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## Illness perceptions and treatment perceptions of patients with chronic kidney disease: Different phases, different perceptions?

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### ABSTRACT

#### Objectives

To examine the variability of illness and treatment perceptions – that have been found to be associated with chronic kidney disease (CKD) patients' outcomes (e.g., quality of life) – across the CKD trajectory, by investigating whether there are differences in perceptions in patients: (1) on varying treatments (pre-dialysis, haemodialysis, peritoneal dialysis), (2) with varying lengths of time on (dialysis) treatment, and (3) over time on dialysis, with an 8-month interval.

#### Design and methods

Mixed cross-sectional and longitudinal design, using self-report questionnaires on illness and treatment perceptions; the study sample consisted of 105 pre-dialysis and 161 dialysis patients; of the 161 dialysis patients, 87 patients filled in the questionnaires again after an 8-month interval. Data were examined using multilevel (multivariate) repeated measurements regression analyses, controlled for background characteristics and repeated measures.

#### Results

Patients on haemodialysis and peritoneal dialysis believed more strongly that their *treatment controls* their illness ( $p < .05$ ,  $p < .01$ , respectively) and

perceived more *illness consequences* ( $p < .001$ ,  $p < .05$ , respectively) than pre-dialysis patients. Haemodialysis patients perceived more *treatment consequences* than pre-dialysis ( $p < .001$ ) and peritoneal dialysis patients ( $p < .01$ ). The perception of *illness understanding* fluctuated between patients with varying lengths of time on dialysis ( $p < .05$ ). Perceived *treatment consequences* were more negative in patients who were on dialysis for longer lengths of time ( $p < .01$ ). Lastly, perceptions of illness and treatment varied within dialysis patients over an 8-month interval, with *treatment control* and *personal control* showing the lowest correlations.

#### Conclusions

Findings suggest that illness and treatment perceptions vary across the CKD trajectory. This indicates that perceptions are amenable to influences and that interventions might potentially be helpful in influencing them in order to improve outcomes.

#### Statement of Contribution

*What is already known on this subject?* Dialysis patients' perceptions of illness understanding and illness symptoms vary over the first year on dialysis. Established haemodialysis patients' perceptions of illness understanding, emotional response and treatment control vary over a 2-year period. Certain illness perceptions as well as treatment perceptions vary as a function of treatment type in patients with CKD stage 5 (dialysis patients, patients with a kidney transplant).

*What does this study add?* Patients' perceptions of illness understanding and *treatment consequences* vary between patients as a function of length of time on (haemo-, peritoneal-) dialysis, taking into account a wide range of time (0–10 years). Illness perceptions and treatment perceptions of patients on haemodialysis and *peritoneal dialysis* vary within patients over an 8-month interval, with perceptions of treatment control and personal control showing the highest variations. Perceptions of illness consequences, treatment consequences and treatment control vary as a function of type of treatment, taking into account *pre-dialysis treatment (CKD stage 4)* and dialysis (haemodialysis, peritoneal dialysis) treatment (CKD stage 5).

## BACKGROUND

Chronic kidney disease (CKD) refers to the progressive and irreversible loss of kidney function. In CKD stages 1–4, treatment (i.e., pharmacotherapy, diet) is focused on slowing the progression of kidney disease and preventing or treating complications and comorbid conditions (NKF-KDOQI, 2002). In CKD stage 5, renal replacement therapy (i.e., dialysis, kidney transplantation) becomes necessary to maintain life. Studies carried out in the Netherlands and the United States have shown CKD (stage 1–5) prevalence rates of 10% and 13%, respectively (Coresh, Astor, Greene, Eknoyan, & Levey, 2003; Coresh *et al.*, 2007; De Zeeuw, Hillege, & De Jong, 2005).

Like in other countries, in the Netherlands, most patients with CKD stage 5 initially depend on dialysis for their survival. Dialysis is an artificial way of blood

purification and fluid management, which are essential functions of the kidneys. There are two principal dialysis modalities: *haemodialysis*, where the blood is purified outside the body via an artificial kidney by the use of a dialysis machine, and *peritoneal dialysis*, where the blood is filtered by means of the patient's peritoneal membrane. Patients on dialysis are extremely dependent on the time-consuming dialysis procedure as well as pharmacotherapy. In addition, patients experience multiple physical symptoms, including fatigue (Murtagh, Addington-Hall, & Higginson, 2007). Several studies have demonstrated lowered quality of life in patients on dialysis regarding physical, social and mental functioning, compared with general population samples (Khan *et al.*, 1995; Merkus *et al.*, 1997; Molsted, Prescott, Heaf, & Eidemak, 2007). Already in the earlier CKD stages, the quality of life is impaired compared with general population samples, with the most pronounced impairment found in physical functioning (Korevaar *et al.*, 2000; Molsted *et al.*, 2007).

