Peer reviewed article

Psychological response and quality of life after transplantation: a comparison between heart, lung, liver and kidney recipients

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Summary

Principles: Various non-specific questionnaires were used to measure quality of life and psychological wellbeing of patients after organ transplantation. At present cross-organ studies dealing specifically with the psychological response to a transplanted organ are non-existent in German-speaking countries.

Methods: The Transplant Effects Questionnaire TxEQ-D and the SF-36 Quality of Life Questionnaire were used to examine the psychological response and quality of life of 370 patients after heart, lung, liver or kidney transplantation. The organ groups were compared with regard to psychosocial parameters.

Results: 72% of patients develop a feeling of responsibility for the received organ and its function. This feeling is even stronger towards the patient's key relationships i.e. family, friends, the treatment team and the donor. 11.6% worry about the transplanted organ. Heart and lung patients report significantly fewer concerns than liver and kidney patients. Overall, only a minority of patients report feelings of guilt towards the donor (2.7%), problems in disclosing their transplant to others (2.4%), or difficulties in complying with medical orders (3.5%). Lung transplant patients show significantly better adherence.

Conclusions: A feeling of responsibility towards those one is close to and towards the donor is a common psychological phenomenon after transplantation of an organ. Conscious feelings of guilt and shame are harboured by only a minority of patients. The fact that heart and lung patients worry less about their transplant might have primarily to do with the greater medical and psychosocial support in this group.

Key words: organ transplant; psychological response; quality of life; transplant effects questionnaire TxEQ-D; differences between organ groups

Introduction

Because of an increasing need to understand health-related quality of life after a medical or surgical intervention, various instruments to measure quality of life have been developed over the past few years in the field of psychosomatic research. The majority of the questionnaires dealing with quality of life, psychological wellbeing and health-related behaviour were not specially designed to address transplant-specific topics. Moreover, instruments – if available at all – are restricted to organ groups, such as the Kidney Transplant Questionnaire (KTQ) [1], the Heart Transplant Symptom Checklist [2], the End-Stage Renal Disease Symptom Checklist (ESRD-SCL) [3], or the Bone Marrow Transplantation Symptoms List [4]. In recent years transplant-specific instruments such as the Transplant Effects Questionnaire (TxEQ) have been developed for the English language. This questionnaire assesses the emotional response to an organ transplant as well as the health behaviour of the organ recipient, and it is suitable for all organ groups [5, 6]. Because there is no German version available the TxEQ was translated and a validated by our group ("*Fragebogen zur psychischen Verarbeitung einer Organtransplantation*", *TxEQ-D*) [7, in press].

Quality of life and psychological responses to transplantation are constructs to assess different psycho-social aspects after organ transplantation. Quality of life is conceptualised as a self-rating multidimensional construct with physical, mental and social aspects comprising the psychological, social and physical status of a subject. Quality of life assessments are often used to evaluate the out-

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come of medical interventions. The psychological response to transplantation reflects the subtle and complex cognitive, emotional and behavioural process after transplantation. For example, SF-36 assesses general psychological wellbeing (mental health), TxEQ-D assesses feelings of guilt and responsibility against the background of the relationship with donor, family and medical staff. Both concepts – quality of life and psychological responses – are likely to correlate, i.e. problems in psychological processing after transplantation may have an effect on the subject's quality of life.

The comparison of organ groups allows identification of group-specific features regarding quality of life as well as psychological processing of transplantation experiences. An important clinical issue may be to identify risk patients, thus serving to plan and implement specific interventions. On the whole there are few studies in transplant medicine research which compare organ groups. The main differences observed to date are that heart and lung patients show the most marked improvement in quality of life after an organ transplant, whilst improvement is less obvious in liver and kidney patients [8–9]. Whereas Beilby et al. [10] found no difference between the quality of life of lung and liver transplant patients, we noted in a prospective study that the quality of life and mental health of liver patients worsens in the medium term post transplantation whilst the corresponding parameters remain stable or even continue to improve for lung patients [11]. Admittedly, these comparisons between organ groups were carried out with non-transplant-specific instruments.

