

Abstract

Aims. To determine if kidney transplantation is associated with increases of perceived control and how changes of perceived control affect the course of psychological distress until one year after transplantation.

Background. Low levels of perceived control are associated with reduced well-being among dialysis patients.

Design. Prospective longitudinal cohort study.

Methods. Perceived control (Mastery Scale) and psychological distress (GHQ-12) were prospectively assessed before (T0; n = 470) and three (T1; n = 197), six (T2; n = 210) and twelve (T3; n = 183) months after transplantation. Differences between T1 and T0 perceived control were used to stratify the sample into three groups (control gain, stable control and control loss). Socio-demographic and clinical variables, including complications, were examined as potential correlates and the course of psychological was distress compared across groups. Data were collected between July 2008 - July 2013.

Results. Perceived control showed a small increase overall, with 35.1 %, 50.0 % and 14.9 % reporting gain, stable level and loss respectively. Patients with secondary schooling were overrepresented in the control loss group. The course of psychological distress varied across perceived control change groups, with patients in the control gain group experiencing a significant reduction of psychological distress.

Conclusion. A considerable number of patients report increased levels of perceived control after transplantation that are associated with a subsequent decrease of psychological distress. Results emphasize the importance of perceived control and could inform interventions to facilitate well-being after kidney transplantation.

Keywords

- 1 Complications; kidney transplantation; nursing; patient-reported outcomes; perceived control;
- 2 psychological distress
- 3

Summary statement

Why is this research or review needed?

- Low levels of perceived control among dialysis patients are associated with increased psychological distress.
- It is unclear if kidney transplantation prompts changes of perceived control and how this might affect the course of psychological distress.

What are the key findings?

- Overall levels of perceived control increase after kidney transplantation.
- Patients who report increased levels of perceived control after kidney transplantation experience a significant reduction of psychological distress.

How should the findings be used to influence policy/practice/research/education?

- Interventions aimed at increasing perceived control among kidney transplant recipients might prove beneficial to address psychological distress.
- To inform interventions, future studies should determine factors differentiating patients who experience improvements of perceived control from those who do not.

1 INTRODUCTION

2 Symptoms of chronic kidney disease and restrictions imposed by its treatment noticeably
3 limit patients' choices regarding, for example, employment and social activities.
4 Consequently, both patients on dialysis and those still in the pre-dialysis phase often
5 experience a loss of autonomy (Polaschek 2003, Jansen *et al.* 2010a, Jansen *et al.* 2010b,
6 Makaroff 2012). A key element of autonomy is perceived control, that is, the degree to which
7 people believe they can influence important aspects of their lives. Besides their association
8 with autonomy (Jansen *et al.* 2010a, Jansen *et al.* 2010b) control beliefs are also important
9 predictors of well-being. Accordingly, low levels of perceived control among dialysis
10 patients are associated with poor quality of life and reduced well-being (Chilcot *et al.* 2011,
11 Griva *et al.* 2009).

13 Background

14 Dialysis treatment involves regular dialysis sessions, dietary and fluid restrictions and
15 taking prescribed medications (Griva *et al.* 2014, Clark, Farrington & Chilcot 2014). In
16 addition, most patients experience unwelcome symptoms, such as fatigue and itching (Thong
17 *et al.* 2009, Danquah *et al.* 2010). Kidney transplantation brings an end to the need for
18 dialysis and alleviates many of the accompanying restrictions and symptoms.

19 Although one study found that levels of perceived control are higher among kidney
20 transplant recipients (Griva *et al.* 2009), it remains unclear whether differences are due to
21 selection bias favoring younger and healthier individuals receiving transplants (Liem *et al.*
22 2007, Rosenberger *et al.* 2010) or instigated by transplantation itself. If changes of perceived
23 control occur, it is further relevant to find out whether these changes affect the course of
24 psychological distress. Addressing these questions could clarify a pathway for adjustment to
25 kidney transplantation.

