ORIGINAL ARTICLE

Differences in emotional responses in living and deceased donor kidney transplant patients

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Abstract

Background: The psychological functioning of living donor (LD) and deceased donor (DD) recipients are important factors for emotional adjustment to transplantation. This study investigated differences in medical, sociodemographic and emotional factors between these two groups.

Methods: A total of 241 kidney transplant recipients (68 LD, 173 DD) completed questionnaires on emotional and behavioural responses to transplantation, including quality of life, anxiety and depression, social support and experience with immunosuppressive medication.

Results: Overall, LD recipients were younger, better educated, more often employed and had a shorter duration of dialysis prior to transplantation. Findings indicate that LD recipients expressed more guilt towards the donor than DD recipients. In addition, more LD recipients experienced clinically significant levels of anxiety. Both groups experienced high levels of negative effects of immunosuppressant medication. No differences between LD and DD recipients were found for gender, relationship status, time since transplantation or transplant rejection treatment during the last 12 months. In addition, perceived social support and quality of life were comparable between the two groups.

Conclusions: Feelings of guilt and anxiety may be an important focus for interventions to improve emotional adjustment to transplantation, especially in LD recipients.

Key words: deceased donor recipient, emotional response, living donor recipient, psychological factors, renal transplantation

Introduction

For most patients with end-stage renal disease, kidney transplantation is the treatment of choice and generally accepted as the optimal treatment [1]. A better quality of life, a reduction of medical expenses, living independently from dialysis and a prolongation of life are the most important described benefits of renal transplantation [2, 3]. However, due to the existing organ shortage, the option of a renal transplant from a deceased donor (DD) is limited and average waiting times on the Eurotransplant waiting list range from 7 to 8 years. Therefore, living donors (LDs) have become more prominent in transplantation centres, with better results in terms of graft function and patient survival compared with deceased donation [4], and it reduces the waiting time for transplantation.

The specific impact of living related renal transplants as compared with deceased donor transplants on psychosocial functioning has received surprisingly little attention so far. Whereas several studies have investigated quality of life in renal transplant patients compared with dialysis [3], with higher quality of life in LD and DD recipients than kidney patients on dialysis [2], only a few studies have systematically examined the differences in psychosocial functioning between LD and DD recipients. Existing studies report comparable levels of quality of life between the two groups [5–7]. However, a new kidney may lead to psychological stressors, such as the need to adhere to the post-transplant regimen, with all the possible medication side effects [8], anxiety or worry of rejection as well as feelings of guilt towards the donor or the donor family. A study investigating the different emotional responses in LD and DD recipients concluded that the different forms of transplantation lead to different emotional responses, with feelings of guilt being more pronounced in LD recipients [5]. However, another study found no differences in worry and feelings of guilt between LD and DD recipients [9]. A recent study found that LD recipients reported better quality of life in the first 5 years after transplantation compared with DD recipients [9, 10]. However, these differences disappeared with longer time since transplantation [9]. Even though quality of life is considered to be an important outcome after transplantation, it is unknown whether LD and DD recipients differ in other psychosocial factors and how these factors may impact the recipient's psychosocial functioning and adjustment to renal transplantation.

The present study thus aimed to assess whether LD and DD recipients differ in transplantation-specific emotional and behavioural outcomes, levels of anxiety and depression, perceived social support, experiences and beliefs in terms of immunosuppressants as well as quality of life, taking into account differences in demographic and clinical variables. In particular, feelings of guilt, as a prominent emotional response in LD recipients, should be investigated in more detail and possible determinants should be explored.

Materials and methods

Study population

This study is a single-centre, cross-sectional study of kidney transplant recipients who were at least 1 year post-transplant and had no non-renal allografts. The study was approved by the Ethics Committee of the Hannover Medical School. Recipients <18 years of age, with insufficient German language skills and with impaired cognitive status interfering with the understanding of the questionnaires were excluded. From all patients consecutively attending the kidney transplant outpatient clinic of Hannover Medical School for a follow-up visit from November 2014 to February 2015, 311 patients met the inclusion criteria. Of the 311 eligible patients, 22 were excluded from the study due to insufficient German language skills ($n = 16$) and cognitive impairment ($n = 6$). In addition, 48 participants refused to participate. Questionnaires were filled out by 241 (77%) participants (for further details see [11]). Of these, 173 of were DD and 68 LD recipients with 35 genetically related donors (parents, siblings, children) and 32 genetically unrelated donors (mainly partners).

