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What's on your mind?

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CHAPTER
3

VALIDATION OF THE
DUTCH VERSION OF THE
TRANSPLANT EFFECTS
QUESTIONNAIRE IN LIVER
TRANSPLANT RECIPIENTS

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ABSTRACT

Little is known about the extent to which transplant recipients face emotional problems with the receipt of a transplanted organ. The Transplant Effects Questionnaire (TxEQ) enables the quantification of these problems. This study evaluates the psychometric properties of the Dutch translation of the TxEQ (TxEQ-NL) in a group of liver transplant recipients. Confirmatory factor analyses of the TxEQ-NL revealed an adequate fit with the original version. However, four items showed factor loadings $<.40$. Internal consistency was acceptable (.66-.79). The small correlations between the TxEQ-NL and generic measures of psychological functioning indicated that the constructs measured are related but distinguishable. Therefore, the TxEQ-NL adds a new dimension to the measurement of psychological functioning of transplant recipients.

INTRODUCTION

Liver transplantation has become the treatment of choice for end stage liver disease. Over the past decades, advances in medical and surgical technology, together with the availability of new immunosuppressive medications, have led to improved clinical outcomes, such as decreased morbidity, better survival rates, and prolonged life expectancy of liver transplant recipients. Nowadays, the 5- and 10-year survival rates of liver transplant recipients are 72% and 62% respectively (European Liver Transplant Registry, 2012).

Due to these improvements, other outcomes such as health-related quality of life and psychosocial consequences of transplantation become increasingly important targets of evaluation.¹ Information about different aspects of life relevant to organ transplant recipients, such as in-depth knowledge of physical, psychological, and social functioning, together with knowledge about health behaviour, may contribute to our understanding of how transplantation influences transplant recipients' lives. Consequently, it may improve the possibility to react appropriately to problems of the transplant recipient regarding these aspects.²

A point of interest with regard to psychological functioning is the emotional response of transplant recipients to the receipt of an organ. Qualitative studies in particular have shown that transplant recipients worry about their transplant,³⁻⁵ have feelings of gratitude and guilt towards donors,⁶⁻⁸ or find it hard to disclose about their transplants.⁹ However, little is known about the extent to which these emotional problems occur, because these aspects are generally not covered by traditional research instruments. To be able to quantify the emotional response to the receipt of a transplant organ, Ziegelmann et al.¹⁰ developed the Transplant Effects Questionnaire (TxEQ). The original English version of the TxEQ (TxEQ-E) was developed on the basis of literature review, a focus group of transplant health care providers, and in-depth interviews with kidney transplant recipients. The TxEQ encompasses five topics important to transplant recipients: worries about the transplant, feelings of guilt towards the donor, disclosure about having a transplant, feelings and behaviour regarding medication adherence, and perceived responsibility to others. Although the TxEQ was initially developed as a research instrument, it has been indicated to be a useful screening tool for assessing problematic responses to the receipt of an organ.^{10,11}

The TxEQ-E has been developed and tested in kidney transplant recipients, but given comparable results of the German version of the TxEQ (TxEQ-D) in a group of heart, lung, liver, and kidney transplant recipients, the TxEQ can be used in other organ transplant groups as well.¹¹ The TxEQ also has demonstrated its capacity for illustrating different emotional responses in transplant recipients.¹⁰⁻¹²

Psychometric testing of the TxEQ-E showed modest to good reliability scores with Cronbach's alpha between .72 and .86, and acceptable test-retest reliability ($r = .60 - .80$).¹⁰ The TxEQ-D showed overall satisfactory reliability scores with Cronbach's alpha between .71 and .79.¹¹

The Short Form Health Survey (SF-36) was used to test the construct validity of the TxEQ, and indicated that the subscales "Worry about the transplant" and "Feelings of

guilt towards the donor” were associated with lower scores on the mental health component of the SF-36. The overall small to moderate correlations ($r = .12 - .30$) indicate that the constructs of the TxEQ and the SF-36 can be distinguished from each other and can be seen as independent constructs.¹¹

The TxEQ was translated into Dutch (TxEQ-NL) to be able to measure the emotional response to the receipt of an organ in Dutch transplant recipients. The aim of this study is to examine the psychometric properties of the TxEQ-NL by testing its factorial structure, internal consistency, and construct validity. To test the construct validity, the relationship between psychological functioning and the emotional and behavioural response to the receipt of an organ, as mentioned by Griva et al.¹² and Klaghofer et al.,¹¹ will be further examined. Therefore, the convergent validity (the degree to which a measure is correlated with other measures to which it is theoretically predicted to correlate with) and divergent validity (the degree to which a measure does not correlate with other measures that it theoretically should be independent of) between the subscales of the TxEQ-NL and measures of depression, anxiety, posttraumatic stress, and positive and negative affect will be examined. The relationship between the subscales of the TxEQ-NL and the concepts personality and coping -known to be related to psychological functioning- also were examined.

Expected convergent and divergent correlations

In general, few researchers have reported on the relationship between emotional responses and psychological functioning, personality style, or coping style of transplant recipients. However, worries about the transplant has been shown to lead to anxiety and depression.^{3-5,13} Kidney transplant recipients who score high on the neurotic personality style were found to complain more about health issues.¹⁴ This might indicate that they worry more about the transplants.

In a recent meta-analysis,¹⁵ both shame ($r = .43$) and guilt ($r = .28$) were associated with depression. The recipients’ feelings of guilt towards the donor after transplantation have also been related to poor organ integration and the development of psychiatric syndromes.^{7,9,16} The recipients’ use of avoidance, suppression, and denial coping have been described as defense mechanisms for dealing with feelings of sorrow, indebtedness, and guilt.¹⁷

Although several researchers have shown that disclosure after a traumatic experience has no effects on symptoms of anxiety, depression, or posttraumatic stress,^{18,19} low disclosure among transplant recipients was found to be related to poor organ integration.⁹ In colorectal cancer patients, an expressive disclosure group intervention was found to improve psychological functioning.²⁰

Medication non-adherence has been associated with anxiety,²¹ depression,²²⁻²⁴ post-traumatic stress,^{25,26} and negative affect²⁷ in transplant recipients. Additionally, personalities with low sense of conscientiousness²⁸ and the use of an active²⁹ or avoidance³⁰ coping style are associated with medication non-adherence.