Thanks to TxEQ-D it is now possible for the first time to compare psychological responses after a heart, lung, liver or kidney transplant. The study asks the following questions: 1) How is the psychological response and quality of life for heart, lung, liver or kidney recipients after an organ transplant? 2) What differences exist between the individual organ groups in terms of psychological response and quality of life after an organ transplantation? Our main hypothesis was that emotional response as well as quality of life will differ between organ groups.

Methodology

Structure of study and patients

This cross-sectional study was carried out with the approval of the Ethics Committee of University Hospital Zurich in September 2006. It included all German-speaking patients who had received a heart (since 1985, n = 111), liver (since 1987, n = 117) or lung transplant (since 1995, n = 115) at University Hospital Zurich and who were still living. They were asked to join the study by mail and concurrently were sent an information letter, a written informed consent form and the questionnaire. From the German-speaking kidney transplant patients (n = 862), electronically registered since 1992, a random sample was selected (n = 431, i.e. every second patient). To avoid heterogeneity from the kidney and liver group only patients with a deceased donor were included. 33 heart, 13 liver and 59 kidney patients did not respond. All in all, 41 heart patients (response rate 52.6%), 66 liver patients (response rate 63.5%), 76 lung patients (response rate 66.1%) and 187 kidney patients (response rate 50.3%) participated in and completed the study (total sample n = 370).

Instruments

German version of the TxEQ Questionnaire (TxEQ-D)

The original English version of the Transplant Effects Questionnaire (TxEQ) contains 23 items with a five-point Likert scale [5, 6]. The factor analysis of the English questionnaire yielded the following five conceptually coherent factors: Worry about transplant, Guilt regarding the donor, Disclosure (of having undergone transplantation), Adherence (to medical treatment) and Responsibility (towards family, friends, medical staff and/or towards the donor). In a validation study [6], both the Transplant Effects Questionnaire (TxEQ) and the Short Form Health Survey (SF-36) were used with 347 kidney transplant patients. The results of this study show that the English TxEQ has good psychometric parameters and is able to illustrate different emotional-response types among patients after a living or deceased organ donation [5, 6].

The German-language version TxEQ-D is available in a validated form (for detailed translation procedure and the validation see Klaghofer et al. [7, in press]). In contrast to the English validation study, the German version (TxEQ-D) was used in a random sample of kidney transplant patients (n = 187) as well as in patients from other organ groups (heart, n = 41; lung, n = 76; liver, n = 66). The latter were included because the original TxEQ questionnaire contains no kidney-specific items and the TxEQ items are related to psychological constructs such as guilt, responsibility or health behaviour which apply to organ transplantation irrespective of the organ type. The validation is based on the same patient sample used to calculate the organ-group differences in this article. In summary, the factorial structure and variance of the English and German versions of the questionnaire are highly comparable. In the German version, the values for internal consistency (Cronbach's alpha) lie between 0.71 (disclosure) and 0.79 (adherence); in the original English version, Cronbach´s alpha lies between 0.72 and 0.86. Furthermore we found substantial correlations with the mental component scale of SF-36, but none with the physical component scale [7].

SF-36 Health Survey (German version)

The SF-36 Health Survey [12] in the validated German version – *Fragebogen zum Gesundheitszustand SF-36* [13] – measures various areas of health-related subjective quality of life. The multidimensional concept of the self-assessment questionnaire takes into account the physical, psychological and social aspects of health-related quality of life. This internationally used instrument consists of eight scales *(Physical functioning*, *Role physical*, *Bodily pain*, *General health*, *Vitality*, *Social functioning*, *Role emotional*, *Mental health)* and two sum scales (mental component scale, physical component scale) which are weighted com-

Table 1a

Sociodemographic and medical data.

