End-Stage Renal Disease and Psychological Trauma: Shame and Guilt in Hemodialysis Patients, Transplantation Recipient and Donor Candidates, and Controls

Nilgün TAŞKINTUNA, Gamze ÖZÇÜRÜMEZ
Baskent University Faculty of Medicine, Department of Psychiatry, Ankara, Turkey

Abstract

Objective: Psychological trauma can be coupled with a broad range of affects, including shame and guilt. We considered end-stage renal disease (ESRD) as a psychological trauma and assessed whether the experience of shame and guilt have negative effect on mood and health-related quality of life (HRQOL) in hemodialysis patients, transplantation recipient and living donor candidates.

Methods: The Beck Depression Inventory, Beck Anxiety Inventory, 12-item General Health Questionnaire and the Guilt and Shame Inventory were administered to all participants. The hemodialysis group consisted of 56 individuals, the recipient candidate group - 66 individuals, and the donor candidate and the control groups consisted of 41 and 51 healthy individuals, respectively.

Results: Although neither guilt nor shame scores reached a significant value in the hemodialysis, recipient and donor candidate groups, hemodialysis patients had the highest depression, anxiety and HRQOL scores.

Conclusion: We conclude that the overwhelming majority of renal transplant candidates evince a healthy psychological response to the pre-transplantation waiting period. Our findings also suggest that kidney donor candidates do not experience the pre-transplantation period as traumatic, sustained by the boost in their sense of well-being. We also conclude that hemodialysis patients are the most negatively affected group, although neither guilt nor shame was detected significantly. Further investigation of the trauma-related emotions in ESRD patients, taking treatment-specific differences into account, represents a promising area of future research.

Keywords: ESRD, shame, guilt, hemodialysis, transplantation

Introduction

End-stage renal disease (ESRD) is an insidious, progressive and irreversible loss of renal function.

The care regimen is complex and demanding, extending into nearly all aspects of patients’ lives. This means severe, extreme lifestyle changes requiring life long treatment. Exposure to extreme stress, exemplified by the loss of an organ function, represents a threat to the psychological integrity. In this respect, ESRD might be considered as psychological trauma based on individual differences, including the treatment modality chosen. ESRD treatment modalities are hemodialysis, continuous ambulatory peritoneal dialysis (CAPD), and kidney transplantation. The psychological response to dialysis and
transplantation reflects a complex cognitive, emotional and behavioural process, such as concern for financial well-being, interpersonal relationships, social activities, security, and fear of death and the unknown, isolation, rejection, and total loss of control (1). Traumatic events can elicit a myriad of emotions. In addition to fear, common emotional responses to traumatic events include anger, shame and guilt, sadness, and the complete absence of emotion or “numbing” (2).

Traumatic shame and guilt have consequences for proneness to depression, anxiety, and other negative affects on psychosocial functioning like health-related quality of life (HRQOL) (3). Shame is a more complex intrapsychic process than is guilt because it involves processes concerning attributes about the core dimensions of the self, identity, and personality. The experience of shame inevitably involves self-appraisal, loss of self-esteem and personal integrity, and negative affects such as feelings of disgrace, disrepute and dishonor (4). Guilt, on the other hand, does not necessarily involve internal appraisal processes about the self and its goodness or badness. It concerns different forms of self-retribution about responsibility for personal actions (5). Unlike traumatic shame, states of guilt typically have less emotional distress, because the focus of evaluation is the act not the self-worth of the person.