### **Common-sense beliefs**

The common-sense model (CSM) of self-regulation of health and illness (Leventhal, Nerenz, & Steele, 1984) provides an explanation for different behavioural and emotional responses to chronic illnesses, like CKD. According to the model, people make sense of a health threat by developing their own cognitive and emotional perceptions (i.e., beliefs) of a health threat. These perceptions then guide coping behaviours which in turn determine outcomes, including quality of life (Hagger & Orbell, 2003; Moss-Morris *et al.*, 2002). Major components include perceptions of how the illness was *caused*, how long it will last (*timeline*), what the *consequences* of the illness are for life, the symptoms that are associated with the illness (*identity*) and how the condition is *controlled* or *cured* by one's own behaviour or treatment (Petrie & Weinman, 2012). Perceptions develop from exposure to a variety of social and cultural information (Cameron & Moss-Morris, 2010). Patients with the same medical condition can have widely different perceptions of their condition (Petrie & Weinman, 2006). The CSM is a dynamic model: outcomes of behaviours generated by perceptions are appraised on an ongoing basis, which may result in the modification of perceptions (Wearden & Peters, 2008). A meta-analysis by Hagger and Orbell (2003) has demonstrated consistent relationships between psychological distress as an outcome and perceptions of greater consequences, lower control/cure beliefs and longer timeline in patients with various medical conditions. A recently published longitudinal study by Kaptein *et al.* (2010a) has provided support for the predictive power of illness perceptions in patients with osteoarthritis, by demonstrating an association between changes in illness perceptions and changes in functional status over a 6-year follow-up.

The CSM has been extended with 'common-sense' beliefs about treatment because treatment is an important facet of the illness trajectory. This is particularly true for CKD where the (dialysis) treatment has a major impact on patients' daily life. Research based on the 'necessity-concerns' framework by Horne (2003) has provided support for this extension, by demonstrating that doubts about personal need for medication and concerns about potential adverse effects are related to low rates of adherence (Horne, Cooper, Gellaitry, Leake-Date, & Fisher, 2007; Horne & Weinman, 2002).

### CSM research in patients with CKD

Several cross-sectional studies have revealed associations between well-being on the one hand and perceptions of illness as well as treatment on the other hand in patients with CKD (Fowler & Baas, 2006; Griva, Jayasena, Davenport, Harrison, & Newman, 2009; Timmers *et al.*, 2008). A longitudinal study by Chilcot (2010) in patients during their first year on dialysis has demonstrated that the baseline perception of a longer *timeline* predicted an increase in depression over a 1-year follow-up, controlled for demographic and clinical characteristics. The perception of greater *emotional reaction* at baseline on the other hand predicted a decline in depression. According to Chilcot (2010), this latter finding may suggest that patients self-regulate their initial distress at baseline and focus on improving their mood. Covic, Seica, Mardare, and Gusbeth-Tatomir (2006) have found that – controlled for clinical characteristics – perceptions of greater *personal control* and *understanding* and fewer *emotional reactions* at baseline predicted improved physical quality of life in established haemodialysis patients (with low comorbidity) over a 2-year period. Lower baseline *consequence* scores were associated with improvements in mental quality of life functioning. Studies have even demonstrated that mortality in patients on dialysis is predicted by the perception of treatment being unable to control the disease, after controlling for relevant confounders (Chilcot, 2010; Van Dijk *et al.*, 2009). According to the authors of these studies, the perception of lower *treatment control* may be associated with self-care and non-adherence behaviours, which in turn may impact upon survival.

### Current study

Knowing that illness perceptions and treatment perceptions of patients on dialysis are related to outcomes raises a new interesting question: whether perceptions of patients with CKD can be influenced in order to improve outcomes. According to the CSM, illness perceptions are constantly being updated as patients acquire new illness knowledge and illness experiences (Leventhal *et al.*, 1984). We wished to gain insight into the variability of perceptions across the CKD trajectory. In case perceptions vary, this may indicate that they are amenable to influences and that interventions might potentially be helpful in influencing illness and treatment perceptions in order to improve associated outcomes. The studies by Chilcot (2010) and Covic *et al.* (2006) have also provided insight into how perceptions change over time. Covic *et al.* have found that, over the 2-year follow-up, patients on haemodialysis had fewer negative emotional reactions to the illness, a better understanding of the illness and the perception that dialysis is more efficient in controlling the illness. Chilcot (2010) has revealed a similar trajectory for illness understanding in dialysis patients over their first year on dialysis. In addition, patients in this study perceived fewer somatic symptoms from their illness over time. Another indication of the dynamic nature comes from cross-sectional and longitudinal research demonstrating associations between type of renal replacement therapy (i.e., dialysis modality, transplantation) on the one hand and illness and treatment perceptions on the other hand (Griva, Davenport, Harrison, & Newman, 2008, 2010; Griva *et al.*, 2009; Timmers *et al.*, 2008). These findings suggest that changes in clinical status and medical treatment bring about changes in illness and treatment perceptions. Treatment is of particular importance in CKD, because treatments differ significantly across the illness trajectory and are associated with different techniques and demands.

## **Study aim and hypotheses**

The aim was to examine the variability of illness perceptions and treatment perceptions across the CKD trajectory in pre-dialysis patients (CKD stage 4) and dialysis patients (CKD stage 5). By also including pre-dialysis patients, the present study can – together with the information from previous studies – provide a more complete picture of the dynamics of CKD patients' illness and treatment perceptions. More specifically, we examined whether there are differences in illness and treatment perceptions in patients: (1) on varying treatments (pre-dialysis, haemodialysis, peritoneal dialysis), (2) with varying lengths of time on (dialysis) treatment, and (3) over time on dialysis with an 8-month interval. We focused on perceptions that have been found to predict outcomes in dialysis patients, that is, *consequences, emotional response, control, timeline* and *understanding*. On the basis of the CSM and the above-described research, we hypothesized that due to illness experiences and knowledge, perceptions will vary as a function of treatment type and length of time on treatment. More specifically, we hypothesized that – as a result of increases in knowledge, experiences and adaptation – perceptions of understanding, personal control, treatment control and emotional response are more favourable in dialysis patients compared with pre-dialysis patients and in patients who are on treatment for longer lengths of time. Furthermore, we expected that perceptions of illness consequences, treatment consequences and timeline are less favourable in dialysis patients and in patients who are on treatment for longer lengths of time, due to increases in the burden of the illness, treatment demands and comorbidities.

