

Psychological and Social Aspects of Living with Chronic Kidney Disease

Daphne L. Jansen¹, Mieke Rijken¹, Monique J.W.M. Heijmans¹,
Ad A. Kaptein² and Peter P. Groenewegen¹

¹NIVEL (Netherlands Institute for Health Services Research)

²Leiden University Medical Centre (LUMC)

The Netherlands

1. Introduction

Chronic Kidney Disease (CKD) draws heavily on patients' daily functioning. The disease, treatment and associated demands have a great impact on physical and emotional well-being and interfere with patients' social roles. Patients with CKD who are being prepared for, or receive renal replacement therapy often experience difficulties in participating in various domains of life, such as paid work, sports and other social and leisure activities (Heijmans & Rijken, 2004). A study among Dutch renal transplant patients revealed that these patients participate less in employment and sports compared with the general Dutch population (Van der Mei et al., 2007). For CKD patients on dialysis it seems in particular difficult to perform paid work, and it is notable that people who are being prepared for renal replacement therapy (pre-dialysis patients) already experience work related problems. Restrictions with respect to performing daily activities, including work, might impede people's feelings of autonomy and self-esteem. Recognising the importance of these aspects for people's well-being, we conducted a series of studies during the last six years with the aim of providing more insight into the psychological and social aspects of living with CKD. More specifically, we investigated the extent to which pre-dialysis patients and patients on dialysis feel autonomous, experience self-esteem and perform paid work, and the extent to which variation in these aspects is related to differences in patients' perceptions of illness and treatment (personal factors) and social support (external factors). Furthermore, we developed an intervention programme aimed at supporting patients' participation in daily activities, including paid work, and feelings of autonomy and self-esteem, by means of influencing illness perceptions, treatment perceptions and social support.

In this chapter we provide an overview of the results of our studies and reflect upon the findings. In the next section the key findings of our empirical research on this topic will be discussed in the context of previous research and existing theories. In the third section the development of the psychological intervention programme will be described. Furthermore, findings of the evaluation of the intervention on feasibility and initial experiences will be discussed, and areas of attention for the development and implementation of interventions in general will be addressed.

2. Review key findings empirical research

In this section we provide an overview of the main findings of our empirical studies carried out during the period 2006-2011 among pre-dialysis patients (CKD stage 4) and patients on dialysis (end-stage renal disease (ESRD), CKD stage 5) in the Netherlands. Data were gathered within a national cohort of pre-dialysis patients (PREPARE-2 study) and a national cohort of patients on dialysis (NECOSAD-2 study) by means of survey research. The findings will be placed in the context of previous research and existing theories.

2.1 Autonomy and self-esteem in patients with CKD

According to Deci and Ryan's Self-Determination Theory (SDT; 1985), autonomy is one of the basic psychological needs for optimal functioning. Autonomy refers to regulation by the self (Ryan et al., 2009). When autonomous, a person experiences his or her behaviour as self-organised and endorsed (Ryan et al., 2009). SDT postulates that the need for autonomy can energise human activity, and must be satisfied for long-term psychological health (Deci & Ryan, 2000). Reis et al. (2000) found that daily variations in the fulfilment of the need for autonomy, independently predicted daily variations in well-being. When the fulfilment of the need for autonomy is hindered, one's experience of self-worth is also damaged, leading to either insecure or low self-esteem (Ryan & Brown, 2003). Research demonstrated that both high self-esteem and stable self-esteem are associated with greater psychological well-being (Paradise & Kernis, 2002). Our study findings demonstrated that both patients in the pre-dialysis phase and patients on dialysis have, on average, moderate feelings of autonomy (Jansen et al., 2010). This indicates that they do not often feel that they can do the things they like to do in everyday life, because of their health condition or otherwise. Despite this, both groups of patients have high mean levels of self-esteem. In our research we have not examined the stability of patients' self-esteem. A Dutch study by Abma et al. (2007) revealed that people with renal disease also consider the maintenance and increase of their self-governance with respect to living their lives, as one of the most important themes that need more attention in renal care.