Perceived control is conceptualized as a learned expectation and therefore, unlike personality traits, can undergo changes. Perceived control was found to deteriorate after cancer diagnosis and during cancer treatment (Henselmans *et al.* 2009, Ranchor *et al.* 2010). Conversely, successful kidney transplantation has predominantly positive consequences for patients and cross-sectional data suggest that levels of perceived control are higher among kidney transplant recipients than dialysis patients (Griva *et al.* 2009). Thus, kidney transplantation might be accompanied by increases of perceived control. At the same time, it is unclear how many patients might experience meaningful improvements of perceived control after transplantation and if potential changes of perceived control are associated with socio-demographic and clinical variables, such as the occurrence of complications. In addition, given its close relation to well-being, changes of perceived control might help explain improvements of psychological distress observed after kidney transplantation (Liem *et al.* 2007, Landreneau, Lee & Landreneau 2010). That is, improvements of perceived control might result in decreased psychological distress. Confirmation of this hypothesized mechanism for improvements of psychological distress could inform interventions aiming to aid adjustment after kidney transplantation.

THE STUDY

Aims

The current study aimed to determine if kidney transplantation is associated with increases of perceived control and how changes of perceived control affect the course of psychological distress until one year after transplantation.

Design

1 This prospective longitudinal cohort study followed a repeated measures design with four
2 assessments, once pre-transplant (T0) and 3 (T1), 6 (T2) and 12 months (T3) after kidney
3 transplantation. Pre-transplant assessments of transplant candidates on the waiting list were
4 repeated annually until participants received a transplant, with the most recent assessment
5 used in analyses.

7 **Participants**

8 Initially, all transplant candidates on the waiting list were invited to participate by mail.
9 Subsequently, ongoing recruitment took place during eligibility assessments for the waiting
10 list. After giving informed consent, patients received the first questionnaire.

11 The flow of participants through the study is depicted in Figure 1. During the study
12 period 897 patients populated the waiting list, of which 40 were excluded due to: (a)
13 insufficient command of the Dutch language ($n = 28$); (b) psychiatric diagnosis ($n = 8$); and
14 (c) inability to complete questionnaires without assistance ($n = 4$). The pre-transplant
15 assessment (T0) was completed by 470 patients, corresponding to a response rate of 55 %.
16 Overall, 510 patients received a kidney transplant during the study period, of which 294 had
17 completed the T0 assessment (58 % of transplantations). Amid transplant recipients,
18 participants were significantly older than non-participants ($p < 0.001$) and reported shorter
19 dialysis vintage ($p < 0.05$). In total, 197, 210 and 183 patients participated in assessments at 3
20 (T1), 6 (T2) and 12 months (T3) post-transplant respectively. Participants who did not
21 complete all four assessments either failed to return one or more questionnaires ($n = 87$),
22 were unable to complete all assessments due to post-transplant intervals of less than one year
23 ($n = 32$), or dropped out of the study ($n = 46$). Reasons for drop-out were voluntary
24 withdrawal ($n = 26$), rejection of the kidney ($n = 11$) and death ($n = 9$). Drop-outs were less
25 likely to have a partner ($p < 0.001$), more often treated with hemodialysis as opposed to being

pre-dialysis patients ($p < 0.01$) and more likely to receive a kidney from a deceased donor ($p < 0.05$). In addition, drop-outs also reported higher psychological distress ($p < 0.05$) and lower levels of perceived control ($p < 0.05$) before transplantation, as compared with the remainder of transplant recipients. These variables were simultaneously entered into a binary logistic regression analysis to assess which variables independently predict drop-out. Results of this multivariate analyses suggested that only relationship status and primary dialysis modality were independent predictors of drop-out.

Data collection

Data were collected by means of self-report via questionnaires and collated from medical records. Data collection took place between July 2008 - July 2013.

Socio-demographic and clinical variables

Age, gender, primary kidney disease, donor type, occurrence of complications and kidney function measured as 24-hour creatinine clearance were collated from medical records. Educational level, relationship status, dialysis vintage and primary dialysis modality were established by self-report.

Perceived control

Perceived control was measured with the Mastery Scale (Pearlin & Schooler 1978), a 7-item instrument assessing general feelings of control over life. An example item is 'I have little control over the things that happen to me'. Items are scored on a 5-point Likert scale running from 'strongly disagree' to 'strongly agree'. The total scale score ranges from 7 to 35, with higher scores indicating more perceived control over life.

Psychological distress

Psychological distress was assessed with the 12-item version of the General Health Questionnaire (Goldberg & William 1988). The GHQ-12 is frequently used to measure psychological distress in chronically ill populations, including kidney transplant recipients (Prihodova *et al.* 2010). It consists to 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: ‘not at all’, ‘no more than usual’, ‘rather more than usual’ and ‘much more than usual’. Items scores are added up to calculate the scale score which ranges from 0-36, with higher scores indicating higher levels of psychological distress.

