

Attitudes towards transplantation and medication among 121 heart, lung, liver and kidney recipients and their spouses

Lutz Goetzmann^a, Urte Scholz^b, Rafaela Dux^c, Michaela Roellin^c, Annette Boehler^d, Beat Muellhaupt^d, Georg Noll^d, Rudolf P. Wüthrich^d, Richard Klaghofer^e

^a Department of Psychosomatic Medicine and Psychotherapy, Segeberger Kliniken, Bad Segeberg, Germany

^b Department of Psychology, Developmental and Health Psychology, University of Konstanz, Germany

^c Department of Psychology, Social and Health Psychology, University of Zurich, Switzerland

^d Department of Internal Medicine, University Hospital Zurich, Switzerland

^e Department of Psychiatry and Psychotherapy, University Hospital Zurich, Switzerland

Summary

QUESTIONS UNDER STUDY: A transplant represents a decisive event for patients and their caregivers. This article deals with the attitudes patients and their spouses have towards the transplantation.

METHODS: In a cross-sectional study, 121 patients and their spouses were surveyed by questionnaire after a heart, lung, liver or kidney transplant. Attitudes were assessed by means of semantic differentials. Based on the results, an 'Attitudes towards Transplantation' Scale was developed. Sense of coherence (SOC-13), quality of life (Sf-36), quality of the relationship (RAS), burnout (BM) and the patient's emotional response to the transplant (TxEQ-D) were additional psychosocial variables measured in order to assess the association between the attitudes and psychosocial characteristics of transplant patients and their spouses.

RESULTS: The majority of patients and their spouses reported positive attitudes towards the transplant, including the attitudes towards medication, their perceived self and fate of being a transplant patient or spouse. Patients and spouses, however, had a negative attitude towards the transplantation in terms of stress and anxiety. Patients reported greater emotional stress from the transplant and rated their post-transplant perceived fate more negatively than their spouses. Attitudes towards the transplant were significantly associated with the sense of coherence and the quality of relationship.

CONCLUSION: The attitudes of patients and spouses to different aspects of the transplant itself and to being a transplant patient or spouse should be deliberately reconsidered and facilitated in the psychosocial counselling with regard to the comprehensibility, manageability and meaningfulness of the transplant experience as well as to potential conflicts in the partnership.

Key words: organ transplant; caregiver; spouse; attitudes; quality of life; sense of coherence; quality of partnership

Introduction

A large number of prospective long-term studies have shown that quality of life after a heart, lung, liver or kidney transplant improves significantly and remains stable over a fairly long period of time [1–10]. Although attitudes play an important role in the processing of chronic diseases or the acceptance of medical interventions [11–13], attitudes towards the transplant have previously been investigated primarily in connection with organ donation or the carrying of an organ-donor ID card [14–16]. Nevertheless, the few studies on the attitudes of transplant patients underscore the direct importance of these attitudes for health behaviour. Chisholm et al. [17] showed that negative attitudes towards medication are associated with non-adherence patient behaviour. In one of the authors own studies [18], we found that lung-transplant patients with a positive attitude towards the transplant display better medication adherence. It is known that the social support provided by the transplant patients' environment is of central importance for their quality of life [19–21], but to our knowledge, the attitudes of family members to the transplant have never before been examined.

The present study records the attitudes of transplant patients, and, for the first time, those of their spouses towards the transplant and the medication as well as towards the effects of the transplant on their perceived self and their perceived fate. Attitudes are cognitive beliefs or emotions related to a certain object or event. According to Ajzen and colleagues [22, 23], people develop attitudes towards an object, event or intervention. These attitudes are influenced by various psychosocial background factors (i.e. personality traits or environmental characteristics), and may affect, together with an individual's subjective norms and per-

ceived behavioural control, the intentions vis-à-vis the individual's behaviour. In transplantation medicine, the knowledge of whether attitudes towards the transplantation experience influence the patient's intentions to follow the doctor's recommendations or the patient's adherence behaviour may be relevant. Until today, however, no comprehensive measure of attitudes toward transplantation for patients and their spouses exists.

Aims and research questions

The aim of this study is the development of a transplant-specific measure by means of semantic differentials encompassing the beliefs and feelings of the patients and their spouses with regard to their transplant experience. We expected that most of the attitudes would be positive on the part of both patients and spouses, and that the attitudes of the healthy spouses would be more positive. Further, we expected that personality-related as well as environmental background factors (such as sense of coherence, quality of partnership) would be associated with the patient's as well as the spouse's attitudes towards the transplantation.