Research on feelings of responsibility is scarce. Only Buldukoglu et al.³¹ described that feelings of responsibility were related to worries about the transplant. This might indicate that feelings of responsibility are indirectly related to psychological functioning.

Table 1. Expected convergent and divergent correlations between TxEQ subscales and measures of psychological functioning, personality, and coping

| TxEQ subscale | Worry about the transplant | Guilt towards the donor | Disclosure about the transplant | Adherence to immunosuppressive medication | Responsibility towards others |
|----------------------------------|----------------------------|-------------------------|---------------------------------|---|-------------------------------|
| <i>Psychological functioning</i> | | | | | |
| Depressive symptoms | + | + | - | - | ○ |
| Anxiety | + | + | - | - | ○ |
| Posttraumatic stress | + | + | - | - | ○ |
| Positive affect | ○ | ○ | ○ | ○ | ○ |
| Negative affect | + | + | - | - | ○ |
| <i>Personality</i> | | | | | |
| Conscientiousness | - | - | + | + | ○ |
| Neuroticism | + | + | ○ | - | + |
| <i>Coping</i> | | | | | |
| Avoidant | + | + | - | - | ○ |
| Task-oriented | ○ | ○ | ○ | + | + |
| Emotional | + | + | - | - | ○ |

Note: + = expected positive correlation; - = expected negative correlation; ○ = null association expected



Table 1 summarizes the expected convergent and divergent correlations of the subscales of the TxEQ-NL with measures for psychological functioning, personality, and coping, based on the literature and general psychological knowledge. When no empirical support between concepts was found in the literature, expected correlations were based on theoretical psychological expectations of connections between these constructs. Overall, we expected to find small correlations (r between .10 and .30), with the correlations in support of convergent validity higher than correlations for divergent validity.

METHODS

Participants and procedure

Data were collected as part of a cross-sectional study on psychological consequences of transplantation among liver transplant recipients at the University Medical Center Groningen, the Netherlands, in April 2010. All liver transplant recipients transplanted at our center between 1979 and October 2009 who were transplanted at an adult age and who were still receiving post-transplant care at our center were invited to participate. Additional inclusion criteria were being able to fill in a Dutch questionnaire and

not being enlisted for re-transplantation. Of the 420 potentially eligible recipients, 373 met the inclusion criteria. They received an information letter, a questionnaire, and an informed consent form regarding permission to obtain data from the recipient's medical record. To ensure a frank response the questionnaires had code numbers and confidentiality was guaranteed. After 4 weeks, a reminder was sent to non-responders and another 2 weeks were allowed for completion. The study met the criteria for an exemption from institutional review board approval (METc2010.039).

Measures

The Transplant Effects Questionnaire and its translation

With permission from the authors, the TxEQ-E was translated into Dutch by three independent translators, and the items were subsequently compared and checked for use of natural language. After consensus was reached on a single Dutch translation for each item, the translated items were translated back into English by a native English speaker to check the accuracy of translation. Based on the back translation two items (8 and 14) were slightly changed to better fit the original English language statements. To test feasibility, the TxEQ-NL was pilot tested in a group (n = 9) of transplant recipients who took part in a prospective study on psychological consequences of liver transplantation. The pilot test did not reveal substantial problems that warranted changes.

The TxEQ consist of 23 items comprising five subscales: worry about the transplant (6 items), guilt towards the donor (5 items), disclosure about the transplant (3 items), adherence to immunosuppressive medication (5 items), and responsibility towards others (4 items). The items are scored on a 5-point Likert scale (1 = *strongly disagree* to 5 = *strongly agree*). To identify recipients with a problematic response a mean value of the items, ranging from 1 to 5, is computed for each subscale. A score >3.5 on the subscales "Worry" and "Guilt" and a score <2.5 on the subscales "Disclosure," "Adherence," and "Responsibility" indicates a problematic response.³² Though these cutoff scores are mentioned in the literature there are no reports on their validity. As for the original version of the TxEQ, a total score is not computed.

Measures used to test the construct validity

Psychological functioning

Depressive symptoms. To assess depressive symptoms the Centre for Epidemiological Studies Depression scale (CES-D) was used.³³ The CES-D consists of 20 items, scored on a 4-point self-report scale (0 = *seldom or never* to 4 = *most of the time-always*). Higher scores indicate more depressive symptoms. Validation of the Dutch version of the CES-D showed good internal consistency scores, with Cronbach's alpha ranging from .79 to .92 depending on the study population. Test-retest reliability was .90 and convergent validity with the Beck Depression Inventory was .66.³⁴

Symptoms of anxiety. In this study the short form of the STAI (STAI-6), developed by Marteau and Bekker,³⁵ was used to measure symptoms of anxiety. The STAI-6 consists of 6 items rated on a 4-point intensity scale (1 = *not at all* to 4 = *very much*). Higher scores indicate more symptoms of anxiety. Validation of the Dutch version of the STAI-

6 has shown good reliability (Cronbach's alpha = .83), and the convergent validity of the STAI-6 with the full form of the STAI showed a correlation of .95.³⁶

Posttraumatic stress symptoms. To measure symptoms of posttraumatic stress the Self-rating Inventory for Posttraumatic stress disorder (SRIP) was used.³⁷ The SRIP is a Dutch screening instrument for posttraumatic stress disorder (PTSD) and registers symptoms of PTSD independently of the degree of traumatization. The 22 items, corresponding to the DSM-IV criteria, are rated on a 4-point self-report scale (1 = *not at all* to 4 = *extremely*). Higher scores indicate more symptoms of posttraumatic stress. The SRIP has good psychometric properties with Cronbach's alpha .90, test-retest reliability .92, and convergent correlation with the Keane MMPI-PTSD of .80.³⁸