Ethical considerations

The study protocol was approved by the hospital’s ethics committee. During recruitment patients were explicitly informed that participation is voluntary and that non-participation would not affect their medical care in any way. Participants did not receive monetary or other incentives for taking part in the study.

Data analysis

Initially, repeated measures GLM was used to examine mean level changes of perceived control and psychological distress from pre- to one year post-transplant. In addition, effect sizes (Cohen’s *d*) were calculated to indicate the magnitude of effects. To describe individual changes, the sample was subsequently stratified into three groups, based on the difference between perceived control scores at T0 and T1. A cut-off of 0.5 SD was used for stratification, because it is commonly regarded as the minimally clinical significant difference (Norman, Sloan & Wyrwich 2003, von der Lippe *et al.* 2014). Thus, the groups were: (1) control gain (T1 score 0.5 SD or more above T0 score); and (2) stable control (T1 score less

than 0.5 SD above or below T0 score); and (3) control loss (T1 score 0.5 SD or more below T0 score). Further analyses were based on these perceived control change groups. ANOVAs and Chi-square tests were performed to determine if perceived control change groups differed with regards to several socio-demographic and clinical variables. Any variables that differed between perceived control change groups, while at the same time being significantly associated with changes of psychological distress, were deemed confounders and used as covariates in subsequent GLMs. To determine if the course of psychological distress varies across perceived control change groups, the interaction effect between group and time on psychological distress was examined with repeated measures GLM. In addition, ANOVAs were performed to allow cross-sectional comparisons of levels of psychological distress in the perceived control change groups at each assessment. Finally, to determine the course of psychological distress in each perceived control change group over time, separate repeated measures GLM's were carried out for each perceived control change group. IBM SPSS 21 for Windows was used to analyse the data (IBM Company, Chicago, IL, USA).

Validity and reliability

Psychometric properties of the Mastery Scale and its Dutch translation are considered to be adequate (Kempen, Jelicic & Ormel 1997). Cronbach's α on the different assessment points ranged from 0.69-0.78, which is consistent with other studies (Ranchor *et al.* 2010). Both the original GHQ-12 and the Dutch version possess good psychometric properties (Koeter *et al.* 1987, Goldberg *et al.* 1997). Cronbach's α in the current sample ranged from 0.87 to 0.90, comparable to other reports (Ranchor *et al.* 2010).

RESULTS

Sample description

Socio-demographic and medical characteristics of the total sample and each perceived control change group are presented in Table 1.

Changes of perceived control and psychological distress

Results for pre- to post-transplant changes of mean levels of perceived control from T0 to each post-transplant assessment point are presented in Table 2. Overall, levels of perceived control changed significantly over time, $F(3, 307) = 4.21, P < 0.01$. A significant increase of perceived control was observed from T0 to T1 and T3 respectively; effect sizes were small. Post-hoc tests did not reveal any further significant changes of perceived control between assessments after transplantation. While 35.1 % of patients demonstrated a meaningful increase (> 0.5 SD) of perceived control from T0 to T1, 50.0 % reported stable levels and 14.9 % reported a decrease. Mean levels of perceived control per change group are also displayed in Table 2.

In addition, Table 2 shows results for pre- to post-transplant changes of mean levels of psychological distress from T0 to each post-transplant assessment point. Psychological distress levels changed significantly over time as well, $F(3, 337) = 8.18, p < 0.001$. Effect sizes indicated a small to medium-sized decrease of psychological distress from T0-T1, T2 and T3 respectively. From T1-T3 psychological distress showed a small, but significant increase, $F(1, 126) = 5.80, P < 0.05$. No further significant changes between assessments were observed.

Changes of psychological distress in relation to changes of perceived control

As presented in Table 1, perceived control change groups were differentiated by educational level. Participants with secondary schooling were overrepresented in the control

loss group, whereas those with elementary schooling were overrepresented in the control gain group. Groups did not differ regarding the distribution of age, gender, relationship status, primary kidney disease, primary dialysis modality, dialysis vintage, donor type, kidney function, or occurrence of complications.

Because educational level differed across groups and was at the same time significantly associated with changes in psychological distress it was deemed a confounder and therefore used as covariate in the subsequent analysis. The significant interaction term suggested that the course of psychological distress differed across perceived control change groups, $F_{\text{time} \times \text{group}}(5, 311) = 2.77, P < 0.05$.