This study's research questions are the following:

1. What are the attitudes of patients and their spouses in terms of the transplant experience, the taking of medications and the perception of their post-transplant self and fate? Are there differences between the patients' attitudes and those of their spouses?
2. Are these attitudes associated with cognitive resources, quality of life, burnout or quality of the partnership? Are there associations between the transplant-related attitudes and the state of health of the patients?

Patients and methods

Study design and sample

Data of this study is part of a larger project on transplant patients and their spouses at the University Hospital Zurich*. Patient inclusion criteria for this cross-sectional study are a heart, liver, kidney or lung transplant operation at the University Hospital Zurich, Switzerland at least six months previously and adequate knowledge of the German language. For caregivers, inclusion criteria are being the patient's spouse or living in a committed partnership with the patient, and adequate knowledge of the German language. The study was approved by the Zurich Cantonal Ethics Committee.

** Data from this research project have been published before. The paper by Goetzmann and colleagues [43] use the same sample while focusing on a different topic (i.e. burnout, sense of coherence, mental health and physical functioning in patients and their partners). The present study has a clear focus on the development of a measure of different dimensions of attitudes for patients and their spouses which was no way included in the above mentioned paper. Moreover, the paper by Scholz et al. [44] investigated the association between provided social support by the spouses on the one hand, and intentions as well as adherence in the patients on the other hand, within the theoretical framework of the theory of planned behaviour [22]. With this paper, minimal overlap ex-*

ists with regard to the subscale "Attitude towards the medication" for the patient and of the bivariate correlation between this attitude scale and the patient's adherence behaviour. Thus, although there is some overlap with the variables used in the present paper, this paper presents the investigation of unique research questions not yet covered by previous publications from this project.

The patients and their caregivers were sent an informational letter, the questionnaire and a written declaration of consent by ordinary post. Afterwards, the study team contacted the patients by phone. If the patients were interested in participating in the study, we asked them to discuss the participation with their spouses. Those patients and caregivers who were willing to participate then completed the questionnaires and sent them back by two separate prepaid return envelopes.

A total of 448 patients were contacted by telephone, of whom 387 were actually reached. The telephone conversation revealed 345 patients as having sufficient German-language skills to participate in the study. During the telephone call, 270 patients consented to participate in the study and affirmed that they would discuss joint participation in the study with one of their caregivers. Two hundred and five patients then returned the questionnaire and the statement of informed consent (response rate = 76%). In addition, the caregivers of 179 patients returned the completed questionnaire and the declaration of informed consent under separate cover (response rate = 66%).

Of the 179 dyads, 121 are married couples or couples living in a committed partnership. All couples are heterosexual. Other caregivers (siblings, parents, etc.) were not included, as spouses are assumed to be affected to a greater extent in terms of their quality of life by their spouse's (i.e. the patient's) illness than more distant family members. In total, 65 patients (24%) and 91 caregivers (34%) who did not return the questionnaire were classified as true dropouts.

The final sample consists of 121 University Hospital Zurich patients who had undergone a heart ($n = 19$), lung ($n = 42$), liver ($n = 29$), or kidney ($n = 31$) transplant, as well as their heterosexual spouses. Two thirds of the patients are men ($n = 81$, 67%). The patients are somewhat older than their spouses (54 years, $SD = 13$, range 23-79 vs. 52 years, $SD = 14$, range 21-84). The majority of the couples had children (patients: $n = 88$, 73%; spouses: $n = 86$, 71%).

Measures

Socio-demographic background factors are age, sex, and educational level. The *patient's state of health* was recorded by means of the diagnosis of the underlying disease, the type of organ transplanted, the time since the transplant surgery and the physical course after transplantation (rejection reactions, hospitalisations over the previous six months). These data were recorded in the University Hospital Zurich's electronic case history. The *spouse's state of health* was covered by the question as to the number of physical ailments and visits to the doctor/hospitalisations over the previous six months. The following questionnaires for patients and their spouses, the German versions of which were validated, are used in the study.

Attitudes towards the transplant

The items on attitudes towards the transplant were developed prior to the study by means of a pilot study. A team of experts composed of clinically and methodologically experienced staff from both the University Hospital Zurich and the Department of Psychology of the University of Zurich developed questions for both patient and caregiver considered relevant in the formation of attitudes towards the organ transplant. These questions were posed in personal interviews to a total of ten transplant patients. The corresponding questions were asked of the caregivers, predominantly spouses, but also siblings or adult children ($n = 10$) in separate interviews. The questions were as follows:

- 1) To patient / caregiver: "How would you rate the transplant experience today?"
- 2) To patient: "How do you feel about having to take immunosuppressive medication?" To caregiver: "How do you feel about your family member having to take immunosuppressive medication?"
- 3) To patient: "How do you feel about yourself in your experience as a transplant patient?" To the caregiver: "How do you feel about yourself in your experience as the caregiver of a transplant patient?"

