



# Comparison of the Quality of Life and Emotional Responses in Kidney Transplant Recipients from Living and Deceased Donors in Nephrology Clinics

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## Abstract

**Background:** Quality of life (QoL) is one of the essential measures in assessing a patient's status after kidney transplant, and emotional response is an important factor in evaluating the patient's compatibility with the transplant. Also, emotional response affects a patient's QoL.

**Objectives:** This study aimed to compare the QoL and emotional responses of kidney recipients from deceased and living donors.

**Methods:** This descriptive comparative study randomly selected 118 kidney transplant patients (67 recipients from living donors and 51 recipients from deceased) referred to the Nephrology Clinic of Tehran University of Medical Sciences for a post-surgery follow-up. The QoL questionnaire for patients with renal transplants introduced by Laupacis et al. and the emotional response questionnaire (ERQ) by Ziegelmann et al. were used in this study. For data analysis, Mann-Whitney, independent t-test, and Pearson's correlation tests were used. All the analyses were performed using SPSS software version 20.

**Results:** The kidney recipients from living donors had significantly higher QoL score (especially emotionally) compared with kidney recipients from deceased donors ( $P=0.04$ ). The score of emotional response was higher in recipients from a living donor, which is related to feeling guilty, transplant disclosure. Furthermore, recipients from a living donor felt guiltier and were unwilling to disclose their transplant compared with recipients from deceased donors.

**Conclusions:** Feeling of guilt and being anxious about transplant disclosure were higher in recipients from living donors. A significant difference was observed in the QoL and emotional response between the two groups of kidney recipients. Therefore, it is important to involve the transplant team, specifically nurses, in the identification of emotional response and planning accordingly to improve the patients' QoL, especially in recipients from a living donor.

**Keywords:** Quality of Life, Emotional Responses, Kidney Transplant

## 1. Background

The renal system is the most important regulator of the body's internal environment (1). Chronic renal disease is a burden to society due to its high prevalence and treatment costs (2). In western societies, the incidence of chronic kidney disease (CKD) is increasing so that approximately 10% of the population over the age of 20 are involved (3). Diabetes is the main cause of CKD. Other causes include hypertension, pyelonephritis, nitrogen and blood urea disorders, glomerulonephritis, renal disease family history, maternal disorders, and kidney cancers (1). In Iran, there were approximately 58,000 people with CKD up to the end of 2016 (4). Depending on the cause of CKD, the available treatment options are different, including dialysis and kid-

ney transplants (2).

There are some limitations for patients with dialysis treatment options. They feel that they are dependent on other individuals and are insecure about their future. Other stressful factors for these patients are feeling of powerlessness, lack of control over the disease and its treatment, limitation imposed by medication, lack of self-confidence, financial burden, and sexual performance (5).

Another option for these patients is kidney transplantation (2). A kidney transplantation is a surgical procedure to place a healthy kidney from a living or deceased donor into a person whose kidneys no longer function properly and is considered as the desired treatment. Patients with kidney transplantation show higher QoL compared with patients under other treatments. Without the

need for hemodialysis, recipients of a successful kidney transplant can live a normal life socially and vocationally. Although the cost during the first year after surgery is higher than the one-year cost of dialysis, the cost for transplant patients significantly decreases in the following years. Finally, the survival of dialysis patients has been widely improved, but transplantation can help them have longer lives (6). In Iran, approximately 3,000 patients with CKD have kidney transplantation annually (5). The three sources for kidney transplants are a family member as a living donor, a living donor for financial compensation or philanthropical reason, and a deceased donor (2, 7).

Studies show an increasing trend in kidney transplants from a living donor in western societies (8). About half of the kidney transplantations in developed countries (e.g., US and UK) are from living donors (9). Since the number of kidney donations from deceased donors is not sufficient, and due to the constant increase in the kidney transplant waiting list, more attention has been paid to living donors recently (10). Receiving a kidney from a family member increases the recipient's life expectancy. The better outcomes of a transplant from a family member is attributed to minimum cold ischemia and similar human lymphocytes antigens. Moreover, when receiving kidney from a family member, the necessity for immunosuppressive diet decreases (11, 12). Receiving kidney from a deceased donor can cause emotional disorder due to the false image of relating the donor's death to the recipient's survival. Recipients from deceased donors are usually from low-income families who cannot afford to receive kidney from a living donor. Since these patients have been on the waiting list for a long period of time, they are more prone to emotional disorders (13).

