Psychological processing of transplantation in lung recipients: a quantitative study of organ integration and the relationship to the donor

Goetzmann, L; Irani, S; Moser, K S; Schwegler, K; Stamm, M; Spindler, A; Buddeberg, C; Schmid, C; Boehler, A; Klaghofer, R

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Abstract

OBJECTIVES: Lung recipients undergo a complex psychological process, including organ integration and processing of attitudes towards the organ donor. DESIGN: Seventy-six lung recipients were asked to participate in a cross-sectional questionnaire study on the psychological processing of lung transplants. METHODS: The questionnaire consisted of statements describing aspects of organ integration and the patient's relationship with the donor. Furthermore, chronic stress/psychological distress (Screening Scale of the Trier Inventory; Symptom Checklist SCL-K-9) and the emotional effects of transplantation/immunosuppression (Transplant Effects Questionnaire; Medication Experience Scale for Immunosuppressants) were assessed. RESULTS: In general, lung recipients perceive the transplant as part of themselves (97.4%) and not as a foreign object (90%). One-third of patients still have frequent thoughts about the donor, whilst the majority (80.3%) do not believe that they have adopted the donor's characteristic traits. Factor analysis reveals the two-dimensional structure of the questionnaire items 'organ integration' (factor 1) and 'relationship to the donor' (factor 2). Poor organ integration predicts low adherence, low disclosure and high feelings of guilt, whilst a close donor relationship predicts chronic stress and psychological distress. CONCLUSIONS: Poor organ integration and a close relationship to the donor should be borne in mind in psychosocial treatment regarding the patient's adherence behaviour and psychological distress.
Psychological Processing in Lung Recipients

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Design: Seventy-six lung recipients were asked to participate in a cross-sectional questionnaire study on the psychological processing of lung transplants.

Methods: The questionnaire consisted of statements describing aspects of organ integration and the patient’s relationship with the donor. Furthermore, chronic stress / psychological distress (Screening Scale of the Trier Inventory, TICS-SCSS; Symptom Checklist SCL-K-9) and the emotional effects of transplantation / immunosuppression (Transplant Effects Questionnaire, TxEQ-D; Medication Experience Scale for Immunosuppressants, MESI) were assessed.

Results: In general, lung recipients perceive the transplant as part of themselves (97.4%) and not as a foreign object (90%). One-third of patients still have frequent thoughts about the donor, whilst the majority (80.3%) do not believe that they have adopted the donor’s characteristic traits. Factor analysis reveals the two-dimensional structure of the questionnaire items “organ integration” (factor 1) and “donor identification” (factor 2). Poor organ integration predicts low adherence, low disclosure and high feelings of guilt, whilst high values for donor identification predict chronic stress and psychological distress.

Conclusions: Poor organ integration and identification with the donor should be borne in mind in psychosocial treatment regarding the patient’s adherence behaviour and psychological distress.

Key words: Lung transplantation, organ integration, donor, chronic stress, psychological distress, adherence, psychosocial treatment.
Psychological Processing in Lung Recipients

Psychological Processing of Transplantation in Lung Recipients: A Quantitative Study of Organ Integration and the Adoption of the Donor’s Traits

In transplantation medicine, there is a growing body of literature dealing with both psychological and physical determinants of quality-of-life and psychological well-being before and after organ transplantation (for lung recipients, Littlefield, Abbey, Fiducia, Cardella, Greig, Levy, Maurer & Winton 1996; TenVergert, Essink-Bot, Geertsma, van Enckevort, de Boer & van der Bij, 1998; Cohen, Littlefield, Kelly, Maurer & Abbey, 1998; Limbos, Joyce, Chan & Kesten, 2000; Goetzmann, Scheuer, Naef, Vetsch, Buddeberg, Russi, & Boehler, 2005). According to this research, both quality-of-life and psychological well-being improve significantly after transplantation. Nevertheless, very little is known about the psychological processes associated with transplantation.

