Regaining control during dialysis

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DOI:
10.33612/diss.193360203

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Document Version
Publisher's PDF, also known as Version of record

Publication date:
2021

Citation for published version (APA):

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Goal disturbance changes pre-post renal transplantation are related to changes in distress

Alicia M. de Vries, Torben Schulz, Ralf Westerhuis, Gerjan J. Navis, Jan Niesing, Adelita V. Ranchor, Maya J. Schroevers

*British Journal of Health Psychology (2017), 22, 524-541.*
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Abstract

Objective: Renal transplantation (RTx) is considered the treatment of choice for End Stage Renal Disease (ESRD) given its association with lower mortality and improved overall quality of life and psychological functioning compared to dialysis. However, much less is known about which factors underlie these psychological improvements across RTx. Goal theory suggests that experienced disturbances in important goals are related to lower psychological functioning. This study aimed to (1) identify the most disturbed and most important goals for patients before RTx, (2) to examine changes in goal disturbance and goal importance pre–post RTx, and (3) to examine whether changes in goal disturbance are associated with changes in psychological distress over time, and if this relationship is mediated by changes in perceived control.

Methods: In this longitudinal study, 220 patients completed questionnaires before and after RTx, including questionnaires to assess goals (GOALS questionnaire), psychological distress (GHQ-12), and perceived control (Mastery scale).

Results: ESRD affected both general and disease specific goals. Approximately 30% of the patients indicated to experience high or very high disturbance before transplantation. Goal disturbance generally decreased significantly pre– to post RTx, whereas goal importance did not change significantly pre– to post RTx. No mediation effect of perceived control was found. Instead, both changes in goal disturbance and perceived control showed independent effects on changes in distress.

Conclusions: Intervention strategies targeting attainable and realistic goal setting, and perceived control in RTx recipients who do not benefit optimally from RTx, might enhance psychological functioning in this population.

Keywords: goal disturbance, psychological distress, perception of control, renal transplantation.
Goal disturbance pre-post renal transplantation

Statement of contribution

What is already known on this subject?
- Kidney transplantation improves patients’ psychological functioning
- Experienced disturbances in important life goals are related to lower psychological functioning in chronic illness

What does this study add?
- Goal disturbance decreases after renal transplantation, and this is related to a decrease in distress over time
- Perceived control does not mediate the relationship between goal disturbance and distress pre-post transplantation
- Changes in perceived control have an additional main effect on changes in distress
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**Introduction**

Chronic kidney disease (CKD) is a major public health problem, affecting more than 10% of the worldwide population (Eckardt et al., 2013; Schieppati & Remuzzi, 2005). Moreover, its prevalence is expected to rise rapidly in light of population aging and increasing prevalence of risk factors for developing CKD, such as diabetes and hypertension (Kearney et al., 2005; Liyanage et al., 2015; Wild, Roglic, Green, Sicree, & King, 2004). End stage renal disease (ESRD) is the last stage of chronic kidney disease, requiring life-sustaining renal replacement therapy, which consists of either dialysis or renal transplantation. Dialysis is considered a burdensome treatment, since it involves a strict and time-consuming therapeutic regimen, dietary and fluid restrictions, and a high amount of medication intake. The preferred treatment for ESRD is renal transplantation, given its association with lower mortality risk, and lower health costs compared to dialysis (Laupacis et al., 1996; Tonelli et al., 2011).

Renal transplantation has been related in longitudinal research to significant improvements in patients’ physical functioning and overall quality of life (Dew et al., 1997; Dontje et al., 2014; Franke et al., 2000; Jofré, López-Gómez, Moreno, Sanz-Guajardo, & Valderrábano, 1998; Tonelli et al., 2011; von der Lippe et al., 2014). Despite inconsistent findings across different studies (von der Lippe et al., 2014), psychological functioning generally was also found to improve after renal transplantation (Griva, Davenport, Harrison, & Newman, 2012; Joshi, Almeida, & Almeida, 2013; Kostro et al., 2016; Landreneau, Lee, & Landreneau, 2010; Tavallaii & Lankarani, 2005). Moreover, cross-sectional findings have also favoured transplantation over dialysis in terms of mental health outcomes (Liem, Bosch, Arends, Heijenbrok-Kal, & Hunink, 2007; Ozcan et al., 2015).