Measures

Sociodemographic and medical information included information on age, gender, education level, relationship status and occupation. Medical and transplant-related data were extracted from medical records: donor type (deceased versus living donor), relationship to donor, time since transplantation, transplant rejection treatment during the last 12 months and type of immunosuppressive medication.

Transplantation-specific emotional and behavioural outcomes were measured using the Transplant Effects Questionnaire (TxEQ; [12, 13]). The 23-item TxEQ contains five subscales that assess worry about the transplant, feelings of guilt towards the donor, disclosure of transplantation, medication adherence and perceived responsibility to do well. Subscale scores range from 1 to 5; higher scores indicate more worry about the transplant, more guilt, more disclosure, more perceived responsibility and greater adherence. Cronbach's α in the current sample was 0.84.

Health-related quality of life (HQoL) was measured with the 12-item Medical Outcome Study Short Form Health Survey (SF-12; [14]). The SF-12 is a standardized, widely used and validated general HQoL questionnaire that has been translated into several languages. It includes 12 questions assessing health domains that are used to compute the physical component summary (PCS) and the mental component summary (MCS) scores. A higher score indicates better quality of life. To facilitate interpretation and comparisons to the norms, normative-based scoring was used [14]. Normative-based scoring involves a linear *t*-transformation to ensure that all SF-12 composite scores have a mean (M) of 50 and SD of 10. The internal consistency in the current sample was α = 0.88.

The Hospital Anxiety and Depression Scale (HADS) [15, 16] assesses anxious and depressive mood on two subscales consisting of seven items each and is widely used to detect anxiety and depression in physically ill patients [17]. The internal consistency in the study sample was α = 0.82 for anxiety and α = 0.87 for depression.

Perceived social support was measured using the 7-item Short Form Social Support Questionnaire (F-SozU; [18]). The F-SozU assesses perceived social support on a 5-point Likert scale (ranging from 1 = not at all to 5 = absolutely), with higher scores indicating higher perceived social support [19]. Cronbach's α in the current sample was 0.92.

To evaluate the subjective experiences and cognitive attitudes of patients with their immunosuppressive medication, the Medication Experience Scale for Immunosuppressants (MESI) was used [20]. The MESI is a short screening instrument with seven items for recording the subjective experience and attitudes of patients after an organ transplant. The sum score ranges between 4 and 33, with higher scores indicating more negative experiences and beliefs in terms of immunosuppressants. The cut-off score of 15 has been shown to differentiate between 'very good' and 'limited' compliance [20]. The internal consistency in the study sample was α = 0.77.

Data analysis

Sociodemographic and medical differences between LD and DD recipients were analysed using independent *t*-tests for continuous variables or chi-square analyses for categorical data. Analysis of covariance was used to examine the effect of transplant type on emotional responses and quality of life, adjusting for significant differences between LD and DD (age, education level, work status and duration of dialysis prior to transplantation). Intercorrelations among study variables were investigated using Pearson's correlation coefficients. In addition, hierarchical multiple linear regression analyses were performed with guilt as the dependent variable. The level of significance was set at P < 0.05.

Results

Differences in medical and Sociodemographic variables between living and deceased donor kidney transplant recipients

Demographic and medical information showed some differences between LD and DD recipients (see Table 1). DD recipients were significantly older [DD: mean 55.5 years (SD 12.7), LD: mean 47.3 years (SD 14.2); $F(1,239) = 18.8$, P < 0.001], had a lower education level ($\chi^2 = 13.5$, P < 0.01), were less often employed ($\chi^2 = 6.95$, P < 0.01) and on average had been on dialysis longer [DD: mean 70.0 (SD 36.3), LD: mean 28.4 (SD 26.0); $F(1,215) = 52.9$, P < 0.001] than LD recipients. Of the LD recipients, 30.9% did not receive dialysis prior to their transplant. The difference in time on dialysis prior to the transplant was anticipated given the elective nature of LD transplantations, which causes shorter delays between dialysis initiation and transplantation. In line with previous research, the differences between LD and DD in terms of work status seem to be more likely due to the significant age differences observed between the LD and DD recipients rather than being attributed to transplant type [5]. In subsequent comparisons between the two groups, these demographic and medical differences were controlled for statistically.