Dating back to the 1970s, there is some literature on how kidney patients deal with caring for a foreign organ. Muslin (1971, 1972) postulated a gradual internalisation of the transplanted organ. In the first stage of this integration, the transplant is perceived as a foreign object. In the next stage, the transplant represents both a “foreign” and an “own” object for the recipient. Only when internalisation is wholly complete is the transplanted organ perceived as a part of the patient’s self. In Muslin’s view, the representation of the donor (i.e. the way the recipient sees the donor) after the transplant is identical to the recipient’s self-representation. Subsequently, the “donor” representation detaches itself from the “self” representation, roaming from the centre of the recipient’s self into the external world.

Lefebvre (1973) agreed with this conception, whilst other authors stressed individual variability and fluidity in the mental integration of the organ (Castelnuovo-Tedesco, 1973; Basch, 1973). Today, organ integration is one of the most important issues for transplant
patients, and the achievement of a positive body image and integration of the new organ correlates with psychosocial well-being (Balck, 2008).

In a qualitative study of our own, we also encountered differences in organ integration (Goetzmann, 2004; Goetzmann, Moser, Vetsch, Naef R, Russi, Buddeberg & Boehler 2007). Furthermore, some patients reported a degree of identification with the donor, believing themselves to have adopted the donor’s characteristic traits. In this study, there have also been indications of a correlation between poor organ integration or identification with the donor on the one hand, and non-adherence behaviour\(^1\) on the other. Based on this qualitative research, we developed five questionnaire items in order to operationalise the concept of organ integration and donor identification.

Our first hypothesis was, that most patients perceive the transplanted organ as a part of themselves, and that enduring identification with the donor is only a minor problem after lung transplantation. The second hypothesis was based on the assumption that both organ integration and donor identification are basic mental processes having an impact on symptoms such as chronic stress, distress, and health behaviour (e.g. adherence). We therefore expected patients with poor organ integration or those who identified with the donor to experience greater stress, distress, or feelings of guilt, and more problems in terms of adherence behaviour. The third hypothesis was that both organ integration and donor identification are predominantly mental processes, and that they will have no significant correlations with the patient’s physical health.

The questions posed by the study are as follows:

1.) How frequent are problems of psychological processing with regard to organ integration, and what role is played by the relationship with the donor?

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\(^1\) Adherence is defined as “the extent to which patients follow the instructions they are given for prescribed treatment” (Haynes, Ackloo, Sahota, Mc Donald & Yao, 2008). In this article, adherence is related to the patient’s immunosuppressive medication.
2.) Are transplant-related parameters reflecting organ integration and patient’s identification with the donor predictors for stress or psychological distress and adherence-behaviour? Are there physical or sociodemographic predictors (such as chronic rejection reaction or patient’s age)?

3.) Is there a correlation between organ integration or identification with the donor on the one hand, and the patient’s physical health status on the other?

Methods

Sample and procedure

All patients who have undergone a lung transplant at the University Hospital Zurich with a time-gap of three months or more between surgery and assessment, an age above 16 years, and sufficient knowledge of the German language were asked to participate in this study. After approval by the Ethics Committee of the University Hospital Zurich, the study was announced by an informative letter to the 96 lung recipients in our programme who met these inclusion criteria. In the next step, the questionnaire was handed out to patients interested in taking part at their subsequent regular post-transplant check-up. In addition, patients signed an informed consent. Seventy-six patients (77%) agreed to participate in the study, completing the questionnaire on the same day.