However, it remains unclear how patients psychologically improve across renal transplantation. In order to understand this process, a useful framework is self-regulation theory. According to the self-regulation perspective, individuals are goal-oriented agents, actively striving to influence and attain personal goals (Heckhausen, Wrosch, & Schulz, 2010). Goals refer to “internal representations of desired states, where states are broadly construed as outcomes, events or processes” (Austin & Vancouver, 1996, p. 338). Having goals is assumed to give a sense of meaning and direct individuals’ lives (Ford & Nichols, 1987). On the other hand, a threat to the attainment of these goals is assumed to elicit distress (Carver & Scheier, 1998; Lavallee & Campbell, 1995; Muller & Spitz, 2010). It has been demonstrated that having a severe medical condition is associated with disturbances in the attainment of personal goals (Boersma, Maes, & Joekes, 2005; Stefanić, Caputi, & Iverson, 2014). Such disturbances due to illness have been related to lower quality of life and higher levels of distress (Boersma, Maes, & van
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Elderen, 2005; Janse, Sprangers, Ranchor, & Fleer, 2015; Offerman, Schroeters, van der Velden, de Boer, & Pruyn, 2010; van der Veek, Kraaij, van Koppen, Garnefski, & Joekes, 2007). Moreover, it has been suggested that the more disturbed goals are considered important, the greater the impact on well-being (Carver & Scheier, 1998). In the context of ESRD and dialysis, it can be hypothesized that patients encounter disturbances in the attainment of important goals, given the interference of the disease with social roles, family responsibilities, increased dependence on caregivers, economic difficulties, reduced sexual ability, and limitations on free-time activities such as being able to go on vacation (Ekelund & Andersson, 2010; Karamanidou, Weinman, & Horne, 2014). ESRD can thus be viewed as a severe life-disabling condition, hindering the pursuit of important goals, and therefore threatening psychological well-being. Transplantation, on the other hand, is likely to reduce or remove many of the aforementioned limitations. Therefore, it could be expected that a decrease in physical constraints and a regained freedom following transplantation is associated with less disturbance in the attainment of important goals, eventually improving psychological functioning.

Goal disturbance is assumed to influence well-being through psychological processes concerning self-evaluations of goal pursuit (Bandura & Cervone, 1983; Bandura, 1997). Such a relevant psychological mechanism is perceived control, defined as “a learned expectation that outcomes depend on one’s own choices and actions” (Mirowsky & Ross, 1998, p. 419). Perceived control is a global belief, spanning across different life domains, as opposed to situation-specific perceptions of control (e.g. control over an illness). These general control beliefs have been associated with lower levels of psychological distress (Gerstorf et al., 2014) and better adjustment to illness (Bárez, Blasco, Fernández-Castro, & Viladrich, 2009; Ranchor et al., 2010). Moreover, perceptions of control are susceptible to change, for example, they can be influenced by perceived health, social participation (Infurna, Gerstorf, Ram, Schupp, & Wagner, 2011), or illness (Ranchor et al., 2010). Empirical evidence on the association between self-regulation and perceived control is largely lacking. Nevertheless, the concept of self-efficacy, referring to a belief in one’s capabilities to carry out a specific action (Bandura, 1997) and closely related to perceived control, has been associated with lower levels of disturbance in the attainment of personal goals, as well as higher levels of psychological functioning (Boersma, Maes, Joekes, & Dusseldorp, 2006; Brands, Stapert, Köhler, Wade, & van Heugten, 2015; Offerman et al., 2010).

According to Bandura (1977), positive experiences in attaining desired outcomes can raise control beliefs. After renal transplantation, patients might encounter less disturbances in the attainment of important goals, which could improve perceived control and eventually increase well-being. Following this line of thinking, it might be suggested that perceived control plays a mediating role in the relationship...
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between goal disturbance and well-being. Accordingly, the mediating role of self-efficacy between goal attainment and well-being has been supported in research (Kuijer and de Ridder 2003; Boersma et al., 2006), as opposed to, for example, a moderating role (Kuijer & de Ridder, 2003). The aims of this study were to 1) determine which goals are most affected in ESRD patients and which goals are considered important before transplantation, 2) examine whether patients experience a change in goal disturbance and goal importance from pre- to post-transplantation, 3) to explore whether goal disturbance changes pre-post transplantation are related to changes in well-being, and whether this relationship is mediated by perceived control.

It was hypothesized that patients would experience goal disturbance pre-transplantation, but there were no clear expectations as to which specific goals would be most disturbed. There were also no clear expectations regarding most important goals pre-transplantation. Secondly, it was expected that goal disturbance would decrease post-transplantation, but there were no expectations regarding changes in goal importance from pre-to post transplantation. Furthermore, it was expected that decreases in goal disturbance were associated with decreases in distress (as an indicator of well-being) from pre- to post transplantation. Finally, we hypothesized that the relationship between goal disturbance changes and distress changes would be mediated by perceived control changes from pre- to post transplantation.

**Methods**

**Participants**
A description of this study has also been reported elsewhere (Schulz et al., 2014). Patients were deemed eligible for participation when they met the following criteria: on a waiting list for a single-organ kidney-only transplant or being eligible for the waiting list, and a minimum age of eighteen. At the time of this study, 897 patients were on the waiting list for kidney transplantation, of whom 40 were excluded because they were not able to understand Dutch, visually impaired or illiterate, or diagnosed with a psychiatric condition (exclusion criteria) (see figure 1). Furthermore, 362 patients declined to participate in the study. 470 patients completed the pre-transplant assessment (T0). Of the 470 patients, 294 received a kidney transplant during the study period (62.6% of the patients who completed T0), of whom 220 completed both the baseline questionnaire and one or both of the post transplant questionnaires, namely three (T1) or six months (T2) post-transplantation. This group of 220 patients constituted the study sample (see table 1 for study sample characteristics). When comparing transplanted participants with transplanted non-participants, only a significant difference on age was found, that is, participants were significantly older compared to non-participants (Mnon-
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participants (SD) = 51.05 (14.06), Mparticipants (SD) = 56.18 (12.35), t(427.20) = -4.28, p < .01).