	Heart (n = 41)	Lung (n = 76)	Liver (n = 66)	Kidney (n = 187)	Total (n = 370)
Sex					
female	4 (10%)	33 (43%)	23 (35%)	65 (35%)	Ratio male/female = 2/1
male	37 (90%)	43 (57%)	43 (65%)	122 (65%)	
Age in years at FU	62.0 (24–75)	45.3 (18–68)	54.3 (24–75)	53.6 (18–78)	52.9 (18–78)
Mean (range					
Age in years at Tx*	48.3 (14–65)	41.1 (14–68)	48.8 (15–68)	46.8 (13–72)	46.2 (13–72)
Mean (range)					
Time in months since Tx*					
Mean (range)	164 (102–239)	50 (2–131)	66 (4–229)	81 (3–163)	81 (2–239)

FU = follow up (inquiry), *Tx = transplantation

posite scales of the eight single scales. The scales consist of 2–10 items with 2- to 10-point Likert scales. To facilitate comparisons all scales are linear T-transformed (mean = 50, SD = 10). Higher values reflect better physical, psychological or social functioning. In the German version the internal consistency (Cronbach's a) of the eight SF-36 scales lies between .74 *(Social functioning)* and .94 *(Physical functioning)*.

Statistical analysis

All analyses were conducted with the program SPSS for Windows, release 12. Descriptive statistics are given in terms of means and standard deviations, counts and percentages respectively. The comparisons of organ groups were carried out by analyses of covariance (covariates: age at Tx und follow-up time) followed by pairwise comparisons according to Bonferroni. We also calculated the rate of agreement and disagreement respectively for each scale of the TxEQ-D by means of the scale values (1 = strongly disagree, 2 = disagree, 3 = uncertain, 4 = agree, 5 = strongly agree). We compared these rates between organ groups by chi-square tests. Comparisons between sample values and values of the normal community sample were conducted by z-tests.

Results

Sociodemographic and medical data

Tables 1a and b show the sample's sociodemographic and medical data.

The ratio between male and female organ recipients is approx. 2:1. Women are markedly under-represented in the heart transplant group. The average time between transplant and inquiry is longest for the heart transplant patients and shortest for the lung transplant patients. Moreover, the latter are the youngest at the time of both transplant and inquiry.

Results of TxEQ-D and SF-36

Table 2 shows means and standard deviations of the German version of the Transplant Effects Questionnaire (TxEQ-D) and of the SF-36 Health Survey, with significance data on the differences between the SF-36 values of the study population and SF-36 standard values [13], as well as significance data on the differences between the organ groups.

As shown in table 2, patients are moderately worried about their transplanted organ. They experience little guilt regarding the donor, and have no difficulty in disclosing their identity as a transplant recipient. They report good adherence, and feel moderately responsible for the transplanted organ.

Comparison with the standard sample of SF-36 representing the general population [13] shows that transplant patients come off worse in the scales *Physical functioning*, *Physical role function*, *General perception of health*, *Social functioning* and

Table 1b

Diagnoses before transplantation, ranked according to frequency (number, percent).

Heart (n = 41)	cardiomyopathy: 18 (44%)
	coronary heart disease: 16 (39%)
	other diagnoses: 7 (17%)
Lung (n = 76)	cystic fibrosis: 30 (40%)
	chronic obstructive pulmonary disease: 26 (34%)
	pulmonary fibrosis: 14 (18%)
	other diagnoses: 6 (8%)
Liver (n = 66)	liver cirrhosis (due to hepatitis C): 15 (23%)
	liver cirrhosis (due to hepatitis B): 12 (18%)
	hepatocellular carcinoma: 7 (10%)
	cryptogenic liver cirrhosis: 6 (9%)
	primary biliary cirrhosis 6 (9%)
	postalcoholic cirrhosis: 5 (8%)
	fulminant hepatic failure: 5 (8%)
	other diagnoses: 10 (15%)
Kidney (n = 187)	hereditary kidney diseases: 43 (23%)
	chronic glomerulonephritis: 40 (21%)
	diabetic nephropathy: 25 (13%)
	chronic renal insufficiency: 14 (8%)
	nephrosclerosis: 10 (5%)
	Alport syndrome: 7 (4%)
	renal dysplasia / aplasia: 7 (4%)
	reflux nephropathy: 7 (4%)
	hypertensive nephropathy: 6 (3%)
	IGA nephropathy: 5 (3%)
	pyelonephritis: 5 (3%)
	other diagnoses:18 (9%)

Table 2

Means and standard deviations of the German version of the Transplant Effects Questionnaire (TxEQ-D) and of the SF-36 Health Survey, with significance data on the differences between the SF-36 values of the study population and the SF-36 norm values [13] as well as significance data on the differences between the organ (n = 370); analyses of covariance, covariates: age at transplantation and follow-up time after transplantation.

