Mental Distress Symptoms and Level of Contentment with Life among Living Kidney Donors: Frequency and Association with Subjective Evaluations

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Introduction

- >24,000 patient in waiting list
  
  *Turkish Transplantation Foundation, [http://www.tonv.org.tr](http://www.tonv.org.tr)*

- There is discrepancy between the need for and supply of cadaveric organs.
- The unmet need of waiting organ transplantation lists → Organ shortage
- Living kidney donation → Is it a new solution for organ replacement treatment?
- Living donors are healthy volunteers.
- There are some legal, ethical, psychological, and medical issues to be concerned about.
Questions about the overall safety and long-term complications
The long-term follow-up of living organ donors is a priority.
Current practice of post-donation follow-up concentrates on medical data accrual.
We have ethical responsibility to monitor and preserve the health of living donors.

Introduction

• Living donors have important emotional, social, and psychiatric considerations that need to be addressed.
• Most studies have shown that living donors have positive experiences after donation.
• Some psychosocial difficulties such as depression, anxiety, stress, and worries about health have been reported in the literature.
• To understand long-term consequences, long-term follow-up studies are important.
• To our knowledge, our study is the first in Turkey to address the long-term mental effects of the donation process and to evaluate contentment with life.
The Stanford integrated Psychosocial Assessment for Transplantation: A Prospective Study of Medical and Psychosocial Outcomes

José R. Maldonado, MD, Yelizaveta Sher, MD, Sermsak Lolak, MD, Heavenly Swendsen, MS, Danica Skibola, MD, Eric Neri, BS, Evonne E. David, LCSW, Catherine Sullivan, MD, and Kim Standridge, MPH

Regular Psychosocial Assessment in 59% of the countries
Psychosocial Assessment in problematic cases in 26%

Living organ donation practices in Europe – results from an online survey

Annette Lennerling,1 Charlotte Lovén,1 Frank JMF Dor,2 Frederike Ambagtsheer,3 Nathalie Duerinckx,4 Mihaela Frunza,5 Assya Pascalev,6 Willij Zuidema,3 Willem Weimar3 and Fabienne Dobbels4

137/331 centre, >40 countries, 2012
Objectives and Hypothesis

• The aims:
  (1) to determine psychological states and wellbeing of living kidney donors
  (2) to assess their interaction and association with subjective evaluations of donors

• The hypothesis:
  (1) Living kidney donors would have depression and anxiety scores similar to those of the normal population
  (2) Subjective complaints would interfere with patients’ psychological state and wellbeing
Methods:

• 858 donors underwent living kidney explantation btw 2006 & 2017
• Design: Cross-sectional study in 2018
• Sample:
  – 620/858 of donors were called via phone
  – 405/620 of donors were reached
  – 260/405 of donors accepted to come and meet
  – 208 living kidney donors completed the evaluation.
• Method: Each of these 208 participants was evaluated in person and gave informed consent prior to inclusion. All procedures were performed in accordance with the ethical standards of the Declaration of Helsinki.
Kidney Transplantation

N: 962
Methods:

- Subjects (208 living kidney donors)
  - Nephrectomy in between 2006 and 2017
  - 123 women (59.1%)
  - Age: 22 to 79 years
Methods:

- Measurements:
  - Sociodemographic Data Collection Form
    - to determine parameters such as sex, age, level of education, and donor relationship to the recipient
  - 4 Question Survey
    - developed by researchers to assess the decision to donate, thought of getting ill easily, thought of offering others to donate.
    - The Subjective evaluation questions are:
      - Do you think that you get ill easily since the operation?
      - How is your relationship with the recipient after the operation?
      - How will you rate your experience of donation?
      - Would you recommend other people to be donors?
Methods:

– **Beck Depression Inventory**
  • aims to establish the severity of depression symptoms objectively rather than making a diagnosis of depression.

– **Beck Anxiety Inventory**
  • aims to measure the frequency of anxiety symptoms experienced by individuals.

– **CLAS:**
  • self-report inventory to assess life satisfaction to better understand differences in subjective wellbeing.
  • has 5 items → ‘I am very content with my life’
  • The average life satisfaction may be more accurately described as neutral.