From the pool of responses, we developed semantic differentials for each theme (experience of the transplant, attitudes towards medication and perception of the post-transplant self). These semantic differentials consisted of items with two adjectives of opposite meaning (e.g. "hopeful", "hopeless"). The patients or their caregivers were asked to indicate on a scale of +3 to -3 the extent to which these adjectives applied to them. The items were identically formulated for both patients and their caregivers (see [Appendix 1](#) and [2](#)).

Psychosocial measures

The following validated measures are used to record the quality of life of patient and spouse, the quality of the relationship from the patient's and the spouse's perspective and the patient's adherence:

Sense of coherence

The Sense of Coherence Scale, Short Version (SOC-13) is a 13-item comprehensive short version of the SOC with a 7-point Likert-type scale [24]. The scale measures the individual's cognitive potential relative to three components: comprehensibility, manageability, and meaningfulness. The German language version of SOC-13 is well validated [25–27]. A mean score is computed over the 13 items, ranging from 1 (lowest SOC) to 7 (highest SOC). The norm value is 5.01 (female 4.96, male 5.08), Cronbach's alpha = 0.85. Norm values are means from a representative survey of the German population ($N = 1,944$).

Quality of life

The SF-36 Health Survey [28] is used in its validated German version [29] as a questionnaire for measuring the overall quality of life in patients who are physically ill. It comprises a total of 36 items in eight subscales (physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, mental health) consisting of 2–10 items each with 2 point to 10 point Likert-

type scales. Cronbach's alpha of the subscales ranges from 0.74 (social functioning) to 0.94 (physical functioning). The subscales are combined into two weighted summary measures (T-scores) on physical health (Physical Component Score or PCS) and on mental health (Mental Component Score or MCS). Higher values indicate better health and quality of life. The norm value for PCS is 50.2 (female 49.1, male 51.4), range 5–69. The norm value for MCS is 51.5 (female 50.7, male 52.4), range 12–73. All norm values are means from a representative survey of the German population ($N = 2,773$).

Quality of relationship

The quality of the relationship between patient and caregiver is assessed by means of the Relationship Assessment Scale (RAS) [30, 31]. The RAS contains seven items (5-point Likert scale, agreement: 1 = not at all, 5 = perfectly) on quality of relationship: general satisfaction, how well the spouse meets one's needs, how well the relationship compares to others, regrets about the relationship, how well one's expectations have been met, love for spouse, and problems in the relationship. A mean score is calculated across the seven items, ranging from 1 to 5. Higher values indicate a greater satisfaction with the relationship. Cronbach's alpha is 0.93. The RAS shows moderate to high correlations with measures of marital satisfaction [30]. Norm values are not available.

Life satisfaction

The Life Satisfaction FLZ Survey [32] assesses satisfaction in eight spheres of life (friends/acquaintances, leisure/hobbies, health, income/financial security, occupation/work, housing/living conditions, family life/children, and relationship with spouse/sexuality) on a 5 point Likert-scale measure (1 = dissatisfied, 5 = very satisfied). A mean score is computed over the eight aspects, ranging from 1 (lowest satisfaction with life) to 5 (highest satisfaction with life). The norm value is 3.78 (female 3.80, male 3.75), Cronbach's alpha = 0.85. Norm values are means from a representative survey of the German population ($N = 5,036$).

Burnout

The Burnout Measure Scale (BM, previously known as the Tedium Measure) gauges the degree of burnout by means of a 21-item set answered on a 7-point Likert-scale in terms of the respondent's agreement (1 = never, 7 = always) [33]. The German version of the questionnaire is validated [34, 35]. A mean score is computed over the 21 items ranging from 1 to 7, with higher values indicating greater burnout; Cronbach's alpha is 0.93. Values between 2 and 3 indicate a good state of well-being, with the cut-off value for an acute crisis being 5. The Burnout Measure Scale correlates highly with fatigue and with the 'emotional exhaustion' dimension of the Maslach Burnout Inventory [35]. Norm values are not available.

Psychological transplant effects

The Transplant Effects Questionnaire TxEQ [36, 37] measures the adherence behaviour as well as the emotional response to an organ transplant by means of five subscales: patient's worry about the transplant, feelings of guilt to-

wards the donor, disclosure of being a transplant recipient, self-reported adherence, and responsibility related to the functioning of the new organ. The German version TxEQ-D is validated in a sample of 370 heart, lung, liver and kidney transplant patients [38]; scale values range from 1 (low in the sense of the scale) to 5 (high). This questionnaire was only used for the patients.