Differences in emotional responses and quality of life between living and deceased donor kidney transplant recipients

LD recipients expressed significantly stronger feelings of guilt towards the donor [$M = 2.72$ (SD 0.49] relative to DD transplant recipients [$M = 2.56$ (SD 0.37); $F(1,239) = 7.22$, P < 0.01]. The mean difference between groups was 0.16 with a 95% confidence interval between 0.04 and 0.27. The effect size was small ($d = 0.39$). After adjustment for age, education level, work status and duration of dialysis (Table 1), the difference in the TxEQ subscale 'guilt' between the two recipient groups remained significant (Table 2). Moreover, the covariate 'duration of dialysis prior to transplantation' was significantly related to the TxEQ subscale 'responsibility' [$F(1,210) = 4.50$, P < 0.05]. Adjusting for this covariate resulted in a statistically significant effect of the between-subjects

factor group: $F(1,210) = 6.46$, P < 0.05 with LD recipients exhibiting significantly higher scores (mean 3.16) compared with DD recipients (mean 2.66). There were no significant differences in the remaining TxEQ subscales 'worry', 'adherence' or 'disclosure with regard to transplant' between the two groups.

Levels of anxiety and depression were found to be similar in both LD and DD transplant recipients. Although the group mean scores for depression [DD: $M = 3.99$ (SD 4.1); LD: $M = 4.19$ (SD = 0.99)] and anxiety [DD: $M = 4.51$ (SD 3.6); LD: $M = 5.27$ (SD 4.2)] were in the normal range, significantly more LD recipients [$n = 21$ (31.3%)] showed levels of anxiety above the normal range compared with DD recipients [$n = 33$ (19.1%); $\chi^2 = 4.17$, P < 0.05]. For depression, 17.9% ($n = 12$) of LD and 19.7% ($n = 34$) of DD recipients scored above the normal range. No differences were found between LD and DD recipients. The findings suggest, however, that clinically significant levels of anxiety and depression occurred for a proportion of individuals.

There were no significant differences between the two transplant groups in perceived social support. Also, the subjective experiences and cognitive attitudes of patients with their immunosuppressive medication (MESI) did not differ between LD and DD recipients. However, the mean score for the MESI in both groups [LD: 15.75 (SD 5.3); DD: 15.13 (SD 5.9)] was above the cut-off scale score of 15 indicating limited compliance. In both groups, the majority of patients reported scores above the cut-off [LD: $n = 48$ (70.6%); DD: $n = 114$ (65.9%), $\chi^2 = 0.49$, P = 0.49], indicating that in both groups patients experience the adverse effects of immunosuppressants intensely.

Quality of life as measured by the SF-12 was found to be similar in both LD and DD transplant recipients. Group mean scores in both subscales were all within 1 SD of those reported in the general population. The number of participants who could be considered to have severely impaired quality of life, defined as a composite score (physical or mental) 2 or more SDs below the general population mean, was calculated. Using this criterion, 10.3% ($n = 7$) of the LD and 5.9% ($n = 10$) of the DD recipients were found to be severely impaired on the mental quality of life scale. Similar results were found for physical quality of life, with 8.8% ($n = 7$) of LD and 13.5% ($n = 23$) DD recipients being impaired. However, mental and physical impairment did not differ between the two transplant groups.

