Chapter 4

Great expectations? Pre-transplant quality of life expectations and distress after kidney transplantation: a prospective study

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ABSTRACT

Objectives. Previous research suggests that prior to kidney transplantation, patients overestimate their post-transplant quality of life (QoL). The current study aimed to corroborate these findings, identify determinants of QoL overestimation, examine its association with subsequent distress, and clarify the role of optimism. Design. Prospective observational study. Methods. Physical, psychological, and social QoL expectations, actual QoL, and distress (GHQ-12) of participants (56% male) were prospectively assessed before (T0; n = 228) and 3 (T1; n = 149), 6 (T2; n = 146), and 12 (T3; n = 114) months after successful transplantation. Results. Patients who were treated with haemodialysis before transplantation reported greater physical QoL overestimation than those who received treatment with peritoneal dialysis. Neither physical nor social QoL overestimation at T1 was prospectively associated with increased distress at T2 or T3. The interaction between optimism and social QoL overestimation at T1 (b = -.56, p < .001) for distress at T2 was significant, with patients low in optimism experiencing more distress after QoL overestimation. Conclusions. QoL overestimation is not associated with subsequent distress. Findings suggest that patients low in optimism are more vulnerable to distress following QoL.
INTRODUCTION

End-stage renal disease is characterized by a deterioration of renal function requiring renal replacement therapy. Available renal replacement therapies are kidney transplantation, haemodialysis, and peritoneal dialysis. Kidney transplantation is currently considered the best treatment option due to better quality of life (QoL) outcomes compared to dialysis (Dobbels, De Bleser, De Geest, & Fine, 2007; Landreneau, Lee, & Landreneau, 2010; Liem, Bosch, Arends, Heijenbrok-Kal, & Hunink, 2007). However, despite improving patients’ QoL, kidney transplantation does not resolve all difficulties and QoL usually remains lower than in healthy individuals (Dew et al., 1997; Dobbels et al., 2007). Nevertheless, patients have high expectations, and previous studies suggest that patients overestimate QoL outcomes they will achieve with a kidney transplant (Smith et al., 2008). It seems plausible that this disillusionment could result in distress, which has been linked to increased health care utilization (Gili et al., 2011; Gureje, 2002). Yet, it has also been suggested that positive illusions are harmless when disconfirmed, probably because people quickly adapt to new circumstances (Taylor, Kemeny, Reed, Bower, & Gruenewald, 2000). Whether overestimation of post-transplant QoL is associated with distress is currently unknown, and this study aims to address this lack of information.

Except for a minority transplanted pre-emptively (i.e., prior to having received dialysis treatment), most patients dialyse before transplantation. Dialysis treatment is time-consuming; it involves considerable restrictions in diet and fluid intake and interferes with daily activities (e.g., work, leisure) and is therefore often experienced as very intrusive (Devins et al., 1990; Griva, Jayasena, Davenport, Harrison, & Newman, 2009). Symptoms such as fatigue, itching and restless legs further add to the burden of illness and associated discomfort imposed by dialysis. Kidney transplantation marks the end of dialysis schedules and restrictions in diet and fluid intake. Consequently, many patients have high expectations of the life transplantation can afford them. After transplantation, however, patients have to take immunosuppressive medication with potentially severe adverse effects (Koller et al., 2010; Rosenberger et al., 2006) to prevent rejection of the kidney, while symptoms associated with advanced stages of end-stage renal disease, such as fatigue may also persist. Thus, despite improvements of physical functioning and overall QoL, patients rarely achieve QoL levels of healthy individuals (Dew et al., 1997; Dobbels et al., 2007).
In the process of screening and selection leading to transplantation, patients are prepared and informed about the medical advantages as well as complications of transplantation. The transplant team provides uniform information about issues such as the possibility of surgical complications, rejection, need for immunosuppression and subsequent possibilities of adverse effects. Nevertheless, patients’ QoL expectations are higher than their actual outcomes (Smith et al., 2008), suggesting that patients find it difficult to anticipate how transplantation will affect their life. Overestimation of post-treatment QoL is not restricted to patients with end-stage renal disease, but has also been observed in patients with cancer (Koller et al., 2000; Winterling, Glimelius, & Nordin, 2008). Fundamentally, these findings might reflect peoples’ inability to accurately predict their emotional reaction to future events. Experimental investigation of affective forecasting suggests people display the so-called impact bias (Gilbert, Pinel, Wilson, Blumberg, & Wheatley, 1998), that is, they overestimate how much a given event will affect their well-being.