No differences were found on gender, age, education, years on dialysis, dialysis modality, psychological distress, and goal disturbance pre- transplantation when comparing completers (transplant recipients who completed T0, T1, and/or T2) and non-completers (transplant recipients who completed only T0).

**Figure 1.** Flowchart diagram of participants
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Table 1. Study sample characteristics (N = 220)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age; M (SD)</td>
<td>52.6 (12.5)</td>
</tr>
<tr>
<td>Male gender; N (%)</td>
<td>120 (54.5)</td>
</tr>
<tr>
<td>Education; N (%)</td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>83 (39.3)</td>
</tr>
<tr>
<td>Medium</td>
<td>93 (44.1)</td>
</tr>
<tr>
<td>High</td>
<td>35 (16.6)</td>
</tr>
<tr>
<td>Partner (yes); N (%)</td>
<td>180 (82.6)</td>
</tr>
<tr>
<td>Dialysis (yes); N (%)</td>
<td>163 (75.8)</td>
</tr>
<tr>
<td>Dialysis modality; N (%)</td>
<td></td>
</tr>
<tr>
<td>Hemodialysis</td>
<td>113 (52.6)</td>
</tr>
<tr>
<td>Peritoneal dialysis</td>
<td>50 (23.3)</td>
</tr>
<tr>
<td>No dialysis</td>
<td>52 (24.2)</td>
</tr>
<tr>
<td>Years on dialysis; M (SD)</td>
<td>3.4 (2.0)</td>
</tr>
<tr>
<td>Donor type</td>
<td></td>
</tr>
<tr>
<td>Deceased donor; N (%)</td>
<td>113 (51.6)</td>
</tr>
<tr>
<td>Living donor; N (%)</td>
<td>106 (48.4)</td>
</tr>
<tr>
<td>Number of transplants; N (%)</td>
<td></td>
</tr>
<tr>
<td>First</td>
<td>201 (91.4)</td>
</tr>
<tr>
<td>Second</td>
<td>16 (7.3)</td>
</tr>
<tr>
<td>Third</td>
<td>3 (1.4)</td>
</tr>
<tr>
<td>Kidney function (24h creatinine clearance)</td>
<td></td>
</tr>
<tr>
<td>T1</td>
<td>54.3 (19.5)</td>
</tr>
</tbody>
</table>

Procedure

Patients on the waiting list were approached with a letter inviting them to participate in the study and asking for permission to retrieve data from their medical records. In case patients gave permission, they completed the entire assessments every year until transplantation took place, after which the most recent assessment pre-transplantation was used in the analyses. The assessments of perceived control, goal disturbance and goal importance took place pre-transplantation (T0) and three months post-transplantation (T1). Distress was also assessed pre-transplantation (T0), three months post-transplantation (T1), and six months post-transplantation (T2). In line with ethical considerations, it was emphasized that participation was completely voluntary and that non-participation or withdrawal from the study would not affect current medical care. There was no renumeration for participants.
Measures

Socio-demographic and medical variables. Information regarding gender, age, donor type, and 24-hr creatinine clearance were retrieved from the medical records. Information on relationship status, educational level, dialysis modality, dialysis vintage, type of transplant, and number of underwent transplantations was reported by patients.

Goal disturbance and goal importance. The goal questionnaire consisted of 39 goals of which 24 general life goals and 15 disease specific goals. The 24 general life goals were assessed with the German GOALS questionnaire (Pöhlmann & Brunstein, 1997), which was forward translated to Dutch and back-translated into German. The GOALS questionnaire is subdivided in six categories, gauged by four items each, namely intimacy, affiliation, altruism, power, achievement, and variation. The first three categories represent communion-oriented goals, the second three agency-oriented goals (Pöhlmann & Brunstein, 1997).

The 15 disease specific goals were devised in collaboration with two consulting nephrologists. Examples of disease-specific goals are: to exercise, to go on vacation, to have a good sex life, to go out. Participants were first asked to rate each of the 39 goals on importance on a 5-point scale, ranging from not at all important (0) to very important (4). Next, participants were asked to indicate for the same goals ‘to what extent they were currently disturbed in achieving this goal’ on a 5-point scale, ranging from ‘not at all’ (0) to ‘very disturbed’ (4). Based on the mean item scores for each of the 39 items of the goal disturbance and goal importance scale, a top 10 was calculated for both the ten most disturbed and most important goals prior to transplantation (table 2 and 3). In addition, the percentages of participants answering highly disturbed and very highly disturbed on the goal disturbance scale, and the participants that answered highly important or very highly important on the goal importance scale, were reported for each of the top 10 goals. The least disturbed goal items contained the most missing values. Therefore, in order to minimize missing data and include the information of as much participants as possible, only the top 10 disturbed goals were summed into an overall total score for further analyses. Change scores in goal disturbance from pre- to post transplantation were calculated by subtracting pre-transplantation goal disturbance scores from post transplantation goal disturbance scores.