Statistics

All analyses are conducted within the framework of a correlational approach using computer software SPSS (PASW Statistics 18). Descriptive statistics are given in terms of means and standard deviations on the one hand, and counts and percentages on the other. In patients as well as in spouses, the factor analysis of the items concerning attitudes towards the transplant is carried out using principal component analysis and orthogonal rotated component matrix (Varimax with Kaiser Normalisation). Criteria for the number of factors are (1) Scree-Test, (2) Eigenvalues ≥ 1 , (3) at least 50% variance explained.

The items pertaining to the factor in question are combined into a scale whose total value is determined by adding together the values of the items and dividing by the number of items (average-value score). The scales therefore range from +3 (very positive) down to -3 (very negative). Criteria for the inclusion of an item in a scale are (1) communalities $\geq .30$, (2) factor loading $\geq .40$; exclusion criteria: factor loading $\geq .40$ on more than one factor. The reliability of the scales is estimated by Cronbach's Alpha.

Differences between organ groups on the one hand and patients and spouses on the other are investigated with a two-factorial MANOVA with the independent variables of (1) organ group and (2) patient/spouse (treated as a repeated measurement factor). Dependent variables are the 'Attitudes towards Transplantation' Scales (ATTS). Pearson correlations are computed to describe the associations between ATTS, Sense of Coherence (SOC), Quality of Life (SF-36), Relationship Assessment Scale (RAS) and Burnout Measure (BM).

Results

Diagnoses and medical data

Tables 1 and 2 show the diagnoses of the diseases leading to an organ transplant in the case of the patients, as well as further medical data.

Table 1 shows, that the most frequent disorders leading to the transplant are cardiomyopathy and coronary heart disease (heart), chronic obstructive pulmonary disease (COPD) and cystic fibrosis (lung); cirrhosis of the liver caused by hepatitis C infection or alcoholic poisoning (liver); and hereditary kidney diseases or diabetic nephropathy (kidney). As can be seen from table 2, rejection reactions occurred most frequently in lung and heart patients over the previous six months, and lung and liver patients were hospitalised most frequently within this time period.

Eighty-two spouses (68%) had had contact with a doctor over the past year, 29 (24%) had suffered from physical ailments in the last six months, and 16 (13%) had been hospitalised in the last six months.

Factor and item analysis of the attitudes

In both the patients' and the spouses' sample, the factor analysis yields four factors according to the criteria indicated in the statistics section that did not differ between the two samples: the Scree Test indicates four factors with an eigenvalue of >1 , the percentage of the variance explained by the four factors is 60%, and all communalities reach a value of over 0.30. The items "Taking the immunosuppressant medications is risk-free vs. risky", "Taking the immunosuppressant medications is helpful vs. not helpful" and "I experience myself today as privileged vs. not privileged" had to be ruled out for creating the scale, since they contain a substantial loading (≥ 0.40) on more than one factor. Table 3 shows the scales of attitudes towards transplantation with the psychometric properties for the patients and their spouses.

In all four scales, Cronbach's Alpha for both patients and spouses lies in a high ('Attitude towards Transplantation', 'Attitudes towards Medication', 'Attitude towards one's perceived Fate') or moderate ('Attitude towards one's perceived Self') range.

For determining the content of the factors or attitude scales:

Heart (n = 19)	n	Lung (n = 42)	n	Liver (n = 29)	n	Kidney (n = 31)	n
Cardiomyopathy	9	Cystic fibrosis	12	Cirrhosis of the liver (due to hepatitis C)	9	Hereditary kidney diseases	8
Coronary artery disease	8	Chronic obstructive pulmonary disease	9	Post-alcoholic cirrhosis	6	Diabetic nephropathy	7
Congenital valve disease	2	Pulmonary fibrosis	5	Primary biliary cirrhosis	3	Kidney dysplasia / aplasia	3
		Other	16	Other	11	Other	13

	Heart (n = 19)	Lung (n = 42)	Liver (n = 29)	Kidney (n = 31)
Rejections in the last 6 months; n (%)	6 (32)	11 (26)	1 (3)	3 (10)
Hospitalisations in the last 6 months; n (%)	2 (11)	16 (38)	11 (38)	6 (19)
Age in years at date of transplantation; M (SD, range)	50 (13, 21–72)	45 (14, 20–68)	52 (13, 18–69)	54 (11, 26–74)
Time in months since date of transplantation; M (SD, range)	118 (73, 12–223)	66 (46, 7–191)	33 (18, 7–75)	43 (20, 10–75)

The items of the first scale (“Attitude towards the Transplantation: Stress, Anxiety”) can be assigned thematically to the attitude towards the transplantation, predominantly in terms of stress or anxiety (a relief / burdensome, not anxiety-producing / anxiety-producing, not taxing / taxing, stress-free / stressful, not unsettling / unsettling).