Quality of life overestimation could have different effects before as opposed to after transplantation. Before transplantation, overestimation of post-treatment QoL might be beneficial, as prior research indicates that the anticipation of positive outcomes is associated with lower distress in heart transplant recipients (Leedham, Meyerowitz, Muirhead, & Frist, 1995), patients with cancer (Koller et al., 2000; Lee et al., 2003), and the general population (MacLeod & Conway, 2005). The reverse also seems to apply, as it has been reported that the anticipation of negative outcomes is associated with higher levels of negative affect (Golub, Gilbert, & Wilson, 2009; Sohl et al., 2012). Thus, the outlook of a brighter future might reduce patients’ current distress and provide hope and strength to help patients cope with the strains of dialysis. Yet, at the same time, overly positive expectations carry a risk for overestimation. When after transplantation a positive expectation turns out to be an overestimation, its previously positive effect on distress might backfire. Worse-than-expected treatment outcomes were related to poor psychological adjustment in patients with cancer (Koller et al., 2000; Stanton et al., 1998; Winterling et al., 2008) and recipients of a liver transplant (Holzner et al., 2001). A study among heart recipients, however, found no relation between overestimation and distress (Leedham et al., 1995). Overall, previous research suggests that QoL overestimation could
have a beneficial influence on distress before transplantation, but a negative influence on distress after transplantation.

If QoL overestimation increases post-transplant distress, it becomes relevant to identify pre-transplant determinants. In absence of research on this subject, it might be speculated that certain illness-related factors associated with QoL, such as dialysis vintage, dialysis modality, symptom burden, or perceived health (Griva et al., 2002; Liem et al., 2007; Rosenberger et al., 2006) could be related to QoL overestimation. Furthermore, dispositional optimism, as a generalized expectation of positive outcomes, will predispose patients to have favorable expectations across a variety of situations. Thus, the likelihood of an overestimation might be higher when optimism is high.

Although high optimism could lead to QoL overestimation, it could also fulfill a different role altogether: Patients high in optimism might experience less distress when their expectations are not met. It has been suggested that optimism improves coping efforts aiming to eliminate stressors directly or altering the appraisal of stressors and evidence for the beneficial effects of optimism on adjustment and distress is compelling (Nes & Segerstrom, 2006; Schulz et al., 2012). The stress buffering quality of optimism has previously been shown among patients with HIV (Pakenham & Rinaldis, 2001). Those who felt that important life goals were threatened were better adjusted if optimism was high. Likewise, optimism might buffer a potential negative influence of QoL overestimation on distress. Thus, even though optimism might increase the likelihood of QoL overestimation, its positive influence on distress could still outweigh its presumably negative influence on QoL overestimation.

The first aim of the current study is to corroborate and extend previous reports concerning overestimation of post-transplant QoL among patients waiting for kidney transplantation (Smith et al., 2008) by using a prospective design and multiple post-transplant assessments and dimensions of QoL. The second aim is to identify pre-transplant determinants of QoL overestimation. The third aim is to examine the association between QoL overestimation and subsequent distress. The fourth aim is to clarify whether dispositional optimism moderates the potentially distressing influence of QoL overestimation. Therefore, the following hypotheses will be tested: (1) before transplantation, patients overestimate their physical, psychological and social QoL after transplantation; (2) pre-transplant dialysis vintage, dialysis modality, symptom burden,
perceived health, and optimism are associated with QoL overestimation; (3) physical and social QoL overestimation is associated with higher levels of subsequent distress, and (4) distress after physical and social QoL overestimation is lower when optimism is high. The influence of psychological QoL overestimation will not be examined, due to substantial conceptual overlap between psychological QoL and distress.

Results of this study will clarify the significance of QoL overestimation in kidney transplantation as a source of distress for patients. First and foremost, findings could aid health professionals in their decision to address or disregard unrealistically high expectations regarding post-transplant outcomes. Furthermore, if overestimations are detrimental, improving patient education might help patients to develop more accurate expectations of their QoL after transplantation to facilitate adjustment.