Table 1. Characteristics of the study population (N = 241)

	LD (n = 68)	DD (n = 173)	P-value
Age, mean (SD)	47.3 (14.2)	55.5 (12.7)	<0.001
Gender (male), n (%)	42 (61.8)	116 (67.1)	ns
Education level[a], n (%)			0.001
Low	16 (23.5)	84 (48.5)	
Middle	36 (53.0)	55 (31.8)	
High	16 (23.5)	34 (19.7)	
Married/cohabitating relationship, n (%)	52 (76.5)	121 (70.3)	ns
Work status (employed), n (%)	38 (55.9)	64 (37.2)	0.006
Time since Tx, months, mean (SD, range)	70.3 (52.9, 11–208)	92.5 (84.4, 11–399)	ns
Living donor, n (%)			
Parent/sibling/child	35 (52.2)		
Partner	28 (41.8)		
Other relative or friend	4 (6.0)		
Transplant rejection treatment last 12 months (yes), n (%)	9 (13.2)	25 (14.5)	ns
Duration of dialysis, months, mean (SD)	28.4 (26.0)	70.0 (36.3)	<0.001

LD = living donor recipients; DD = deceased donor recipients; Tx = transplantation.
[a]Education level: low ≤9 years of school, middle = 10 years of school, high >10 years of school attendance. P-values indicate significant difference between LD and DD samples in the respective Sociodemographic variables. Analysis of variance or chi-square test were used as appropriate.

Table 2. Quality of life and emotional responses of LD and DD transplant patients

Variables	LD (n = 68)	DD (n = 173)	F	P-value	Adjusted P-value[a]
TxEQ, mean (SD)					
Guilt	**2.72 (0.49)**	**2.56 (0.37)**	**7.22**	**0.008**	**0.045**
Worry	2.91 (0.93)	2.77 (0.77)	1.38	0.242	0.439
Adherence	4.34 (0.69)	4.38 (0.64)	0.238	0.626	0.940
Responsibility	2.93 (1.1)	2.71 (1.0)	2.30	0.131	**0.012**
Disclosure	4.35 (0.88)	4.42 (0.69)	0.478	0.534	0.780
HADS					
Anxiety, mean (SD)	5.27 (4.2)	4.51 (3.6)	1.97	0.193	0.597
Anxiety (cut-off ≥8), n (%)	**21 (31.3)**	**33 (19.1)**	**$\chi^2 = 4.17$**	**0.033**	–
Depression, mean (SD)	4.19 (3.9)	3.99 (4.1)	0.124	0.725	0.916
Depression (cut-off ≥8), n (%)	12 (17.9)	34 (19.7)	$\chi^2 = 0.10$	0.457	–
FSozU, mean (SD)	4.27 (0.99)	4.19 (1.0)	0.251	0.617	0.768
MESI, mean (SD)	15.75 (5.3)	15.13 (5.9)	0.584	0.445	0.747
MESI (cut-off ≥15), n (%)	48 (70.6)	114 (65.9)	$\chi^2 = 0.49$	0.544	–
SF-12, mean (SD)					
Physical	46.43 (10.5)	44.05 (10.6)	2.49	0.116	0.354
Mental	48.03 (11.5)	49.55 (9.9)	1.07	0.331	0.501

LD = living donor recipients; DD = deceased donor recipients; TxEQ = Transplant Effects Questionnaire: subscale scores ranging from 1 to 5); HADS = Hospital Anxiety and Depression Scale: 0–7 normal, 8–10 borderline abnormal, >11 abnormal; FSozU = Short-Form Social Support Questionnaire: higher scores indicate higher perceived social support; MESI = Medication Experience Scale for Immunosuppressants: cut-off between 'very good' and 'limited' compliance = 15; SF-12 = 12-item Short Form Health Survey: mean = 50, SD = 10. Significant values are highlighted in bold.
[a]Adjusted for age, education level, work status and duration of dialysis.