The items of the second scale (“Attitudes towards Medication”) refer to the taking of medication (problem-free / problematic, not anxiety-producing / anxiety-producing, not bad / bad, not stressful / stressful).

The items of the third scale (“Attitude towards one’s perceived Self”) refer to the attitude vis-à-vis the patients’ or their spouses’ self, i.e. how they experience their self as transplant patients or the spouses of transplant patients (grateful / ungrateful, strong / weak, relaxed / tense, not strange / strange, self-determining / not self-determining).

The items of the fourth scale (“Attitude towards one’s perceived Fate”) relate to the attitude that understands the transplant as a positive or negative fateful event in the biography of the patients or their spouses (hopeful / hopeless, positive / negative, great / catastrophic, full of opportunity / devoid of opportunity).

Characterisation of attitudes towards transplantation, differences between patients and their spouses and differences between organ groups

In addition, table 3 shows the “Attitude towards the Transplantation: Stress, Anxiety”, the “Attitude towards the Medication”, the “Attitude towards one’s perceived Self”, and the “Attitude towards one’s perceived Fate”. Both patients and spouses have fairly negative attitudes towards the transplantation in terms of stress and anxiety. For both

groups, the values for this emotional attitude lie in the negative range, which indicates more stress. All further ATTS values for patients and spouses lie in the moderately positive range, with both groups indicating a predominantly positive attitude towards their medication, their perceived self and their perceived fate as a transplant patient or as the spouse of a transplant patient. Overall, the attitudes of the spouses are more positive than those of the patients themselves. The spouses report a significantly more positive attitude towards the transplantation in terms of stress and anxiety ($F(1,116) = 9.98, p = 0.002$) and towards their perceived fate ($F(1,116) = 4.62, p = 0.034$). Moreover, organ groups do not differ significantly in their attitudes towards the transplant (four ATTS: (1) $F(3,116) = 1.29, p = 0.283$; (2) $F(3,116) = 0.73, p = 0.534$; (3) $F(3,116) = 0.92, p = 0.435$; (4) $F(3,116) = 1.84, p = 0.190$). Nor do any significant interactions occur between organ groups and patients / spouses (four ATTS: (1) $F(3,116) = 2.13, p = 0.100$; (2) $F(3,116) = 1.25, p = 0.296$; (3) $F(3,116) = 0.65, p = 0.585$; (4) $F(3,116) = 0.40, p = 0.754$).

Correlations with psychosocial and somatic variables

Table 4a shows the correlations between the four “Attitudes towards Transplantation Scales” (ATTS) on the one hand with sex and age, sense of coherence (SOC-13), quality of life (SF-36, physical / mental component scores), quality of relationship (RAS) and burnout (BM) for patients and spouses on the other. Table 4b shows the correlations between the ATTS on the one hand and the patient’s emotional processing of the transplant (TxEQ-D) as well as the patient’s physical variables on the other.

Table 3: Items of the ‘attitudes towards transplantation’ scales (ATTS): item-total correlations ($r(it)$), Cronbach’s Alpha, and scale means and standard deviations for patients (P) and their spouses (S), p-values for differences in scale means between patients and spouses, Pearson correlation (r) between patients and spouses ($n = 121$).

Scale Items	$r(it)$	Patients		Spouses		Patients M (SD)	Spouses M (SD)	p (P-S)	r (P-S)
		Cronbach’s Alpha	$r(it)$	Cronbach’s Alpha					
Attitude towards transplantation: stress, anxiety¹		.89		.88		-0.79 (1.72)	-0.56 (1.62)	0.002	0.29
1. A relief / burdensome	0.71		0.60						
2. Not anxiety-producing / anxiety-producing	0.75		0.75						
3. Not taxing / taxing	0.71		0.75						
4. Stress-free / stressful	0.69		0.70						
5. Not unsettling / unsettling	0.79		0.75						
Attitude towards medication²		0.79		0.84		1.30 (1.31)	1.18 (1.50)	0.377	0.28
1. Not a problem / problematic	0.60		0.65						
2. Not anxiety-producing / anxiety-producing	0.63		0.68						
3. Not bad / bad	0.69		0.66						
4. A relief / burdensome	0.47		0.72						
Attitude towards one’s perceived self³		0.74		0.75		1.50 (1.08)	1.47 (1.37)	0.921	0.30
1. Grateful / ungrateful	0.42		0.60						
2. Strong / weak	0.59		0.56						
3. Relaxed / tense	0.48		0.59						
4. Not strange / strange	0.54		0.46						
5. Self-determining / not-self-determining	0.49		0.44						
Attitude towards one’s perceived fate⁴		0.87		0.94		1.92 (1.33)	2.24 (1.16)	0.034	0.36
1. Hopeful / hopeless	0.67		0.79						
2. Positive/ negative	0.79		0.90						
3. Great / catastrophic	0.67		0.84						
4. Full of opportunity / devoid of opportunity	0.75		0.90						

Note: ¹ “For me, the transplant is ...”; ² “For me, taking the immunosuppressive medication is...”; ³ “In my identity as a patient / spouse of a transplant patient, I currently feel...”; ⁴ “For me, the transplant experience is...”