Positive and Negative Affect. The Positive And Negative Affect Schedule (PANAS) is a 20-item self-report measure of positive and negative affect, reflecting positive mood and pleasurable engagement with the environment (Positive Affect), and subjective distress and unpleasurable engagement with the environment (Negative Affect). Higher scores indicate higher levels of either positive or negative affect. Respondents rate each emotion on a 5-point self-report scale (1 = *very slightly or not at all* to 5 = *extremely*). The Dutch version of the PANAS showed internal consistency scores of .83 for the Positive affect scale and .79 for the Negative affect scale.³⁹

Personality

Personality styles of Neuroticism and Conscientiousness. The personality styles of Neuroticism and Conscientiousness were assessed using two subscales of the NEO Five-Factor Inventory (NEO-FFI), a self-report questionnaire designed to measure the five major domains of personality.⁴⁰ Each domain consist of 12 items rated on a 5-point Likert scale (1 = *totally disagree* to 5 = *totally agree*). Higher scores indicate higher levels of the personality style. In the Dutch version of the NEO-FFI Cronbach's alpha of the subscale Neuroticism ranged from .80 to .88 and of the subscale Conscientiousness from .69 to .81 depending on the study population.⁴¹

Coping

Avoidance, task oriented, and emotional coping styles. A short form of the Coping Inventory for Stressful Situations (CISS-SF) was used. The CISS-SF assesses three dimensions of responses to stressful circumstances: task-oriented, emotional, and avoidance coping.⁴² The CISS-SF consists of 21-items with 7 items per subscale rated on a 5-point self-report scale (1 = *not at all* to 5 = *very much*). Higher scores indicate higher levels of the coping style. The Dutch version of the CISS has good psychometric properties with Cronbach's alpha of .87 for task oriented coping and emotional coping, and .82 for avoidance coping. Test-retest reliability is .78 for task oriented coping and avoidance coping, and .90 for emotional coping.⁴³

Data Analysis

Factorial structure

To test the factorial structure of the TxEQ-NL a Confirmative Factor Analysis (CFA) was conducted using M-Plus 6.0 (Muthen & Muthen, Los Angeles, CA, 2010). Goodness of

fit was evaluated using several descriptive criteria: chi-square (X^2), chi-square/degrees of freedom (X^2/df), and root means square error of approximation (RMSEA). The X^2 statistic was used to evaluate the appropriateness of the structural equation model.

If the P value associated with the X^2 value is $>.05$, the model shows a good fit with the data. The relative chi-square (X^2/df) aims to make the test less dependent on the sample size. A ratio between 0 and 2 indicates a good fit; whereas a ratio between 2 and 3 indicates an acceptable fit. The RMSEA quantifies the divergence between data of this study and the original model per degree of freedom. Values below .05 indicate a close fit, whereas values up to .08 indicate an adequate fit.⁴⁴ Factor loadings of $\geq.40$ are considered sufficient. The Akaike Information Criterion (AIC) was used to compare different models. The AIC is a descriptive measure in which the model with the lowest AIC is the preferred model.

If one or more items on the subscales of the TxEQ-NL remained unanswered, data were excluded from analysis for that subscale. If one or more items were missing on all subscales of the TxEQ-NL the case was excluded from all analysis.

Descriptive statistics, reliability, and construct validity

Descriptive statistics, reliability, and construct validity analyses were performed using PASW 18.0. (SPSS inc., Chicago, IL, 2010). Differences between responders, non-responders, and the total eligible patient group were examined using the Mann-Whitney U-test for continuous data and Chi-square test for categorical variables. Reliability was examined using the internal consistency coefficient Cronbach's alpha (α) and the mean inter-item correlation coefficient (MICC) for each subscale. In general, Cronbach's alpha for diagnostic instruments are considered sufficient if $\geq.80$, but for instruments used for screening of individuals an internal consistency score $>.90$ is recommended.⁴⁵ For research instruments a Cronbach's alpha between .70 and .80 is considered acceptable.⁴⁶ However, the value of alpha is somewhat dependent on the number of items in a scale, whereas the inter-item correlation coefficient does not have this dependency. Briggs and Cheek⁴⁷ recommend that the MICC should fall in the range of .20-.40.

Analysis of convergent and divergent correlations between the TxEQ-NL and measures of psychological functioning, personality, and coping was performed using Spearman's correlation coefficients. Correlations between .50 and 1.00 were interpreted as strong, correlations between .30 and .50 as moderate, correlations between .10 and .30 as small, and correlations $<.10$ as weak.⁴⁸ To correct for the number of repeated tests, the significance level of .05 was adjusted by Bonferroni correction to $<.01$ for psychological functioning measures, $<.025$ for personality measures, and $<.016$ for coping measures. Squared correlation (r^2) also were computed for each correlation to indicate the percentage of overlap between constructs.

RESULTS

Participants

Of the 373 eligible liver transplant recipients, 281 completed the questionnaire, resulting in a response rate of 75%. One responder’s data on the TxEQ-NL were insufficient and were excluded from analysis. Sociodemographic and medical data are presented in Table 2.

Men and women were equally present in the study population. Age at the time of survey and age at transplantation showed wide ranges of 26-80 and 16-68 years respectively. Mean time since transplantation was 9.9 years, again with a wide range of 6 months to 31.5 years. Most respondents lived together with a partner (79%) and were of Dutch nationality (89%). Diagnoses before transplantation were mainly primary sclerosing cholangitis, primary biliary cirrhosis, and cryptogenic liver cirrhosis. All responders were on immunosuppressive medication at time of the survey.

Although responders were older than the non- responders at the time of the survey and at the time of transplantation, and time since transplantation was shorter for excluded recipients, responders did not significantly differ from the total study population (Table 2).