Scales	Organ groups Total[1] M (SD)	 Heart M (SD)	 Lung M (SD)	 Liver M (SD)	 Kidney M (SD)	p[2] Norm	p[3] Groups	Bonferroni[3]
TxEQ-D								
Worry	2.56 (.70)	2.20 (.67)	2.30 (.66)	2.60 (.98)	2.74 (.82)	–[4]	<.001	K> H, Lu[5]
							Li> Lu	
Guilt	1.71 (.84)	1.56 (.66)	1.56 (.63)	1.78 (.79)	1.79 (.70)	–	.037	K> Lu
Disclosure	4.42 (.73)	4.23 (.71)	4.43 (.76)	4.46 (.81)	4.45 (.70)	–	.102	–
Adherence	4.35 (1.06)	4.27 (.79)	4.71 (.43)	4.07 (.89)	4.32 (.74)	–	<.001	Lu > H, Li, K
Responsibility	3.00 (.73)	2.95 (1.00)	3.06 (1.00)	3.07 (1.13)	2.96 (1.07)	–	.832	–
SF-36								
Physical functioning	47.11 (9.71)	46.21 (9.57)	49.77 (7.93)	45.83 (9.85)	46.7 (10.21)	<.001	.523	
Role physical	45.88 (11.97)	44.02 (12.49)	49.94 (10.02)	44.25 (12.66)	45.24 (12.04)	<.001	.061	–
Bodily pain	50.54 (11.71)	46.68 (12.06)	53.28 (9.90)	49.48 (12.02)	50.63 (12.01)	ns	.346	–
General health	45.13 (10.52)	44.50 (8.78)	46.43 (9.15)	46.12 (11.55)	44.39 (10.99)	<.001	.567	–
Vitality	49.02 (10.92)	49.18 (10.46)	51.95 (9.30)	47.03 (12.27)	48.49 (10.96)	ns	.090	–
Social functioning	48.96 (10.88)	48.96 (10.56)	52.31 (8.19)	48.16 (12.03)	47.87 (11.28)	<.05	.059	–
Role emotional	49.24 (10.58)	49.28 (10.53)	52.61 (7.20)	47.28 (11.92)	48.52 (11.02)	<.05	.004	Lu > H, Li, K
Mental health	49.79 (10.60)	50.91 (9.13)	52.12 (10.91)	48.71 (11.85)	48.97 (10.22.)	ns	.059	–
Physical component scale	46.49 (10.63)	43.47 (10.49)	49.10 (8.77)	45.78 (10.90)	46.34 (11.09)	<.001	.831	–
Mental component scale	50.28 (10.34)	51.73 (7.56)	52.82 (9.74)	48.65 (11.85)	49.51 (10.37)	ns	.005	Lu > Li, K

[1] TxEQ-D / SF-36 mean values and standard deviations of the whole sample according to Klaghofer et al. [7];
[2] differences between study results and SF-36 norm values (M = 50, SD = 10); [3] differences between organ groups;
[4] TxEQ-D norm values are not available; [5] Abbreviations: H = heart, Lu = lung, Li = liver, K = kidney

Emotional role function as well as in the physical sum scale. There is no difference in the scales *Bodily pain*, *Vitality*, and *Psychological wellbeing* or in the psychological sum scale.

The organ-group comparison in table 2 shows that in the scale *Worry about transplant* there is a significant difference between the organ groups heart/lung and kidney, as well as between the liver and lung group. Heart and lung transplant patients worry less about the transplanted organ than patients after kidney transplant, and lung transplant patients worry less than liver transplant patients. Moreover, lung transplant patients claim a significantly higher adherence than the other organ groups, and – at least in comparison with kidney transplant patients – feel less guilt. In the *Disclosure* of recipient status and *Responsibility* scales, there are no significant differences between organ groups.