In recent years, the QoL has been considered as a very important factor in health. Health and performance improvement has been considered as one of the important factors in patients with renal failure (14). The QoL is a multi-dimensional concept that includes physical health, disease prognosis, and treatment, economic and social aspects of the patient's life that can be changed with time. (15). In many studies, the QoL has been identified as a key factor after transplant (16).

Another factor affected by kidney transplantation in recipients from living and deceased donors is the emotional response, which refers to a set of behaviors, reactions, and assumptions of the recipient toward the transplanted kidney; emotional response may include depression, anxiety, feeling guilty and responsible after the transplant surgery, anxiety about transplant disclosure, and medication compliance. Recipients may show different emotional responses depending on whether the kidney was received from a deceased, living, or relative donor. The patients' response, such as feeling guilty and frustration can affect their QoL, performance, and behavior (17). Kim et

al. showed that kidney transplant can affect the recipients' QoL and emotional responses (18). Moreover, de Groot et al. showed that recipients who received kidney from a living donor had a better QoL, less performance degradation from a physical problem, higher social involvement, and a better overall health (19). In addition, de Groot et al. found that kidney recipients from a deceased donor had a higher sense of responsibility for taking care of themselves. In 2016, Zimmerman et al. (20) investigated the emotional response in terms of anxiety, medication compliance, transplant disclosure, and QoL among kidney recipients from deceased or living donors and did not report a significant difference between the two groups. However, recipients from a living donor felt guiltier and had a higher level of anxiety in comparison to kidney recipients from a deceased donor. Accordingly, this study aimed to identify the emotional response as an important factor in balancing emotional reactions after transplant surgery.

Thus, the emotional response of kidney recipients depends on whether they received the kidney from a living or deceased donor; as a result, this can impact their QoL.

## 2. Objectives

Therefore, characterizing, managing, and balancing emotional responses can improve the recipients' QoL. Due to the high number of CKD patients and very limited and controversial studies in this field, this study aimed to compare the QoL and emotional responses of kidney recipients from deceased and living donors.

## 3. Methods

This descriptive comparative study randomly selected 118 kidney transplant patients referred to Nephrology Clinics in Medical Sciences University of Tehran city including Milad, Laleh, Erfan, and Shahid Modares hospital. Out of 118 subjects, 67 patients received a kidney from a living donor and 51 from a deceased donor.

Inclusion criteria were having passed at least six months from the transplantation, having no mental disorder, over 18 years of age or older, and willingness to participate in the study.

We used two questionnaires, including the QoL and emotional response questionnaire (ERQ). The QoL questionnaire, specific to patients with kidney transplantation, includes 25 questions in five different components, including physical characteristics, fatigue, fear and uncertainty, appearance, and emotional components. These components are rated based on a Likert scale (from 1 to 7). The validity of this tool was confirmed by content validity and face validity. In addition, the reliability of the tool using Cronbach's alpha was 0.076 in the study by Tayebi and 0.094 in our study (21).

The ERQ is designed to quantify the emotional responses in kidney transplant patients. The scores of this 23-item questionnaire range from 'totally disagree' (scale 1) to 'totally agree' (scale 5) based on the Likert scale. Also, the scale evaluates being anxious about the transplant surgery, feeling guilty toward the donor, disclosure of transplant, and drug compliance. In the study by Zimmerman et al. (20), the reliability of the tool based on Cronbach's alpha was calculated as 0.84. In this study, we achieved face and content validity, and Cronbach's alpha for reliability was achieved 0.85 for questioners.

#### 4. Results

The descriptive statistics are shown in Table 1. Most of the recipients from the living donors (34.8%) were in the age range of 31 - 34 years, and most of the recipients from the deceased donors (33.13%) were in the age range of 59 - 75 years.

Inferential findings, including mean and standard deviation, and range for the emotional responses in recipients from a living and deceased donor are presented in Table 2. The independent t-test results indicated that the mean of emotional response was higher in recipients from a living donor due to feeling guilty toward the donor and transplant disclosure.

The mean, standard deviation, and range of QoL in recipients from a living and deceased donor are presented in Table 3. The Mann-Whitney test results showed that the QoL mean is significantly higher in recipients from a living donor compared with recipients from a deceased donor, which is attributed to the emotional component. The results showed a significant difference in QoL between the two groups ( $P = 0.04$ ); the mean QoL in recipients from a living donor was 78.72, and the mean QoL in recipients from a deceased donor was 66.37. In the emotional component of QoL, there was a significant difference between the two groups ( $P = 0.02$ ) such that the mean score of the emotional component in recipients from a living donor was 19.21 and that of the recipients from a deceased donor was 15.31.