Instruments

The questionnaire included demographics such age, gender and employment. Five items were adopted from a previous qualitative study of lung recipients (Goetzmann et al., 2007). These statements were an operationalisation of two concepts: one that the transplanted organ might be a “foreign part” of the person in the first stage of integration, and a “part of
the self” in a later, more mature stage of integration, and that this development may be interrupted (for example by psychological conflicts or physical complications); and two, that the patient, experiencing an identification with the donor, is mentally preoccupied with the donor, and believes that he has adopted some of the latter’s character traits. We added the dimension “current perceived importance of transplant events” to assess how intensely patients were currently preoccupied with the earlier transplant. The questions were answered by means of a 5-point Likert Scale (1 = Totally incorrect, 2 = Not correct, 3 = Unsure whether the statement is correct or not, 4 = Correct, 5 = Totally correct). The questionnaire items concerning organ integration are “I perceive the graft as a foreign object in myself” (organ as foreign object) and “The transplanted lung became a part of myself” (organ as part of the self). The items regarding donor identification are “I often think of the donor” (thoughts of the donor) and “Sometimes I have the impression that I have adopted some of the donor’s traits.” (adoption of donor’s traits). The item “The events accompanying transplantation don’t matter to me today” relate to the current perceived importance of transplant events.

In addition, the following validated questionnaires were used to assess patients’ chronic stress and psychological distress, as well as the emotional effects of the transplant and immunosuppression.

The 12-item Screening Scale of the Trier Inventory for the Assessment of Chronic Stress (TICS-SSCS) (Schulz, Scholtz & Becker, 2004) measures patients’ chronic overall stress on a 5-point Likert scale ranging from 0 (never) to 4 (very often). It contains 12 items of the 57-item Trier Inventory for the Assessment of Chronic Stress (TICS), yielding the following dimensions of chronic stress: chronic worry, overwork, excessive demands at work, excessive social stress, and lack of social recognition.

The Symptom Checklist SCL-K-9 (Klaghofer & Brähler, 2001) is a short version of the Symptom Checklist SCL-R (Derogatis, 1977). The SCL-90-R measures psychological...
distress and psychopathological symptoms in terms of hostility, obsessive-compulsive symptoms, depression, interpersonal sensitivity, paranoid ideation, anxiety, somatisation, phobic anxiety, and psychotic ideation. The German short version of SCL-K-9 is rated on a 5-point Likert scale between 0 (not at all) and 4 (very much), and is computed with nine items showing the highest correlation with the Global Severity Index (GSI-90), a summary of the SCL-R-90 designed to assess overall psychological distress over the last seven days. The SCL-K-9 has a one-dimensional factor structure, a Cronbach’s alpha of .87, and a mean value comparable to the GSI-90 (19).

The Transplant Effects Questionnaire (TxEQ-D) measures the emotional response to organ transplantation with five subscales: Patient’s worry about the transplant, Feelings of guilt towards the donor, Disclosure of transplant, Self-reported adherence, and Responsibility related to the functioning of the new organ (Ziegelmann, Griva, Hankins, Harrison, Davenport, Thompson & Newman, 2001; Griva, Ziegelmann, Thompson, Jayasena, Davenport, Harrison & Newman 2002). The five scales of the validated German version TxEQ-D show an internal consistency (Cronbach’s alpha) of between 0.71 (Disclosure) and 0.79 (Adherence) (Klaghofer, Sarac, Schwegler, Schleuniger, Noll, Mullhaupt, Ambuehl, Boehler, Irani, Buddeberg & Goetzmann, 2008).

The Medication Experience Scale for Immunosuppressants (MESI) is a short screening instrument recording the subjective experiences and cognitive attitudes of patients vis-à-vis their immunosuppressive medication (Goetzmann, Klaghofer, Spindler, Wagner-Huber, Scheuer & Buddeberg, 2006). The scale shows an internal consistency (Cronbach’s alpha) of 0.78 and a theoretical range of 4 to 33, with higher values indicating more negative experiences and attitudes.
Physical parameters

The forced expiratory volume in one second (FEV$_1$) served as a measure of pulmonary function. Spirometry was performed with a mass flow-meter (66200 Autobox®, Sensor Medics, Yorba Linda, CA). Criteria for acceptability, reproducibility and predicted normal values were according to the European Community of Coal and Steel ECCS (Quanjer, Tammeling, Cotes, Pedersen, Peslin & Yernault, 1993). In addition, the diagnosis of the underlying disease leading to the lung transplant, the date of surgery, and current diagnosis of bronchiolitis obliterans syndrome (BOS) were recorded. The term "chronic rejection" was used to describe the bronchiolitis obliterans syndrome according to the criteria of the International Society of Heart and Lung Transplantation (Estenne, Maurer, Boehler, Egan, Frost, Hertz, Mallory, Snell & Yousem, 2002).