## **METHOD**

Data for the present study were collected in two large multicentre studies in the Netherlands: the Pre-dialysis Patients Records Study phase 2 (PREPARE-2) and the Netherlands Cooperative Study on the Adequacy of Dialysis phase 2 (NECOSAD-2; Termorshuizen *et al.*, 2003; Timmers *et al.*, 2008).

### **Sample of pre-dialysis patients**

PREPARE-2 study is a multicentre prospective observational study, started in 2004. At the end of 2006, PREPARE-2 was operating in 18 pre-dialysis outpatient clinics in community and university hospitals throughout the Netherlands, and 196 patients were included in the study. Patients with CKD stage 4 (severe CKD) aged 18 years or older who were treated by a nephrologist and who had been recently (within the previous 6 months) referred to pre-dialysis care were eligible for inclusion in PREPARE-2. All patients had to be suitable for renal replacement therapy. Patients with chronic transplant dysfunction were excluded from the study if the transplantation occurred within the previous year. Clinical (medical records) and quality of life (self-report) data are collected at inclusion and every 6 months thereafter until start of dialysis, transplantation, end of study or death. All patients gave written informed consent. The PREPARE-2 study was approved by the institutional review boards of all participating hospitals.

For the present study, data were collected in 2006 by means of an additional survey, measuring illness perceptions and treatment perceptions. This survey was sent in two phases to all patients recruited at that time: in the period July–September 2006 to 123 patients and in November–December 2006 to another 62 newly recruited patients. Patients filled in the questionnaire at home. Of the 185 patients having received the questionnaire, 109 returned the questionnaire (response rate 59%). The

questionnaires of 105 cases were eligible for analysis. The other four had too many missing values with respect to the illness and treatment perception variables.<sup>1</sup>

### **Sample of dialysis patients**

NECOSAD-2 is a prospective cohort study in over 2,000 dialysis patients who were recruited on a continuous basis since 1997 in more than 40 dialysis centres and hospitals in the Netherlands. Inclusion criteria were being older than 18 years and having no previous history of renal replacement therapy. Clinical (medical records) and quality of life (self-report) data are collected every 6 months. Patients gave their informed consent before being included. The NECOSAD-2 study was approved by the Medical Ethical Committees of the participating dialysis centres and hospitals. In January 2006, there were still 250 patients on dialysis participating in the NECOSAD-2 study. Data for the present study were collected by means of an additional survey – measuring illness perceptions and treatment perceptions – among these patients in March–April 2006 and 8 months later (November 2006). Patients filled in the questionnaires at home or in the dialysis centre and returned them by mail. At the time, the additional survey was distributed, one patient from the cohort had died, and one patient had a renal transplant, resulting in a total of 248 patients that could be approached. Of these 248 patients, 166 patients returned the questionnaire (response rate 67%). Eight months later, 129 of these 166 respondents again received the same questionnaire (measurement two), which was returned by 87 persons (response rate 67%). The 37 persons who did not receive the questionnaire for the second time had dropped out during the 8-month period for different reasons: change of address, being transplanted, unwilling or deceased. Of the 166 patients who returned the first questionnaire, 161 questionnaires were eligible for analysis. The other five had too many missing values with respect to the illness and treatment perception variables.<sup>1</sup>

### **Measures**

#### *Dependent variables*

Perceptions of *illness consequences*, *timeline*, *personal* and *treatment control*, *understanding* and *emotional response* were measured with the Brief Illness Perception Questionnaire (BIPQ; Broadbent, Petrie, Main, & Weinman, 2006). Each perception was measured with one item scored on an 11-point scale, ranging from 0 to 10. Items were coded so that high scores represent strong beliefs on these particular dimensions.

To assess patients' perceptions of the *consequences* associated with their *current treatment* rather than the illness, the Treatment Effects Questionnaire (TEQ, originally developed as the IEQ-Tx by Greenberg & Peterson, 2002; adapted by Griva, Jayasena, Davenport, Harrison, and Newman, 2009) was used. The TEQ consists of 20 items, for example, 'I worry about treatment side-effects', 'My life revolves around this treatment' and 'Treatment prevents me enjoying myself'. Items were scored on an 8-point scale ranging from 0 to 7 (strongly disagree – strongly agree). Scores were summed across individual ratings with higher scores indicating beliefs in a greater disruption from treatment. The Cronbach's alpha for the scale in the present study was .93.

These data were collected through the surveys among pre-dialysis patients (one measurement) and dialysis patients (two measurements).

### *Independent variables*

*Type of treatment* was classified as pre-dialysis treatment (pharmacotherapy/diet in most cases), haemodialysis and peritoneal dialysis. *Length of time on dialysis treatment* was determined by calculating the years that have gone by (at the time of measurement), since the start date of the dialysis treatment. For pre-dialysis patients, length of time on dialysis treatment was set to zero years.

Data on patients' dialysis modality were derived from the last known regular NECOSAD-2 measurement at the time of the implementation of the current study. Data regarding the start date of the dialysis treatment were also derived from (baseline) NECOSAD-2 data.

### *Background variables*

Socio-demographic data were collected including gender, age, educational level [highest level of completed education, classified as low (primary education, lower secondary and lower vocational education), moderate (intermediate secondary and intermediate vocational education) and high (higher vocational education and university)], and living status (married/living together with a partner vs. living without a partner).