Finally, we investigated whether these differences between LD and DD recipients depended on the time since transplantation. Participants were divided into two time period groups based on the median (≤58 months versus >58 months). Thirty-eight LD and 82 DD recipients were transplanted ≤58 months ago and 28 LD and 88 DD recipients were transplanted >58 months ago. LD recipients [$M = 2.82$ (SD 0.52)] transplanted ≤58 months on average reported more guilt than DD recipients [$M = 2.60$ (SD 0.36); $F(1,118) = 7.18$, P < 0.01]. For LD and DD recipients transplanted >58 months, this difference disappeared [LD: $M = 2.58$ (SD 0.44); DD: $M = 2.52$ (SD 0.38); $F(1,114) = 0.43$, P = 0.51]. No other differences emerged between LD and DD within the first 58 months after transplantation. However, in the longer run, DD recipients showed more disclosure [LD: $M = 4.12$ (SD 1.1); DD: $M = 4.50$ (SD 0.68); $F(1,114) = 5.29$, P < 0.05], less anxiety [LD: $M = 5.82$ (SD 4.3); DD: $M = 4.20$ (SD 3.3); $F(1,114) = 4.38$, P < 0.05] and higher mental quality of life [LD: $M = 44.64$ (SD 12.3); DD: $M = 50.39$ (SD 9.9); $F(1,114) = 6.35$, P < 0.05] than LD recipients.

Associations between emotional, Sociodemographic and medical variables

Correlational analysis (Table 3) between emotional, Sociodemographic and medical variables (time since transplantation, duration of dialysis, transplant rejection treatment last 12 months) showed that increasing guilt was associated with a shorter duration of dialysis prior to transplantation ($r = -0.14$, P < 0.05), less likely being in a relationship ($r = -0.14$, P < 0.05) and being genetically related with the donor ($r = -0.18$, P < 0.01).

To investigate which variables accounted for the variance in guilt, hierarchical multiple linear regression analyses were conducted. The analyses were performed separately for the two transplant groups, but only for the LD recipients did a significant model emerge (Table 4). The findings indicated that relationship status, level of anxiety and perceived social support were significantly associated with the TxEQ subscale 'guilt', explaining 36% of the variance. The model was significant [$F(1331) = 2.91$,

P < 0.001]. Whereas lower levels of anxiety and lower perceived social support were associated with higher levels of guilt, being in a relationship showed a positive association with guilt. The only differences that occurred between genetically related and genetically unrelated donor recipients were that the genetically unrelated donor recipients were significantly younger and reported significantly more 'perceived responsibility to do well'.

As can be seen in Table 3, the MESI score was significantly related to higher education level, being employed, more worry, higher anxiety and depression scores and lower mental and physical quality of life scores. A subanalyses showed that patients with scores above the cut-off showed significantly more anxiety [above cut-off: $M = 5.25$ (SD; below cut-off: $M = 3.69$ (SD 3.9); $F(1,235) = 9.38$, P < 0.01], more depression [above cut-off: $M = 4.68$ (SD 4.1); below cut-off: $M = 2.81$ (SD 3.6); $F(1,235) = 11.8$, P < 0.01] and lower mental [above cut-off: $M = 48.1$ (SD 10.5); below cut-off: $M = 51.2$ (SD 9.7); $F(1,235) = 4.89$, P < 0.05] and physical quality of life [above cut-off: $M = 43.1$ (SD 10.8); below cut-off: $M = 48.2$ (SD 9.4); $F(1,235) = 12.6$, P < 0.001] compared with patients with scores below the cut-off. No differences between the two groups emerged for age, gender, time since transplantation, duration of dialysis, relationship status, work status or transplant rejection treatment during the last 12 months.

Discussion

The present study was designed to examine and compare the psychosocial factors between LD and DD kidney recipients. After controlling for medical and Sociodemographic variables, different emotional responses were found between the two groups. In particular, feelings of guilt were found to be more prominent in LD recipients irrespective of the patients' age, education level, work status or duration of dialysis prior to transplantation. The higher levels of guilt in LD recipients are in line with the results of earlier studies [5, 12]. The physical cost of the donation, the sacrifice made by the donor and the perceived ongoing risk of having only one kidney may lead to feelings of

Table 3. Correlations between emotional, Sociodemographic and medical variables in the combined transplant sample (N = 241)