Statistical analysis

The statistical evaluation was carried out with SPSS 15.0 for Windows. Descriptive-statistics data were expressed in absolute numbers, per cent, means, and standard deviation (SD). The factor analysis of the items concerning the current perceived importance of transplant events, organ integration and donor identification was performed using principal component analysis, followed by varimax rotation with Kaiser normalisation. The prediction of chronic stress (TICS-SCSS) and psychological distress (SCL-K-9) as well as the effects of transplantation (TxEQ-D) and immunosuppression (MESI) were investigated by multiple regression analyses (method: enter); beta weights and adjusted R-square values are presented.
Results

Sociodemographic data and diagnoses

Seventy-six of the 96 patients took part in this survey, yielding a response rate of 77%. Table 1 shows the sociodemographic data and diagnoses of the underlying lung diseases.

Table 1

As Table 1 shows, the sample comprised more men (56%) than women (44%). The mean age of respondents was 48.3 years. On average, the lung transplant had taken place 48 months previously, with a range of 3 to 133 months and a right-skewed distribution. The largest diagnostic group consisted of patients with cystic fibrosis, followed by those suffering from chronic obstructive pulmonary disease (COPD).

Means and standard deviations of chronic stress, psychological distress, the effects of transplantation and immunosuppression

Table 2 shows means, standard deviations (SD) and ranges of chronic stress (TICS-SSCS), psychological distress (SCL-K-9), effects of transplantation (TxEQ-D) and immunosuppression (MESI).

Table 2

The mean value of chronic stress is 0.5 standard deviation below the norm (Schulz, Scholtz & Becker, 2004), and the mean value of psychological stress is 0.5 standard deviation above the norm (Klaghofer & Brähler, 2001).
Means and frequencies of the statements concerning the current perceived importance of transplant events, organ integration and donor identification

Table 3 shows the mean values and standard deviations of the statements relating the current perceived importance of transplant events, organ integration and donor identification.

Table 3

The mean value of Statement 1 (“The events accompanying transplantation don’t matter to me today”) shows that transplant events are currently perceived as important by almost half of the patients. Patients’ responses to Statement 2 (“I perceive the graft as a foreign object in myself”) indicate that they do not experience the transplanted lung as a foreign object. The mean value of Statement 3 (“The transplanted lung became a part of myself”) can be interpreted as indicative of good organ integration among these lung recipients. The mean value of Statement 4 (“I often think of the donor”) shows that patients are not normally very preoccupied with the donor. They do, however, report a degree of uncertainty as to whether the statement is correct or not. Statement 5 emphasises the identification with the donor (“Sometimes I have the impression that I have adopted some of the donor’s traits”). In our sample, patients’ experience of having adopted certain traits of the donor is very slight.

Even though nearly half of the patients report that the events around the transplant still matter to them today, most of them claim to perceive the transplanted lung not as a foreign object, but as a part of themselves. Despite this, one-third still frequently think about the donor.
Although the majority do not believe that they have adopted any of the donor's personal traits, almost 20% are either unsure of this, or actually report believing that this may be the case.

*Results of the factor analysis concerning the current perceived importance of transplant events, organ integration and donor identification*

The factor analysis revealed two factors with an eigenvalue greater than 1 which explain 61% of the variance. In addition, the scree-plot clearly indicates a solution with two factors. Items 2 and 3 constitute factor 1 (“organ integration”), and items 1, 4 and 5 constitute factor 2 (“donor identification”). The factor loadings and communalities are presented in Table 4.