2.2 Labour participation in patients with CKD

People often regard participation in paid work as an important life activity. It generates income which in turn makes it possible to participate in other life domains as well. Moreover, a literature review by Waddell and Burton (2006) provided evidence that work is generally good for physical and mental health and well-being, and that unemployment is associated with negative health effects. Within our sample of 109 pre-dialysis patients, 42% (N = 45) were younger than 65 years and therefore were part of the potential labour force. Fifty-one percent of these patients had a paid job for at least 12 hours per week (definition of labour participation as applied by Statistics Netherlands (CBS)) in 2006 (Jansen et al., 2010). Furthermore, the results showed that, despite of their health condition, patients of working age placed relatively high importance on carrying out a paid job. It should be noted here that employers in the Netherlands must pay at least 70% of the salaries of sick employees for the first two years. Consequently people who are on long-term sick leave are in fact still employed. This means that our employed sample may also include patients on long-term sick leave. Fritschka et al. (2000) found a higher employment rate in their study among pre-dialysis patients in Germany, and demonstrated that 63% of the patients aged 18-64 years were employed on a full-time basis. A more recent Danish study by Sondergaard and Juul

(2010) revealed a labour participation rate of 57%, irrespective of the number of working hours, in pre-dialysis patients aged below 65. Of our sample of 166 patients on dialysis, 37% (N = 62) were younger than 65 years. Within this group 24% had a paid job for at least 12 hours per week (in 2006; Jansen et al., 2010). Previous studies among working-age patients on dialysis carried out in Europe as well as in the United States found comparable labour participation rates, however, some studies found higher rates (Table 1). It should be noted that the studies vary with respect to the labour participation definitions and age ranges used.

Sample	Labour participation rate	Country	
Dialysis patients < 65 yrs	20%	Sweden	Theorell et al., 1991
Haemodialysis patients < 60 yrs	22%	Denmark	Molsted et al., 2004
Dialysis patients < 63 yrs	24%	United States	Braun Curtin et al., 1996
Dialysis patients < 55 yrs	19%	United States	Kutner et al., 2008
Dialysis patients < 65 yrs	38%	Netherlands	De Wit et al., 2001
Haemodialysis patients	34% (full-time)	Germany	Fritschka et al., 2000

Table 1. Labour participation rates of working-age patients on dialysis

Previous research among renal patients has detected specific predictors of employment of patients on dialysis, and showed that occupational status before dialysis, a higher educational level and a good physical condition are important determinants (see Heijmans & Rijken et al., 2004; see Kutner et al., 2008). Kutner et al. (2008) investigated the association between dialysis facility characteristics and employment rates. They found that offering a late dialysis shift, as well as peritoneal dialysis or home haemodialysis training and more frequent haemodialysis were associated with higher facility employment rates, after adjusting for patient/social worker ratio, rurality of unit location, and unit size. However, patient-level characteristics were not taken into account, and due to the design of the study the associations observed between facility characteristics and patient employment could not be interpreted as cause-and-effect relationships. Another study by Kutner et al. (2010) revealed that higher levels of energy expenditure reflected in usual activity levels were associated with increased likelihood of continued employment after dialysis start.

The labour participation rate of 24% found in our study among Dutch dialysis patients of working age is considerably lower than that of the general Dutch population in the ages of 15-64 years, of which 65% were employed for at least 12 hours per week in 2006. Compared to a representative sample of people with a chronic illness in the Netherlands, the dialysis patients' employment rate found in our study is also low. Among this sample of chronically ill people (aged 15-64 years) 35% had a paid job for at least 12 hours per week in 2006 (Van den Brink-Muinen et al., 2009). The labour participation rate of pre-dialysis patients deviates to a lesser extent from the Dutch labour participation rate. This is plausible, since the restrictions of the illness and treatment are less profound in this phase of the illness, compared to the dialysis phase. We wish to mention here that the working-age groups in our studies among (pre-)dialysis patients comprised a high percentage of older patients. Notwithstanding that, our results suggest that labour participation in (pre-)dialysis patients is indeed lower than in the general Dutch population. We also compared the (pre-)dialysis patients' employment rates of the group aged below 55 years and the group aged 55-64 years with rates of the general population by age (Table 2). The employment rates of the patients on dialysis still lag behind. The employment rate of the pre-dialysis patients aged

55-64 years appears to be comparable with the employment rate of the general population aged 55-64 years. The employment rate of the patients aged below 55 years is however considerably lower compared to the employment rates in the general population aged between 25 and 54 years.