For pre-dialysis patients, information about comorbid conditions (i.e., the presence of diabetes mellitus type 2, hypertension, cerebrovascular accident, vascular problems, ischaemic heart disease and heart failure) was recorded. Data regarding pre-dialysis patients' clinical characteristics were derived from the last known regular PREPARE-2 measurement at the time of the implementation of the current study. Data with respect to pre-dialysis patients' socio-demographic characteristics were collected through the survey among these patients.

For dialysis patients, severity of the health condition was determined by the level of serum albumin. Serum albumin is an important predictor of patient morbidity and mortality in dialysis patients (Blake, Flowerdew, Blake, & Oreopoulos, 1993; Plantinga *et al.*, 2007). Data regarding dialysis patients' remaining socio-demographic characteristics were collected through the survey among these patients (measurement one).

### **Data set**

The data set on illness perceptions and treatment perceptions consisted of data provided by the survey in pre-dialysis patients (one measurement within PREPARE-2) and the surveys in dialysis patients [only measurement one within NECOSAD-2; only measurement two within NECOSAD-2; measurement one and two within NECOSAD-2 (with an interval of 8 months<sup>2</sup>)]. The data were combined into one data set, because this resulted in a larger sample size beyond what would be available in separate analyses of the measurement within PREPARE-2 and the first or second measurement within NECOSAD-2.

### **Statistical analysis**

Descriptive statistics were computed to describe the background characteristics, the illness perceptions and treatment perceptions of the sample of pre-dialysis patients and patients on dialysis (at baseline), separately.

Analysis of variance (ANOVA) and chi-square tests were conducted to investigate whether the responding and non-responding patients differed regarding socio-demographic and clinical characteristics and to examine differences between pre-

dialysis patients and dialysis patients with respect to socio-demographic characteristics.

### *Multilevel analysis*

To investigate the relationship between the dependent and independent variables, multilevel (multivariate) repeated measurements regression analyses (Snijders & Bosker, 1999) were conducted. The choice for this type of analysis stemmed from the need to take into account the repeated measures within individuals. For each dependent variable (seven variables in total), a separate multilevel model analysis – with a random and fixed part – was conducted.

The random part of the model (individual level) took into account the possibility that individual scores measured at time point one and at time point two (with an 8-month interval) are very similar. To control for the correlation between the two measurements within individuals, for both measurements, a separate variance and covariance between the measurements were modelled. In addition, the strength of the correlation between the measurements is an indicator of whether dialysis patients' illness perceptions and treatment perceptions vary over time (8-month interval).

The fixed part of the model took into account the possibility that patients score systematically higher or lower on a second measurement. To capture the potential systematic difference between the group mean of measurement one (within PREPARE-2 and NECOSAD-2) and the group mean of measurement two (within NECOSAD-2), an indicator variable (labelled 'measurement two') was put into the model.

In the fixed part of the model, the independent variables *type of treatment* [pre-dialysis (reference group), haemodialysis, peritoneal dialysis] and *length of time on dialysis treatment* (in years) were entered. With respect to time on dialysis, a linear term and a quadratic term (i.e., squared term) were included into the model, to test for linear and quadratic associations. It could, for example, be possible that perceptions become more/less favourable over time (linear association) or that they become more/less favourable at first and become less/more favourable later on (quadratic association). Lastly, demographic characteristics, including gender, age, living status and educational level, were controlled for in the fixed part of the model. The analyses were performed using MLwiN software (Rasbash, Charlton, Browne, Healy, & Cameron, 2005).

## **RESULTS**

Responding and non-responding pre-dialysis patients do not differ significantly with respect to age, gender, living status, educational level and number of comorbid conditions.

Responding and non-responding dialysis patients on the first measurement do not differ with respect to age, gender, living status, type of treatment, time on dialysis and serum albumin level. Patients on dialysis invited for the second measurement do not differ with respect to the above-mentioned characteristics compared with those not invited.

### **Socio-demographic and clinical characteristics study samples**

Characteristics of the sample of 105 pre-dialysis patients and baseline characteristics of the sample of 161 patients on dialysis are depicted in Table 1. The age distribution



of pre-dialysis patients (59%  $\geq$  65 years) and gender distribution (63% male) corresponds to patients who started dialysis in the Netherlands in 2006 (51%  $\geq$  65 years; 61% male, Renine Foundation).

#### [TABLE 1]

The sample of dialysis patients comprises a higher percentage of older patients (61%  $\geq$  65 years) compared with figures of the Dutch dialysis population in January 2006 (49%  $\geq$  65 years, Renine Foundation). The gender distribution within the sample of dialysis patients (65% male) corresponds to prevalent patients on dialysis in the Netherlands in January 2006 (58% male, Renine Foundation). A large majority of the dialysis patients (70%) receive haemodialysis, which is comparable with the percentage haemodialysis patients within the Dutch dialysis population in January 2006 (76%, Renine Foundation).

The two groups (pre-dialysis group and dialysis group) were compared with respect to age, gender, living status and educational level. No significant differences were observed.

#### **Illness perceptions and treatment perceptions**

Table 2 displays the mean illness perceptions and treatment perceptions scores of the pre-dialysis sample and the dialysis sample (at baseline). On the whole, patients reported relatively low levels of perceived *personal control*. They, however, do believe that the treatment they receive can control their illness (*treatment control*) to a rather large extent, patients on dialysis in particular. Patients do not believe strongly that their illness affects them emotionally (*emotional response*).