*Table 4*

*Prediction of chronic stress, psychological distress, and the emotional effects of transplantation / immunosuppression*

According to the assumption that both organ integration and donor identification are basic mental processes that may have an impact on chronic stress, psychological distress or the patient’s health behaviour, we defined both organ integration and donor identification as predictors for the dependent variables of chronic stress and distress, and the emotional / behavioural effects of the transplantation / immunosuppression. Furthermore, we included the parameter “chronic rejection reaction” (BOS) (as one of the most obvious physical complications after a lung transplant) and the sociodemographic parameter “patient's age” as predictors in the multiple regression model.
Table 5 shows the results of the regression analysis for the two factors “organ integration” and “donor identification”, as well as BOS and age as predictors; chronic stress, psychological distress, and the emotional effects of transplantation / immunosuppression are considered as the dependent variables.

Table 5

As shown by Table 5, poor organ integration predicts guilt towards the donor (TxEQ-D), low disclosure (TxEQ-D), and low adherence (TxEQ-D). Donor identification is a predictor for chronic stress (TICS-SCSS), psychological distress (SCL-K-9), worries about the transplant (TxEQ-D), and feelings of guilt (TxEQ-D). The physical parameter BOS is not a predictor for the dependent psychosocial variables. Age of patient predicts responsibility (TxEQ-D), with elderly people experiencing a greater sense of responsibility vis-à-vis the transplant.

Associations with physical health (FEV₁, BOS diagnosis, time since transplantation)

There is no significant correlation between the two dimensions "organ integration" / "donor identification" on the one hand, and current lung function (FEV₁) or current occurrence of a chronic rejection reaction (BOS) on the other. Furthermore, there are no significant differences between patients with cystic fibrosis and those with another lung disease. Time since transplantation is not significantly correlated (Spearman's rho) with "organ integration" / "donor identification".

Discussion

Seventy-six lung recipients were asked to comment on transplant integration and their imagined relationship with the donor. The main finding of the present quantitative study is
that poor organ integration and the perceived adoption of the donor’s imagined character traits are not typical transplant-related phenomena, which means that the majority of patients have considerable potential for adaptation. Nevertheless, a minority of patients are concerned about such experiences, whose association with poor adherence or psychological distress underline the clinical importance of these findings.

Current perceived importance of the transplant events, organ integration and donor identification: Mean values and frequencies

In our survey, we first assessed the current importance ascribed by patients to transplant events. We learned that almost half of the patients still considered incidents relating to the transplant to matter in their current lives. This result was statistically independent of the amount of time elapsed since transplantation. It shows that transplantation as a life event plays a sustained and important role in the life of lung recipients.

There is a high degree of organ integration among lung recipients at least three months after transplantation or later on. Generally, patients experience the transplanted organ as a part of themselves and not as a foreign body. In previous publications, Muslin (1971, 1972) and other authors (Lefebvre, Combez & LeBeuf, 1973) describe organ integration as a long-term, step-by-step process. This process may be interrupted by emotional difficulties of any kind, causing the transplanted organ to remain a foreign, possibly hostile object in the patient’s body as well as in his or her representational world. However, poor organ integration appears only in a minority of patients.

In our survey, the patients were also asked to comment on their attitudes towards the donor: firstly, whether they often think of the donor, and secondly, whether they have internalised some of the donor’s imagined characteristics. One-third of patients (32.9%) still think about the donor frequently, and almost 20% are either not sure whether they have adopted some of the donor’s characteristics (11.2%), or actually report having acquired some of the latter’s
traits (7.9%). We interpret this process in terms of an identification: the idea of having incorporated the donor’s personality traits, e.g. his laughter, as one patient in the previous interview study stated (Goetzmann et al., 2007), may be the result of the projection of one’s own attributes onto the representation of the donor.

Results of the factor analysis concerning the current perceived importance of transplant events, organ integration and donor identification

The factor analysis revealed a two-dimensional structure of the questionnaire items. Factor 1 consists of the items that the lung is a part of the patient or the lung is a foreign object. Factor 2 consists of the items that the patient often thinks of the donor, or has adopted some of the donor’s traits. The current perceived importance of the transplant events also forms part of factor 2. That this item is part of the “donor identification” factor underscores the very important role played by the donor in the patient’s emotional processing of the transplant. Persistent thoughts about the donor may the cause patients to remain attached to earlier transplant events. Furthermore, the two-dimensional structure shows that the statements fit quite well into the psychodynamic construct of organ integration / donor identification, forming a short questionnaire on these clinically important topics.