	Dutch general population (15-64 years)*	Sample pre-dialysis patients (19-64 years)	Sample dialysis patients (32-64 years)
15-24 yrs	39%		
25-34 yrs	82%		
35-44 yrs	80%	57%	32%
45-54 yrs	75%		
55-64 yrs	40%	41%	19%
Total group	65%	51%	24%

Table 2. Labour participation (paid job \geq 12 hrs pw) in the Dutch general population, the sample of pre-dialysis patients (N=45) and patients on dialysis (N=62) of working age in 2006; * source: CBS, Statistics Netherlands

Looking at the labour participation rates found in our studies among dialysis and pre-dialysis patients, the findings indicate that people already resign from their jobs in the pre-dialysis phase. These findings are in line with the findings of the study by Van Manen et al. (2001) among 659 dialysis patients aged 18-64 years. This study revealed that drop out of the labour market already occurs before patients start with dialysis treatment: at the start of the dialysis treatment, 35% of the patients had a paid job compared to 61% in the general Dutch population in 1997, the year the study was carried out. This is alarming, since research identified prior occupational status as an important predictor of employment in dialysis patients. In addition, Van Manen et al. found that labour participation in dialysis patients decreased as patients were on dialysis for a longer time: the percentage of employed patients on dialysis decreased from 31% to 25% in patients on haemodialysis, and from 48% to 40% in patients on peritoneal dialysis after one year on dialysis. Our results also suggest that resignation from paid work further continues in the dialysis phase. Findings from a study conducted by Kutner et al. (2010) also point to job resignation during the pre-dialysis phase and the initiation phase of dialysis treatment. Their study showed that, among 585 incident patients who were working for pay during the year before dialysis, only 191 (32.6%) continued working approximately 4 months after dialysis start.

These results point to the importance and necessity of work-related support and guidance at an early stage of the illness process. Research indicates that renal patients themselves also report to have problems with respect to work. The study by Abma et al. (2007) revealed that patients struggle with whether they can work and what kind of work they can do. A Swedish study among pre-dialysis patients and patients on dialysis demonstrated that around 30% of the pre-dialysis patients, and more than 50% of the patients on dialysis reported problems with respect to work and regarding leisure time (Ekelund & Anderson, 2007).

What have we learned from scientific research?

- patients in the pre-dialysis and dialysis phase, on average, have moderate feelings of autonomy and high levels of self-esteem
- patients in the pre-dialysis phase already resign from paid work, and resignation from paid work further continues in the dialysis phase

- patients themselves consider self-governance with respect to living their lives as an important topic and report difficulties with respect to work and leisure time

What is important for clinical practice?

- it is important that patients are being supported in their efforts to carry out paid work, and - more generally - in their sense of autonomy, in an early phase of the illness process in order to prevent drop out of paid work and other daily activities

What needs to be investigated further?

- it is recommended that research investigates why patients, who have a comparable clinical status, differ in the extent to which they feel autonomous, experience self-esteem and participate in paid work; it is then important to focus on potentially modifiable factors; by gaining insight into this matter, starting points can be generated for the development of interventions

2.3 The role of perceptions of illness and treatment

One of the objectives of our studies was to investigate (pre-)dialysis patients' illness perceptions and treatment perceptions in relation to employment, and more generally perceived autonomy and self-esteem. The findings of two previous studies inspired us to investigate these relationships. First, the study by Braun Curtin et al. (1996) which demonstrated that dialysis patients with and without a paid job differed regarding their attitudes towards work. Employed patients did not feel limited by their health in the hours they worked or the kind of work in which they could engage. Patients without work on the other hand, perceived their health as a barrier to find work. These findings are interesting since both patient groups did not differ with respect to objective health indicators. Second, a study by Petrie et al. (1996) among myocardial infarction (MI) patients, which showed that illness perceptions are related to return to work. In particular, perceptions of the duration and the consequences of the illness predicted the speed of return to work.

Patients' perceptions of their illness are the central concepts of the Common Sense Model (CSM; Leventhal et al., 1984), which is a self-regulation model of health threat. According to this model people make sense of a health threat by developing their own cognitive and emotional representations of that threat. These representations or perceptions develop from exposure to a variety of social and cultural sources of information - news stories, education in schools, personal experiences of illness, witnessing illness experiences of others, portrayals of illness in books and movies, and other experiences (Cameron & Moss-Morris, 2004). CSM postulates that both cognitive and emotional representations determine how patients cope with their illness and adapt to their illness. The representations generally consist of the following components:

- *identity* - patients' beliefs about the label of the illness and associated symptoms;
- *cause* - patients' beliefs about factors or conditions that have caused the illness;
- *timeline* - patients' beliefs about the expected duration of the illness;
- *personal control* - patients' beliefs about how much their own actions will help to control the illness;
- *treatment control* - patients' beliefs about how much their prescribed treatment will be effective in controlling or curing the condition;
- *consequences* - patients' beliefs about the impact of the illness on their physical, social and psychological well-being;
- *coherence* - patients' beliefs about how well they understand the illness;

- *representation of emotional reaction* - patients' beliefs about how much they are emotionally affected by the illness, e.g. whether they experience fear or worry.