In Turkey, the prevalence of ESRD has increased by almost 8% in the last decade and there are approximately 60000 ESRD patients. Despite its enormous costs, hemodialysis is the main treatment modality by which 87% of all patients are treated, because the suspicions about organ donation are still widespread in our country (6). Hemodialysis not only consumes substantial amount of time, but also strains physical health and limits daily life profoundly. Also research findings emphasize that psychiatric morbidity is higher in hemodialysis patients compared to both CAPD patients and transplantation recipients. For patients with ESRD on hemodialysis, full recovery is not a realistic aim. A goal is maintaining these patients’ quality of life including maximizing functioning, relieving symptoms and minimizing mental distress (7). Due to the long wait for cadaver kidneys, living-donor use in our country is high and living related donors are involved in substantial number of transplantations carried out by our transplantation team. It offers several potential benefits from a medical point of view. Advantages include; enhanced allograft compatibility, flexibility in terms of timing and access to transplantation for the recipient, and requirement for lower doses of postoperative immunosuppressant agents (8). There are two aspects presently acknowledged to represent the end-points by which any ESRD treatment should be evaluated; survival and quality of life. HRQOL is becoming an increasingly important concept in the evaluation of different therapeutic interventions of ESRD. The majority of studies demonstrated statistically significant pre-and post-transplant improvements in physical, mental, and social aspects of HRQOL (9). On the one hand, transplantation restores the ESRD patient’s freedom and relieves him/her from dietary restrictions; on the other hand, it exposes the recipient to side effects of pharmacological treatment and to fear of rejection. Although most of the studies rate donors’ HRQOL to be better than or equivalent to that of the general population and a boost in self-esteem has been documented as a factor increasing the sense of well-being (10,11), recently, more concern has been raised about safety of donors (12). There have been some reports of high risk of developing psychiatric disorder and a corresponding decline in psychosocial functioning (13). Given findings suggesting that emotional responses to trauma may play a role in psychopathology (14), an understanding of the effects of emotions elicited by different types of traumatic events seems particularly important.

To our knowledge, only two studies evaluating shame and guilt in heart, lung, liver and kidney transplant recipients had been reported (15,16), and assessment of these emotions in ESRD patients as well as living-donor candidates has not been undertaken. Therefore, the aim of this study is to investigate shame and guilt in hemodialysis patients, renal transplantation recipient and donor candidates and, to compare mood and HRQOL in these groups and healthy controls. We considered ESRD as trauma, and assessed whether the experience of shame and guilt has any negative effect on mood and HRQOL.

**Method**

This cross-sectional study was conducted at the Hemodialysis and Transplantation Units of Başkent Medical Faculty. The hemodialysis group consisted of 56 individuals (23 women and 33 men, mean age: 46.64±13.43, age range: 19-73 years). The recipient candidate group consisted of 66 individuals (19 women and 47 men, mean age:42.32±11.59, age range: 18-65 years). The donor candidate group included 41 healthy individuals (26 women and 15 men, mean age: 42.15±8.76; age range: 25-58 years). The control group consisted of 51 healthy individuals (23 women and 28 men, mean age: 34.61±7.25, age range: 23-55 years) who were recruited from the circle of friends of the hospital staff. In the control group, those with a history of chronic illness or trauma or treatment for any psychiatric disorder, and those currently undergoing treatment for a diagnosed mental disorder were excluded from the study. The participants were informed by the researchers that the study aims on the assessment of various psychological parameters, and informed consent was obtained. The research protocol was approved by the Medical Faculty Ethics Committee. Data were collected between March and June 2009. Apart from sociodemographic data, all participants were requested to complete the Beck Depression Inventory (BDI), Beck Anxiety Inventory (BAI), 12-item General Health Questionnaire (GHQ-12), and the Guilt and Shame Inventory (GSI).

The hemodialysis patient and control questionnaires consisted of the same 16 items that covered the following topics: socio-demographic information (sex, age, level of education, occupation, working status, income level, marital status), physical disorders other than ESRD, tobacco and/or alcohol consumption at the time of the survey, drug abuse at the time of the survey.

The recipient candidate questionnaire consisted of 32 items covering the following topics: socio-demographic information (sex, age, level of education, occupation, working status, income level, marital status), psychiatric history of the recipient candidate and his/her family, physical disorders other than ESRD, tobacco and/or alcohol consumption at the time of the
survey, drug abuse at the time of the survey, duration of ESRD
and dialysis treatment, type of dialysis (hemodialysis-HD versus
APD, dialysis schedule, reason for deciding to undergo
transplantation, degree of relationship with the living donor
candidate, type and adequacy of preoperative information
provided by the transplantation unit physician, worries about the
transplantation process, including concerns about the donor
candidate.