METHOD

Participants

The flow of participants in the study is depicted in Figure 1.
All patients on the waiting list for a single-organ kidney-only transplant at the hospital or assessed as preliminary eligible for this waiting list who were at least eighteen years old were invited to participate. During the period of data collection, 791 patients populated this waiting list, 38 of whom were excluded, because they were (1) unable to understand Dutch (n = 28), (2) diagnosed with a psychiatric condition (n = 8), or (3) unable to complete questionnaires without assistance (n = 2). A further 309 patients declined to participate. Most non-participants did not disclose their reasons not to participate (84%). Others perceived participation as too burdensome (16%) or felt that questions were too personal (<1%). A total of 444 patients completed the pre-transplant assessment (T0). When participants and non-participants were compared on age and gender, it was found that participants, M = 53.6, SD = 12.4, were older than non-participants, M = 49.3, SD = 13.4, with t(751) = 4.51, p < .001. Of 444 patients completing the pre-transplant assessment, 228 received a kidney transplant during the study period. For 92% of patients it was their first kidney transplant, while 7% and 1% received their second or third transplant, respectively. A total of 149, 146, and 114 patients, respectively, participated in the assessments at 3 (T1), 6 (T2), and 12 months (T3) post-transplant. Incomplete assessments were due to drop-out (n = 35) or participants not returning one or more questionnaires (n = 44). Other participants (n = 62) were unable to complete all assessments, because of post-transplant intervals of less than one year when data collection was concluded. Reasons for drop-out were voluntary withdrawal (n = 25), rejection of the kidney (n = 4) and death (n = 6). Drop-outs were less likely to have a partner, Χ²(1) = 6.37, p < .05, and reported lower optimism, t(222) = 2.56, p < .05 and higher distress, t(224) = -2.21, p < .05 before transplantation. No differences were found with regards to age, gender, education, dialysis modality, dialysis vintage, pre-transplant QoL, or QoL expectation.

Participants (56.1% male) were on average 51.6 years (SD = 12.5) of age. Seventy-eight per cent had a partner and participants were distributed over three educational categories as follows: I = elementary schooling (40.2%), II = secondary schooling (44.3%), and III = university (15.5%). The three most common comorbidities before transplantation were hypertension (63%); back problems, rheumatoid arthritis, or other joint complaints (20%); serious bowel disorder (14%). Prior to transplantation, 19.3% of patients did not dialyse (i.e. pre-emptive transplantation), while 57.5% were treated with haemodialysis and 23.2% with peritoneal dialysis; average dialysis vintage was 3.4 years (SD = 2.1). Fifty-five
per cent had received a kidney from a living donor, and average kidney function measured as 24-hour creatinine clearance was 60.5 mL ($SD = 20.5$) at 3, 61.6 mL ($SD = 21.5$) at 6, and 65.3 mL ($SD = 23.2$) at 12 months post-transplant.

**Procedure**

Assessments for this longitudinal prospective study took place on four occasions, once pre-transplant (T0) and three times post-transplant, respectively 3 months (T1), 6 months (T2), and 12 months (T3) after kidney transplantation. Pre-transplant assessments were repeated every year until patients received a transplant, and the most recent pre-transplant assessment was used in analyses. The initial wave of recruitment began in July 2008. On this date, all patients on the waiting list were sent an information letter from the research team, inviting them to participate in the study and asking for permission to use medical data from their hospital records. To prevent potential misunderstandings, it was emphasized that participation is voluntary and that non-participation would not affect medical care in any way. After giving informed consent, patients received the first questionnaire. Non-respondents received a reminder after 3 and 7 weeks. Ongoing recruitment took place during eligibility assessment for the kidney transplantation waiting list. All patients preliminary assessed as eligible were informed about the study by the consulting nephrologist. If consent was given, patients were contacted by the research team and invited to participate in the study following the same steps as in the initial wave. Data were collected between July 2008 and 2011, and the average interval between T0 and T1 was 9 months. Respondents were not paid for their participation. The study protocol was approved by the hospital’s ethics committee.

**Measures**

*Socio-demographic and medical variables*

Age, gender, donor type and 24-hour creatinine clearance were taken from medical records. Educational level, relationship status, dialysis vintage and main dialysis modality were established by patient self-report.
Expected and actual QoL

At pre-transplant assessments, respondents were asked to rate their expected post-transplant QoL. It was anticipated that patients would give ratings with a stable situation after transplantation in mind and therefore deemed unnecessary to specify a timeframe (e.g., 6 months after transplantation). At all pre- and post-transplant assessments, respondents were also asked to rate their actual QoL. Physical, psychological and social dimensions of QoL were rated separately. Ratings were recorded on a 10-point visual analogue scale (VAS) based on Cantril’s ladder (Cantril, 1965), with scale anchors 1 (worst imaginable QoL) and 10 (best imaginable QoL). An overestimation occurs when the QoL expectation is higher than the actual QoL post-transplant. Therefore, disparities between QoL expectation and actual QoL were calculated by subtracting actual post-transplant scores from expectation scores for each dimension of QoL, so that positive disparity scores indicate an overestimation. Furthermore, patients were categorized into three groups according to whether their expectation had been unmet, met, or exceeded. Disparities equivalent to a medium-sized effect (Cohen’s $d > .5$) were deemed relevant. This corresponded to an expectation-outcome disparity of one point that was subsequently used for categorization.