Table 3

Absolute and relative frequencies of patients who assert (= 1) or deny (= 0) that they worry about the transplant (>3.5 on the 5-point Likert scale), feel guilty (>3.5), have problems disclosing that they are transplant recipients (<2.5), have low adherence (<2.5) or a low sense of responsibility (<2.5), overall and broken down into individual organ groups, and providing significance data on the differences between the organ groups (n = 370).

TxEQ-D	Organ groups Total	 Heart	 Lung	 Liver	 Kidney	p[1]
Worry	43 11.6%	1 2.4%	3 3.9%	12 18.2%	27 14.4%	.008
Guilt	10 2.7%	1 2.4%	2 2.6%	2 3.0%	5 2.7%	.998
Disclosure	9 2.4%	1 2.4%	2 2.6%	3 4.5%	3 1.6%	.616
Adherence	13 3.5%	1 2.4%	0 .0%	4 6.1%	8 4.3%	.213
Responsibility	104 28.1%	12 29.3%	16 21.1%	19 28.8%	57 30.5%	 .487

[1] Significance on differences between the organ groups

When questioned on quality of life, lung patients achieve significantly higher values in the SF-36 scale *Role emotional* than all other organ groups. Lung patients have a significantly higher score in the mental component scale than liver and kidney patients. All in all, lung patients show the most favourable scores for self-assessment of quality of life in all of the SF-36 scales with significant differences in some of the psychological scales.

Table 3 shows the absolute and relative frequencies of patients who assert (= 1) or deny (= 0) that they worry about the transplant (>3.5 on the 5-point Likert scale), feel guilty (>3.5), have problems disclosing that they are transplant recipients (<2.5), have low adherence (<2.5) or a low sense of responsibility (<2.5), both overall and when split into individual organ groups. Moreover, data on the statistical significance of the differences between the organ groups are indicated.

As may be gathered from table 3, 11.6% of the patients admit to *worry about the transplant*. Only a minority (2.7%) report feelings of guilt towards the donor, problems with disclosure of their recipient status (2.4%), or low adherence (3.5%). 72% of the patients report that they feel responsible towards their treatment team, family, friends, and the donor, in regard to the functioning of the transplanted organ.

The organ-group comparison in terms of the frequency with which transplant-specific forms of response (TxEQ-D) are given, as shown in Table 3, reveals that significantly more liver and kidney patients worry about the transplanted organ compared with recipients of a heart or lung.

Discussion

In this study we investigated how organ recipients responded to their transplant, what sort of quality of life they experienced, and in what areas differences between different organ groups existed. Whereas previous studies consistently showed that quality of life substantially improves after organ transplantation, and can even achieve the scores of general population samples [8, 10, 14–18], to date few findings exist on how the different organ groups respond psychologically to the transplant. Thus far only two studies based on relatively small samples have been published on this subject [19, 20]. For quantitative assessment of the psychological response to an organ transplant, we translated the Transplant Effect Questionnaire TxEQ developed by Ziegelmann et al. [5] into German. Using TxEQ-D as well as the SF-36 Quality of Life Survey for several organ groups, we compared different organs in terms of the psychological response to a transplant and quality of life.

In the total group of recipients we found that patients worry to a moderate extent about their transplant (M = 2.56 on a 5-point Likert scale), experience little guilt regarding the donor (M = 1.71), and do not shy away from disclosing their identity as a transplant recipient (M = 3.42). They also report good adherence (M = 4.35) and feel responsible towards family members, friends, their treatment team and/or the donor of the transplanted organ (M = 3.0). Accordingly, the number of patients who feel guilt in regard to the donor and shame when revealing their status as a transplant recipient is very low. By the same token, 72% of all patients state that they would feel responsible towards their family, friends and treatment team, but also towards the donor, as regards the functioning of their transplanted organ. At the same time the frequency of sound medical adherence lies markedly above 90%. On the background to these statements it must be borne in mind that (1) the response rate for the study is slightly under 60% and (2) that among those who declined to take part in the study the number of patients with low adherence was possibly quite high, thus leading to a bias in the estimation of treatment adherence. Moreover, response behaviour may be influenced by social desirability, with patients in any case affirming that they take their medication.