Cross-sectional analysis revealed that before transplantation mean levels of psychological distress did not differ between the three groups, whereas differences were greatest at T1, $F(2, 171) = 14.88, P < 0.001$. While differences between the groups were non-significant at T2, levels of psychological distress differed significantly at T3, $F(2, 125) = 5.32, P < 0.01$. Post-hoc tests showed that at T1 psychological distress was higher in the control loss group than in both other groups (both $P < 0.001$). At T3, only the difference between control loss and control gain group remained significant ($P < 0.01$).

As presented in Table 2, separate longitudinal analysis of perceived control change groups further illustrated differences in the course of psychological distress. Visual inspection of the course of psychological distress per group as presented in Figure 2 suggested that the control loss group experienced a sharp increase of psychological distress from T0-T1 that dropped back to pre-transplant levels from T1-T2. However, longitudinal analysis showed that the control loss group did not experience significant changes of psychological distress between any of the assessments (all $P > 0.09$). Consequently, the overall effect was also non-significant; effect sizes were small to very small. The stable control group showed a minor decrease of psychological distress that subsequently levelled

off. Although in this group a significant decrease of psychological distress at T1 was observed, no further significant changes between assessments took place. Therefore, the overall effect was also non-significant; again, effect sizes were small to very small. The control gain group displayed a steep decrease of psychological distress immediately after transplantation that was maintained until one year post-transplant. This group experienced a large and significant decrease of psychological distress from T0-T1. Thereafter, distress levels in this group increased slightly from T1 to T2, $F(1, 37) = 7.46, P < 0.05$ and T3, $F(1, 37) = 13.11, P < 0.01$. Yet, compared with pre-transplant levels psychological distress remained significantly lower both at T2 and T3; effect sizes were medium to large. Consequently, the overall effect for changes of psychological distress was also significant in this group, $F(2, 82) = 9.48, P < 0.001$.

DISCUSSION

This study aimed to investigate whether kidney transplantation is associated with changes of perceived control, to identify correlates thereof and to examine whether changes of perceived control affect the course of psychological distress. Overall levels of perceived control increased after transplantation, although the effect was small. Individually, a third of patients reported improvements, whereas half experienced no clinically significant change and the remainder a decline of perceived control. The group who reported loss of control included mainly patients with secondary schooling. Alongside the changes of perceived control small to medium-sized improvements of psychological distress were also observed. Results further indicated that increases of perceived control were associated with decreases of psychological distress.

1 Despite being freed from dialysis treatments and its accompanying restrictions and
2 despite commonly observed improvements of health status after kidney transplantation (Liem
3 *et al.* 2007, Landreneau, Lee & Landreneau 2010) the majority of patients do not experience
4 meaningful increases of perceived control. This illustrates that successful transplantation does
5 not resolve all difficulties patients with renal disease encounter. Results parallel reports of
6 declines of perceived control as result of diagnosis and treatment of cancer (Henselmans *et*
7 *al.* 2009, Ranchor *et al.* 2010, Bárez *et al.* 2009). This study gives the first account of a
8 treatment-induced increase of perceived control among kidney transplant recipients.
9 Nevertheless, levels of perceived control remained low compared with a considerably older
10 general population sample from the same region (Kempen *et al.* 2005). Given that perceived
11 control declines with age (Specht, Egloff & Schmukle 2013) this comparison illustrates that
12 even after successful kidney transplantation levels of perceived control in this population
13 remain overall poor.

14 The observed small improvements of psychological distress are in line with other
15 studies reporting better mental health among kidney transplant recipients as compared with
16 dialysis patients (Liem *et al.* 2007, Landreneau, Lee & Landreneau 2010). However, earlier
17 studies were based on cross-sectional comparisons of dialysis patients and kidney transplant
18 recipients. Consequently, findings might have been influenced by selection bias, as kidney
19 transplant recipients are generally younger and healthier (Liem *et al.* 2007, Rosenberger *et al.*
20 2010). The prospective design of the present study effectively rules out selection bias as an
21 alternative explanation for earlier findings and instead suggests that improvements of
22 psychological distress are due to transplantation rather than pre-existing differences between
23 these groups. Concerning socio-demographic and clinical correlates, results indicated that
24 perceived control change groups differed according to educational level. Participants with
25 secondary schooling were overrepresented in the control loss group, underlining the link

1 between education and perceived control (Specht, Egloff & Schmukle 2013). Perhaps
2 patients with secondary schooling are apt to perceive potential threats such as rejection of the
3 transplant, but feel ill-equipped to deal with them, while those with elementary schooling
4 disregard similar threats altogether. Perceived control change groups did not differ regarding
5 the occurrence of complications or other socio-demographic and clinical variables.