Cantril’s ladder is commonly used in QoL research, because it is easy to administer and intuitively understood by respondents. Research has shown that Cantril’s ladder and other single item measures of QoL, such as VAS, have good validity and test-retest reliability (Bernhard, Sullivan, Hurny, Coates, & Rudenstam, 2001; de Boer et al., 2004). In the present study VAS correlated significantly and moderately with multiple-item measures of related concepts, thereby indicating satisfactory convergent validity. Across assessments, physical QoL correlated significantly (all $r > 0.47$, $p < .001$) with health status (EQ-5D index; (The EuroQol Group, 1990)), psychological QoL correlated significantly (all $r > 0.54$, $p < .001$) with happiness (Subjective Happiness Scale; (Lyubomirsky & Lepper, 1999)) and social QoL correlated inversely and significantly (all $r > -0.36$, $p < .001$) with impediments to affiliation goals (GOALS; Pöhlmann & Brunstein, 1997).

Optimism

Dispositional optimism was assessed before transplantation with the Life Orientation Test (Scheier & Carver, 1985), which measures generalized expectations of positive outcomes.
The eight items of the Life Orientation Test are scored on a 5-point Likert scale running from 1 (strongly disagree) to 5 (strongly agree). An example item is ‘In uncertain times, I usually expect the best’. The sumscore ranges from 8 to 40, with higher scores indicating greater optimism. Internal consistency, retest reliability, and construct validity of the original Life Orientation Test and the Dutch version are good (Terrill, Friedman, Gottschalk, & Haaga, 2002; Vinck, Wels, Arickx, & Vinck, 1998). Cronbach’s α in the current sample was .72.

Symptoms
For the purpose of measuring the most common physical symptoms associated with end-stage renal disease and adverse effects of immunosuppression, a symptom checklist was constructed. Items from the End Stage Renal Disease Symptom Checklist-Transplantation Module (Franke et al., 1999), the Modified Transplant Symptom Occurrence and Symptom Distress Scale-59R (Dobbels et al., 2008), the Symptom Checklist-90 (Derogatis, Rickels, & Rock, 1976), and the Psychosocial Adjustment to Illness Scale (Derogatis, 1986) were selected and compiled. This resulted in a 32-item symptom checklist with good face validity and approved by a consulting nephrologist. Examples of symptoms include fatigue, nausea, joint ache, and bruises. The number of symptoms experienced by respondents was added up, creating a sumscore with a potential score range from 0 to 32.

Perceived health
Perceived health was measured with the EQ-VAS of the EQ-5D questionnaire (The EuroQol Group, 1990). The EQ-VAS records respondents’ perceived health on a vertical VAS ranging from 0-100, comparable to a thermometer. The endpoints are labeled 0 (worst imaginable health state) and 100 (best imaginable health state). Studies in the general population and different patient populations show that the EQ-5D with VAS has acceptable reliability and validity (Brazier, Roberts, Tsuchiya, & Busschbach, 2004; Cleemput et al., 2004).

Distress
Distress was assessed with the 12-item version of the General Health Questionnaire (GHQ; (Goldberg & William, 1988)), which is frequently used to measure distress in medical populations. It consists of even parts of positively and negatively worded items. An example of a negatively worded item is ‘Have you recently lost much sleep over worry?’ There are
four answering categories: 0 (Not at all), 1 (No more than usual), 2 (Rather more than usual), and 3 (Much more than usual). Items scores are added up to calculate a sumscore ranging from 0 to 36, with higher scores indicating higher levels of distress. The GHQ was assessed at all four measurement points. Both the original GHQ-12 and the Dutch version possess good psychometric properties (Goldberg et al., 1997; Koeter & Ormel, 1991). Cronbach’s $\alpha$ in the current sample ranged from 0.86 to 0.92, which is consistent with other reports (Koeter & Ormel, 1991).

**Statistical analyses**

A general linear model with repeated measures was used to evaluate pre- to post-transplant changes in actual QoL, as well as differences between expected and actual QoL. Effect sizes (Cohen’s d) were computed to indicate the magnitude of the effect. Frequency analyses were performed to determine the percentage of respondents, whose expectation was unmet, met or exceeded. Analysis of covariance and partial correlation coefficients were used to investigate the relationship between QoL overestimation and pre-transplant dialysis modality, dialysis vintage, number of symptoms, perceived health, and optimism whilst adjusting for pre-transplant QoL. Pearson correlation coefficients were calculated to identify potential socio-demographic and medical confounders associated with predictors and outcomes. Hierarchical regression analyses were conducted to investigate main and interaction effects of QoL overestimation (i.e., the disparity score of expected QoL and actual QoL at T1) and optimism on distress at T2 and T3 while controlling for pre-transplant distress, pre-transplant QoL, T1 QoL, potential confounders, the interaction between optimism and T1 QoL, as well as between identified confounders and optimism. Interaction effects were tested and plotted according to procedures described by Aiken and West (1991). Distress was regressed separately on physical and social QoL overestimation. Regression of distress on psychological QoL overestimation was considered inappropriate, because of substantial conceptual overlap.