Table 4a contains predominantly significant correlations between the ATTS and the sense of coherence (SOC-13). Patients with high SOC-13 values indicate positive attitudes towards their medication ($r = 0.25$, $p \leq 0.01$), their perceived self ($r = 0.52$, $p < 0.001$), and their perceived fate ($r = 0.21$, $p \leq 0.05$). A comparable picture exists with the spouses, although this group harbours a significant negative correlation between sense of coherence (SOC-13) and the attitude towards the transplantation in terms of stress and anxiety ($r = 0.20$, $p \leq 0.05$). Among the patients, there are predominantly significant correlations between their attitude towards the transplant in terms of stress and anxiety) and their physical or mental quality of life (SF-36). More specifically, there is a negative correlation between the attitude towards the transplantation in terms of stress and anxiety (physical component score: $r = -0.25$, $p \leq 0.01$) and a positive correlation between the attitude towards the medication (physical component score: $r = 0.25$, $p \leq 0.01$; mental component score: $r = 0.25$, $p \leq 0.01$) and the perceived self (physical component score: $r = 0.26$, $p \leq 0.01$; mental component score: $r = 0.59$, $p < 0.001$), and the perceived fate ($r = 0.38$, $p < 0.001$). No significant correlation exists between mental quality of life and attitude towards transplantation in terms of stress and anxiety. In the spouses' group, the correlations between mental quality of life (SF-36) and the individual dimensions of the ATTS are sig-

nificant ($r = 0.19 - r = 0.57$, $p \leq 0.05 - p < 0.001$). There are no significant correlations in terms of physical quality of life (SF-36).

Significant correlations between the ATTS and the rating of the partnership (RAS) exist in both groups. The better the rating of the couple's relationship, the more positive are the attitudes towards the medication (patients: $r = 0.27$, spouses: $r = 0.32$, $p \leq 0.01$), perceived self (patients: $r = 0.35$, spouses: $r = 0.56$, $p < 0.001$) and perceived fate (patients: $r = 0.28$, spouses: $r = 0.25$, $p \leq 0.01$). A significant negative correlation is found with the spouse's attitude towards transplantation in terms of stress and anxiety ($r = -0.27$, $p \leq 0.01$). No significant correlation is found between the patient's assessment of the quality of the relationship and the patient's attitude towards the transplantation in terms of stress and anxiety.

In addition, significant correlations ($r = 0.24$ and $r = -0.35 - r = -0.68$, $p \leq 0.01 - p < 0.001$) exist between the ATTS and burnout in the patients (BM). Among the spouses, the findings are not quite so clear-cut, although here too there are significant correlations between burnout and a negative attitude towards medication ($r = -0.31$, $p \leq 0.01$) or towards the perceived self as spouse of a transplant patient ($r = -0.56$, $p < 0.001$).

Patients also completed the TxEQ-D questionnaire, which is used to survey the emotional processing of the transplant

Table 4a: Correlations between the 'attitudes towards Transplantation' scales (ATTS) and sociodemographic as well as psychosocial variables (sense of coherence scale, SOC-13; physical component score, SF-36, mental component score, SF 36, relationship assessment scale, RAS, burnout measure scale, BM), $n = 121$.

	Patient				Spouse			
	Attitude towards transplantation: stress, anxiety	Attitude towards medication	Attitude towards one's perceived self	Attitude towards one's perceived fate	Attitude towards transplantation: stress, anxiety	Attitude towards medication	Attitude towards one's perceived self	Attitude towards one's perceived fate
Gender (1 = m, 2 = f)	0.24**	-0.08	0.15	0.11	0.23*	0.07	-0.15	-0.08
Age in years	-0.25**	0.02	0.04	-0.05	-0.22*	0.19	0.12	0.07
Sense of Coherence Scale (SOC-13)	-0.18	0.25**	0.52***	0.21*	-0.20*	0.28**	0.55***	0.20*
Physical Component Score (SF 36)	-0.25**	0.25**	0.26**	0.16	0.05	0.02	0.02	0.09
Mental Component Score (SF 36)	-0.11	0.25**	0.59***	0.38***	-0.20*	0.21*	0.57***	0.19*
Relationship (RAS)	-0.08	0.27**	0.35***	0.28**	-0.27**	0.32**	0.56***	0.25**
Burnout (BM)	0.24**	-0.36***	-0.68***	-0.35***	0.18	-0.31**	-0.56***	-0.15

