Psychosocial care of living kidney donors

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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). 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. Positive outcomes for living donors included improvements in the donor-recipient relationship, donor self-esteem, and social recognition. Studies have also consistently found that a small proportion of donors (<10%) regretted their decision to donate or would not donate again. The proportion of donors who felt pressure to donate their kidney varied across studies. The majority 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. 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.

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 questionnaire 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 counseling and support regarding family, disability, intellectual, emotional or other pressures
3. Determine that the donor's decision is voluntary, without coercion
4. Permit 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:

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 put down by CARI.

ACKNOWLEDGEMENTS
We would like to acknowledge Kristen Penberthy who helped to analyze the data.

REFERENCES
## APPENDIX

### Table 1 Characteristics of included qualitative and questionnaire studies

<table>
<thead>
<tr>
<th>Study ID</th>
<th>n responded</th>
<th>Response rate</th>
<th>Study design</th>
<th>Setting</th>
<th>Main findings (themes, questionnaire results)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anderson et al. 2005</td>
<td>12</td>
<td>100%</td>
<td>In-depth interview, face to face (phenomenology)</td>
<td>Norway</td>
<td>- Strong feelings of responsibility and obligation towards recipients</td>
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<td></td>
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<td></td>
<td>Post Tx, related</td>
<td>'Strange' feeling of undergoing surgery as a fit individual</td>
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<td>- Surgery was painful, recovery was troublesome</td>
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<td>- Dual role of being a patient and relative stressful</td>
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<td>- Witnessing their loved one's experience of illness and threat of losing the recipient influenced their decision to donate</td>
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<td>- 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</td>
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<td>- Impact of giving the gift of life was emotional and life changing</td>
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<td>Brown et al. 2008</td>
<td>12</td>
<td>100%</td>
<td>In-depth interview (phenomenology)</td>
<td>Canada</td>
<td>- No significant change in donor QoL except for the SF-36 social functional subscale which showed significant improvement</td>
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<td>Post-Tx, related</td>
<td>- A significant reduction in depression symptom frequency was found after donation</td>
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<td></td>
<td>- A significant decrease in depression scores</td>
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<td>- For most donors, the decision to donate was easy and spontaneous</td>
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<td>- Parents willing to donate out of love for their child</td>
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<td>- For siblings, the decision is complex and can lead to family conflicts</td>
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<td>- Donor partners feel anxious due to the risks of surgery</td>
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<td>- Donors did not express regret following donation</td>
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<td>- All donors initially made an instantaneous, voluntary decision to donate</td>
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<td>- 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.</td>
</tr>
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<td>Gill &amp; Lowes 2008</td>
<td>11</td>
<td>55%</td>
<td>Interview study (phenomenology, thematic content analysis)</td>
<td>UK</td>
<td>Pre and post Tx, related</td>
</tr>
<tr>
<td>Franklin &amp; Crombie 2003</td>
<td>100 (50 per study)</td>
<td>Not stated</td>
<td>2 qualitative, in-depth interview and observational studies exploring psychological, social and cultural aspects of donation (phenomenology &amp; ethnography)</td>
<td>UK</td>
<td>Post Tx, related</td>
</tr>
<tr>
<td>Study ID</td>
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| Heck et al. 2004  | 31          | 97%           | Semi-structured interview, face to face | Germany       | - 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  
- 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, \( P = 0.007 \))  
- 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  
- Scored higher on psychological scales than normal German population  
- Would donate gain (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 |
| Johnson et al. 1999 | 524         | 60%           | Questionnaire: SF-36 Quality of Life health questionnaire, mailed | USA           | Post Tx, related/unrelated  
- 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%)  
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- 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 |
| Shrestha et al. 2008 | 66          | 85%           | Questionnaire, Medical Outcome Survey Short Form 36 | UK            | Donors and potential donors  
- 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  
- Scored higher on psychological scales than normal German population  
- Would donate gain (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 |
| Jordan et al. 2004 | 112         | 91%           | Questionnaire (semi-structured interview): 4 standardized, face to face | Germany       | Post Tx  
- Scored higher on psychological scales than normal German population  
- Would donate gain (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  
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<th>Participants (pre- or post-transplant, related or non-related)</th>
<th>Main findings (themes, questionnaire results)</th>
</tr>
</thead>
</table>
| Lennerling et al. 2004<sup>19</sup> | 154         | 74%           | Newly designed questionnaire, mailed | Norway, Sweden                   | Pre Tx, related and non-related | • 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%)  
• 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%)  
• 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  
• 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                                                                 |
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</table>
| Pradel et al.    | 25          | 16%           | Focus group (content analysis) | USA                      | Pre and post Tx, related and unrelated                        | • 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 |
| 2003             |             |               |                       |                          |                                                               |                                               |
| Reimer et al.    | 47          | 72%           | Questionnaire: SF-36 Health Survey, BSI (mental distress), mailed | Germany                  | Pre-Tx, related                                               | • 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  
• 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) |
<p>| 2006             |             |               |                       |                          |                                                               |                                               |
| Sanner et al.    | 39          | 100%          | In-depth interview (1 pre-Tx, 1 post-Tx) | Sweden                  | Pre and post Tx, related                                      |                                               |
| 2005             |             |               |                       |                          |                                                               |                                               |</p>
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</tr>
</thead>
<tbody>
<tr>
<td>Schover et al. 1997</td>
<td>167</td>
<td>67%</td>
<td>Newly developed questionnaire, mailed</td>
<td>USA Post Tx,</td>
<td>• 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</td>
</tr>
<tr>
<td>Schweitzer et al. 2003</td>
<td>67</td>
<td>100%</td>
<td>Consultation interview, in-depth interview (content analysis)</td>
<td>Pre and post Tx, related and unrelated</td>
<td>• 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 • Developed a psychiatric disorder (e.g. depressive, anxiety, adjustment) (31%) • Decline in psychosocial function • Decrease in SF-36 scores (P &lt; 0.05)</td>
</tr>
<tr>
<td>Smith et al. 2004</td>
<td>48</td>
<td>94%</td>
<td>Questionnaire: SF-36 Health survey, patient health questionnaire, psychiatric assessment</td>
<td>Australia Pre and post Tx, related and unrelated</td>
<td>• 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</td>
</tr>
<tr>
<td>Waterman et al. 2004</td>
<td>91</td>
<td>100%</td>
<td>Telephone questionnaire</td>
<td>USA Pre Tx, related and unrelated</td>
<td></td>
</tr>
</tbody>
</table>

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