards recipients • ‘Strange’ feeling of undergoing surgery as a fit individual • Surgery was painful, recovery was troublesome • Dual role of being a patient and relative stressful
Brown <i>et al.</i> 2008 ²⁴	12	100%	In-depth interview (phenomenology)	Canada	Post-Tx, related	<ul style="list-style-type: none"> • Witnessing their loved one’s experience of illness and threat of losing the recipient influenced their decision to donate • Intrapersonal factors (philosophy of life) and interpersonal factors (social support networks) influenced the decision to be tested as a potential donor and the process of donation • Impact of giving the gift of life was emotional and life changing
Frade <i>et al.</i> 2008 ²⁵	32	100%	Before and after questionnaire study	Portugal	Post-Tx, related	<ul style="list-style-type: none"> • No significant change in donor QoL except for the SF-36 social functional subscale which showed significant improvement • A significant reduction in depression symptom frequency was found after donation • A significant decrease in depression scores • For most donors, the decision to donate was easy and spontaneous
Franklin & Crombie 2003 ¹⁷	100 (50 per study)	Not stated	2 qualitative, in-depth interview and observational studies exploring psychological, social and cultural aspects of donation (phenomenology & ethnography)	UK	Post Tx, related	<ul style="list-style-type: none"> • Parents willing to donate out of love for their child • For siblings, the decision is complex and can lead to family conflicts • Donor partners feel anxious due to the risks of surgery • Donors did not express regret following donation
Gill & Lowes 2008 ²⁷	11	55%	Interview study (phenomenology, thematic content analysis)	UK	Pre and post Tx, related	<ul style="list-style-type: none"> • All donors initially made an instantaneous, voluntary decision to donate • Donors derived immense personal satisfaction from this outcome and it helped to confirm to them that what they had done had been worthwhile. The transplant did not have a detrimental effect on donor-recipient relationships.

Table 1 Continued

Study ID	n responded	Response rate	Study design	Setting	Participants (pre- or post-transplant, related or non-related)	Main findings (themes, questionnaire results)
Heck <i>et al.</i> 2004 ¹⁸	31	97%	Semi-structured interview, face to face	Germany	Post Tx, related	<ul style="list-style-type: none"> • Psychological strains cause by: side-effects and complications of the recipient, own health concerns, mourning for deceased recipient • Family life improved but deteriorated with worsened physical condition/recipient depression
Johnson <i>et al.</i> 1999 ²	524	60%	Questionnaire: SF-36 Quality of Life health questionnaire, mailed	USA	Post Tx, related/unrelated	<ul style="list-style-type: none"> • Parent donors scored higher than unrelated donors • 88% found donation to be little or no financial burden • 84% related pain as mild or absent • Uncertainty about future health was extremely stressful (1%), very stressful (2%) • Wish they had not donated: strongly agree (1%), agree (3%), unsure (3%), disagree/strongly disagree (93%) • Perioperative complications associated with higher level of stress (odds ratio 3.5, $P = 0.007$)
Shrestha <i>et al.</i> 2008 ²⁶	66	85%	Questionnaire, Medical Outcome Survey Short Form-36	UK	Donors and potential donors	<ul style="list-style-type: none"> • Age, sex, time since donation, and relationship to recipient did not affect QoL • 83% would donate again • QoL in living donors was not significantly different to potential donors
Jordan <i>et al.</i> 2004 ⁹	112	94%	Questionnaire (semi-structured interview): 4 standardized, face to face	Germany	Post Tx	<ul style="list-style-type: none"> • Scored higher on psychological scales than normal German population • Would donate again (97%) • Entirely satisfied with their decision to donate (91%) • Anxiety and depression (5%) • Did not feel external pressure to donate (51%) • Some reported no support from families, anger towards other siblings' unwillingness and partners not wanting them to donate • Slightly higher degree of psychosis in younger donors

Table 1 Continued

Study ID	n responded	Response rate	Study design	Setting	Participants (pre- or post-transplant, related or non-related)	Main findings (themes, questionnaire results)
Lennerling <i>et al.</i> 2004 ¹⁹	154	74%	Newly designed questionnaire, mailed	Norway, Sweden	Pre Tx, related and non-related	<ul style="list-style-type: none"> • Strongest motives: wish to help, self-benefit from the recipient's improved health, identification with the recipient • Weak or rare motives: sense of guilt regarding past relationships, pressure from others, religious motive, increased self-esteem • Concerns: recipient health, fear of surgery and long-term consequences, objections from others • Most potential donors initiated the assessment (64%)
Minz <i>et al.</i> 2005 ¹⁰	75	100%	Questionnaires: modified Beck's depression inventory, Spielberger's state and trait anxiety, social support, face to face	India	Pre and post Tx, related	<ul style="list-style-type: none"> • Difficult to decide to donate (6.6%) • Felt pressure from others to donate (5.3%) • Postoperative pain stressful (10.6%) • Worried about having one kidney (5.3%) • Donor-recipient relationship improved (68%) • Negative impact on relationship with family (4%) • Regret (0%) • Would donate again (96%) • Mild depression (5.3%)
Neuhaus <i>et al.</i> 2004 ²¹	19	95%	Newly designed questionnaire, mailed	Switzerland	Post Tx, related (parents only)	<ul style="list-style-type: none"> • For most, the decision was not influenced by partners, relatives or staff • Improved relationships towards child recipient • Although satisfied, cadaveric transplantation was preferred • Donors expected more attention, respect and appreciation • Two expressed desire for more intensive psychological support by the renal team at the time of transplantation • No financial or employment problems were reported
Ozcurumez <i>et al.</i> 2004 ¹¹	22	82%	Two newly designed questionnaires, distributed at follow-up visits	Turkey	Post Tx, related	<ul style="list-style-type: none"> • Adequately informed about the process prior to surgery (83.3%) • Highly satisfied with quality of life post transplant (72.2%) • Would donate again (94.4%) • Dissatisfaction – preoperative information inadequate and perceived negative effects of transplant on health