These cognitive and emotional representations can be activated and developed at the same time (Broadbent et al., 2009a; Cameron & Moss-Morris, 2004). Two important aspects of illness perceptions are, that patients' beliefs about their condition are often at variance from those who are treating them, and secondly, patients' perceptions vary widely, even in patients with the same medical condition (Petrie et al., 2007). Many studies have investigated the relationships between illness perceptions and outcomes in different patient populations. A meta-analysis of 45 empirical studies among patients with various medical conditions, demonstrated that perceptions that the illness was curable/controllable were significantly and positively related to the adaptive outcomes of psychological well-being, social functioning and vitality, and negatively related to psychological distress and disease state. Conversely, perceptions of illness consequences, timeline and identity exhibited significant, negative relationships with psychological well-being, role and social functioning and vitality (Hagger & Orbell, 2003). In addition, studies provided evidence that illness perceptions are associated with eating and exercise self-efficacy in patients with coronary heart disease, attending rehabilitation in MI patients, and self-management in patients with diabetes (see Petrie et al., 2007). Besides representations of illness, patients' beliefs about their prescribed medical treatment (i.e. beliefs about necessity and concerns) also play a role in how patients cope with and adapt to their illness. Studies have demonstrated that beliefs about treatment are related with adherence and treatment decisions (Horne et al., 2007; Horne & Weinman, 2002).

2.3.1 Content of CKD patients' illness and treatment perceptions

From the findings of our studies, among pre-dialysis patients and patients on dialysis, it is notable that both patient groups on average reported relatively low levels of perceived personal control over the illness (Jansen et al., 2010). Personal control over the illness refers to the feeling that one can influence the course of the illness, and one can fit the illness and its treatment into daily life. In a study by Broadbent et al. (2006), using the same measurement instrument, people with diabetes and people with asthma both reported higher mean levels of personal control (M=6.7, on a scale from 0 to 10) compared with the mean personal control levels found in our studies among pre-dialysis patients (M=4.7) and patients on dialysis (M=4.9). Previous studies have shown that dialysis patients' beliefs of personal control are important for patients' health related quality of life (Covic et al., 2004; Timmers et al., 2008). In order to manage their illness, pre-dialysis patients and dialysis patients obviously depend on medical treatment, i.e. pharmacotherapy and dialysis. Our findings also show that, on average, patients believe that their treatment positively influences their illness, this is particularly true for patients on dialysis. However, the fact that patients are dependent on medical treatment does not mean that there are no opportunities for personal control. For dialysis patients it is very important to engage in self-care behaviours. Virtually all patients with ESRD are likely to be required to monitor food and fluid intake and to take multiple medications, in addition to following a generally healthy lifestyle overall with regard to smoking, alcohol, weight maintenance, regular exercise, etc. (Braun Curtin et al., 2005). However, the extreme dependence on the dialysis treatment might predominate and overshadow the extent to which one self can influence the course of the illness. For pre-dialysis patients it is of great importance as well to practice

self-care behaviours, such as following a healthy diet and performing daily exercise in order to optimise their health condition (Sijpkens et al., 2008). Patients in this stage of the illness, however, got the news that they have to start with renal replacement therapy in the near future, which indicates that despite of their self-care activities they apparently were not able to maintain sufficient renal function. This knowledge might have a negative effect on patients' personal control beliefs. Sijpkens et al. (2008) state that in the pre-dialysis phase the long foreseen implications of kidney disease become immediate and many patients experience feelings of helplessness and hopelessness. Moreover, our study results showed that pre-dialysis patients are quite worried about their illness, which also could be related to the prospect that one has to start with the dialysis treatment soon.

In addition, the results of our studies revealed that dialysis patients, on average, believe that their illness has rather serious consequences for their daily life. Pre-dialysis patients also believe that their illness affects their daily life, but to a somewhat lesser extent. Furthermore, the mean scores indicated that patients on dialysis perceive moderate disruption from their treatment in daily life, and pre-dialysis patients perceive mild disruption from their current treatment. Previous studies among patients with ESRD have emphasised the importance of beliefs related to the experienced impact of ESRD and its treatment for patients' quality of life (Fowler & Baas, 2006; Griva et al., 2009; Timmers et al., 2008). Moreover, the type of treatment might also play a role in patients' perceptions of personal control. The study by Timmers et al. (2008) among haemodialysis (HD) patients and peritoneal dialysis (PD) patients showed that patients on PD experienced more personal control, compared to HD patients.