In sum, few patients reported emotional difficulties in processing an organ transplantation. Most of them exhibited good health behaviour (adherence) and a feeling of responsibility. We conclude that the overwhelming majority of organ transplant patients evince a mature psychological response to the organ transplant, and only a small minority report specific problems in handling the new situation after transplantation.

The organ group comparison reveals an important and surprising result – namely, that heart and lung transplant patients worry significantly less about the transplanted organ than patients after liver or kidney transplantation. This result is surprising, since the risk of medical complications (such as pulmonary infection) is particularly high after a lung transplant. There are various possible explanations for this result: both lung and heart transplant patients probably perceive themselves as more at risk in health terms than the other organ groups. However, due to psychological defence mechanisms, e.g. risk denial or affect isolation, these patients scarcely report conscious worries about the transplanted organ. An additional factor may be that both heart and lung transplant patients receive particularly intensive medical and psychosocial treatment which counteracts worries about the new heart or lung. We presented the results of our study in an information seminar framework for lung transplant patients and their family members at which lectures are regularly given on relevant research results. The discussion showed that family members were likely to attribute the relatively slight fears of their transplant-recipient partners to the latter's disengagement from their feelings. The patients themselves, on the other hand, pointed to the advantages of a closely meshed follow-up treatment providing feelings of security.

For the rest, there are no differences between the organ groups in the TxEQ scales *Feelings of guilt*, *Disclosure* of one's transplant-recipient status, and *Responsibility*. Comparable processing mechanisms evidently take place in the different organ groups in these areas. The comparison of the SF-36 scores shows that lung patients also report the highest scores in the mental component scale dealing with the totality of psychological quality of life. We think the fact that these patients were most severely threatened before transplantation, and thus benefit most in terms of health improvement and relief, accounts for their good performance [10].

Limitations of the study

The most important limitation of the study is the 60% response rate. On the one hand this can be ascribed to the fact that the invitation for participation in the study was only sent by mail and no personal contact was established with the subjects. On the other hand our return is comparable to the the rates commonly seen in psychosocial studies. It must be assumed, however, that patients with non-adherence behaviour, or those who have trouble processing their transplants are more likely to be found among the non-participants. On the background of the fact that non-adherence can be linked to the rate of non-participation this clearly is a selection bias. Beside this argument, participants may also report good adherence because this health behaviour is strongly desired and socially more accepted. Moreover, it is conceivable that patients, who have problems with their new identity as expressed by their difficulty to disclose themselves as transplant recipients, are unlikely to participate in a psychosocial study. This selection bias could also have influenced the results of our study. There are two additional limitations: to limit the extent of the questionnaire, no further sociodemographic data such as the patient's education or professional status, etc., were collected. Also, in line with the psychosocial objectives of this investigation, no further clinical data (such as number of rejections, morbidity) were used.

Conclusions

We conclude that during follow-up liver and kidney transplant patients in particular should be actively questioned about their worries concerning the transplanted organ and the concerns discussed with the patients and their families. Studies on the psychological response to an organ transplant should concentrate primarily on patients with difficult long-term courses, especially with regard to the question of how dysfunctional responses can be corrected by means of psychosocial or psychotherapeutic interventions.

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ADDENDUM

Fragebogen zur psychischen Verarbeitung einer Organtransplantation (TxEQ-D)

Mit diesem Fragebogen interessieren wir uns für Ihre persönliche Beurteilung, wie Sie heute Ihre Erfahrungen mit der Organtransplantation sehen. Im Folgenden finden Sie Aussagen, die andere Personen über ihre Transplantation gemacht haben. Schätzen Sie bitte das Ausmass ein, mit dem Sie den Aussagen zustimmen bzw. nicht zustimmen, indem sie das entsprechende Kästchen ankreuzen.