The donor candidate questionnaire consisted of 28 items
investigating the following: socio-demographic information (sex,
age, level of education, occupation, working status, income level,
marital status), psychiatric history of the donor candidate and
his/her family, physical disorders, tobacco and/or alcohol
consumption at the time of the survey, drug abuse at the time of
the survey, degree of relationship with the recipient, amount of
time to decide to donate, type and adequacy of preoperative
information about donation, worries about the transplantation
process, including concerns about the recipient candidate.

The BDI is a 21-item self-report inventory for measuring the
severity of depression which was developed by Beck et al. in
1961, and then revised by Beck and associates in 1979 (17). It
was adapted for the Turkish population by Hisli (18). It is
composed of items relating to symptoms of depression such as
hopelessness and irritability, cognitions such as guilt or feelings
of being punished, as well as physical symptoms such as fatigue,
weight loss, and lack of interest in sex.

The BAI is another 21-item self-report inventory used for
measuring the severity of an individual’s anxiety which was
created by Beck et al. in 1988 (19) and was adapted for the
Turkish population by Ulusoy et al. (20). It consists of questions
about how the subject has been feeling in the last week,
expressed as common symptoms of anxiety such as numbness,
hot and cold sweats, or feelings of dread. Each question has the
same set of four possible answer choices: not at all, mildly (it did
not bother me much), moderately (it was very unpleasant, but I
could stand it), severely (I could barely stand it).

The GHQ-12 is a measure of current mental health and, since
its development by Goldberg in the 1970s, it has been extensively
used in different settings and different cultures for detecting
HRQOL, the severity of the psychological distress and disease
burden (21). The questionnaire was originally developed as a 60-
item instrument, however, at present, a range of shortened
versions of the questionnaire including the GHQ-12 is available. It
was adapted for the Turkish population by Kilic in 1996 (22). This
scale focuses on breaks in normal functioning. It only covers
disorders or patterns of adjustment associated with distress.
Each item on the scale has four responses from “better than
usual” to “much less than usual.” Higher scores indicate lower
HRQOL.

The GSI is a 24-item, 5-point Likert type self-report inventory
which was developed by Johnson et al. in 1987 (23). It is molded
out from the 36-item version which was designed to rate shame-
proneness and guilt-proneness. Each twelve item group
constitutes two subscales: items 3, 6, 7, 11, 12, 14, 16, 17, 21, 22,
23, 24 form the guilt subscale and items 1, 2, 4, 5, 8, 9, 10, 13, 15,
18, 19, 20 form the shame subscale. The Turkish validity and
reliability study was undertaken by Şahin and Şahin in 1992
(24,25). Higher scores obtained from the subscales provide the
opportunity to comment on which emotion is experienced more
profoundly by the individual.

Statistical analysis was performed using SPSS version 11.0.
Descriptive statistics were used to assess data of the three
socio-demographic questionnaires for hemodialysis patients,
controls, recipient and donor candidates. In order to analyse
the effect of socio-demographic characteristics on dependent
variables, i.e. BDI, BAI, GHQ-12 and GSI scores, two one-way
MANOVAs were carried out. One-way ANOVA was used to
investigate differences among the four groups, and the Tukey’s
post-hoc test was then used to analyze the differences between
the groups. To assess within-group difference in the recipient
candidate group, living related donor versus cadaveric kidney
transplant candidates, t-test was used.

Results

In this study, data from 214 participants (91 females, 123
males) were analysed. Some socio-demographic characteristics
of the group are summarized in Table 1. The mean time on
dialysis for the hemodialysis group was 38.83±43.38 months
(ranging from less than a month to 216 months). The mean time