**RESULTS**

**QoL overestimation**

Table 1 shows pre-transplant, expected and post-transplant ratings for three QoL dimensions, as well as results of general linear model with repeated measures comparing
pre-transplant QoL ratings, respectively expected QoL ratings with actual post-transplant QoL ratings. Across assessments, significant changes of QoL were noted on all dimensions, $F(2, 179) = 30.74, p < .001$ for physical, $F(2, 190) = 4.13, p < .05$ for psychological and $F(2, 179) = 23.59, p < .001$ for social QoL. Compared to pre-transplant ratings, QoL increased on all dimensions and improvements were maintained throughout all assessments, all contrasts $F > 4.57, p < .05$ with the exception of psychological QoL at T3, $F(1, 78) = 3.58, p > .05$. The effect sizes were moderate for improvements of physical QoL and small for psychological and social QoL. However, significant differences were also observed between expected and actual QoL ratings, $F(3, 174) = 9.12, p < .001$ for physical, $F(3, 182) = 8.43, p < .001$ for psychological and $F(3, 181) = 7.69, p < .001$ for social QoL. Post-transplant QoL was lower than expected for all dimensions and this disparity continued throughout all assessments, all contrasts $F > 6.02, p < .05$. The magnitude of this effect was moderate for physical QoL and small for psychological QoL and social QoL overestimation.

**Table 1.** Means (SD) of actual and expected physical, psychological and social QoL at baseline level (T0) and follow-up assessments; results of within patient comparison and effect sizes.

<table>
<thead>
<tr>
<th>Variable</th>
<th>T0</th>
<th>Expected</th>
<th>T1</th>
<th>T2</th>
<th>T3</th>
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<tbody>
<tr>
<td><strong>Physical QoL</strong></td>
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<tr>
<td>T0 versus T1-T3</td>
<td>6.20 (1.59)</td>
<td>8.11 (1.12)</td>
<td>7.38 (1.53)</td>
<td>7.27 (1.49)</td>
<td>7.39 (1.35)</td>
</tr>
<tr>
<td>F within patient contrast and effect size d</td>
<td>45.22*** (d = 0.76)</td>
<td>50.53*** (d = 0.69)</td>
<td>39.67*** (d = 0.79)</td>
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<tr>
<td>Expected versus T1-T3</td>
<td>11.23** (d = 0.56)</td>
<td>13.74*** (d = 0.65)</td>
<td>16.93*** (d = 0.60)</td>
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<tr>
<td><strong>Psychological QoL</strong></td>
<td>7.15 (1.46)</td>
<td>8.09 (1.10)</td>
<td>7.76 (1.34)</td>
<td>7.65 (1.38)</td>
<td>7.69 (1.24)</td>
</tr>
<tr>
<td>T0 versus T1-T3</td>
<td>9.28** (d = 0.43)</td>
<td>4.57* (d = 0.35)</td>
<td>3.58 (d = 0.39)</td>
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<tr>
<td>F within patient contrast and effect size d</td>
<td>8.09** (d = 0.27)</td>
<td>12.30** (d = 0.36)</td>
<td>20.53*** (d = 0.35)</td>
<td></td>
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<tr>
<td><strong>Social QoL</strong></td>
<td>6.64 (1.56)</td>
<td>8.05 (1.11)</td>
<td>7.52 (1.42)</td>
<td>7.38 (1.69)</td>
<td>7.36 (1.54)</td>
</tr>
<tr>
<td>T0 versus T1-T3</td>
<td>30.40*** (d = 0.59)</td>
<td>44.90*** (d = 0.46)</td>
<td>31.76*** (d = 0.47)</td>
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</tr>
<tr>
<td>F within patient contrast and effect size d</td>
<td>13.34** (d = 0.42)</td>
<td>6.02* (d = 0.48)</td>
<td>22.94*** (d = 0.54)</td>
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* p < 0.05; ** p < 0.01; *** p < 0.001
Across assessments, 55-61% of patients overestimated their physical QoL compared with 17-20% underestimating it. In the case of psychological QoL, 41-44% of patients overestimated their QoL compared with 21-22% who underestimated it. Similarly, 41-50% of patients overestimated their social QoL, compared with 16-23% who underestimated it. Physical, psychological and social QoL improved significantly after transplantation, but improvements were smaller than patients had expected. Overestimations were reported by a substantial proportion of patients and were more pronounced for physical than for psychological and social dimensions of QoL.