The analysis of the correlation coefficient and deceptive statistics in recipients from a deceased donor showed that there was a correlation between age and emotional responses scores in the aspects of feeling responsible toward the donor and transplant disclosure so that as the recipients' age increased, the associated scores decreased. Correlation analysis in QoL components showed that in recipients from a living donor, there was a correlation between age and income level with the QoL score so that as the age and income increased, QoL score decreased. Moreover, the results showed a correlation between education level and QoL, specifically in physical and appearance dimensions, so that the associated score in these two dimen-

sions increased as the education level increased. In addition, there was a correlation between the duration of undergoing dialysis and three aspects of physical, emotional, and fear in QoL analysis, so that the longer the recipients received dialysis, the higher their score in these three aspects were. Correlation analysis in recipients from a deceased donor showed that there was a negative correlation between the recipient's age and fear aspect of QoL, so that with increase in age, we observed a decrease in fear score. There was a significant correlation between income level and the two aspects of fear and emotion in QoL analysis. Moreover, there was a correlation between age and two aspects of fear and appearance, so that as the age increased, the score in these two aspects increased.

#### 5. Discussion

In this study, we compared the QoL, and emotional responses in kidney transplant recipients from living and deceased donors referred to training hospitals in Tehran for a follow-up. The results showed that there is a significant difference in the QoL of kidney recipients from living donors and recipients from deceased donors, specifically in the emotional aspect; this is in line with the results of de Groot et al. (19). However, a study by Zimmerman et al. (20) showed no significant difference in QoL between these two groups. In order to improve kidney recipients' QoL, it is important to recognize the need for emotional and social support. Ignoring such needs may impact the recipients' QoL after the transplant surgery.

While most of the recipients from a living donor had a high school degree, most of the recipients from a deceased donor had primary school education. In the study by Kim et al. (22), college graduates had the highest percentage (52.4%) of kidney transplants, with most of the recipients receiving a kidney from a living donor. In western societies, receiving kidney from a living donor is increasing (8). Most of the participants received a kidney from a non-relative living donor. However, receiving a kidney from a family member of relatives yields and decreases the need for immunosuppressive diet (11, 12). However, 90% of donors in Iran are non-relative living donors who have financial motivation for their donation (23).

Despite the challenges associated with a non-relative living donor with financial motivations, this kind of donation has received significant attention to fill the gap between demand and supply and is used in other countries; however, Iran is the only country in which non-relative living donors can donate their kidney for financial compensation (24, 25).

On the other hand, the analysis of the mean of emotional responses showed that the total score of emotional responses in recipients from a living donor was higher compared with recipients from a deceased donor. There

**Table 1.** Demographic Information of the Participants

Variable	Living, No. (%)	Deceased, No. (%)
<b>Gender</b>		
Male	34 (54.6)	30 (63.8)
Female	28 (45.4)	18 (36.2)
<b>Age range</b>		
17 - 30	11 (16.7)	8 (15.7)
31 - 44	23 (34.8)	13 (25.5)
45 - 58	19 (28.8)	13 (25.5)
59 - 75	12 (18.2)	17 (33.13)
<b>Marital status</b>		
Married	52 (43.3)	39 (76.5)
Single	10 (14.9)	10 (19.6)
Divorced	2 (3)	3 (3.9)
Widowed	3 (4.5)	0 (0)
<b>Employment status</b>		
Worker	5 (7.7)	5 (9.8)
Officer	7 (10.8)	5 (9.8)
retired	12 (18.5)	18 (35.3)
Housewife	22 (33.8)	11 (21.6)
Self-employed	8 (12.3)	4 (7.8)
Unemployed	11 (16.9)	8 (15.7)
<b>Income IRR)</b>		
Less than one million	21 (41.2)	16 (40)
Between one and two million	24 (47.1)	20 (50)
Between two and three million	4 (7.8)	3 (7.5)
More than three million	2 (3.9)	1 (2.5)
<b>Education</b>		
Elementary school	18 (30.5)	16 (35.6)
Middle school	14 (23.7)	2 (4.4)
High school	16 (27.1)	20 (44.4)
College	11 (18.6)	7 (15.6)

was a significant difference in the feeling of guilty toward the donor and transplant disclosure between the two groups, with the recipients from a living donor having a higher score as compared with the recipients from a deceased donor. Zimmerman et al. (20) showed that feeling of guilty is significantly higher in the recipients from a living donor; however, they reported no significant difference in transplant disclosure between the two groups. The results of Gozdowska et al. in comparison of emotional and social impacts in the recipients from living and deceased donors in others study is same as our results (26).