Table 2. Characteristics of all eligible transplant recipients, excluded recipients, non responders and responders and comparisons between groups

| Characteristic | All (n = 420) (%) | | Excluded (n = 47) (%) | | Non responders (n = 92) (%) | | Responders (n = 281) (%) | | Significance |
|-------------------|----------------------------|-----------|-------------------------------|-----------|-----------------------------|-----------|------------------------------|-----------|----------------------|
| Gender | | | | | | | | | |
| Male | 51.0 | | 46.8 | | 51.1 | | 51.6 | | ns ^a |
| Female | 49.0 | | 53.2 | | 48.9 | | 48.4 | | |
| Living situation | na | | na | | na | | | | |
| With partner | | | | | | | 79 | | - |
| Alone | | | | | | | 21 | | |
| Nationality | na | | na | | na | | | | |
| Dutch | | | | | | | 89 | | - |
| Other | | | | | | | 11 | | |
| Medical diagnosis | PSC 19 PBC 12 ALD 11 | | Hep. B 19 PBC 13 ALF 13 | | PSC 18 PBC 12 ALD 12 | | PSC 22 PBC 12 Crypt 12 | | ns ^a |
| Characteristic | All (n = 420) | | Excluded (n = 47) | | Non responders (n = 92) | | Responders (n = 281) | | Significance |
| | Mean | Range | Mean | Range | Mean | Range | Mean | Range | |
| Age | 55.1 | 24.7-79.7 | 53.5 | 25.7-75.5 | 52.3* | 24.7-77.8 | 56.4* | 25.4-79.7 | *p <.01 [†] |
| Age at Tx | 45.4 | 15.9-68.9 | 45.6 | 19.8-64.2 | 42.2 | 17.2-67.1 | 46.4 | 15.9-68.9 | *p <.01 [†] |
| Time since Tx | 9.7 | 0.6-31.1 | 7.9* | 0.8-23.0 | 10.1 | 0.9-28.6 | 9.9 | 0.6-31.1 | *p <.05 [†] |

Note: Tx, transplantation; na, not available; ns, not significant; PSC, Primary Sclerosing Cholangitis; PBC, Primary Biliary Cirrhosis; ALD, Alcoholic Liver Disease; Hep. B, Hepatitis B Cirrhosis; ALF, Acute Liver Failure; Crypt, Cryptogenic Cirrhosis;

^aX²test, [†]Mann-Whitney U-test, *Significant differences between groups

Table 3. Standardized factor loadings of the confirmatory factor analysis of the TxEQ-NL

| Item | Factor and statement | Estimate | Standard error |
|--|--|-------------|----------------|
| <i>Factor 1: Worry about the transplant</i> | | | |
| 1 | With regard to my transplant I feel that I am carrying around something fragile | 0.57 | 0.05 |
| 3 | I am hesitant to engage in certain activities because I am afraid of doing harm to my transplant | 0.55 | 0.05 |
| 9 | I am worried about damaging my transplant | 0.56 | 0.05 |
| 12 | I monitor my body more closely than before I had the transplant | 0.30 | 0.06 |
| 16 | I worry each time my anti-rejection drug regime is altered by my doctor | 0.61 | 0.05 |
| 18 | I keep wondering how long my transplant will work | 0.47 | 0.06 |
| <i>Factor 2: Guilt towards the donor</i> | | | |
| 8 | I do not have any feelings of guilt toward the donor | 0.34 | 0.07 |
| 14 | I feel guilty about having taken advantage of the donor | 0.55 | 0.06 |
| 17 | The donor had to suffer to make me feel better | 0.58 | 0.06 |
| 19 | Sometimes I think that I have 'robbed' the donor of a vital part | 0.36 | 0.07 |
| 23 | I have the feeling that the donor/the donors' family has some control over me | 0.65 | 0.06 |
| <i>Factor 3: Disclosure about having a transplant</i> | | | |
| 5 | I am uncomfortable with other people knowing that I have a transplant | 0.56 | 0.05 |
| 13 | I have difficulty in talking about my transplant | 0.75 | 0.04 |
| 15 | I avoid telling other people that I have a transplant | 0.96 | 0.04 |
| <i>Factor 4: Adherence to immunosuppressive medication</i> | | | |
| 2 | Sometimes I think I do not need my anti-rejection medicines | 0.25 | 0.06 |
| 7 | Sometimes I forget to take my anti-rejection medicines | 0.88 | 0.02 |
| 11 | I find it difficult to adjust to taking my prescribed anti-rejection drug-regime | 0.57 | 0.05 |
| 20 | When I am too busy I may forget my anti-rejection medicines | 0.84 | 0.02 |
| 22 | Sometimes I do not take my anti-rejection medicines | 0.77 | 0.03 |
| <i>Factor 5: Perceived responsibility towards others</i> | | | |
| 4 | I think that I have a responsibility to the transplant team to do well | 0.63 | 0.05 |
| 6 | I feel that I owe the donor/the donor's family something that I will never be able to repay | 0.50 | 0.06 |
| 10 | I think that I have a responsibility to the donor/the donors' family to do well | 0.66 | 0.05 |
| 21 | I think that I have a responsibility to my friends and my family to do well | 0.54 | 0.06 |

Note: Factor loadings <.40 are in boldface

Confirmatory factor analysis

The CFA was conducted using the five factor structure of the original English version of the TxEQ. Although the chi-square statistic showed a *P* value <.05 (X^2 466, *p* <.001), the other goodness of fit indices showed an adequate fit (X^2/df 466/220 = 2.1; RSMEA = .063; AIC = 19578) of the original model in our data. Table 3 shows the standardised factor loadings of the CFA on the items of the TxEQ-NL in our data.