Furthermore, the mean scores indicate that patients believe that their illness affects their daily life (*illness consequences*) to a rather large extent, this is especially true for patients on dialysis. In addition, the mean scores indicate that patients on dialysis believe treatment disrupts life (*treatment consequences*) to a moderate level, and pre-dialysis patients perceive a mild level of disruption from their current treatment.

Lastly, patients believe that they understand their illness (*understanding*) rather well and believe that their illness will last for a long time (*timeline*).

#### [TABLE 2]

#### **Perceptions of illness and treatment across the CKD trajectory**

##### *Type of treatment*

The findings of the multilevel analyses show that patients on haemodialysis and patients on peritoneal dialysis perceive more *illness consequences* compared with patients in the pre-dialysis phase (Table 3). Patients on peritoneal dialysis and patients on haemodialysis do not differ regarding this dimension. Furthermore, patients on haemodialysis perceive more *treatment consequences* compared with patients in the pre-dialysis phase (Table 3) and compared with patients on peritoneal dialysis ( $p = .01$ , not shown in Table). Lastly, patients on haemodialysis and peritoneal dialysis believe more strongly that their *treatment controls* the illness than patients who receive a pre-dialysis treatment (Table 4). Patients on peritoneal dialysis and patients on haemodialysis do not differ regarding this dimension.

[TABLE 3, TABLE 4]

*Length of time on dialysis treatment*

The results of the multilevel analyses reveal a quadratic association between length of time on dialysis and perceived *illness understanding* (Table 3). Figure 1 shows that patients who just started dialysis reported lower levels of understanding than pre-dialysis patients. Patients who are on dialysis for a moderate amount of time reported higher levels of understanding, compared with patients who just started dialysis and patients who are on dialysis for long lengths of time (parabolic shape). This pattern is observed in both haemodialysis and peritoneal dialysis patients.

[FIGURE 1].

The results furthermore demonstrate a linear association between length of time on dialysis and perceived *treatment consequences* (Table 3). Figure 2 shows that patients who are on dialysis for a longer length of time perceive their treatment as more disruptive for daily life compared with patients who are not yet on dialysis (pre-dialysis patients) or who are on dialysis for a shorter time. This pattern is observed in both haemodialysis and peritoneal dialysis patients.

[FIGURE 2.]

*8-month interval*

Lastly, the results of the multilevel analyses provide insight into the extent to which perceptions vary within patients on dialysis over an interval of 8 months, by examining the correlation coefficients between the two measurements in the random part of the model. The correlations between the perceptions at measurement one and measurement two are not that strong (Tables 3 and 4), indicating that the perceptions vary over an interval of 8 months. This is particularly true for the perception of *personal control* over the illness ( $r = .37$ ) and the perception of *treatment control* over the illness ( $r = .31$ ). The correlation between the perceptions of *treatment consequences* at two points in time shows the strongest correlation ( $r = .79$ ).

**DISCUSSION**

This study has examined the variability of illness perceptions and treatment perceptions across the trajectory of CKD in (pre-)dialysis patients. This insight provides an indication of whether perceptions of patients with CKD are amenable to influences and consequently whether interventions might potentially be helpful in influencing illness and treatment perceptions.

**Type of treatment**

As hypothesized, patients on haemodialysis and peritoneal dialysis believe more strongly that their current treatment controls their illness, and perceive more consequences of their illness compared with pre-dialysis patients. Furthermore, haemodialysis patients perceive more consequences of their treatment compared with pre-dialysis patients. A possible explanation for the first finding is that pre-dialysis patients are aware of the fact that soon their current treatment will no longer suffice. The observed differences in consequences are plausible, because the dialysis phase is characterized by specific disease aspects and intensive and time-consuming treatment

demands. Haemodialysis patients also perceive more treatment consequences than patients on peritoneal dialysis. An extra analysis was conducted to examine whether patients on the two dialysis modalities differ regarding their serum albumin levels (an indicator of patients' health condition), and no significant differences were observed. Knowing that haemodialysis patients (in most cases) have to go to the hospital three times a week for half a day to perform the dialysis procedure, it is however likely that treatment causes greater interference with daily life in this patient group than in patients on peritoneal dialysis. Our study has not demonstrated differences in perceived illness understanding, personal control, emotional response and timeline.

The study by Griva *et al.* (2009) has not demonstrated any differences in illness and treatment perceptions between patients on haemodialysis and peritoneal dialysis. Timmers *et al.* (2008) on the other hand did find differences in perceptions of personal control and understanding. The inconclusive findings might be the result of using a global dialysis modality classification. There are several ways by which haemodialysis as well as peritoneal dialysis can be performed. The importance of a more specific classification is underlined by a study by Griva *et al.* (2010) that has revealed differences in beliefs about treatment consequences between patients on different peritoneal dialysis modalities. Patients performing the peritoneal dialysis procedure manually four times a day (Continuous Ambulatory Peritoneal Dialysis) perceived more disruption associated with their treatment relative to patients performing the procedure automatically overnight by means of a machine (Automated Peritoneal Dialysis).