Ummel et al. (8), in assessing the experience of kidney

recipients and donors, reported depression and anxiety in the recipients from a living donor as compared with the recipients from a deceased donor. The results of Kim et al. (27) in comparison of emotional and social impacts in the recipients from living and deceased donors in other studies is the same as our results. In this study, feeling of guilt, fear of transplant disclosure, feeling worried, and in general negative emotional responses were higher in recipients from a living donor.

In our study, 85% of recipients from a living donor experienced no to mild depression, while 63% of recipients from a deceased donor experienced no to mild depression,

**Table 2.** Mean, Standard Deviation, and Range of Emotional Responses Aspects of the Recipients

Emotional Response Aspect	Recipients from a Living Donor			Recipients from a Deceased Donor			P-Value (t-Test)
	Mean (SD)	Min	Max	Mean (SD)	Min	Max	
Worried about transplant	9 (29)	19.94	6.50	12 (30)	19.71	6.72	0.67
Feeling guilty toward the donor	5 (20)	12.75	5.31	5 (25)	10.33	4.18	0.009
Transplant disclosure	3 (15)	6.81	3.45	3 (15)	5.63	3.13	0.04
Feeling responsible	4 (20)	13.43	3.94	4 (20)	13.03	5.04	0.66
Medication compliance	5 (21)	9.43	4.94	5 (17)	8.56	3.86	0.31
Emotional response total score	33 (89)	62.35	14.03	44 (107)	56.98	14.05	0.045

**Table 3.** Mean, Standard Deviation, and Range of Quality of Life Aspects of the Recipients

Quality of Life	Recipients from a Living Donor			Recipients from a Deceased Donor			P-Value (Mann-Whitney Test)
	Mean (SD)	Min	Max	Mean (SD)	Min	Max	
Physical	6 (42)	19.18	10.7	6 (42)	16.84	10.05	0.17
Appearance	4 (23)	8.88	5.87	4 (22)	7.88	4.90	0.51
Fear/uncertainty	4 (28)	14.32	8.01	4 (38)	11.86	8.37	0.07
Emotional	6 (42)	19.21	10.02	4 (20)	15.31	10.42	0.02
Fatigue	5 (35)	17.12	8.31	5 (35)	14.47	8.63	0.06
Quality of life total score	46 (137)	78.72	34.04	25 (151)	66.37	36.65	0.04

which implies happier life, and as a result, a higher QoL in recipients from a living donor. In a study by Parsaei Mehr et al. (28), males experienced less depression compared to females in both groups of recipients from living and deceased donors. According to Parsaei Mehr et al. (28) and as the results of this study showed, since recipients from a deceased donor spend significant time on the waiting list, they are more prone to mental disorder risk, and therefore experience a stronger emotional response. In fact, long time of waiting for a kidney transplant causes mental disorders in these patients.

### 5.1. Conclusions

In this study, the QoL and emotional responses in kidney recipients from living and deceased donors were compared. The results showed that recipients from a living donor were younger, had lower education level, and received the kidney from a non-relative donor. Also, recipients from a living donor felt guiltier toward the donor and were more worried about transplant disclosure, and there was a significant difference between these two components. Recipients from a living donor experienced higher QoL, specifically in the emotional aspect, as compared with recipients from a deceased donor. In general, the transplant team, specifically nursing team, needs to recognize the feeling of guilty and fear of transplant disclosure and ensure compatibility in transplant assignment, especially

for recipients from a living donor. The results of this study can assist healthcare providers, community health experts, and nurses to improve recipients' QoL through identification of feeling or guilty toward the donor and fear of transplant disclosure, and thereby provide consultations to mitigate these emotions. Our results can help healthcare policymakers to recognize the impact of psychological interventions and managerial approaches in improving patients' self-sufficiency, happiness, and QoL.

The results of this study showed that nursing team's supports in transplant and dialysis wards can develop patient's quality of life and their mental and emotional status. For future studies, intervention on emotional and mental supports before transplantation can be useful on quality of life and adaptive reaction in recipients from living and deceased donors.

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