Four items show a factor loading of <.40. This concerns item 12 (“I monitor my body more closely than before I had the transplant”) of the subscale “Worry,” item 8 (“I do not have any feelings of guilt towards the donor”) and item 19 (“Sometimes I think that I have ‘robbed’ the donor of a vital part”) of the subscale “Guilt,” and item 2 (“Sometimes I think I do not need my anti-rejection medicines”) of the subscale “Adherence.” Additional CFAs, in which items with a factor loading <.40 separately were excluded from analysis, did not reveal a better fit with our data ($X^2 P$ <.05; X^2/df between 2.02 and 2.31; RSMEA between .061 and .068; AIC between 15894 and 18722). Only when all items with a factor loading <.40 were excluded from analysis, did the CFA show a substantial decline in AIC from 19578 in the original model to 14143. However, the fit of this model was also adequate (X^2 325, *P* <.001; X^2/df 325/142 = 2.3; RSMEA = .068).

Reliability

The internal consistency scores were satisfactory for the subscales “Disclosure” and “Adherence,” with Cronbach’s alphas of .79 and .78 respectively (Table 4). The Cronbach’s alphas for the subscales “Worry,” “Guilt,” and “Responsibility” were modest, ranging from .66 to .68, but sufficient given the MICCs of .26, .34, and .33 respectively. When the items with a factor loading <.40 were deleted from analysis, the internal consistency estimates improve for the subscales “Worry” (from .68 to .69) and “Adherence” (from .78 to .85). For the subscale “Guilt” the internal consistency score improved if item 8 was deleted (from .66 to .73), but decreased when item 19 was deleted (from .66 to .54).

The internal consistency scores are comparable to the scores of the English and German versions of the TxEQ for the subscales “Adherence” and “Disclosure” (Table 4), but lower for the other subscales.^{10,11}

Table 4. Internal consistency scores of the TxEQ-NL and Cronbach’s Alpha of the English version (TxEQ-E) and German version (TxEQ-D) of the Transplant Effects Questionnaire

| Scale | n | Items | Possible score range | Observed score range | Mean | SD | MICC | Cronbach’s Alpha | | |
|----------------|-----|-------|----------------------|----------------------|------|------|------|------------------|--------|--------|
| | | | | | | | | TxEQ- NL | TxEQ-E | TxEQ-D |
| Worry | 278 | 6 | 1.0-5.0 | 1.0-4.5 | 2.80 | 0.73 | .26 | .68 | .81 | .73 |
| Guilt | 279 | 5 | 1.0-5.0 | 1.0-4.2 | 1.74 | 0.60 | .34 | .66 | .76 | .74 |
| Disclosure | 280 | 3 | 1.0-5.0 | 1.0-5.0 | 4.36 | 0.74 | .57 | .79 | .86 | .71 |
| Adherence | 279 | 5 | 1.0-5.0 | 1.8-5.0 | 4.17 | 0.80 | .44 | .78 | .79 | .79 |
| Responsibility | 280 | 4 | 1.0-5.0 | 1.0-5.0 | 3.49 | 0.86 | .33 | .66 | .72 | .73 |

Note: SD, standard deviation; MICC = mean inter-item correlation coefficient; α = Cronbach’s alpha

Table 5. Observed convergent and divergent correlations and squared correlations between TxEQ subscales and measures of psychological functioning, personality, and coping

| TxEQ subscale | Worry | | Guilt | | Disclosure | | Adherence | | Responsibility | |
|----------------------------------|--------------|-----------------------|--------------|-----------------------|--------------|-----------------------|--------------|-----------------------|----------------|-----------------------|
| | <i>r</i> | <i>r</i> ² | <i>r</i> | <i>r</i> ² | <i>r</i> | <i>r</i> ² | <i>r</i> | <i>r</i> ² | <i>r</i> | <i>r</i> ² |
| <i>Psychological functioning</i> | | | | | | | | | | |
| Depressive symptoms | .29* | .08 | .17* | .03 | -.19* | .04 | -.12 | .01 | .05 | <.01 |
| Anxiety | .30* | .09 | .22* | .05 | -.22* | .05 | -.14 | .02 | .07 | <.01 |
| Posttraumatic stress | .27* | .07 | .16* | .03 | -.27* | .07 | -.08 | .01 | -.07 | <.01 |
| Positive affect | <.01 | <.01 | -.07 | <.01 | .08 | .01 | .12 | .01 | .22* | .05 |
| Negative affect | .29* | .08 | .20* | .04 | -.17* | .03 | -.11 | .01 | .04 | <.01 |
| <i>Personality</i> | | | | | | | | | | |
| Conscientiousness | -.14* | .02 | -.28* | .08 | .24* | .06 | .20* | .04 | .09 | .01 |
| Neuroticism | .32* | .10 | .28* | .07 | -.23* | .05 | -.18* | .03 | <.01 | <.01 |
| <i>Coping</i> | | | | | | | | | | |
| Avoidant | .20* | .04 | .17* | .03 | -.06 | <.01 | -.09 | .01 | .22* | .05 |
| Task-oriented | .07 | <.01 | -.07 | <.01 | .07 | <.01 | .12 | .01 | .15* | .02 |
| Emotional | .34* | .12 | .36* | .13 | -.25* | .06 | -.20* | .04 | -.09 | .01 |

Note: * Bonferroni adjusted level of significance (two-tailed): psychological functioning $p < .01$, personality $p < .025$, Coping $p < .016$; expected convergent correlations are in boldface; Expected divergent correlations are in Italic typeface.

Construct validity

Table 5 summarises the findings regarding the convergent and divergent correlations of the subscales of the TXEQ-NL with measures of psychological functioning, personality, and coping.

Twenty-six of the 34 expected convergent correlations between the subscales of the TxEQ-NL and measures of psychological functioning, coping, and personality were confirmed. The expected convergent correlations between the subscale “Disclosure” and avoidance coping; between the subscale “Adherence” and measures of psychological functioning, and avoidance and task-oriented coping; and between the subscale “Responsibility” and the personality style of neuroticism were not supported by our data. Thirteen of the 16 expected divergent correlations were confirmed. The subscale “Disclosure” was negatively correlated with the personality style of neuroticism, and the subscale “Responsibility” was positively correlated with positive affect and avoidant coping style. All expectations regarding the direction of the convergent correlations were met.