6 Concerning the second aim results suggest that the course of psychological distress
7 differed across perceived control change groups, with increases of perceived control being
8 associated with decreases of psychological distress. Patients who reported a loss of control
9 did not experience any changes of psychological distress as a result. Those with stable levels
10 of control initially reported a minor reduction of psychological distress directly after
11 transplantation, but this reduction was not maintained. Six and twelve months after
12 transplantation distress levels in this group reverted back to pre-transplant levels. Only
13 patients reporting increases of perceived control experienced considerable and lasting
14 changes of psychological distress, in this case manifesting as large reductions of
15 psychological distress after transplantation. Positive prospective associations between
16 perceived control and aspects of mental well-being, such as psychological distress have been
17 observed previously (Henselmans *et al.* 2009) and are in line with current results. Two other
18 studies among patients with cancer lend further support to findings of the current study. One
19 study demonstrated that increasing levels of perceived control are associated with reductions
20 of psychological distress later on (Bárez *et al.* 2009). Another study suggested that a decrease
21 of perceived control by itself is not sufficient to increase levels of psychological distress
22 (Ranchor *et al.* 2010). Overall, findings indicate that pre- to post-transplant changes of
23 psychological distress are partially due to changes of perceived control instigated by
24 transplantation. Notably, decreased levels of perceived control do not automatically result in
25 increased psychological distress. Instead, reductions in psychological distress seem to follow

1 from increased levels of perceived control, which might be considered an ameliorating factor
2 in the development of psychological distress.

3 Current results highlight the importance of perceived control for patients' well-being
4 and have several potential implications. Findings suggest that the majority of patients do not
5 experience clinically significant improvements of perceived control, despite improvements of
6 health status and liberation from dialysis and associated restrictions. At the same time, even
7 patients with stable or deteriorating levels of perceived control seem not to be at risk of
8 increased psychological distress. This suggests that the observation that patients with
9 secondary schooling are more likely to experience a loss of control by itself has only modest
10 relevance for clinical practice. However, given the significance of increased levels of
11 perceived control in the reduction of psychological distress, interventions could prove
12 beneficial. An earlier study among patients with coronary heart disease, for example,
13 suggests that providing information and appropriate strategies for managing symptoms and
14 adverse events increases perceived control and thereby reduces anxiety (Moser *et al.* 2012).
15 Tailored interventions aiming to increase levels of perceived control are likely to result in
16 improvements of psychological distress, with immediate benefits for patients' quality of life
17 and well-being. Moreover, because of the association of high psychological distress with
18 increased health care use (Gili *et al.* 2011) interventions targeting perceived control might in
19 the long-term also potentially reduce health care costs.

21 **Strengths and limitations**

22 Strengths of this study lie in its prospective longitudinal assessment of outcomes with
23 multiple post-transplant assessment points and an adequate sample size. This design
24 permitted the comparison of patients before and after transplantation and in doing so it was
25 possible to describe changes at the individual level that had not been reported previously.

several limitations nevertheless apply. Although it is plausible that the observed improvements were caused by kidney transplantation, due to lack of a control group alternative explanations cannot be entirely ruled out. The inverse relationship between age and perceived control (Specht, Egloff & Schmukle 2013) would however suggest that the observed effects were not caused by ageing. Whether findings can be generalized to the larger population of kidney transplant recipients is uncertain, as this study was carried out at a single transplant centre with predominantly rural catchment area. Finally, patients without a partner and those who had undergone hemodialysis treatment were more likely to drop out of the study. If and how this might have affected results remains speculative.

CONCLUSION

In sum, roughly a third of patients experience meaningful improvements of perceived control after kidney transplantation and increasing levels of perceived control are associated with subsequent reductions of psychological distress. Future studies should address limitations and corroborate and extend findings by including multiple sites and a control group from the general population.

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Conflict of interest

No conflict of interest has been declared by the author(s).

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