2.3.2 Patterns of CKD patients' illness and treatment perceptions

Leventhal et al. have emphasised the potential value of examining interrelations between combinations of illness perceptions in relation to outcomes in patients with chronic physical illness (Kaptein et al., 2010). In our studies we therefore also looked at interrelations between illness and treatment perceptions. We found similar patterns of significant interrelations in both patient groups. As (pre-) dialysis patients perceive more consequences from their illness, they experience less personal control, more physical symptoms, greater concern, higher levels of emotional response, and greater disruption from the treatment. However, different patterns were observed as well. It is notable that pre-dialysis patients' feelings of greater personal control are associated with both cognitive and emotional representations (i.e. lower illness consequences, higher treatment control, lower concern and emotional response scores). Whereas dialysis patients' feelings of personal control are solely associated with cognitive representations (i.e. lower illness consequences, higher treatment control, lower identity, higher understanding, and lower treatment disruption scores). It is furthermore notable that pre-dialysis patients' beliefs of greater treatment disruption are associated with beliefs that the treatment cannot control the illness. Whereas dialysis patients, beliefs of greater treatment disruption are associated with beliefs that they themselves cannot control the illness. Like Griva et al. (2009) we found relationships between the illness perception dimensions and treatment (disruption) beliefs hereby, in addition to Griva and colleagues, providing support for extending the Common Sense Model with treatment related beliefs (Horne & Weinman, 2002). It seems important to take the patterns of interrelations into account when focusing on influencing perceptions shown to be related to better outcomes.

2.3.3 CKD patients' illness and treatment perceptions and outcomes

As already discussed in the previous sections, several studies have investigated the relationship between illness perceptions and treatment perceptions of patients with ESRD on the one hand, and quality of life on the other hand (e.g. Covic et al., 2004; Fowler & Baas, 2006; Griva et al., 2009; Timmers et al., 2008). From all these studies, it can be concluded that more perceived personal control, less perceived (negative) consequences (from both the illness and treatment), and a lower emotional response are generally associated with better outcomes in patients on dialysis. Covic et al. (2006) investigated whether illness perceptions of patients on haemodialysis, reported at a certain point in time, could actually explain subsequent changes in quality of life outcomes over time. Their results showed that baseline emotional response, personal control and coherence explained changes in the physical component of quality of life over a two year period. Baseline illness consequences appeared to explain changes in the mental component of quality of life during the two year follow-up period. Horne et al. (2001) investigated the treatment beliefs of patients on haemodialysis with respect to medication and fluid-diet restrictions, and found associations between these specific treatment beliefs and adherence to these treatments.

In our studies we have investigated whether differences in patients' illness and treatment perceptions are associated with variation in autonomy and self-esteem. We did this by means of multivariate analyses in which we controlled for differences in socio-demographic and clinical characteristics (Jansen et al., 2010). The results demonstrated that the illness and treatment beliefs explained a substantial amount of variance in autonomy and self-esteem, after controlling for background characteristics. With respect to pre-dialysis patients, the results illustrated that less perceived disruption from the treatment upon life is a significant contributor to self-esteem, and makes a close to significant contribution to autonomy (global measure). Treatment in the pre-dialysis phase in most cases includes taking pharmacotherapy and following a diet. Although these treatments may be less disruptive than dialysis treatment, the findings show that the way patients perceive their treatment is already a significant theme in this stage of the illness. According to Leventhal et al. (1984) illness representations are constantly updated as new experiences and knowledge are acquired. In this transition phase of treatments, in which patients receive information on all available renal replacement therapies, it therefore can be expected that patients are occupied with treatment in general, both their current treatment as well as their future treatment.

With respect to the patients on dialysis, the results showed that the perception of personal control over the illness is an important contributor to patients' feelings of autonomy (global measure). Thus, the belief that one's own actions will help to control the illness is related with global autonomy feelings. In light of these findings it is important to point out the difference between *personal control* and *autonomy*, since autonomy is often incorrectly equated with ideas of internal locus of control (Deci & Ryan, 2000). Beliefs of personal control reflect beliefs regarding the extent to which one feels that one can control or influence an outcome. However, people are autonomous when they act in accordance with their authentic interests or values. Furthermore, the results showed that beliefs that the illness and treatment have little impact on daily life are positively associated with autonomy (health related measure). Thus, patients who do not feel that the illness and treatment impede their lives, do not feel that their health stops them from doing the things they would like to do. Lastly, less concern about the illness, and less perceived treatment disruption were significant contributors to a higher self-esteem in patients on dialysis. It should be noted that a large amount of variation in people's autonomy and self-esteem levels

remained unexplained. Braun Curtin et al. (1996) provided evidence for the role of another psychological factor. They found that patients who themselves believed that dialysis patients should work, and had this notion reinforced by significant others were more likely to be employed. This suggests that the extent to which people in patients' social environment (e.g. patients' partners or doctors) support patients in their efforts to carry out activities, including work, also plays an important role.