Prediction of chronic stress, psychological distress and the emotional effects of transplantation / immunosuppression

In the multiple regression model, we tested whether organ integration and donor identification predict chronic stress, psychological distress or the emotional effects of the transplant / immunosuppression. Furthermore, we integrated physical and sociodemographic parameters (BOS, age) into the model. We assumed that psychological questions regarding the incorporation of the organ into the patient’s world as well as questions of identification with the donor represent basic mental processes that may influence the degree of symptoms
such as stress, distress, feelings of guilt, or the patient’s health behaviour, i.e. adherence. The results show that patients reporting problems with organ integration are primarily affected by feelings of guilt. It appears to be difficult to accept an organ psychologically whilst feeling guilty towards the donor. Poor organ integration is also predictive of low disclosure, in other words, patients avoid revealing themselves as transplant recipients. These patients report particular difficulties in terms of adherence behaviour. The rate of immunosuppressant non-adherence stands at about 23% among transplant patients, making it one of the most important issues in transplantation medicine (Dew, DiMartini, de Vito Dabbs, Myakowski, Steel, Unruh, Switzer, Zomak Kormos & Greenhouse, 2007). Thus, to prevent non-adherence, the process of organ integration should be carefully addressed by the treating physicians. Patients with signs of donor identification report more stress, distress, guilt and worries. These findings show that identification with the donor goes hand in hand with further psychosocial symptoms and problems. Thus, patients who are able to integrate their new organ report better adherence, and those who build an aloof, separate relationship with the donor report less stress or distress.

Because a chronic rejection reaction (BOS) is not a predictor of stress / distress or the other psychosocial parameters, we might postulate that psychosocial strains tend to be caused by poor organ integration or donor identification, and only to a lesser extent, if at all, by the current physical status of the transplanted organ. Moreover, patient’s age predicts sense of responsibility only: Elderly patients clearly feel more responsible towards their new organ.

*Associations of organ integration and donor identification with physical health, age and time since transplantation*

Because we have found no significant correlations between physical health on the one hand and organ integration / donor identification on the other, integrating a transplant and sorting out one’s relationship with the donor would appear to be a psychological process.
that is not influenced, or at least not directly influenced, by the current physical status of the transplanted organ. Remarkably, we found that neither the age of the patient nor the time elapsed between the surgery and the post-transplant assessment influenced the outcomes in terms of organ integration and the donor/recipient relationship. It would therefore appear that both the psychological integration of the organ and the donor/recipient relationship are organised and more or less definitively shaped during the first few months after transplantation. Furthermore, for some people the process of adaptation and integration may start before the transplant, as patients prepare themselves for the procedure.

Addressing the limitations of the study, the cross-sectional design should be considered first. Thus, there are no definitive causal connections between the different possible psychosocial parameters. Longitudinal studies are needed in this area. Furthermore, the statements concerning the perception of both the organ and the donor do not currently meet the statistical criteria of a validated questionnaire, and it is only a very brief measure with two or three items per section. Because of this limitation, the data of the study have to be interpreted with some caution. However, one interesting result may be that qualitative findings – chiefly, that poor organ integration is associated with non-adherence – have now been confirmed by quantitative means.

Conclusions

Problems with organ integration and identification with the donor only affect a minority of lung recipients. It is important for health professionals to know that these problems are quite rare, but that when they occur, they are usually in association with psychological distress, feelings of guilt and shame, and above all, poor adherence, which underscores
their clinical relevance. There is a need to be able to identify individual differences
between patients in processing a lung transplant, as well as to be able to predict a sub-
group of patients who will be likely to suffer from psychosocial stress and problems
including non-adherence behaviour. The aim of future research on this topic should be to
develop tools for measuring organ integration and perception of the donor that meet the
conditions of a validated questionnaire.


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