Cronbach’s α for the baseline top 10 goal disturbance score before transplantation (T0) was .88, and 3 months post-transplantation (T1) .91. Cronbach’s α for the baseline top 10 goal importance score pre-transplantation (T0) was .85, and 3 months after transplantation (T1) .88.
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Distress. Distress was assessed by means of the 12-item version of the General Health Questionnaire (GHQ; Goldberg & William, 1988), a well-documented self-report measure of distress in general and medical populations. The GHQ consists of an equal number of positively and negatively worded items. An example of a positively worded item is ‘Have you recently been able to enjoy your normal day-to-day activities?’ 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). Item scores are summed, with a final score ranging from 0 to 36, higher scores indicating higher levels of distress. Both the original GHQ-12 and the Dutch translation show good psychometric properties (Goldberg et al., 1997). Change scores in distress from pre- to post transplantation were calculated by subtracting pre-transplantation distress scores from post transplantation distress scores. Short-term (T0-T1) and long-term (T0-T2) changes in distress were calculated. Cronbach’s α for the baseline score of distress before transplantation (T0) was .86, 3 months after transplantation (T1) .89, and 6 months after transplantation (T2) .90.

Perceived control. Perceived control was assessed with the widely used 7-item Mastery scale (DeSocio, Kitzman, & Cole, 2003; Shanahan & Bauer, 2004), developed by Pearlin and Schooler (1978). Mastery is defined as “the extent to which one regards one’s life-chances as being under one’s own control in contrast to being fatalistically ruled” (Pearlin & Schooler, 1978, p. 5). An example item of the scale is ‘There is little I can do to change many of the important things in my life’. Items are scored on a 5-point Likert scale, ranging from ‘strongly disagree’ (1) to ‘strongly agree’ (5). 5 of the 7 items are negatively worded. The total score ranges from 7 to 35, where higher scores indicate more perceived control over life. According to previous research, the Mastery scale has good psychometric properties (Eklund, Erlandsson, & Hagell, 2012; Marshall & Lang, 1990). Change scores in perceived control from pre- to post transplantation were calculated by subtracting pre-transplantation perceived control scores from post transplantation perceived control scores. Cronbach’s α for the baseline score of perceived control before transplantation (T0) was .67, and 3 months after transplantation (T1) .76.

Statistical analyses
Analyses were conducted using SPSS version 20.0.0 and Mplus version 7.1. Assumptions for analyses. The scales used for the analyses were controlled for normality. Neither the goal disturbance change scores, perceived control change scores nor distress change scores violated the assumption of normality. Pearson correlations for parametric and Spearman correlations for nonparametric data were calculated to study the associations between the hypothesized predictor and the dependent variables, and possible confounders. As shown in table 4, the results of the correlations indicate that of the sociodemographic variables, no variables are related to both the independent variable (goal disturbance T0-T1)
and the dependent variables (distress T0-T1 or distress T0-T2). Creatinine clearance (a clinical measure of kidney function) was not significantly correlated with the predictor and dependent variables. Therefore, these variables were not included in the model. According to the multicollinearity statistics, the tolerance value was not lower than .10, indicating no problem with multicollinearity. The value of the Durbin Watson test was 1.80, therefore independent residuals can be assumed. The distribution of standardized residuals showed that the assumptions of normality and linearity were met.

Descriptives of distress, perceived control, and goal disturbance changes. Though not part of the research question, pre- to post transplantation changes in distress, perceived control and goal disturbance were also analyzed with paired samples t-tests.

Goal disturbance and goal importance pre-transplantation. A top 10 of most disturbed and most important goals before transplantation was derived by looking at the mean scores of the individual items on disturbance and importance. Mean scores of these items were also reported after transplantation.

Changes in goal disturbance and goal importance pre- post transplantation. Paired samples t-tests were used to analyze pre- to post renal transplantation changes in disturbance and importance of individual goal items. Bonferroni correction was applied in order to correct for multiple testing, setting the overall alpha level to 0.005 (0.05/10). Effect sizes were calculated with Cohen’s d. The Cohen’s d values were interpreted as follows: < .20: very small effect, .20 - .50: small effect, .50-.80: moderate effect, > .80: large effect. In order to correct for dependence among means, Morris and DeShon’s (2002) equation 8 was applied to the data.