We also examined the relationships between (pre-)dialysis patients' illness perceptions and treatment perceptions on the one hand, and labour participation (defined as the performance of paid work for at least 12h per week) on the other hand within the working-age group (18-64 years). We were not able to demonstrate clear relationships between illness and treatment perceptions and labour participation. However, the results of the bivariate analyses showed some trends. Employed dialysis patients perceived less severe physical symptoms from the illness, less impact from the illness, greater personal control, and less disruption from the treatment compared with unemployed patients. It is noteworthy that employed dialysis patients also reported less treatment control and less understanding compared with unemployed patients. This might indicate that employed patients are less focused on, or occupied with factors that lie outside of their control or reach. Pre-dialysis patients who were employed perceived their illness as better controllable by self-care and medical care, and their treatment as less disruptive than unemployed patients. However, employed patients had a stronger emotional response compared with unemployed patients. A possible explanation for this latter finding might be that these patients are more upset or scared for the future consequences in view of their work, for example whether they can continue working. Previous studies also have provided evidence for the role of illness perceptions in employment. As described earlier, Petrie et al. (1996) found a relationship between illness perceptions regarding duration and the consequences of the illness and return to work in MI patients. Recently, Hoving et al. (2010) conducted a literature review on illness perceptions and work participation in patients with somatic diseases and complaints. The findings showed that, overall, non-working patients perceived more serious consequences, expected their illness to last a longer time, and reported more symptoms and emotional responses. Working patients on the other hand had a stronger belief in the controllability of their condition and a better understanding of their disease. The authors concluded that the findings suggest that illness perceptions play a role in the work participation of patients with somatic diseases or complaints, although it is not clear how strong this relationship is and which illness perception dimensions are most useful.

The absence of clear relationships in our sample of pre-dialysis and dialysis patients might be caused by the small group sizes. The number of (pre-)dialysis patients of working age was low. A possible additional explanation might be that patients of older age or patients in this stage of the illness do not value a paid job as that important anymore, i.e. performing paid work does not contribute to their feelings of autonomy, and in turn their self-esteem. According to Self-Determination Theory, one of the requirements for need satisfaction, including the need for autonomy, is that people engage in an activity because they find the activity interesting and enjoyable or accept the value of the activity as personally important (autonomous motivation) (see Deci & Ryan, 2000). Renal patients in advanced illness stages may be aware of the fact that they are seriously ill, and therefore other life domains or life goals might have become more important, and work moves to the background. Consequently, a possible negative impact of for example a low degree of perceived personal control over the illness is not reflected in one's employment

status. In this line of reasoning, we are assuming that people who place less value on doing work, might be less affected by the work limitations caused by their illness. Patients who on the other hand regard work as an important activity might be more affected by limitations, and therefore, perhaps more inclined to resign from work. Therefore, pre-dialyses patients were asked about the importance of performing paid work, and the results indicated that these patients regard paid work still as of considerable importance. When trying to increase feelings of autonomy and self-esteem, it seems important to take into account the life domains people find really important, explore their corresponding goals and focus on these goals.

On the whole, our results show that beliefs of more personal control, less impact of the illness and its treatment and less concern were the most important contributors to perceived autonomy and self-esteem. With respect to labour participation similar trends were observed, i.e. beliefs of greater personal control and less impact of the illness and treatment were associated with employment. These findings point to the likely importance of positively influencing these perceptions in order to improve patients' autonomy, self-esteem and labour participation. The results are in line with the findings from previous studies, which showed that beliefs of more personal control, less perceived (negative) consequences from the illness and treatment, and a lower emotional response were generally associated with better quality of life outcomes in patients on dialysis.