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1	Age	–																	
2	Time since transplantation	−0.03	–																
3	Duration of dialysis	0.12	−0.14*	–															
4	Education level	−0.09	0.03	−0.11	–														
5	Relationship	0.21**	−0.05	0.02	0.01	–													
6	Work status	0.39**	−0.08	0.13	−0.22**	−0.01	–												
7	Living donor (genetically related versus genetically unrelated)	0.38**	0.10	0.43**	−0.18**	0.01	0.20**	–											
	TxEQ																		
8	Guilt	−0.10	−0.12	−0.14*	0.10	−0.14*	0.03	−0.18**	-										
9	Worry	−0.18**	0.01	−0.01	−0.02	−0.01	−0.02	−0.07	0.06	–									
10	Adherence	0.18**	0.08	0.10	−0.02	0.19**	0.08	0.06	−0.29**	−0.13*	–								
11	Responsibility	0.10	−0.12	0.10	−0.03	0.13*	0.09	−0.05	0.16*	0.52**	−0.09	–							
12	Disclosure	0.19**	0.04	−0.02	−0.02	0.07	0.00	0.07	−0.09	−0.40**	0.35**	−0.25**	–						
	HADS																		
13	Anxiety	−0.26**	0.03	−0.04	−0.01	−0.09	0.02	−0.10	0.04	0.49**	−0.11	0.17**	−0.39**	–					
14	Depression	−0.15*	0.06	−0.01	−0.03	0.12	0.06	−0.01	0.03	0.32**	−0.13	0.08	−0.32**	0.70**	–				
15	FSozU	0.11	0.05	−0.12	0.01	0.15*	−0.04	−0.04	−0.06	−0.11	0.14*	−0.04	0.22**	−0.42**	−0.54**	–			
16	MESI	−0.03	0.11	−0.05	0.17**	−0.06	0.13*	−0.03	0.06	0.19**	0.03	0.03	−0.13*	0.26**	0.29**	−0.05	–		
	SF-12																		
17	Physical	−0.08	−0.08	−0.12	0.13*	0.03	−0.30**	−0.14*	0.01	−0.06	−0.08	−0.01	0.09	−0.19**	−0.43**	0.18**	−0.26**	–	
18	Mental	0.16*	−0.03	−0.01	0.01	0.10	0.01	0.06	0.05	−0.32**	0.10	−0.08	0.29**	−0.63**	−0.65**	0.39**	−0.21**	0.16*	
19	Transplant rejection treatment last 12 months	−0.13	0.16*	−0.03	−0.02	−0.04	−0.01	0.02	−0.08	0.07	0.03	−0.05	−0.01	0.08	0.11	−0.05	0.08	−0.12	−0.13*

*P < 0.05, **P < 0.01.

Table 4. Hierarchical multiple regression analysis to predict the TxEQ subscale 'guilt' in LD transplant patients (*n* = 45)

Predictor	B	SE B	β	P
Relationship status	0.62	0.23	0.51	0.01
FSozU	−0.31	0.09	−0.62	0.01
HADS anxiety	−0.07	0.03	−0.56	0.02
Age	−0.02	0.01	−0.47	0.06
Education level	0.21	0.11	0.29	0.08
SF-12 physical	−0.01	0.01	−0.30	0.08
Work status	0.28	0.17	0.28	0.12
Time since transplantation	−0.01	0.02	−0.08	0.61
Transplant rejection treatment in the last 12 months	−0.54	0.33	−0.23	0.12
Duration of dialysis prior to transplantation	0.00	0.00	−0.03	0.87
Living donor (genetically related versus genetically unrelated)	0.01	0.21	0.01	0.96
HADS depression	0.03	0.03	0.21	0.35
SF-12 mental	0.01	0.01	0.03	0.88

guilt in the recipient. In contrast, DD recipients do not have any existing relationship with the donor prior to or after the transplantation. Interestingly, higher levels of perceived social support were associated with lower feelings of guilt in LD recipients. This is in line with previous research indicating that levels of social support predict quality of life in transplant recipients [21]. No differences with regard to feelings of guilt were found between genetically related and genetically unrelated donor recipients. However, we did not collect variables characterizing the relationship between living-related or living-unrelated donors and recipients, such as perceived closeness or quality of the donor–recipient relationship. It remains unclear if the satisfaction with the relationship and the emotional bond with the donor may be associated with feelings of guilt. As found for social support, higher levels of relationship satisfaction might be associated with lower feelings of guilt. Some studies found higher depression and disrupted family relationships after donation to a family member [22]. Further studies should investigate the quality of the donor–recipient relationship in detail.