| Table 1. Socio-demographic characteristics of the sample of the study (N=214) |
|-----------------|------|------|
| **Variables**   | **Mean** | **SD** |
| Age             | 46.6  | 13.4  |
| Hemodialysis    | 42.3  | 11.5  |
| Recipient candidate | 42.1  | 8.8   |
| Donor candidate | 34.6  | 7.3   |
| Control         |  |
| **Gender**      | **Frequencies** |
| Male            | 123  |
| Female          | 91   |
| **Consuming alcohol** | **Yes** | **No** |
| Yes             | 10   | 204  |
| No              | 66   | 148  |
| **Smoking**     | **Frequencies** |
| Yes             | 27   |
| No              | 187  |
| **Source Dependent Variables** | **SS** | **Df** | **Mean Square** | **F** |
| Sex             | Depression | 20.7 | 1 | 20.7 | 0.3 |
| Anxiety         | 444.5 | 1 | 444.5 | 4.1* |
| GSA             | 13.9 | 1 | 13.9 | 0.6 |
| Guilt           | 60.2 | 1 | 60.2 | 0.3 |
| Shame           | 195.4 | 1 | 195.4 | 2.2 |
| **Error**       | 210  |
from diagnosis of ESRD to taking transplantation decision for the recipient candidates was 69.96±78.52 (range:1358) months. Prior to transplantation, 7 (10.6%) of the recipient candidates were on CAPD and 59 (89.4%) were on hemodialysis. In the majority of the patients (n=52, 78.8%), the hemodialysis frequency was three times a week, and 4 (6.1%) had had a kidney transplantation previously. Forty-two (63.6%) of the recipient candidates stated that a physician had informed them about the transplantation process before the surgery and 42 (63.6%) were satisfied with this information. In the donors group, 32 (78.0%) participants reported that they were informed by a physician and 24 (75.0%) were satisfied with this information.

Fourteen (34.1%) of the donor candidates donated their kidneys to their spouses, twelve (29.3%) to their children, 4 (9.8%) to their parents, 10 (22.0%) to their brothers and 2 (4.8%) to their sisters. Eight (12.1%) of the recipient candidates were going to undergo a living donor procedure with graft from their spouses, 5 (7.6%) from their mothers, 5 (7.6%) from their brothers, 4 (6.1%) from their sisters, 2 from their fathers (%3.0) and 42 (63.6%) from cadaver.

For recipient candidates, the most frequent concern was risk of graft rejection (n=32, 48.5%), and the most common worry about their donor for the living related kidney recipient candidates was the fact that they will live the rest of their lives with a single kidney (n=19, 86.9%). For donor candidates, the most frequent personal concern was the potential complications related to the operation (n=8, 19.5%) and interestingly enough, 18 (43.9%) reported that they did not have any personal concern at all, and the most common worries about their recipients were (n=25, 61.0%) the general health status of the recipient after the operation and potential rejection of the donated kidney (n=14, 34.1%).

In order to analyse the effect of socio-demographic variables on BDI, BAI, GHQ-12 and GSI scores two one-way MANOVAs were carried out. The results are summarized in Table 2 and Table 3. It was found out that there was a significant main effect of the gender of the participants, Wilks’ lambda=0.9, F(5,206)=3.32, p<0.01. The results of the post-hoc analysis has revealed that women had significantly higher anxiety score (X=12.0) than men (X=9.1). Additionally, the results of the analysis showed the significant main effect of education as well, Wilks’ lambda=0.8, F(20, 674)=2.3, p<0.01. It was found out that higher educated participants had significantly higher guilt score (X=53.7) than the rest of the groups.

Four one-way ANOVAs were carried out to investigate whether BDI, BAI, GHQ-12 and GSI scores differed across donor and recipient candidates, hemodialysis patients and controls. Using one-way ANOVA more than once increases the risk of Type I Error. To counter-balance this risk, the critical value for p was taken to be 0.01 instead of 0.05 (0.01 is smaller than 0.5 divided by the number of analysis). The results are summarized in Table 4.

When the mean BDI score was the dependent variable, a difference between the groups was observed, F(3, 209) = 19.502, p<0.001. In order to further investigate the differences between the groups, a Tukey’s test was performed. It turned out that the recipient candidates had significantly higher depression scores than donor candidates (X Mean Receivers Depression =11.64, SD=8.07; X Mean Donors Depression = 5.44, SD=4.78; p<0.01). The hemodialysis patients had the highest BDI scores which were significantly higher than those in the donor and recipient candidates and controls (X Mean Hemodialysis Depression =18.38, SD=11.23; X Mean Control Depression = 9.16, SD=8.74; p<0.001 for all differences).