2.3.4 The course of CKD patients' illness and treatment perceptions

Identifying perceptions related to adaptive outcomes is a first step. In view of developing interventions aimed at altering (unhelpful) perceptions, it is additionally important to know whether these perceptions can be influenced in order to improve adaptive functioning. We investigated the illness perceptions and treatment disruption beliefs across the trajectory of CKD, in pre-dialysis patients and patients on dialysis (Jansen et al., in preparation). In so doing we aimed to elucidate the dynamics of patients' illness and treatment perceptions across the illness trajectory. This knowledge is important for determining whether perceptions vary and, consequently, whether interventions could potentially target perceptions of patients with CKD stage 4 and 5.

As mentioned previously, it is assumed that illness representations are constantly being updated as new illness knowledge and illness experience are acquired (Leventhal et al., 1984). Some years ago, a pilot study was conducted to change treatment beliefs of patients on haemodialysis who used phosphate-binding medication, by means of a psycho-educational intervention (Karamanidou et al., 2008). This brief intervention seemed to be able to change treatment beliefs immediately after the intervention. Randomised controlled trial studies by Petrie et al. (2002) and Broadbent et al. (2009b) among myocardial infarction (MI) patients suggest that perceptions of illness can be changed by means of a psychological intervention, and showed that the intervention resulted in improved outcomes, including an earlier return to work.

Two interesting longitudinal studies in patients with ESRD have provided knowledge about how perceptions of illness and treatment change over time. Covic et al. (2006) investigated the illness representations of patients on established haemodialysis with low co-morbidity over a 2-year period. Following this 2-year period, patients had fewer negative emotional reactions to the disease, a better understanding, and the perception that dialysis is more efficient in controlling their illness. Chilcot et al. (2010) revealed a similar trajectory for illness understanding in dialysis patients over their first year on dialysis: over a one year

follow-up, patients' understanding significantly increased. In addition, illness identity decreased suggesting that individuals tended to identify their illness with fewer somatic symptoms over time. Previous research in other patient populations also demonstrated longitudinal changes in illness perceptions, as well as associated changes in health outcomes (see Kaptein et al., 2010). Another indication of the dynamic nature of illness and treatment perceptions of patients with CKD comes from a study by Griva et al. (2008). This longitudinal study suggests that changes in clinical state and treatment bring about changes in illness and treatment perceptions. In this study the researchers compared the illness perceptions and treatment perceptions of 41 patients with ESRD pre to post kidney transplantation (i.e., still on dialysis compared to six months after transplantation). After the transplantation, patients expressed different perceptions, including lower illness and treatment disruptiveness, and stronger control beliefs. Cross-sectional studies have also demonstrated differences in illness and treatment perceptions between patients who receive different treatments for their ESRD (Griva et al., 2009; Griva et al., 2010; Timmers et al., 2008). Treatment is of particular importance in CKD, since treatments differ significantly across the different phases of the illness (pre-dialysis, dialysis, transplantation), and are associated with different intense demands.

We examined whether patients who received different treatments (pre-dialysis treatment, haemodialysis treatment and peritoneal dialysis treatment) and who were on dialysis treatment for different lengths of time differed in their beliefs about the illness and treatment (for pre-dialysis patients the value regarding time on dialysis was set to zero years). In these analyses we adjusted for socio-demographic characteristics. We investigated these relationships using data provided by the sample of pre-dialysis patients at one measurement point and data provided by the sample of dialysis patients at two measurement points (either at only measurement point one, only measurement point two or at both measurement point one and two with an interval of eight months). We analysed the data by means of an analysis in which we could combine the multiple measurements (pooled cross-sectional analysis). Because of the multiple observations over time for a part of the dialysis patient group, we also took the dependency of these observations into account when analysing the data. We did this by controlling for the correlation between the measurements within individuals.

The results of the analyses demonstrated an association between time on dialysis treatment on the one hand and beliefs about *understanding* and beliefs about *treatment disruption* on the other hand. The association between time on dialysis and perceived understanding of the illness indicated 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 (quadratic association).

The association between time on dialysis and perceived treatment disruption indicated that patients who are on dialysis for a longer period of time perceive their treatment as more disruptive for daily life compared to patients who are not yet on dialysis or who are on dialysis for a shorter time. These findings indicate that perceptions of treatment disruption and understanding vary between patients as a function of time on dialysis.

The results of the analyses also provided insight into the extent to which perceptions vary within patients on dialysis over an interval of eight months, based upon the correlation between the perceptions measured at time point one and time point two. The results showed that the correlation of perceptions of *personal control* and perceptions of *treatment*

control was $r = 0.37$ and $r = 0.31$, respectively. These findings suggest that these perceptions vary within patients over an interval of eight months. The correlations regarding the other perception dimensions were higher and ranged from $r = 0.50$ to $r = 0.79$.