Lavallee LF, Hatch PM, Michalos AC, McKinley T: Development of the contentment with life assessment scale (CLAS): Using daily life experiences to verify levels of self-reported life satisfaction. Social Indicators Research. 2007, 83; 201-244
# Results

## Sociodemographic Parameters (N=208)

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>female</td>
<td>123</td>
<td>59.1</td>
</tr>
<tr>
<td>male</td>
<td>85</td>
<td>41.9</td>
</tr>
<tr>
<td><strong>Age at study (y)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22-79 (48.74 ±11.78)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Relationship to the recipient</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>spouse</td>
<td>65</td>
<td>31.25</td>
</tr>
<tr>
<td>first degree</td>
<td>73</td>
<td>35.09</td>
</tr>
<tr>
<td>second degree</td>
<td>43</td>
<td>20.68</td>
</tr>
<tr>
<td>third or fourth degree</td>
<td>8</td>
<td>3.85</td>
</tr>
<tr>
<td>other (emotionally related)</td>
<td>19</td>
<td>9.13</td>
</tr>
<tr>
<td><strong>Time since donation (y)</strong></td>
<td>1-11</td>
<td>4.55 ± 2.50</td>
</tr>
</tbody>
</table>

Abbreviation: M, mean; SD, standard deviation
### Mental Health Status and Level of Contentment with Life Score (N=208)

<table>
<thead>
<tr>
<th>Score Range</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>BDI scores</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-9</td>
<td>168</td>
<td>81.2</td>
</tr>
<tr>
<td>9-16</td>
<td>31</td>
<td>15</td>
</tr>
<tr>
<td>17-29</td>
<td>6</td>
<td>2.8</td>
</tr>
<tr>
<td>30-63</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>5.27 ± 5.54 (range:0-63)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BAI scores</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-7</td>
<td>142</td>
<td>63.3</td>
</tr>
<tr>
<td>8-15</td>
<td>51</td>
<td>24.5</td>
</tr>
<tr>
<td>16-25</td>
<td>11</td>
<td>5.3</td>
</tr>
<tr>
<td>26-63</td>
<td>4</td>
<td>1.9</td>
</tr>
<tr>
<td>5.94 ± 5.54 (range:0-63)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CLAS scores</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5-19</td>
<td>29</td>
<td>13.9</td>
</tr>
<tr>
<td>20-35</td>
<td>179</td>
<td>86.1</td>
</tr>
<tr>
<td>26.5 ± 6.40 (range:6-35)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3.8% above the clinical cut off scores at BDI.
7.2% above the clinical cut off scores at BAI.

%86 of respondents were satisfied with life (better than normal)
# Results

Subjective Evaluation Questions and Results (N=208)

<table>
<thead>
<tr>
<th>Question</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you think that you get ill easily after the operation?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>33</td>
<td>15.9</td>
</tr>
<tr>
<td>How is your relationship with the recipient after the operation?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>unchanged</td>
<td>134</td>
<td>64.4</td>
</tr>
<tr>
<td>better</td>
<td>68</td>
<td>32.7</td>
</tr>
<tr>
<td>worse</td>
<td>5</td>
<td>2.4</td>
</tr>
<tr>
<td>How will you rate your experience of donation?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>perfect</td>
<td>104</td>
<td>50.0</td>
</tr>
<tr>
<td>good</td>
<td>51</td>
<td>24.5</td>
</tr>
<tr>
<td>pleasant</td>
<td>48</td>
<td>23.1</td>
</tr>
<tr>
<td>regretful</td>
<td>5</td>
<td>2.4</td>
</tr>
<tr>
<td>Would you recommend other people to be donors?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>207</td>
<td>99.5</td>
</tr>
</tbody>
</table>

Thought of getting ill easily: ↑ BDI, ↑ BAI, ↓ CLAS (p<0.001).
Regretfulness: ↑ BDI, ↓ CLAS (p<0.001).
Improved or unchanged relationship: ↓ BDI (p<0.001).
Results

- The ones in the first year of operation depicted higher depression ($M=8.25$, $SD=10.12$, $t:-2.18$, $df: 203$, $p < .05$) and lower life satisfaction ($M=21.94$; $SD=8.11$; $t:3.09$, $df: 203$; $P < .01$) scores.
Results

• Finally postoperative complications were found to increase anxiety (M=8.67, SD=9.04, t: -2.38, df: 206, P < .05) and lower satisfaction of life (M=23.75, SD=6.95, t: 2.24, df: 206, P < .05).