**Pre-transplant characteristics and QoL overestimation**

The relationship between pre-transplant characteristics and QoL overestimation, adjusted for pre-transplant QoL, was examined. Analyses of covariance adjusting for pre-transplant physical, psychological and social QoL, respectively, revealed significant differences between dialysis modalities in physical QoL overestimation at T2, \( F(2, 97) = 3.29, p < .05 \) and T3, \( F(2, 76) = 3.95, p < .05 \). *Post-hoc* tests showed that patients who had been treated with haemodialysis before transplantation demonstrated greater physical QoL overestimation at T2 and T3 than those treated with peritoneal dialysis, both \( p < .05 \).

Partial correlations adjusting for pre-transplant physical, psychological, or social QoL respectively indicated that neither dialysis vintage, all \( r < .26, p > .05 \) nor pre-transplant number of symptoms, all \( r < .20, p > .05 \) perceived health, all \( r < -.22, p > .05 \), or optimism, all \( r < -.19, p > .05 \) were significantly associated with physical, psychological or social QoL overestimation at any assessment.

**QoL overestimation, optimism and distress**

Results of hierarchical regression analyses testing for main effects of QoL overestimation at T1 and interaction effects of T0 optimism and QoL overestimation at T1 on distress at T2 and T3 are presented in Table 2. T1 symptoms correlated significantly with physical QoL overestimation at T1 (\( r = .20, p < .05 \)), as well as T2 (\( r = .29, p < .01 \)) and T3 (\( r = .34, p < .01 \)) distress and were therefore considered a confounder and accordingly controlled for in analyses. No other socio-demographic or medical confounders were identified. Besides T1 symptoms, analyses were adjusted for pre-transplant distress, pre-transplant QoL and T1
optimism, as well as for T1 QoL. Results indicated that neither physical nor social QoL overestimation at T1 were significantly associated with distress at T2 or T3.

Table 2. Regression of distress at T2 and T3 on disparity scores of physical, respectively social quality of life, optimism and their interaction.

<table>
<thead>
<tr>
<th></th>
<th>Distress T2</th>
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<th>Distress T3</th>
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<td>β</td>
<td>$R^2$ change</td>
<td>β</td>
<td>$R^2$ change</td>
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<tr>
<td>Symptoms T1</td>
<td>0.06</td>
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<td>Distress T0</td>
<td>0.30**</td>
<td>0.22</td>
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<tr>
<td>Physical QoL T0</td>
<td>0.13</td>
<td>0.18</td>
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<tr>
<td>Optimism</td>
<td>-0.21</td>
<td>0.04</td>
<td></td>
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<tr>
<td>Physical QoL T1</td>
<td>-0.22</td>
<td>0.27***</td>
<td>-0.39</td>
<td>0.18*</td>
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<tr>
<td>Disparity expected-T1 physical QoL</td>
<td>0.09</td>
<td>0.00</td>
<td>-0.13</td>
<td>0.02</td>
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<tr>
<td>Optimism x symptoms T1</td>
<td>-0.08</td>
<td></td>
<td>-0.05</td>
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<tr>
<td>Optimism x physical QoL T1</td>
<td>-0.01</td>
<td>0.07*</td>
<td>0.36</td>
<td>0.06</td>
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<tr>
<td>Optimism x disparity expected-T1 physical QoL</td>
<td>-0.31</td>
<td>0.02</td>
<td>0.13</td>
<td>0.00</td>
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<tr>
<td>Cum. $R^2$</td>
<td>0.36</td>
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<td>0.27</td>
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<th></th>
<th>Distress T2</th>
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<td>$R^2$ change</td>
<td>β</td>
<td>$R^2$ change</td>
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<td>Distress T0</td>
<td>0.20</td>
<td>0.20</td>
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<tr>
<td>Social QoL T0</td>
<td>-0.03</td>
<td>0.12</td>
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<tr>
<td>Optimism</td>
<td>-0.13</td>
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<tr>
<td>Social QoL T1</td>
<td>-0.38*</td>
<td>0.26***</td>
<td>-0.46*</td>
<td>0.21**</td>
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<tr>
<td>Disparity expected-T1 social QoL</td>
<td>0.01</td>
<td>0.00</td>
<td>-0.15</td>
<td>0.02</td>
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<tr>
<td>Optimism x social QoL T1</td>
<td>-0.20</td>
<td>0.05*</td>
<td>0.21</td>
<td>0.06*</td>
</tr>
<tr>
<td>Optimism x disparity expected-T1 social QoL</td>
<td>-0.56****</td>
<td>0.10****</td>
<td>-0.05</td>
<td>0.00</td>
</tr>
<tr>
<td>Cum. $R^2$</td>
<td>0.41</td>
<td></td>
<td>0.29</td>
<td></td>
</tr>
</tbody>
</table>

Note. QoL = quality of life; *p < 0.05; **p < 0.01; ***p < 0.001.