### **Length of time on dialysis treatment**

The finding that the perception of illness understanding varies between patients with varying lengths of time on dialysis is in line with the (longitudinal) research findings of Chilcot (2010) and Covic *et al.* (2006). Both studies have demonstrated improvements in understanding in dialysis patients either over a random 2-year period (Covic *et al.*) or over the first year on dialysis (Chilcot). This latter study finding also corresponds to the nature of the observed association in the present study, indicating that patients who are on dialysis for some years reported higher levels of understanding than patients who just started dialysis. Our study has also provided insight into the perceived understanding in patients who are on dialysis for long lengths of time (longer than 5 years). The findings have revealed a decline in understanding among these patients. It is important to note that this is a specific group of patients. Annually, approximately 20% of all patients on dialysis in Netherlands die (Oppe, Treur, Barendregt, & De Charro, 2007). In addition, an American study has demonstrated that a year accrued on haemodialysis is associated with a 6% increase in the risk of death, all else equal (Chertow, Johansen, Lew, Lazarus, & Lowrie, 2000). The decline in understanding may therefore be the result of a medical situation that is becoming more exceptional and complex. Second, the findings have shown that the perception of the consequences of the treatment is more negative in patients who are on dialysis treatment for longer lengths of time, as hypothesized. In contrast to our expectations, the findings have not revealed differences in perceived personal control, treatment control, illness consequences, emotional response and timeline.

### **8-month interval**

Lastly, the results suggest that dialysis patients' perceptions of in particular *personal control* and *treatment control* vary within patients over an interval of 8 months. These variations were not observed between patients with varying lengths of time on dialysis, which might have to do with power differences between the two approaches. The observed variation in *treatment control* over time is in accordance with the study by Covic *et al.* that has revealed improvements in treatment control after a 2-year period. Although the study by Chilcot has not revealed changes in control scores (over the first year of dialysis), the results did reveal that the variability in *personal control* scores varied over time, suggesting that there was more divergence as time went by.

In contrast to the study by Covic *et al.*, the present study has not demonstrated (clear) variation in the perception of emotional reaction. Our study on the other hand has revealed variation in the perception of personal control, which was not observed in the studies by Covic *et al.* and Chilcot. The different findings might have been caused by the different research designs. Another explanation may be that patients in the different studies were exposed to other conditions, which may have influenced their perceptions. In the study by Covic *et al.*, it is for example mentioned that a psychologist is part of the dialysis staff and a permanent presence in the dialysis centre's treatment process. In the Netherlands, psychological support is not yet a primary area of attention in renal care (cf. Kaptein *et al.*, 2010ab). In line with the studies by Chilcot and Covic *et al.*, the present study has not demonstrated (clear) variation in the illness perception dimension timeline. The findings of our study have shown that both pre-dialysis patients and patients on dialysis reported high scores on this dimension with little variation, which might indicate that patients immediately are aware of the chronic character of CKD.

### **Study limitations and recommendations**

The present study has not provided information about *when* patients' perceptions are varying the most and therefore are possibly most amenable to influences. An illness perception intervention study by Petrie, Cameron, Ellis, Buick, and Weinman (2002) to alter maladaptive illness perceptions of patients with a first myocardial infarction, however, suggests that it is important to intervene in an early phase of the illness process when perceptions might not be very well established yet and may be more apt to change. The present study had a partial cross-sectional design. A longitudinal study among patients in the earlier phases of CKD is needed to investigate changes in illness and treatment perceptions during the course of CKD. By comparing patients' perceptions at different points in time, such a study can also provide information about *when* patients' perceptions are most variable. In addition, it is important that future research focuses on whether changes in perceptions of patients with CKD are associated with changes in outcomes, for example, outcomes regarding quality of life, participation and hospitalization rates. It is furthermore important to note that the included data and the size of the data set imposed restrictions on the analyses that could be performed. Interesting questions that remain unanswered are whether the association between length of time on dialysis on the one hand and perceptions on the other hand is different for patients on different treatments, and which clinical characteristics explain variation in patients' perceptions.

## Implications

The findings suggest that perceptions of illness and treatment that are relevant for CKD patients' outcomes vary across the CKD trajectory. The findings are promising because they suggest that perceptions are amenable to influences. This means that interventions might potentially be helpful in influencing illness and treatment perceptions to improve associated outcomes. Following this, it seems however appropriate to note that the effect of experiences or knowledge related to (changes in) medical treatment or clinical state on patients' perceptions of illness and treatment may have different magnitudes than the impact of a psychological intervention on patients' perceptions. However, a pilot study by Karamanidou, Weinman, and Horne (2008) has shown that a brief intervention is able to improve haemodialysis patients' treatment beliefs and knowledge with respect to phosphate-binding medication, immediately after the intervention. By giving realistic information and providing tools for incorporating the illness and the (future) dialysis treatment into daily life, chances that illness and treatment perceptions become obstacles for successful adaptation to CKD may be reduced. Connecting to this, it seems also important that the (future) dialysis treatment matches patients' personal preferences and personal situations. Consequently, illness perceptions and treatment perceptions may be more favourable for adaptation.

## Footnotes

1. That is no valid scores on any of the items of the BIPQ and no valid scores on more than nine of the items of the TEQ.
2. For dialysis patients who provided data at time point two, time on dialysis was allowed to vary over time.