Notes *** $p < 0.001$, ** $p \leq 0.01$, * $p \leq 0.05$

Table 4b: Correlations between the 'Attitudes towards Transplantation' Scales (ATTS) and the patient's emotional response to the transplantation (Transplant Effects Questionnaire, TxEQ-D) as well as the patient's physical variables (rejection, hospitalisation, age at the date of transplant, time since transplantation), $n = 121$.

	Attitude towards transplantation: stress, anxiety	Attitude towards medication	Attitude towards one's perceived self	Attitude towards one's perceived fate
TxEQ-D				
Worry about transplant	0.31**	-0.24**	-0.25*	-0.20*
Guilt regarding donor	0.06	-0.16	-0.36***	-0.25**
Disclosure	-0.14	0.12	0.29***	0.17
Adherence	-0.02	0.39***	0.17	0.10
Responsibility	-0.15	0.05	0.15	0.01
Physical variables				
Rejections in the last 6 months (yes)	-0.13	0.12	0.03	0.06
Hospitalisations in the last 6 months (yes)	0.06	-0.17	-0.08	-0.12
Age in years at date of transplant	-0.22*	0.04	0.05	-0.05
Time in months since date of transplant	-0.06	-0.03	0.05	0.07

Notes *** $p < 0.001$, ** $p \leq 0.01$, * $p \leq 0.05$

as well as adherence behaviour (see table 4b). There are significant correlations between worry about the transplant and all scales of the ATTS ($r = 0.31$ and $r = -0.20 - r = -0.25$, $p \leq 0.01 - p \leq 0.05$), as well as between feelings of guilt on the one hand and the attitude towards one's perceived self on the other ($p < 0.001$; $p \leq 0.01$). Moreover, the results show that feelings of guilt towards the donor go hand in hand with a negative attitude towards both one's perceived self ($r = -0.36$, $p < 0.001$) and one's perceived fate ($r = -0.25$, $p \leq 0.01$). A positive correlation exists between the disclosure of the transplant and the attitude towards one's perceived self as a transplant recipient ($r = 0.29$, $p < 0.001$). Patients with a positive attitude towards their perceived self speak more openly about the transplant. As was to be expected, adherence behaviour correlates highly significantly with a positive attitude towards the medication ($r = 0.39$, $p < 0.001$).

An examination of the correlations between the physical state of health of the patients (organ rejection, time since transplant, number of hospitalisations in the last six months) and their attitudes towards the transplant (ATTS) reveals no significant correlations.

Discussion

Overall, it is noteworthy that factor analyses revealed almost the same results in patients and spouses. This indicates a highly comparable structure of attitudes towards transplantation in both samples which is measured by the ATTS. This multidimensional instrument is short and without any problems in applicability. Further research is needed in greater samples of different organ groups to replicate and validate our findings. In doing so, attention should also be paid to standardising the time interval between transplantation and measurement of attitudes.

Characteristics of the attitudes towards transplantation

An organ transplant represents a critical event both in the life of the patients and in that of their spouses. We therefore posed the question as to what attitudes both patients and their spouses have towards the transplant, bearing in mind further psychosocial and physical variables. The significant findings of our study indicate that both patients and their spouses have predominantly positive attitudes towards the transplantation with respect to medication, their perceived self and their fate of being a transplant patient or spouse of a transplant patient. However, both patients and spouses report a negative attitude towards the transplantation in terms of stress and anxiety. This finding shows the emotional stress that goes hand in hand with a transplant both for the patients and their spouses, even when both groups manage to develop a positive attitude towards the medication, their perceived self or towards their perceived fate either as a transplant recipient or spouse of the patient. The fact that the majority of patients have a positive attitude to their immunosuppressants probably has to do with the latter's function as a life-preserving pharmacological intervention. Patients are doubtless under pressure to come to terms with the immunosuppressants, given that they could not live without them. Further, the identity as a transplant patient

or caregiver (spouse) to a transplant patient is experienced by the overwhelming majority of those questioned as positive, and thus, for example, described with the adjectives "strong, relaxed, privileged" or "autonomous".