• Relationships between donors and recipients (biological or emotional) did not impact postoperative psychological outcomes or life satisfaction (BAI P > .05; BDI P > .05; CLAS P > .05).

• CLAS scores were correlated with anxiety and depression scores, showing that donors who reported more symptoms experienced lower life satisfaction.

Table 4. Correlations of Psychopathological Symptoms and Life Satisfaction With Each Other and Sociodemographic Parameters

<table>
<thead>
<tr>
<th>Correlation (Pearson r, N = 208) with</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>BDI</td>
</tr>
<tr>
<td>------------</td>
</tr>
<tr>
<td>Sociodemographic parameters</td>
</tr>
<tr>
<td>Age (y)</td>
</tr>
<tr>
<td>Time since donation (y)</td>
</tr>
<tr>
<td>Psychopathological symptoms</td>
</tr>
<tr>
<td>Depression Scores (BDI)</td>
</tr>
<tr>
<td>Anxiety Scores (BAI)</td>
</tr>
</tbody>
</table>

Pearson Correlation: * P < .01.
Discussion

• Living donors are still the main source of kidneys for renal replacement treatment in Turkey.
• In our study 208 of 405 of the donors contacted were able to complete the study in person.
• This really good response rate (51.35%), as most of them were coming from other cities, may show that the experience didn’t affect the donors negatively.
• Our results showed that psychological states or mental distress of living donors were similar to those of the normal population.
• This may be interpreted as indicating that the procedure has no negative effect on donors’ moods and does not increase anxiety symptoms. These findings were in accordance with the results of previous studies.
Discussion

• We also reported post-donation contentment with life status of donors. Almost 86% of respondents were satisfied with life.
• In addition to results of mental state and life satisfaction, there were some striking results related to subjective evaluations.
• The majority of kidney donors in the study emphasized that they would definitely make the same decision again (97.6%), similar to findings in other studies.
• Only 5 donors (2.4%) claimed that they regretted their experience of donation and reported a higher score of depression and lower life satisfaction.
• Except for 1 donor, the other 207 (99.5%) claimed that they would advise other people to become donors.
• Donors who thought about getting ill easily after the operation were found to be more depressive and anxious, with lower life satisfaction. This should be interpreted as indicating that those donors with somatic symptoms need to be evaluated further.
Discussion

• Results suggest that screening anxiety and mood during the first year after the operation procedure by reviewing psychometric data deserves further attention.
• To the best of our knowledge, this study is the first study in Turkey to assess the long-term mental effects of the donation process and to evaluate donors’ contentment with life.
• On the other hand, one limitation of our study is its retrospective nature: this limitation must be kept in mind when interpreting our data.
• As this was a retrospective study, it was not possible to make a statement about the mental health status of the sample prior to donation.
Summary

• The results of this study confirm that the majority of living kidney donors are comfortable with their decision to donate and do not experience negative consequences related to mood, anxiety, emotional well-being, family relationship, or personal health.

• Overall, these results suggest that the vast majority of donors have a positive experience, encouraging transplantation teams to continue performing living donor kidney transplantations.
Conclusions

• Living kidney donation is a safe procedure that does not have a negative impact on donors’ life satisfaction and mental status.

• However, it is crucial to identify risk factors for psychosocial distress in donors:
  – firstly to ensure that healthy individuals are not harmed and
  – secondly to develop better ways to help them manage the transplantation process.

• The results of unvalidated additional survey questions in particular underlined the importance of follow-up with donors in the first year and that screening for donors’ subjective experiences is useful in providing additional insight.

• We aim to investigate factors that predict contentment with life and mood states within recipient, donor, and control groups pre- and post-donation in a prospective study design.

• It is important to conduct extended follow-up studies of Turkish living kidney donors
Kidney Transplantation Team

• The principal investigators:
  – Göde Öğüten Evrim (MD, Psychiatrist)
  – Soykan Barlas (MD, surgeon)
  – Barış Akın (MD, surgeon)

• External collaborators:
  – Ceyda Soykan (Psych)
References

- Turkish Transplantation Foundation. [http://www.tonv.org.tr](http://www.tonv.org.tr)
- Wiedebusch S et al. Quality of life, coping, and mental health status after living kidney donation. Transplant Proc 2009;41:1483e8