Overall, the correlations between the TxEQ-NL and measures of psychological functioning indicated significant, but small effect sizes (between .10 and .30), and the percentage of variance explained by these measures was low ($r^2 = <.01-.09$). This indicated that an association existed between these constructs, but that the constructs measured were different. This means that the TxEQ measures a distinguishable and independent construct when compared to other scales measuring psychological functioning.

Correlations between the subscale “Worry” and the personality style of neuroticism and emotional coping, and between the subscale “Guilt” and emotional coping, show moderate effect sizes (between .30 and .50). This indicates that coping style and personality style could be potential determinants of the emotional response to the receipt of an organ. However, the variance explained by these construct remains small ($r^2 = <.01-.10$). Comparison of the effect sizes of the convergent and divergent correlations per subscale showed satisfactory differences in strength of the correlations for four subscales. Only the subscale “Adherence” showed minimal differences in strength between convergent and divergent correlations.

DISCUSSION

The TxEQ-NL has been shown to be a valid and reliable instrument to measure the emotional response to the receipt of an organ in Dutch liver transplant recipients. The confirmatory factor analysis of the TxEQ-NL, revealed an adequate fit with the original English version of the TxEQ. The reliability of the TxEQ-NL was satisfactory for the subscales “Disclosure” and “Adherence,” and given the MICC, was sufficient for the subscales “Worry,” “Guilt,” and “Responsibility.” With respect to construct validity, overall small correlations were found between the subscales of the TxEQ-NL and measures of psychological functioning, personality, and coping.

Overall, the reliability scores of the TxEQ-NL were somewhat lower than in the English and German versions of the TxEQ.^{10,11} Although the reliability scores of the TxEQ-NL were not perfect, the scores were within acceptable standards of reliability used for research instruments in social sciences.⁴⁶ However, there are some implications for the use of the TxEQ-NL as a screening tool. To make inferences about individuals, an internal consistency score $>.90$ is recommended.⁴⁵ Therefore, the use of the TxEQ-NL as a screening instrument should be done carefully.

The significant correlations of the subscales of the TxEQ-NL with coping and personality indicated that coping style and personality style are potential determinants of the emotional response to the receipt of an organ. The significant correlations of the subscales of the TxEQ-NL with measures of psychological functioning indicated that an association exists between these constructs. The overall small effect sizes, however, indicated that the constructs measured are different. This means that the TxEQ-NL measures a distinguishable and independent construct when compared to other scales measuring psychological functioning. Therefore, it can be argued that the TxEQ-NL adds a new dimension to the measurement of psychological functioning of transplant recipients.

However, the merely adequate fit of the TxEQ-NL with the original five factor model of the TxEQ-E indicates that there are a few differences regarding item-response between these two instruments. This could be due to cultural differences, but the rich tradition of translating English questionnaires into Dutch generally does not reveal issues regarding cultural differences.

Based on the results of the CFAs, it seems appropriate to measure the emotional

response to the receipt of a transplant with a version of the TxEQ-NL without the four items with a factor loading $<.40$. However, the CFA model without these items also had only show an adequate fit in our data. Because the TxEQ-NL was only validated in liver transplant patients, deleting these four items might be premature. Alternatively, the four items could be reformulated to make them less equivocal, which should be addressed in future research.

In this respect, some points regarding these items with poor factor loadings need to be addressed. First, Item 12 (“I monitor my body more closely than before I had the transplant”) was also troublesome in the validation study of the German version of the TxEQ, because it loaded higher on the subscale “Responsibility” (.50) than on the subscale “Worry” (.22).¹¹ This might indicate that this item may not have a distinctive character when phrased in this way, because it can be seen as worrying about the transplant as well as taking responsibility, but also because transplant recipients have to monitor their body before the transplant as a consequence of their chronic illness. Therefore, rephrasing this item in a way that reflects worrying about the transplant more closely might be a solution to this problem.

Second, item 8 (“I do not have any feelings of guilt towards the donor”) and item 19 (“Sometimes I think that I have ‘robbed’ the donor of a vital part”) both refer to specific feelings of guilt towards the donor. These feelings may play a major role in cases where the transplant organ was donated by a living donor.¹² In our population of liver transplant recipients, nearly all transplanted organs were retrieved from cadaveric donors, which may have influenced the results on these items.

Third, in the subscale “Adherence,” item 2 (“Sometimes I think I do not need my anti-rejection medicines”) showed a factor loading $<.40$, and also minimal differences between convergent and divergent correlations were found. This may have been due to the broad focus of this subscale; it encompasses both emotional and behavioural aspects of medication adherence. Indeed, in the original version of the TxEQ, the items regarding emotional aspects of medication taking were originally placed in an additional factor, but finally grouped into the adherence subscale.¹⁰ It might be worthwhile to differentiate between adherence behaviour and emotions regarding medication taking, or, as in the other subscales, focus solely on emotional aspects.

Some issues regarding the cutoff scores used for the TxEQ also need to be addressed. To identify problematic responses to the receipt of an organ, cutoff scores have been reported in the literature.³² However, the rationale behind these cutoff scores has not been described, nor has validity regarding sensitivity and specificity of the cutoff scores been reported. Although the TxEQ has been shown to be able to identify different responses to the receipt of an organ in different types of organ transplant recipients⁴⁹ and in recipients who received an organ from a living or a cadaveric donor,¹² additional research is warranted to examine the validity of the cutoff scores.

Specific measures like the TxEQ are also believed to be more sensitive to small, but clinically relevant, changes in outcomes.² To our knowledge, no studies have been performed to test if the TxEQ is sensitive to detect changes in the emotional response over time. Prospective studies measuring the emotional response to the receipt of an organ over time are therefore required.