The association between goal disturbance and distress changes pre-post transplantation and the role of perceived control as a mediator. Structural equation modelling (SEM) was used to examine the hypothesized relationships between the variables. The strength of SEM is the possibility to include multiple predictors and dependent variables in one model and to test different paths simultaneously, while taking into account direct and indirect effects among variables. The variables were placed in the model in accordance with the literature and self-regulation theory. Short-term distress changes (T0-T1) and long-term distress changes (T0-T2) were entered in the model as dependent variables. Goal disturbance T0-T1 was entered as an independent variable. Mastery T0-T1 was entered into the model as a mediator. Since distress T0 and goal disturbance T0 are assumed to respectively influence changes in distress and goal disturbance pre-post transplantation, these variables were entered as covariates. The mediation effect of perceived control
T0–T1 was assessed through bootstrapping, which is a computer-based method of resampling (Kline, 2011). With this method, indirect effects are estimated through 95% bias-corrected confidence intervals. A bootstrap of 20,000 samples was used. Regarding the interpretation of results, if zero is not between the lower and upper bound of the confidence interval, it can be claimed that the indirect effect is not zero with 95% confidence (Hayes, 2009).

**Results**

**Descriptives of distress, perceived control, and goal disturbance changes**

Firstly, change scores in distress, perceived control and goal disturbance were assessed. Distress scores pre- transplantation decreased significantly 3 months (T1) after transplantation (M\text{pre} = 10.9 (4.9), M\text{post} = 8.8 (5.7)), t (182) = 4.3, p < .01, and 6 months (T2) after transplantation (M\text{pre} = 11.08 (5.1), M\text{post} = 9.4 (5.9)), t (184) = 3.6, p < .01. Perceived control scores pre-transplantation increased significantly 3 months after transplantation (M\text{pre} = 22.6 (4.7), M\text{post} = 23.9 (4.6)), t (173) = -3.5, p < .01. Lastly, goal disturbance pre-transplantation decreased significantly 3 months after transplantation (M\text{pre} = 16.1 (9.2), M\text{post} = 11.2 (8.9)), t (159) = 6.1, p < .01.

**Goal disturbance and goal importance pre-transplantation**

Chronic kidney failure affected on average most often the goal ‘to be able to eat and drink what I like’, with 38.2% of the participants indicating high or very high disturbance (see table 2). The second and third most disturbed goals were ‘to fully enjoy life’ and ‘to go on vacation/to travel’, with 31.1% and 36.1% indicating high disturbance or very high disturbance, respectively. The most important life goal was ‘Having relationships characterized by mutual trust’, followed by ‘giving affection and love’, and ‘receiving affection and love’, with 81.6%, 81.0%, and 80.1% of the participants scoring high importance or very high importance, respectively (see table 3).
Table 2. Top 10 disturbed goals pre-transplantation and change scores pre-post transplantation

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Goal</th>
<th>T 0 Mean (SD)</th>
<th>T 1 Mean (SD)</th>
<th>t</th>
<th>Effect size (Cohen’s D)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>165</td>
<td>To be able to eat and drink what I like (38.2)</td>
<td>1.96 (1.18)</td>
<td>1.07 (1.06)</td>
<td>8.22*</td>
<td>0.64</td>
</tr>
<tr>
<td>2</td>
<td>161</td>
<td>To fully enjoy life (31.1)</td>
<td>1.74 (1.32)</td>
<td>1.25 (1.27)</td>
<td>4.17*</td>
<td>0.33</td>
</tr>
<tr>
<td>3</td>
<td>166</td>
<td>To go on vacation/to travel (36.1)</td>
<td>1.73 (1.38)</td>
<td>1.32 (1.28)</td>
<td>3.30*</td>
<td>0.26</td>
</tr>
<tr>
<td>4</td>
<td>171</td>
<td>To be able to arrange my time schedule myself (29.2)</td>
<td>1.61 (1.27)</td>
<td>0.98 (1.15)</td>
<td>5.61*</td>
<td>0.43</td>
</tr>
<tr>
<td>4</td>
<td>163</td>
<td>To decide for myself how to live my life (28.8)</td>
<td>1.61 (1.34)</td>
<td>1.20 (1.30)</td>
<td>3.35*</td>
<td>0.26</td>
</tr>
<tr>
<td>5</td>
<td>162</td>
<td>To exercise (27.8)</td>
<td>1.53 (1.35)</td>
<td>1.14 (1.17)</td>
<td>3.31*</td>
<td>0.26</td>
</tr>
<tr>
<td>6</td>
<td>163</td>
<td>To have a good sex life (28.2)</td>
<td>1.51 (1.41)</td>
<td>1.33 (1.39)</td>
<td>1.56</td>
<td>0.12</td>
</tr>
<tr>
<td>7</td>
<td>167</td>
<td>To follow my own interests (21.6)</td>
<td>1.47 (1.24)</td>
<td>0.99 (1.19)</td>
<td>4.12*</td>
<td>0.32</td>
</tr>
<tr>
<td>8</td>
<td>165</td>
<td>To support others (24.2)</td>
<td>1.45 (1.31)</td>
<td>1.01 (1.16)</td>
<td>3.96*</td>
<td>0.31</td>
</tr>
<tr>
<td>9</td>
<td>167</td>
<td>To help people in need (24.0)</td>
<td>1.38 (1.32)</td>
<td>1.01 (1.24)</td>
<td>3.22*</td>
<td>0.25</td>
</tr>
</tbody>
</table>