The positive attitude towards one's perceived self may be explained by various factors. For one thing, quality of life is known to increase markedly after an organ transplant [patients: 1–10; caregivers: 8, 39], i.e. one's identity as a transplant patient or spouse is determined by the increase in physical, emotional and social quality of life. A further factor may be the personal growth or maturation of the patients within the context of so-called "post-traumatic growth" [40]. This maturation is probably also reflected in the positive identity of the spouses, who have witnessed the different phases of the patients' disease and the uncertainties of the transplant. There are also indications that, owing to the exceptional experiences resulting from the transplant, transplant patients form part of a group of people differing markedly from other individuals [41]. The feeling of having experienced something unique might contribute to the positive identity of the patients as well as of their spouses. Also positive are the attitudes towards their fate as a transplant patient, or as the spouse of a transplant patient. The more positive attitudes of the spouses may have to do with the fact that the transplant was instrumental in saving the life of their nearest and dearest, whilst it is the patient who must also live with the health drawbacks of the transplant, for example acute or chronic rejection reactions [42].

Associations between the attitudes towards transplantation and psychosocial core variables

The rating of the quality of the relationship assumes a central role with regard to attitudes towards the transplant: the better the couple's relationship is rated, the more positive the attitudes towards the transplant. Only the attitude towards the transplantation in terms of stress and anxiety shows no significant correlation with the quality of the relationship. We assume that a patient who feels at ease in, and cherishes, his relationship will also in general be more positively disposed to the transplant and more able to take health challenges in his stride. On the other hand, it seems fair to assume that the spouses are more able to tolerate the stresses of a transplant when they are satisfied with their relationship with the patient, whose life the transplant has saved. As these are only cross-sectional correlational analyses, however, no causal conclusions can be drawn.

The correlations between the attitudes towards the transplant and the different scales of the TxEQ-D, which records the emotional response to a transplant as well as adherence behaviour, turn out as expected. Patients' feelings of guilt towards the donor go hand in hand with a more negative attitude towards perceived self and one's perceived fate. Clearly, the patients' ability to perceive their self positively goes hand in hand with their feelings of guilt. As one would expect, patients with a positive feeling of self as a transplant recipient are also more able to talk about their transplant experience. Moreover, adherence behaviour (which is surveyed in the TxEQ-D) correlates highly significantly with a positive attitude towards the medications.

Examination of the correlations between the patients' state of health (organ rejection, time since transplant, number

of hospitalisations in last six months) and their attitudes towards the transplant reveals no significant correlations. Moreover, there is no difference between organ groups in terms of the attitudes of the patients and their spouses. The results show that the personality or psychosocial health of patients and their spouses is connected to the development of the attitudes investigated, rather than attitudes towards the transplant being related to transplanted organ type or with the patient's state of health.

Strengths of the study and limitations

The *strength of the study* lies in the fact that it is one of the very first to examine the perspectives of both patients and their spouses in the context of organ transplant, investigating the associations between different dimensions of attitudes towards the transplant and patient adherence. A number of *limitations* also need to be addressed, however. Firstly, the response rate for the questionnaires is relatively low. The explanation is to be found in the dyadic design of the study, according to which both patients and spouses were to fill out a questionnaire. Secondly, since patients were initially contacted by telephone, only those individuals who at the time were being treated as outpatients and whose physical health was comparatively stable were included. In addition, it must be borne in mind that the high values for self-reported patient adherence may be an expression of the social desirability of this behaviour. Further, there is a large range regarding the time since transplantation (7–223 months). However, we found no significant correlation between the time since transplantation and the attitudes towards the transplantation (ATTs). It also has to be considered that norm values of the psychosocial variables are mostly based on a representative sample (i.e. by the majority healthy people), except for TxEQ-D, where norms are based on transplant patients. A final limitation lies in the mentioned cross-sectional nature of the study, which does not permit any statements on causality.

Conclusions

Patients as well as spouses report primarily positive attitudes towards the transplant. Cognitive coping resources and quality of the partnership are of great importance for attitudes towards the transplant and should be borne in mind and promoted in the psychosocial treatment of transplant patients and their spouses with regard to the comprehensibility, manageability and meaningfulness of the transplant experience as well as potential conflicts in the partnership.

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Correspondence: Lutz Goetzmann, MD, Department of Psychosomatic Medicine and Psychotherapy, Segeberger Kliniken, Am Kurpark 1, DE-23795 Bad Segeberg, Germany, [lutz.goetzmann\[at\]segebergerkliniken.de](mailto:lutz.goetzmann[at]segebergerkliniken.de)

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Appendix

[Appendix 1: ‘Attitudes towards Transplantation Scale’ – Patient \(pdf\).](#)

[Appendix 2: ‘Attitudes towards Transplantation Scale’ – Caregiver \(pdf\).](#)