		stimmt völlig	**stimmt**	**unsicher, ob es stimmt**	**stimmt nicht**	**stimmt überhaupt nicht**
1	Was mein transplantiertes Organ angeht, habe ich das Gefühl, dass ich etwas Zerbrechliches mit mir herumtrage.	☐1	☐2	☐3	☐4	☐5
2	Manchmal denke ich, dass ich meine Medikamente gegen die Abstossung nicht brauche.	☐1	☐2	☐3	☐4	☐5
3	Ich zögere, bei bestimmten Aktivitäten mitzumachen, weil ich Angst habe, dass ich meinem transplantierten Organ schaden könnte.	☐1	☐2	☐3	☐4	☐5
4	Ich denke, ich habe gegenüber dem Transplantationsteam die Verantwortung, dass alles gut geht.	☐1	☐2	☐3	☐4	☐5
5	Ich fühle mich unwohl in Gegenwart anderer Leute, die wissen, dass ich transplantiert bin.	☐1	☐2	☐3	☐4	☐5
6	Ich habe das Gefühl, dass ich dem Spender bzw. der Familie des Spenders etwas schulde, das ich nie zurückbezahlen kann.	☐1	☐2	☐3	☐4	☐5
7	Manchmal vergesse ich, meine Medikamente gegen die Abstossung einzunehmen.	☐1	☐2	☐3	☐4	☐5
8	Ich habe dem Spender gegenüber keine Schuldgefühle.	☐1	☐2	☐3	☐4	☐5
9	Ich mache mir Sorgen, dass ich mein transplantiertes Organ beschädigen könnte.	☐1	☐2	☐3	☐4	☐5
10	Ich denke, ich habe gegenüber dem Spender / der Familie des Spenders die Verantwortung, dass alles gut geht.	☐1	☐2	☐3	☐4	☐5
11	Ich finde es schwierig, mich an die vorschriftsmässige Einnahme der Medikamente zu gewöhnen.	☐1	☐2	☐3	☐4	☐5
12	Ich beobachte meinen Körper genauer als vor der Transplantation.	☐1	☐2	☐3	☐4	☐5
13	Es fällt mir schwer, über meine Transplantation zu sprechen.	☐1	☐2	☐3	☐4	☐5
14	Ich habe Schuldgefühle, dass ich von der Situation des Spenders profitiert habe.	☐1	☐2	☐3	☐4	☐5
15	Ich vermeide es, anderen Leuten zu sagen, dass ich transplantiert bin.	☐1	☐2	☐3	☐4	☐5
16	Ich mache mir jedes Mal Sorgen, wenn mein Arzt etwas an meinen Medikamenten ändert.	☐1	☐2	☐3	☐4	☐5
17	Der Spender musste leiden, damit es mir jetzt besser geht.	☐1	☐2	☐3	☐4	☐5
18	Es beschäftigt mich ständig, wie lange das transplantierte Organ funktionieren wird.	☐1	☐2	☐3	☐4	☐5
19	Manchmal denke ich, dass ich dem Spender etwas Lebenswichtiges «geraubt» habe.	☐1	☐2	☐3	☐4	☐5
20	Wenn ich zu sehr beschäftigt bin, kann es vorkommen, dass ich meine Medikamente gegen die Abstossung vergesse.	☐1	☐2	☐3	☐4	☐5
21	Ich denke, ich habe gegenüber meinen Freunden und meiner Familie die Verantwortung, dass alles gut geht.	☐1	☐2	☐3	☐4	☐5
22	Manchmal nehme ich meine Medikamente gegen die Abstossung nicht ein.	☐1	☐2	☐3	☐4	☐5
23	Ich habe das Gefühl, dass der Spender / die Familie des Spenders irgendwie Kontrolle über mich ausübt.	☐1	☐2	☐3	☐4	☐5

Scoring: To achieve comparability with the original version in English we scored with the following procedure:
1. Recode items 1, 3, 4, 6, 8, 10, 12, 16 to 19, 21, 23 (1 = 5) (2 = 4) (3 = 3) (4 = 2) (5 = 1)
2. Calculate scale value for “guilt regarding donor” = sum score of items 8, 14, 17, 19 and 23, divided through 5
Calculate scale value for “worry about transplant” = sum score of items 1, 3, 9, 12, 16 and 18, divided through 6
Calculate scale value for “adherence” = sum score of items 2, 7, 11, 20 and 22, divided through 5
Calculate scale value for “responsibility” = sum score of items 4, 6, 10 and 21, divided through 4
Calculate scale value for “disclosure” = sum score of items 5, 13 and 15, divided through 3

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