*p ≤ 0.005

1 within parenthesis the percentage of participants indicating high or very high disturbance at baseline
### Table 3. Top 10 important goals pre-transplantation and change scores pre-post transplantation

<table>
<thead>
<tr>
<th>N</th>
<th>Goal</th>
<th>T 0 Mean (SD)</th>
<th>T 1 Mean (SD)</th>
<th>t</th>
<th>Effect size (Cohen’s D)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Having relationships characterized by mutual trust (81.6)</td>
<td>3.21 (1.14)</td>
<td>3.21 (1.02)</td>
<td>0.00</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td>Giving affection and love (81.0)</td>
<td>3.20 (0.99)</td>
<td>3.14 (1.00)</td>
<td>0.87</td>
<td>0.06</td>
</tr>
<tr>
<td>3</td>
<td>Receiving affection and love (80.1)</td>
<td>3.17 (1.02)</td>
<td>3.06 (1.03)</td>
<td>1.46</td>
<td>0.11</td>
</tr>
<tr>
<td>4</td>
<td>Being able to be a partner (79.2)</td>
<td>3.14 (1.19)</td>
<td>2.99 (1.22)</td>
<td>1.83</td>
<td>0.14</td>
</tr>
<tr>
<td>5</td>
<td>To fully enjoy life (74.0)</td>
<td>3.02 (.97)</td>
<td>2.96 (1.04)</td>
<td>0.72</td>
<td>0.06</td>
</tr>
<tr>
<td>6</td>
<td>To decide for myself how to live my life (75.3)</td>
<td>2.94 (1.04)</td>
<td>2.78 (1.00)</td>
<td>2.01</td>
<td>0.16</td>
</tr>
<tr>
<td>7</td>
<td>To fulfil obligations towards others (70.7)</td>
<td>2.93 (0.98)</td>
<td>2.89 (0.86)</td>
<td>0.47</td>
<td>0.04</td>
</tr>
<tr>
<td>8</td>
<td>To be able to arrange my time schedule myself (69.5)</td>
<td>2.89 (1.00)</td>
<td>2.83 (1.03)</td>
<td>0.58</td>
<td>0.05</td>
</tr>
<tr>
<td>9</td>
<td>To have a profound relationship (66.3)</td>
<td>2.78 (1.31)</td>
<td>2.66 (1.31)</td>
<td>1.31</td>
<td>0.10</td>
</tr>
<tr>
<td>10</td>
<td>To be supported by others (63.3)</td>
<td>2.72 (1.08)</td>
<td>2.56 (1.03)</td>
<td>1.62</td>
<td>0.13</td>
</tr>
</tbody>
</table>

*p ≤ 0.005

2 within parenthesis the percentage of participants indicating high or very high importance at baseline
### Table 4. Correlations between variables (N = 220)

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<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
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<tbody>
<tr>
<td>1. Age</td>
<td>-</td>
<td>-.10</td>
<td>.02</td>
<td>.19*</td>
<td>.12</td>
<td>-.19*</td>
<td>-.16*</td>
<td>-.10</td>
<td>.15*</td>
<td>.06</td>
<td>.15*</td>
<td>.04</td>
<td>-.01</td>
</tr>
<tr>
<td>2. Education</td>
<td>-</td>
<td>-.12</td>
<td>-.02</td>
<td>-.14*</td>
<td>.06</td>
<td>-.02</td>
<td>.19**</td>
<td>.05</td>
<td>.03</td>
<td>.02</td>
<td>-.09</td>
<td>-.07</td>
<td>-.08</td>
</tr>
<tr>
<td>3. Gender</td>
<td>-</td>
<td>.06</td>
<td>-.11</td>
<td>.18*</td>
<td>.00</td>
<td>.08</td>
<td>-.09</td>
<td>-.06</td>
<td>.02</td>
<td>-.06</td>
<td>.02</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Partner</td>
<td>-</td>
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<td>.01</td>
<td>-.02</td>
<td>-.02</td>
<td>-.02</td>
<td>.03</td>
<td>.05</td>
<td>.03</td>
<td>.02</td>
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</tr>
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<td>-.08</td>
<td>-.17*</td>
<td>.18*</td>
<td>.08</td>
<td>.16</td>
<td>.10</td>
<td>-.13</td>
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<tr>
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<td>.04</td>
<td>-.10</td>
<td>-.13</td>
<td>-.07</td>
<td>.15</td>
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<td>7. Distress T0</td>
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<td>.25**</td>
<td>-.51**</td>
<td>-.47**</td>
<td>.12</td>
<td>-.02</td>
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<tr>
<td>8. Perceived Control T0</td>
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<td>.21**</td>
<td>.09</td>
<td>-.51**</td>
<td>.04</td>
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<tr>
<td>9. Goal disturbance T0</td>
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<td>-.09</td>
<td>.07</td>
<td>-.58**</td>
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</tr>
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<td>10. Distress T0-T1</td>
<td>-</td>
<td>.65**</td>
<td>-.46*</td>
<td>.33*</td>
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</tr>
<tr>
<td>12. Perceived Control T0-T1</td>
<td>-</td>
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<td></td>
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<td>13. Goal disturbance T0-T1</td>
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* p≤0.05, ** p<0.01
Chapter 2