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## TABLES AND FIGURES

**Table 1.** Socio-demographic and clinical characteristics of the samples

	Pre-dialysis patients ( <i>n</i> = 105)	Patients on dialysis ( <i>n</i> = 161)
Gender – <i>N</i> (%)		
Male	66 (63)	104 (65)
Female	38 (37)	56 (35)
Age, mean in years ( <i>SD</i> )	64.4 (14.7) Range: 19–92	66.3 (11.7) Range: 32–89
Age, in groups – <i>N</i> (%)		
18–49 years	19 (18)	16 (10)
50–64 years	24 (23)	46 (29)
≥ 65 years	61 (59)	99 (61)
Living status – <i>N</i> (%)		
Married/living together with a partner	68 (65)	102 (66)
Living without a partner	37 (35)	52 (34)
Educational level – <i>N</i> (%)		
Low	45 (43)	59 (39)
Moderate	44 (42)	66 (43)
High	15 (14)	27 (18)
Type of dialysis treatment – <i>N</i> (%)		
Haemodialysis	na	113 (70)
Peritoneal dialysis	na	48 (30)
Time on dialysis, mean in years ( <i>SD</i> )	na	3.6 (2.3) Range: 0.1–9.0
Time on dialysis, in groups – <i>N</i> (%)		
Up to 2 years	na	50 (31)
2–5 years	na	73 (45)
5–10 years	na	38 (24)
Serum albumin, mean in g/L ( <i>SD</i> ) <sup>a</sup>	–	36.9 (4.4) Range: 22.6–45.8
Comorbid diseases, mean ( <i>SD</i> )	1.5 (1.2) Range: 0–5	–
Comorbid diseases, in groups – <i>N</i> (%)		
No comorbid diseases	22 (24)	–
One comorbid disease	28 (30)	–
Two or more comorbid diseases	43 (46)	–

Note. Na, not applicable; –, not assessed.

<sup>a</sup>Normal serum albumin values are 40–50 g/L.



**Table 2.** Mean (SD) illness perceptions and treatment perceptions scores of pre-dialysis patients and dialysis patients

	Pre-dialysis patients ( <i>N</i> = 94–105)	Patients on dialysis at time point I ( <i>N</i> = 154–156)
	<i>M</i> ( <i>SD</i> )	<i>M</i> ( <i>SD</i> )
BIPQ – Illness consequences (0–10)	6.7 (2.5)	7.7 (2.0)
BIPQ – Timeline (0–10)	9.3 (1.7)	9.2 (1.7)
BIPQ – Personal control (0–10)	4.7 (2.9)	4.9 (3.2)
BIPQ – Treatment control (0–10)	6.8 (2.9)	8.3 (2.0)
BIPQ – Understanding (0–10)	7.3 (3.1)	7.7 (2.7)
BIPQ – Emotional response (0–10)	5.0 (3.1)	5.0 (3.2)
TEQ – Treatment consequences (0–140)	38.8 (25.9)	63.4 (25.0)

*Note.* A higher score on the dimensions implies greater perceived illness consequences, timeline, personal control, treatment control, understanding, emotional response, treatment consequences.

**Table 3.** Multilevel regression model on the association of time on dialysis, type of treatment and perceptions of treatment consequences, illness consequences, understanding, emotional response, controlled for background characteristics and multiple observations within individuals (final model), total sample (N = 235–245)

	Treatment consequences	Illness consequences	Understanding <sup>a</sup>	Emotional response
Random effects (individual level)				
Variance measurement one	Estimate (SE) <sup>b</sup> 602.00 (55.76)	Estimate (SE) <sup>b</sup> 4.92 (0.45)	Estimate (SE) <sup>b</sup> 7.83 (0.71)	Estimate (SE) <sup>b</sup> 9.33 (0.85)
Variance measurement two	609.20 (84.00)	3.33 (0.52)	5.63 (0.87)	6.76 (0.99)
Covariance measurement one/two	479.40 (61.05)	2.00 (0.44)	3.72 (0.71)	5.34 (0.82)
Correlation measurement one/two	0.79	0.50	0.56	0.67
Fixed effects				
Constant	Estimate (SE) <sup>c</sup> 37.95 (2.58)	Estimate (SE) <sup>c</sup> 6.68 (0.22)	Estimate (SE) <sup>c</sup> 2.76 (0.28)	Estimate (SE) <sup>c</sup> 4.85 (0.30)
Measurement 2	-4.39 (1.86)*	-1.16 (0.21)***	0.33 (0.26)	-0.62 (0.25)*
Time on dialysis (in years)	2.22 (0.85)**	-0.03 (0.07)	-0.75 (0.33)*	-0.03 (0.10)
Time on dialysis (in years) squared	-	-	0.07 (0.04)*	-
Haemodialysis (ref: pre-dialysis)	21.41 (4.80)***	1.39 (0.40)***	1.23 (0.71)	0.61 (0.56)
Peritoneal dialysis (ref: pre-dialysis)	7.94 (5.42)	0.96 (0.45)*	0.51 (0.80)	-0.02 (0.63)
Female (ref: male)	3.77 (3.44)	-0.18 (0.28)	-0.47 (0.37)	0.88 (0.40)*
Age in years	-0.31 (0.13)*	-0.01 (0.01)	-0.00 (0.01)	-0.05 (0.01)**
Married/living together with a partner (ref: living without partner)	5.61 (3.50)	0.03 (0.29)	0.68 (0.37)	0.18 (0.40)
Moderate education (ref: low)	-1.70 (3.51)	0.06 (0.29)	0.30 (0.37)	-0.31 (0.41)
High education (ref: low)	-0.55 (4.71)	-0.30 (0.38)	-0.07 (0.49)	-0.87 (0.54)

Note. In case no significant quadratic association was observed, the results of the analyses are presented in which solely the linear association was tested.

<sup>a</sup>Scores are recoded so that higher scores indicate lower levels of understanding by variances.

<sup>c</sup>Unstandardized regression coefficients.

\* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ .

**Table 4.** Multilevel regression model on the association of time on dialysis, type of treatment and perceptions of personal control, treatment control, timeline controlled for background characteristics and multiple observations within individuals (final model), total sample ( $N = 243-245$ )

	Personal control <sup>a</sup>	Treatment control <sup>a</sup>	Timeline
Random effects (individual level)	Estimate (SE) <sup>b</sup>	Estimate (SE) <sup>b</sup>	Estimate (SE) <sup>b</sup>
Variance measurement one	9.04 (0.82)	5.79 (0.53)	2.45 (0.22)
Variance measurement two	8.00 (1.26)	6.12 (0.97)	2.19 (0.33)
Covariance measurement one/two	3.12 (0.94)	1.81 (0.67)	1.32 (0.25)
Correlation measurement one/two	0.37	0.31	0.57
Fixed effects	Estimate (SE) <sup>c</sup>	Estimate (SE) <sup>c</sup>	Estimate (SE) <sup>c</sup>
Constant	5.30 (0.30)	3.13 (0.24)	9.35 (0.16)
Measurement 2	0.34 (0.34)	0.78 (0.30)*	0.08 (0.15)
Time on dialysis (in years)	-0.13 (0.10)	-0.06 (0.08)	-0.03 (0.05)
Time on dialysis (in years) squared	-	-	-
Haemodialysis (ref: pre-dialysis)	0.52 (0.55)	-0.93 (0.45)*	-0.07 (0.29)
Peritoneal dialysis (ref: pre-dialysis)	-0.48 (0.62)	-1.54 (0.50)**	-0.03 (0.33)
Female (ref: male)	-0.27 (0.39)	-0.26 (0.32)	0.12 (0.21)
Age in years	-0.02 (0.01)	-0.02 (0.01)*	0.04 (0.01)***
Married/living together with a partner (ref: living without partner)	0.65 (0.39)	-0.15 (0.32)	-0.20 (0.21)
Moderate education (ref: low)	0.27 (0.40)	-0.23 (0.32)	-0.06 (0.21)
High education (ref: low)	0.59 (0.52)	-0.63 (0.42)	-0.16 (0.28)

Note. In case no significant quadratic association was observed, the results of the analyses are presented in which solely the linear association was tested.

<sup>a</sup>Scores are recoded so that higher scores indicate lower levels of personal control and treatment control.

<sup>b</sup>Variances.

<sup>c</sup>Unstandardized regression coefficients.

\* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ .

Figure 1. Quadratic association between time on dialysis and perception of illness understanding (high understanding scores signify low levels of perceived understanding).

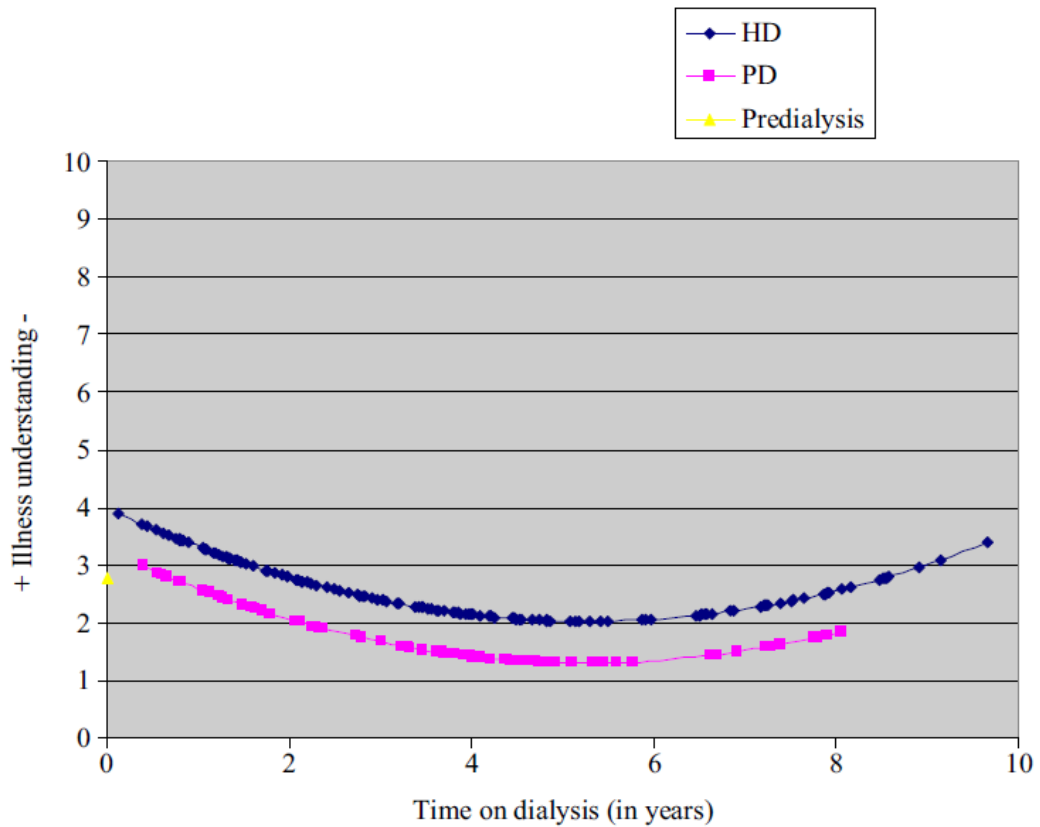


Figure 2. Linear association between time on dialysis and perception of treatment consequences (high treatment consequences scores signify high levels of perceived disruption from the treatment).