Table 1 Continued

Study ID	n responded	Response rate	Study design	Setting	Participants (pre- or post-transplant, related or non-related)	Main findings (themes, questionnaire results)
Pradel <i>et al.</i> 2003 ¹⁵	25	16%	Focus group (content analysis)	USA	Pre and post Tx, related and unrelated	<ul style="list-style-type: none"> • Potential donors not hesitant to donate but mainly concerned about ineligibility, lack of information provided before the surgery, temporary lifestyle restrictions, health insurance • Positive experiences: improvement of recipient's health, social recognition, opportunity to take time off, strengthened donor-recipient relationships • Concerns: minimal follow up care, felt deserted by the health care team post transplant
Reimer <i>et al.</i> 2006 ³	47	72%	Questionnaire: SF-36 Health Survey, BSI (mental distress), mailed	Germany	Post Tx, related	<ul style="list-style-type: none"> • Family conflict (10%) • Did not feel pressure to donate/did not have doubts (94%) • Worried about possibility of graft failure (85%) • Would donate again (96%) • Self-esteem improved (30%) • Experienced problems with employer (19%) • Quality of life within normal range
Sanner <i>et al.</i> 2005 ²⁰	39	100%	In-depth interview (1 pre-Tx, 1 post-Tx)	Sweden	Pre and post Tx, related	<ul style="list-style-type: none"> • Examination period was the most stressful due to imperfect coordination and excessive time wasting • Postoperative pain the most painful experience (44%) • Delay in conducting examinations a stress factor (33%) • Most donors thought the possibility to withdraw, stressed by doctors, was a myth • Operation easier than expected (54%) • Wished for better psychological care in some critical situations (regressive reactions, pain attacks, rejection) • Feelings of abandonment, being exploited and ignored by staff (11 donors)

Table 1 Continued

Study ID	n responded	Response rate	Study design	Setting	Participants (pre- or post-transplant, related or non-related)	Main findings (themes, questionnaire results)
Schover <i>et al.</i> 1997 ¹²	167	67%	Newly developed questionnaire, mailed	USA	Post Tx,	<ul style="list-style-type: none"> • Would donate again (90%) • Impacted negatively on health (15%) • Negative financial consequences (23%) • Post-surgery depression (7%) • Disappointed with the emotional experience of being a donor (4%) • Dissatisfaction related to: conflicts in the donor-recipient relationship, inadequate information provided pre-operatively, and perceived damage to health and finances • Minority suffered psychosocial morbidity • Mental health help should be accessible to those who experience donor or recipient negative outcomes
Schweitzer <i>et al.</i> 2003 ¹³	67	100%	Consultation interview, in-depth interview (content analysis)	Germany	Pre and post Tx, related and unrelated	<ul style="list-style-type: none"> • Own idea to donate (85%) • Donors more eager than recipients • Problem cases characterized by: unilateral dependent close relationships, unrealistic expectations, anxious avoidance of problem confrontation, past family experience with medical trauma • Couples with unresolved problems are at higher risk for complicated outcomes • Few suffered from disappointment
Smith <i>et al.</i> 2004 ²³	48	94%	Questionnaire: SF-36 Health survey, patient health questionnaire, psychiatric assessment	Australia	Pre and post Tx,	<ul style="list-style-type: none"> • Developed a psychiatric disorder (e.g. depressive, anxiety, adjustment) (31%) • Decline in psychosocial function • Decrease in SF-36 scores ($P < 0.05$)
Waterman <i>et al.</i> 2004 ¹⁴	91	100%	Telephone questionnaire	USA	Pre Tx, related and unrelated	<ul style="list-style-type: none"> • Potential donors were very willing and comfortable donating • Concerns: recipients would die if they could not donate, evaluation and surgery would cause pain and anxiety, did not understand what donation would require

BSI, brief symptom inventory; QoL, quality of life SF, short form; Tx, transplantation.