Strengths and limitations

Given the number of liver transplant recipients included ($n = 281$) and the response rate of 75%, it can be concluded that the TxEQ was validated in a representative sample of Dutch liver transplant recipients. Furthermore, the broad range of time since transplantation and age of recipients at follow-up increases the representativeness of the sample. The use of several psychological constructs and the concepts “Personality” and “Coping” to test the construct validity contributes to the validity of TxEQ.

Limitations of our study were that only liver transplant recipients were included and that almost all our recipients received an organ from deceased donors. Results may be different for other organ transplant groups or for transplant recipients who receive an organ from living donors. Therefore validation of the TxEQ-NL in other organ transplant recipients is required.

Conclusion

The TxEQ-NL is a valid and reliable research instrument for measuring the emotional response to the receipt of an organ in transplant recipients. However, future research in which issues regarding ambiguous items are addressed is needed to enhance the reliability and validity of the TxEQ-NL. Research to validate the TxEQ-NL in other organ transplant recipients, to test the sensitivity and specificity of the cutoff scores used to identify problematic responses, and to examine the sensitivity of the TxEQ-NL to detect changes over time also is warranted.

The TxEQ-NL adds a new dimension to the measurement of psychological functioning of transplant recipients and can be used as a transplant-specific research instrument to monitor emotional problems and adherence of liver transplant recipients. Using the TxEQ-NL as a screening instrument should be done carefully but makes it possible to identify transplant recipients with emotional problems with the receipt of a transplant organ and subsequently offer them adequate support.

REFERENCES

1. Engle D. Psychosocial aspects of the organ transplant experience: What has been established and what we need for the future. *Journal of clinical psychology*. 2001;57(4):521-549.
2. Cleemput I, Dobbels F. Measuring patient-reported outcomes in solid organ transplant recipients: An overview of instruments developed to date. *Pharmacoeconomics*. 2007;25(4):269-286.
3. Baines LS, Joseph JT, Jindal RM. Emotional issues after kidney transplantation: A prospective psychotherapeutic study. *Clin Transplant*. 2002;16(6):455-460.
4. Goetzmann L, Moser KS, Vetsch E, et al. What do patients think after a lung transplantation about their self, lung and social network? A quantitative analysis of categorical interview data. *Psychosoc Med*. 2006;3:Doc03.
5. Jones JB, Egan M. The transplant experience of liver recipients: Ethical issues and practice implications. *Soc Work Health Care*. 2000;31(2):65-88.
6. Achille MA, Ouellette A, Fournier S, Vachon M, Hebert MJ. Impact of stress, distress and feelings of indebtedness on adherence to immunosuppressants following kidney transplantation. *Clin Transplant*. 2006;20(3):301-306.
7. Mai FM. Graft and donor denial in heart transplant recipients. *Am J Psychiatry*. 1986;143(9):1159-1161.
8. Ullrich G, Schmidt S, Scharf E, Penkert J, Niedermeyer J, Schulz W. Lung transplant recipients' views on the integration of their new organs. *Disabil Rehabil*. 2010;32(9):713-722.
9. Goetzmann L, Irani S, Moser KS, et al. Psychological processing of transplantation in lung recipients: A quantitative study of organ integration and the relationship to the donor. *Br J Health Psychol*. 2009;14(Pt 4):667-680.
10. Ziegelmann JP, Griva K, Hankins M, et al. The transplant effects questionnaire (TxEQ): The development of a questionnaire for assessing the multidimensional outcome of organ transplantation--example of end stage renal disease (ESRD). *Br J Health Psychol*. 2002;7(4):393-408.
11. Klaghofer R, Sarac N, Schwegler K, et al. [Questionnaire on emotional response after organ transplantation: German validation of the transplant effect questionnaire (TxEQ-D)]. *Zeitschrift für psychosomatische Medizin und Psychotherapie*. 2008;54(2):174-188.
12. Griva K, Ziegelmann JP, Thompson D, et al. Quality of life and emotional responses in cadaver and living related renal transplant recipients. *Nephrol Dial Transplant*. 2002;17(12):2204-2211.
13. Pelgur H, Atak N, Kose K. Anxiety and depression levels of patients undergoing liver transplantation and their need for training. *Transplant Proc*. 2009;41(5):1743-1748.
14. Prihodova L, Nagyova I, Rosenberger J, Roland R, van Dijk JP, Groothoff JW. Impact of personality and psychological distress on health-related quality of life in kidney transplant recipients. *Transpl Int*. 2010;23(5):484-492.
15. Kim S, Thibodeau R, Jorgensen R. Shame, guilt, and depressive symptoms: A meta-analytic review. *Psychol Bull*. 2011;137(1):68-96.
16. Fukunishi I, Sugawara Y, Takayama T, et al. Psychiatric problems in living-related transplantation (I): Incidence rate of psychiatric disorders in living-related transplantation. *Transplant Proc*. 2002;34(7):2630-2631.
17. Sanner MA. Transplant recipients' conceptions of three key phenomena in transplantation: The organ donation, the organ donor, and the organ transplant. *Clin Transplant*. 2003;17(4):391-400.
18. Bowen A, Shelley M, Helmes E, Landman M. Disclosure of traumatic experiences, dissociation, and anxiety in group therapy for posttraumatic stress. *Anxiety, Stress, Coping*. 2010;23(4):449-461.
19. Sloan D, Marx B, Greenberg E. A test of written emotional disclosure as an intervention for posttraumatic stress disorder. *Behav Res Ther*. 2011;49(4):299-304.
20. Carmack C, Basen Engquist K, Yuan Y, et al. Feasibility of an expressive-disclosure group intervention for post-treatment colorectal cancer patients: Results of the healthy expressions study. *Cancer*. 2011;117(21):4993-5002.