To test whether the influence of physical and social QoL overestimation at T1 on distress at T2 and T3 is moderated by T0 optimism, the interactions between T0 optimism and T1 QoL, as well as between T0 optimism and T1 symptoms were included as additional covariates. The interaction between T0 optimism and physical QoL overestimation at T1 was not significantly associated with distress at T2 or T3. The interaction between T0 optimism and social QoL overestimation at T1 was significantly associated with distress at T2, but not T3. Simple slope analyses indicated that social QoL overestimation was associated with significantly more distress among patients low in optimism. This interaction effect was plotted and is depicted in Figure 2.
The interactive effect of optimism and the disparity between expected and T1 social QoL on distress at T2. Patients with low optimism report higher distress after social QoL overestimation; QoL = quality of life; ***p < 0.001

Physical and social QoL overestimation at T1 is not associated with subsequent distress. However, optimism moderates the relationship between social QoL overestimation and distress, as patients low in optimism report higher levels of short-term distress after social QoL overestimation.

DISCUSSION
The main aim of this study was to investigate the impact of QoL overestimation on post-transplant distress. Although physical, psychological and social QoL did improve after transplantation, results demonstrated that prior to transplantation patients had overestimated the scale of this improvement, thus confirming the first hypothesis. Outcomes further revealed that QoL overestimation was greatest for physical QoL and that almost half of all patients had overestimated their physical, psychological and social QoL.
6, and 12 months after transplantation. The second hypothesis was partly confirmed, as some differences between dialysis modalities with regards to QoL overestimation were observed. Patients who had received haemodialysis treatment before transplantation reported greater overestimation of physical QoL after transplantation than those who had been treated with peritoneal dialysis. However, other pre-transplant characteristics, such as dialysis vintage, symptom burden, perceived health or optimistic were not related to QoL overestimation. The third hypothesis was disconfirmed, as neither physical nor social QoL overestimation 3 months after transplantation was associated with subsequent distress. The fourth hypothesis was also disconfirmed. Contrary to expectations, high optimism did not protect patients from the distressing influence of physical or social QoL overestimation. Instead, 6 months after transplantation patients low in optimism experienced more distress following social QoL overestimation. Thus, rather than high optimism acting as a buffer, results suggest that low optimism might be a risk factor for the development of increased distress early after kidney transplantation in case of social QoL overestimation.

The finding that almost half of all patients overestimate their post-transplant QoL corroborates and extends previous results demonstrating that QoL expectations of patients on the waiting list for a kidney transplant are higher than their actual post-transplant QoL (Smith et al., 2008). On a more fundamental level, these results might be interpreted as an example of the impact bias (Gilbert et al., 1998), suggesting that patients expect major changes in their QoL after transplantation, without taking into account that in many respects their lives will still be the same. Yet, this finding might also be explained by poorer health outcomes of overestimators. However, additional analyses indicated that patients who overestimated their social QoL after transplantation reported similar levels of health status at T1 than patients whose expectations were met or exceeded. Other findings suggest that the impact bias might be a universal occurrence among patients on the waiting list for kidney transplantation, given that QoL overestimation was unrelated to pre-transplant dialysis vintage, symptom burden, perceived health, or optimism. There was, however, some evidence that physical QoL overestimation is more pronounced for patients who had been treated with haemo- as opposed to peritoneal dialysis. Further analyses suggested that the explanation for this finding is lower QoL outcomes among haemodialysis patients rather than differences in expectations between these groups.
Neither physical, nor social QoL overestimation 3 months after transplantation was associated with subsequent short-term or long-term distress. These results are consistent with two earlier studies among recipients of a heart transplant (Leedham et al., 1995) and patients close to completion of their cancer treatment (Winterling et al., 2008). Neither study found that expectation-outcome disparities were prospectively associated with patient adjustment later on. Only one study among women with breast cancer undergoing surgery reported disconfirmed expectations to be prospectively related to poorer psychological adjustment (Stanton et al., 1998). Contradictory results might be explained by differences with regards to the consequences of the procedures. Kidney transplantation improves patients’ QoL (Landreneau et al., 2010), while cancer treatment is initially associated with a temporary deterioration of QoL (Ranchor et al., 2010). It might therefore be hypothesized that the negative influence of unmet expectations is negligible if the treatment nevertheless improves patients’ situation, as seen in kidney transplant recipients, but not patients with breast cancer.