Changes in goal disturbance and goal importance pre-post transplantation

Regarding change scores in goal disturbance pre-post transplantation, all top 10 disturbed goals showed a significant decrease in disturbance after transplantation, except for the goal ‘to have a good sex life’ (see table 2). The largest change in disturbance was found for the goal: ‘to be able to eat and drink what I like’, with a medium effect size. Small effect sizes were found for ‘to fully enjoy life’, ‘to go on vacation/to travel’, ‘to be able to arrange my time schedule myself’, ‘to decide for myself how to live my life’, ‘to exercise’, ‘to follow my own interests’, ‘to support others’, and ‘to help people in need’. The results, as shown in table 3, indicate that no significant changes were found in goal importance, suggesting that goal importance at pre-transplantation remained stable after transplantation.

The association between goal disturbance and distress changes pre-post transplantation and the role of perceived control as a mediator

Based on the SEM model (see figure 2), goal disturbance T0-T1 was significantly related to both short-term changes (T0-T1) in distress ($\beta = 0.343$, 95% CI [0.186, 0.514], $p < 0.001$) and to long-term changes (T0-T2) in distress ($\beta = 0.237$, 95% CI [0.010, 0.477], $p = 0.046$). Perceived control T0-T1 was significantly related to short-term changes in distress ($\beta = -0.359$, 95% CI [-0.477, -0.246], $p < 0.001$) and to long-term changes in distress ($\beta = -0.183$, 95% CI [-0.613, -0.050], $p = 0.023$). Concerning the mediation analysis, no mediation effect of perceived control T0-T1 was found between goal disturbance T0-T1 and short-term changes in distress, or goal disturbance T0-T1 and long-term changes in distress. That is, the standardized indirect effect of perceived control as a mediator between goal disturbance T0-T1 and short-term changes in distress was 0.082, and the 95% confidence interval ranged between -0.019 and 0.183. When long-term changes in distress were considered as dependent variable in the model, a standardized indirect effect of 0.042, and a 95% confidence interval between -0.012 to 0.096 was obtained. Since the confidence intervals included zero, this means that the mediation effects were not considered different from zero.
Discussion

The findings of the present study support the assumption that ESRD has an impact on personal life goals, and that goal disturbance significantly decreases from pre- to post renal transplantation. Moreover, a decrease in goal disturbance pre-post transplantation was related to lower levels of psychological distress, and this effect was maintained up to 6 months after transplantation. However, in contrast to our hypothesis, no significant mediation effect was found for perceived control in explaining the relationship between a decrease in goal disturbance and a decrease in psychological distress pre- to post transplantation. Instead, both changes in perceived control and changes in goal disturbance independently showed a main effect on short- and long-term changes in psychological distress pre- to post transplantation.

It should be noted that the majority of top 10 disturbed goals consisted of disease-related goals (7 out of 10 goals). Interestingly, the most important life goals reported in this sample before transplantation pertained to the ‘intimacy’ category, like ‘having relationships characterized by mutual trust’ and ‘receiving and giving

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3 Goal disturbance T0 and Distress T0 were included as covariates in the model, but are not shown in the figure.
affection and love’ (4 out of 10). No goals related to power or achievement were mentioned in the top 10 of most disturbed and most important goals. Our finding that the top 10 most disturbed goals pre-transplantation (mainly disease-related) do not correspond to the top 10 most important goals pre- transplantation (mainly interpersonal goals) might reflect the strategy of reprioritising (Janse et al., 2014). This goal adjustment strategy is characterized by attaching less importance to goals that have become difficult to attain, and instead focus on important goals in less disturbed life domains. Specifically, the strategy of goal disengagement (investing less effort in pursuing an unattainable goal) might become more important when growing old and being confronted with increased constraints and challenges (Heckhausen, Wrosch, & Schulz, 2010). This might also explain why no power- or achievement oriented goals were reported, like ‘having a high social status’; i.e. patients might have abandoned these goals and instead shifted towards more attainable goals in order to avoid distress before transplantation. However, this should be interpreted with caution since no goal adjustment strategies before transplantation were assessed.