When the mean BAI score was the dependent variable, a difference between the groups was found, F (3, 209)= 19.643, p<0.001. A Tukey test was performed to investigate which groups differed from each other. The hemodialysis patients had the highest BAI scores (X Mean Hemodialysis Anxiety = 17.93, SD=13.93) which were significantly different from the recipient, donor candidates and controls (X Mean Donors Anxiety = 4.58, SD= 5.55; X Mean Receivers Anxiety = 7.41, SD= 5.16; X Mean Controls Anxiety = 10.24, SD= 9.54; p<0.001 for all differences). Also, the controls had higher BAI scores than the donors which nearly reached significance (p=0.023). The results are summarized in Table 4.

When the mean GHQ-12 score was the dependent variable, a difference existed between the groups, F(3, 209) = 3.562, p<0.001. A Tukey’s test was performed to investigate the differences across the groups. The hemodialysis patients had the highest scores (X Mean Hemodialysis SF = 14.80, SD= 7.81) which were significantly different from those in the recipient and donor candidates, and controls (X Mean Donors SF = 7.56, SD=3.65; X Mean Receivers SF = 10.45, SD= 5.00; X Mean Controls SF = 9.92, SD= 5.61; p<0.001 for all differences).

When the mean shame score was the dependent variable, a difference between the groups was detected, F (3, 209)=4.8, p<0.001. A Tukey’s test was performed to investigate the differences across the groups. The control groups had the highest scores (X Mean Control Shame = 43.9, SD= 9.2) which were significantly different from those in the donor candidates.

When the mean guilt score was the dependent variable, the difference across the groups did not reach significance. However, p=0.01 indicates that there might be a pattern.

**Discussion**

ESRD is a life-threatening chronic illness, in which the kidneys cease to function. As a result of ESRD, patients must undergo some form of renal replacement therapy, either dialysis or transplantation, to perform the functions normally carried out by the kidneys. In the purest sense, psychological trauma
involves exposure to a life-threatening experience. In this respect, we considered ESRD as a psychological trauma based on individual differences, including the treatment modalities used. Research findings suggest that emotional responses to trauma may play a role in related psychopathology (14,26,27). Recently, increased attention has been devoted particularly to shame and guilt because they are frequently reported following traumatic experiences (28). Several studies indicate that guilt and shame may be experienced in cadaver kidney, liver, heart and lung transplant recipients (15,16), however, to our knowledge, there are no research studies regarding the emotional response in hemodialysis patients as well as in recipient and living-donor candidates. In this study, we investigated shame and guilt in hemodialysis patients, transplantation recipient and donor candidates. We hypothesized that shame, which is a self-conscious moral emotion resulting from a negative appraisal of oneself, would lead to higher depression and anxiety scores and worse HRQOL compared to guilt, which is thought to result from a negative appraisal of one’s behavior only.

Hemodialysis patients had the highest depression, anxiety, and HRQOL scores compared to the other three groups, although their shame and guilt scores did not reach significance. Our results indicate that the negative effects of ESRD on mood and HRQOL are most prominent in the hemodialysis patients. This finding is consistent with the results of previous studies conducted in our country (29,30). Although most of the recipient candidates were undergoing hemodialysis as well, and even for a longer period of time compared to hemodialysis group, high levels of depression and anxiety in the hemodialysis group might be attributed to several reasons including unavailability of transplantation option in the near future for these patients. Since even the healthcare providers of patients with hemodialysis have been reported to experience traumatic stress (31), further investigations in larger patient groups with trauma-specific tools are necessary to assess the dimensions of such an experience.

In the recipient candidate group, we found that the most common worry about their donor was whether donation would harm the donor’s quality of life, and the most common concern about themselves was about the viability and functioning of the transplanted kidney. We found no within-group difference in means of living related donor versus cadaveric kidney transplant candidates. Neither guilt nor shame scores reached a significant value in the recipient candidate group despite feelings of responsibility towards the donor and the transplant. Still, depression scores were higher in recipient candidates compared to those in the donor candidates. This finding might be attributed to prolonged experience with a debilitating, chronic illness such as ESRD and to uncertainty about the future. We conclude that the overwhelming majority of recipient candidates evince a mature psychological response to the pre-transplantation period.