In the short-term, patients low in optimism were more distressed by social QoL overestimation than those high in optimism. In the long-term, however, low optimism did not increase patients’ vulnerability to higher distress after social QoL overestimation. Thus, despite low optimism patients seem able to adjust to social QoL overestimation in the long-term. A potential explanation might be that although patients’ expectations are not entirely met, they increasingly come to appreciate their improved situation. Levels of distress in this study were comparable to levels reported for other chronically ill populations in the Netherlands and higher than in the general population (Verhaak, Heijmans, Peters, & Rijken, 2005). Therefore, the finding that patients low in optimism experience higher levels of short-term distress after overestimation of post-transplant social QoL has significant clinical relevance. Distress has been identified as a major contributing factor to increased health care utilization (Gili et al., 2011; Gureje, 2002). Consequently, clinicians should be alert that social QoL overestimation can be associated with increased distress, while at the same time being aware that this effect is short-lived in most cases. It seems advisable to explore patients’ social QoL expectations prior to kidney transplantation and enquire after transplantation whether their expectations have been met, so that implications for patients’ well-being can be discussed. Interventions to modify expectations are premature at this point. On the one hand, distressing effects of social QoL overestimation are short-lived and
most patients seem able to adjust in the longer term. On the other hand, previous research suggests that high expectations could have positive effects on well-being before transplantation. Thus, although too high expectations might increase the likelihood of QoL overestimation, they might also provide a positive outlook that helps patients to deal with the strains of dialysis. Whether this is the case and whether these potentially beneficial effects outweigh distressing effects of social QoL overestimation after transplantation remains currently unknown. More research is needed to clarify this issue in order to determine whether interventions to modify expectations could benefit patients.

The strengths of this study lie in its prospective assessment of outcomes, which strongly supports the direction of the portrayed relationships. However, the external validity of findings could be restricted by the fact that the catchment area of the University Medical Center Groningen is largely rural and might therefore not entirely represent a large urban population. The single centre approach has both disadvantages and advantages. While it is uncertain whether results can be generalized to the larger population of kidney transplant recipients, information provided to patients of a single transplant centre is more uniform and hence results are less likely to reflect differences in patient education. In how far the sample is representative of the population under study is somewhat uncertain. Although participants were on average five years older than non-participants, expected and actual QoL were not associated with age, and therefore it seems is unlikely that results were affected by the age difference. It has however been suggested that people with lower education or foreign background might be underrepresented in research (Regber et al., 2013), while findings with regard to selection bias due to health are inconsistent, demonstrating over-as well as underrepresentation of people in poor health (Kho, Duffett, Willison, Cook, & Brouwers, 2009). Consequently, some caution is warranted in generalizing current results to the wider population of kidney transplant recipients. Some statistical limitations also need to be considered. The use of difference scores has been criticized in recent years because of drawbacks such as low reliability and difficulties to disentangle the respective influence of the components (Edwards, 2001). In the analyses, the QoL outcome was controlled for to ensure that the difference score would not be unduly influenced by the QoL outcome component at the expense of the expectation component. However, it is possible that this procedure was overly restrictive and might have obscured a potentially small, but nonetheless existing effect. The use of VAS could have influenced results, as
single-item measures might be more susceptible to transient states such as mood and thus be less stable over time, despite good test-retest reliability (de Boer et al., 2004). The validity of the measures, however, was supported by satisfactory convergent validity with multiple-item measures of related concepts. Results could further have been influenced by the use of the original Life Orientation Test. However, a thoroughly validated Dutch version of the revised Life Orientation Test was not available, and correlations between the original and revised version of the Life Orientation Test are exceptionally high (Scheier, Carver, & Bridges, 1994). In addition, a repetition of the analyses with a subset of five items identical to those of the revised version produced similar results, while the interaction between optimism and the disparity between expected and T1 physical QoL was also significantly associated with distress at T2 in these analyses. Finally, given that only one of four expected interaction patterns was observed, there is a possibility that this interaction might not be replicated in forthcoming studies.

In conclusion, patients on the waiting list for a kidney transplant overestimate their post-transplant QoL. In addition, patients low in optimism experience higher short-term distress following social QoL overestimation. Further research should investigate underlying reasons for QoL overestimation, for example, the role of patient education or individual differences in information processing. Future studies could also explore the effects of QoL overestimation on other relevant outcomes, such as health care utilization. Most importantly, future studies should attempt to clarify whether overestimation of post-transplant QoL has beneficial effects on well-being before transplantation and whether these potential benefits outweigh its negative effects after transplantation.
REFERENCES


CHAPTER 4


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