After adjusting for the covariate 'duration of dialysis prior to transplantation', a significant difference on the TxEQ subscale 'responsibility' emerged between LD and DD recipients, with higher scores in LD recipients. It seems that receiving dialysis prior to the transplantation may lead to higher perceived responsibility to do well for LD recipients. This finding is in contrast with another study where DD recipients felt more responsible with respect to taking care of themselves than LD recipients [9]. Further research should investigate these findings in more detail.

The findings on quality of life are consistent with those of other studies [5, 6]. Quality of life seems to be unaffected by transplant type. Both LD and DD recipients reported equivalent quality of life levels, with mean scores being within 1 SD of the mean of a normal population. To our knowledge, this is the first study comparing levels of anxiety and depression between LD and DD recipients. The mean scores in both groups were within 1 SD of the mean of a normal population. However, that masks the fact that a substantial number of transplant patients in both groups showed anxiety levels above a cut-off value indicating severe impairment. Moreover, significantly more LD recipients scored above the clinical cut-off on the anxiety subscale of the HADS than DD recipients [LD: *n* = 21 (31.3%); DD: *n* = 33 (19.1%)]. Also,

with regard to depression, clinically significant results were found in 17.9% (*n* = 12) of LD and 19.7% (*n* = 34) of DD recipients. These findings indicate that even though the mean scores were close to those found in the normal population, a substantial number of patients reported significantly increased anxiety and depression scores indicating limitations in emotional responses. This finding might be of clinical relevance, as higher levels of anxiety might be associated with poorer outcomes, such as adherence. Another important variable potentially influencing adherence may be the high rate of participants in both groups (LD = 70.6%, DD = 65.9%) who experience high levels of negative effects of their immunosuppressant therapy, which was also related to higher levels of anxiety, depression and lower mental and physical quality of life.

Time since transplantation might have an impact on emotional responses. Whereas feelings of guilt were significantly more pronounced in LD recipients only in the shorter term, less disclosure, higher anxiety and lower mental quality of life scores were found in LD recipients only in the longer term (>58 months since transplantation) in our sample. Further studies should investigate subgroups of patients (e.g. high levels of anxiety, negative effects of the immunosuppressant therapy) in more detail to identify high-risk recipients.

Interestingly, even though LD recipients reported more feelings of guilt and responsibility and higher levels of anxiety, the differences in adherence ratings did not differ between LD and DD recipients. The TxEQ subscale 'adherence', the MESI total scores and the prevalence of chronic transplant rejection as a proxy for non-adherence did not differ between groups. This suggests that more pronounced emotional responses are not necessarily associated with adherence. Overall, the majority of patients reported MESI scores above the cut-off of 15. It has been suggested that patients with a score ≥15 should be spoken to by their medical team with regard to their attitudes towards and experiences with immunosuppressants, as well as with regard to their adherence behaviour.

It should be recognized, however, that despite the observed differences between LD and DD recipients, for a variety of variables (e.g. worry, adherence, quality of life, social support) no significant differences between the two groups were found.

The study has some limitations. First, the study has a cross-sectional design. Due to the fact that the psychosocial variables had not been evaluated prior to transplantation, it is possible that the difference already existed and is not due to the type of transplant received. DD recipients had a longer duration of dialysis before transplantation than LD recipients, which could also result in differences of psychosocial factors prior to transplantation, as it is known that a longer duration of dialysis leads to lower quality of life [23]. However, even if a difference in psychosocial factors existed before transplantation, it remains unclear whether the difference remained the same after transplantation or became larger. So, it is still possible that the type of transplant determines the psychosocial factors after transplantation. Second, this is a single-centre study and not representative of the total German LD and DD populations.

In conclusion, some emotional responses seem to differ between LD and DD kidney recipients. In particular, feelings of guilt towards the donor, the perceived responsibility to do well and the occurrence of clinically significant anxiety appear to be more pronounced in LD transplant recipients. This study emphasizes the recognition of emotional responses as an important indicator for emotional adjustment to transplantation, which should be considered in interventions for patients.

Acknowledgments

Conflict of interest statement

None of the authors declare any conflicts of interest. The results presented in this paper have not been published previously in whole or part.

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