Although the favorable results of living organ donation continue to grow with improved survival, immuno-suppression and surgical technical progression, the long-term physical and psychological consequences are not clearly established for donors who are faced with major operation without any potential health benefit for themselves (32). We are in line with Noyan et al. that living organ donation is a controversial area for medical ethics and ensuring donor’s volunteerism as well as psychological health is important. That is why we think that our study findings may contribute to the less investigated area of donors’ pre-transplantation psychological status. Nearly half of the subjects in our donor candidate group did not have any personal concern regarding transplantation. The most common worry about their recipient was the general well-being of the recipient after the transplantation. Our donor candidates did not only have lower depression and anxiety scores but also had better HRQOL compared to the other groups, including the controls. We assume that this might be explained by enhanced self-esteem and self-regard related to kidney donation, and well-assessment of the donor candidates in means of pre-transplant psychiatric evaluation. Our findings suggest that, for the majority of kidney donor candidates, waiting-period of the transplantation process is not a traumatic experience, and there is a boost in sense of well-being.

Interestingly enough, controls had the highest shame scores. This finding suggests that GSI is not a state but a trait inventory.

### Table 4. ANOVA results for all dependent variables

<table>
<thead>
<tr>
<th>Groups</th>
<th>Recipients Mean</th>
<th>Donors Mean</th>
<th>Hemodialysis Mean</th>
<th>Control Mean</th>
<th>F(df=3,209)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>11.6</td>
<td>5.4</td>
<td>18.4</td>
<td>9.2</td>
<td>19.5^a</td>
<td>0.000</td>
</tr>
<tr>
<td>Anxiety</td>
<td>7.4</td>
<td>4.6</td>
<td>17.9</td>
<td>10.2</td>
<td>19.6^b</td>
<td>0.000</td>
</tr>
<tr>
<td>HRQOL</td>
<td>10.5</td>
<td>7.6</td>
<td>14.8</td>
<td>9.9</td>
<td>13.5^c</td>
<td>0.000</td>
</tr>
<tr>
<td>Shame</td>
<td>39.5</td>
<td>37.3</td>
<td>42.1</td>
<td>43.9</td>
<td>4.8^d</td>
<td>0.003</td>
</tr>
<tr>
<td>Guilt</td>
<td>49.3</td>
<td>48.0</td>
<td>49.9</td>
<td>53.2</td>
<td>3.9</td>
<td>0.01</td>
</tr>
</tbody>
</table>

*a Significant post-hoc difference (Tukey’s honestly significant difference test) between Hemodialysis and all other groups (p=0.001), and between Recipients and Donors (p=0.002).
*b Significant post-hoc difference (Tukey’s honestly significant difference test) between Hemodialysis and all other groups (p=0.001), and between Control and Donors (p=0.002).
*c Significant post-hoc difference (Tukey’s honestly significant difference test) between Hemodialysis and all other groups (p=0.001).
*d Significant post-hoc difference (Tukey’s honestly significant difference test) between Donors and all other groups except for Recipients (p=0.001).
and its use might be limited in research studies such as ours. This finding might also be attributed to an Eastern culture-based quality of self-consciousness which becomes prominent in face of other people’s miseries such as loss of an organ and chronic disease (33). The effect of socio-demographic variables on mood and HRQOL on the other hand are consistent with the findings of previous studies: women had higher anxiety levels than men (34,35) and higher educated participants had higher guilt scores (36).

The current study was based on cross-sectional comparison of four groups. A better understanding of trauma-related shame and guilt in ESRD patients, taking treatment modalities into account, would be possible by designing prospective, qualitative studies which use state rather than trait inventories for evaluating these specific emotions. The study has additional limitation because of differences in age, gender and educational status. Although there was no significant difference between the groups in respect to guilt scores, statistical analysis pointed out that in larger groups, the difference could become significant. For a better assessment of the psychological response to ESRD and different treatment modalities, more specified instruments should be developed and used. Understanding the effects of trauma-related shame and guilt in ESRD patients is important to plan adequate and effective modes of psychiatric intervention.

Acknowledgements

Authors would like to thank to Assist. Prof. PhD. Sedat Işıklı from Hacettepe University Department of Psychology for his tremendous help in statistical analysis, and the Head of Nephrology Department Prof. Dr. Nurhan Özdemir and the Co-head of General Surgery Department Prof. Dr. Hamdi Karakayali from Başkent University Faculty of Medicine for their support on collecting the data.

References