21. Sketris I, Waite N, Grobler K, West M, Gerus S. Factors affecting compliance with cyclosporine in adult renal transplant patients. *Transplant Proc.* 1994;26(5):2538-2541.
22. De Geest S, Moons P, Dobbels F, Martin S, Vanhaecke J. Profiles of patients who experienced a late acute rejection due to nonadherence with immunosuppressive therapy. *J Cardiovasc Nurs.* 2001;16(1):1-14.
23. Cukor D, Rosenthal DS, Jindal RM, Brown CD, Kimmel PL. Depression is an important contributor to low medication adherence in hemodialyzed patients and transplant recipients. *Kidney Int.* 2009;75(11):1223-1229.
24. DiMatteo MR, Lepper HS, Croghan TW. Depression is a risk factor for noncompliance with medical treatment: Meta-analysis of the effects of anxiety and depression on patient adherence. *Arch Intern Med.* 2000;160(14):2101-2107.
25. Favaro A, Gerosa G, Caforio ALP, et al. Posttraumatic stress disorder and depression in heart transplantation recipients: The relationship with outcome and adherence to medical treatment. *Gen Hosp Psychiatry.* 2011;33(1):1-7.
26. Shemesh E, Lurie S, Stuber ML, et al. A pilot study of posttraumatic stress and nonadherence in pediatric liver transplant recipients. *Pediatrics.* 2000;105(2):E29.
27. Butler JA, Peveler RC, Roderick P, Smith PW, Horne R, Mason JC. Modifiable risk factors for non-adherence to immunosuppressants in renal transplant recipients: A cross-sectional study. *Nephrol Dial Transplant.* 2004;19(12):3144-3149.
28. Dobbels F, Vanhaecke J, Dupont L, et al. Pretransplant predictors of posttransplant adherence and clinical outcome: An evidence base for pretransplant psychosocial screening. *Transplantation.* 2009;87(10):1497-1504.
29. Gremigni P, Bacchi F, Turrini C, Cappelli G, Albertazzi A, Bitti PER. Psychological factors associated with medication adherence following renal transplantation. *Clin Transplant.* 2007;21(6):710-715.
30. Stilley C, DiMartini A, de Vera M, et al. Individual and environmental correlates and predictors of early adherence and outcomes after liver transplantation. *Progress in Transplantation.* 2010;20(1):58-66.
31. Buldukoglu K, Kulacak O, Kececioğlu N, Alkan S, Yılmaz M, Yucetin L. Recipients' perceptions of their transplanted kidneys. *Transplantation.* 2005;80(4):471-476.
32. Goetzmann L, Sarac N, Ambuhl P, et al. Psychological response and quality of life after transplantation: A comparison between heart, lung, liver and kidney recipients. *Swiss Med Wkly.* 2008;138(33-34):477-483.
33. Radloff LS. The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement.* 1977;1:385-401.
34. Bouma J, Ranchor AV, Sanderman R, Van Sonderen E. *Measurement of depressive symptoms with the CES-D. A manual (in Dutch).* Groningen: Northern Center of Health Research; 1995.
35. Marteau TM, Bekker H. The development of a six-item short-form of the state scale of the Spielberger State-Trait Anxiety Inventory (STAI). *The British Journal of Clinical Psychology.* 1992;31:301-306.
36. Van der Bij AK, De Weerd S, Cikat RJLM, Steegers EAP, Braspenning JC. Validation of the Dutch short form of the state scale of the Spielberger State-Trait Anxiety Inventory: Considerations for usage in screening outcomes. *Community Genetics.* 2003;6(2):84-87.
37. Hovens JE, Falger PR, Op den Velde W, Meijer P, de Groen JH, van Duijn H. A self-rating scale for the assessment of posttraumatic stress disorder in Dutch resistance veterans of world war II. *J Clin Psychol.* 1993;49(2):196-203.
38. Hovens JE, Bramsen I, van der Ploeg HM, Reuling IE. Test-retest reliability of the Trauma and Life Events Self-report Inventory. *Psychol Rep.* 2000;87(3 Pt 1):750-752.
39. Peeters FPML, Ponds RWHM, Vermeeren MTG. Affect and self-report of depression and anxiety (in Dutch). *Tijdschrift voor Psychiatrie.* 1996;38(3):240-250.
40. McCrae RR, Costa PT. Validation of the five-factor model of personality across instruments and observers. *Journal of personality and social psychology.* 1987;52(1):81-90.
41. Hoekstra HA, Ormel J, De Fruyt F. *NEO-PI-R en NEO-FFI persoonlijkheidsvragenlijsten. Handleiding.* Amsterdam: Hogererefe; 2007 (in Dutch).

42. Cohan SL, Jang KL, Stein MB. Confirmatory factor analysis of a short form of the Coping Inventory for Stressful Situations. *Journal of clinical psychology*. 2006;62(3):273-283.
43. De Ridder DTD, Van Heck GL, Endler NS, Parker JDA. *Coping inventory for stressful situations: CISS handleiding*. Lisse: Swets Test Publisher; 2004 (in Dutch).
44. Schermelleh-Engel K, Moosbrugger H, Müller H. Evaluating the fit of structural equation models: Tests of significance and descriptive goodness-of-fit measures. *Methods of Psychological Research*. 2003;8(2):23-74.
45. Nunnally JC, Bernstein IH. *Psychometric theory*. Third edition ed. New York: McGraw-Hill; 1994.
46. Peterson RA. A meta-analysis of Cronbach's coefficient alpha. *Journal of Consumer Research*. 1994;21(2):381-391.
47. Briggs SR, Cheek JM. The role of factor analysis in the development and evaluation of personality scales. *Journal of Personality*. 1986;54(1):106-148.
48. Cohen J. *Statistical power analysis for the behavioral sciences*. 2nd ed. New Jersey: Lawrence Erlbaum; 1988.
49. Goetzmann L, Ruegg L, Stamm M, et al. Psychosocial profiles after transplantation: A 24-month follow-up of heart, lung, liver, kidney and allogeneic bone-marrow patients. *Transplantation*. 2008;86(5):662-668.