A significant decrease in goal disturbance was found from pre- to post transplantation in all top 10 disturbed goals (as reported by patients before transplantation), except for having a good sex life. The lack of improvement in this goal has also been reported by other researchers (Pertuz, Castaneda, Rincon, & Lozano, 2014; Raggi et al., 2012). Specifically, Raggi et al. (2012) found in a retrospective study within a comparable sample of patients a deterioration of the desire and frequency of sexual activity after renal transplantation. Nonetheless, this negative change in sexual functioning did not affect relationship quality, which also seems reflected in our study given the low disturbance and high reported importance in the intimacy domain.

Contrary to expectations, this study did not find a mediating effect of perceived control in the relationship between goal disturbance changes and distress changes pre- to post transplantation. This finding suggests that renal transplantation might independently affect perceived control and goal disturbance, and perceived control is not influenced merely by a change in goal disturbance. The individual effect of perceived control on distress pre- to post transplantation highlights its additional contribution to better psychological functioning after transplantation. This finding is supported by a large body of literature reporting the favourable effect of perceived control on well-being (Bárez, Blasco, Fernández-Castro, & Viladrich, 2009; Gerstorf et al., 2014; Ranchor et al. 2010).

The strength of this study is its longitudinal design and considerable sample size. To date, the majority of literature in this field includes cross-sectional research or only extends to the period shortly after transplantation. To our knowledge, this is
Goal disturbance pre-post renal transplantation

the first study using a self-regulation framework in understanding how patients psychologically benefit from renal transplantation. The found impact of ESRD on goal pursuit is in line with previous research among other chronically ill patients (Boersma, Maes & van Elderen, 2005; Muller & Spitz, 2010; Offerman et al., 2010). Our longitudinal results confirm the idea originated in self-regulation theory that lower goal disturbance is related to higher levels of well-being (Carver & Scheier, 1998; Emmons, 2003). Hence, the newly acquired insight in the role of goals in reduced distress from pre- to post- transplantation can be an important focus of psychological interventions, especially given the evidence that well-being post-transplantation on average remains lower compared to the general population (Weber et al., 2014; Karam et al., 2003). Specifically, well-being post-transplantation could be promoted by helping individuals setting realistic, concrete, and attainable (new) goals in important life domains (Janse et al., 2014; Wrosch, Scheier, Miller, Schulz, & Carver, 2003).

Several limitations of this study should also be pointed out. Primarily, goal disturbance and importance were both assessed by means of a goal taxonomy, not providing an opportunity for patients to freely stipulate and rate their personal life goals. Therefore, important (new) goals might be missing. This might also explain why goal importance did not change pre-post transplantation. For example, no goal concerning ‘being healthy’ was included in the current taxonomy, whereas this goal has been rated as the most important goal in other illnesses (Boersma, Maes, & van Elderen, 2005; Coffey, Gallagher, & Desmond, 2014). Besides, some items may not have been applicable and therefore completed poorly, such as the goal ‘to raise children’. In future research, renal patients should be asked for their own personal goals pre- and post-transplantation, and goal characteristics of each goal can be assessed, such as importance, effort, disturbance, and attainability (Janse, Fleer, Smink, Sprangers & Ranchor, 2016). Secondly, in order to endorse disease-specific goals in the current population and minimize missing data, items were added to the goals questionnaire and only top 10 items were used for the analyses. Though these adaptations were considered relevant, it should be noted that these adaptations might have affected psychometric properties, and therefore results need to be interpreted with caution. Moreover, although approximately 30% of the patients indicated to experience a high or very high disturbance in the top 10 ranking of disturbed goals, the overall mean of goal disturbance was low: on a Likert scale the mean disturbance scores were lower than 2 (0 indicating not disturbed and 4 very disturbed). Therefore, these results might differ in patients experiencing higher goal disturbance. It should also be noted that participants were recruited from a waitlist for transplantation, and might represent a healthier group of patients, since patients excluded from transplantation are generally older and face more physical complications and comorbidities (Kiberd, Boudreault, Bhan, & Panek, 2006). As such, the risk of selection bias might prevent generalization of
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the findings concerning goal disturbance before transplantation to the larger ESRD population. Lastly, all concepts were assessed at the same time-points; therefore our results cannot establish causality. This also makes the directionality of the relationship between goal disturbance, perceived control and distress uncertain. It may be that a decrease in distress is related to an increase in perceived control, and consequently a decrease in goal disturbance. Further research should be undertaken to study the direction of these associations. Future research might also explore different adjustment strategies and changes in goal strategies across renal transplantation, in order to understand how patients adapt their goals to the challenges faced in end stage renal disease.

Enhancing self-regulation skills and perceived control might have an additional contribution in optimizing well-being for those patients who show limited psychological improvements after transplantation. Future randomized controlled trials are required to examine whether self-regulation skills and perceived control can indeed be enhanced and whether this leads to higher well-being in transplant patients who do not psychologically benefit from transplantation, or report reduced well-being after transplantation.
References


Chapter 2


Goal disturbance pre-post renal transplantation