The findings that perceptions of understanding and perceptions of treatment control vary are in line with the (longitudinal) research findings of Covic et al. (2006) and Chilcot et al. (2010). These studies however also revealed changes in illness perceptions which we did not observe in our study and vice versa. The different findings might have been caused by the fact that different research designs were used, or by the fact that patients in these studies were exposed to other conditions which may have influenced their perceptions.

Our results furthermore demonstrated that perceptions of *illness consequences*, *treatment disruption* and *treatment control* vary between patients as a function of treatment type. Patients on HD and PD perceived more illness consequences compared with patients in the pre-dialysis phase. These differences are plausible, since the dialysis phase is characterised by specific disease aspects and intensive and time-consuming treatment demands. Moreover, various studies have demonstrated impaired functioning with respect to physical, mental, and social domains in patients on dialysis treatment (e.g. Khan et al., 1995; Molsted et al., 2007). Furthermore, patients on HD perceived more treatment disruption compared with patients in the pre-dialysis phase and patients on PD. It should be noted that, since we were not able to control for clinical characteristics and due to the cross-sectional design, this disruption cannot be simply attributed to HD.

Lastly, patients on HD and PD believed more strongly that their treatment controls the illness than patients who receive a pre-dialysis treatment. For patients on dialysis, dialysis is not an option but a vital need. Treatment control for these patients has a different meaning than for many other patients with a chronic disease. This may also explain the stronger beliefs in treatment control in patients on dialysis compared to pre-dialysis patients who use medication or follow a diet, and are much less dependent on their treatment compared to patients on dialysis.

Our study findings suggest that certain beliefs (pre-)dialysis patients hold about their illness and treatment vary across the illness trajectory, and therefore offer starting points for the development of interventions to target illness and treatment perceptions of patients with CKD. One of the perceptions that varies across the illness trajectory is the perception of treatment disruption. It seems important that interventions focus particularly on reducing the perceived negative impact of treatment on daily life, since our findings suggest that greater treatment disruption is negatively associated with perceived autonomy and self-esteem in both pre-dialysis patients and patients on dialysis. In addition, patients' illness perceptions regarding personal control, illness consequences and concern also seem to play an important role in patients' perceived autonomy and self-esteem. Moreover, patients in the pre-dialysis phase and/or dialysis phase, on average, reported unfavourable scores with respect to these illness perceptions. From our investigation of the relationships between the illness and treatment perceptions, it was also noticed that pre-dialysis patients' beliefs about greater treatment disruption were associated with beliefs of less treatment control, but not with personal control. Whereas a reverse pattern was found for patients on dialysis. Based on these findings it seems important to promote awareness among pre-dialysis patients regarding the opportunities to integrate treatment in daily life by means of their own efforts. In addition, it was notable that pre-dialysis patients' beliefs of little personal control were associated with higher levels of concern and emotional impact. It is therefore advised to, besides enhance personal control beliefs, reduce feelings of concern regarding the illness

and treatment to more 'realistic standards'. However, because some perceptions of illness seem to be more stable than others, it is recommended to intervene on these perceptions as early as possible, preferably when people are likely to form their perceptions. The illness perception intervention study by Petrie et al. (2002) in MI patients also suggests that it is important to intervene in an early stage of the illness process.

What have we learned from scientific research?

- patients in the pre-dialysis phase and dialysis phase, on average, have relatively low levels of personal control over the illness; pre-dialysis patients are, generally, quite worried about their illness; patients on dialysis, on average, experience rather serious consequences of their illness in daily life
- on the whole, beliefs of more personal control, less (negative) impact of the illness and its treatment, and less concern were the most important contributors to perceived autonomy and self-esteem (taking into account socio-demographic and clinical characteristics); with respect to labour participation similar trends were observed
- perceptions of treatment disruption and understanding vary between (pre-) dialysis patients as a function of time on (dialysis) treatment
- perceptions of personal control and treatment control vary within dialysis patients over an interval of eight months
- perceptions of illness consequences, treatment disruption and treatment control vary between (pre-)dialysis patients as a function of treatment type (pre-dialysis, haemodialysis, peritoneal dialysis)

What is important for clinical practice?

- the findings point to the importance of self-management support on combining CKD and its (dialysis) treatment with daily activities, including paid work; by giving realistic information and providing tools and support on fitting the illness and (future) treatment into daily life, positive (realistic) beliefs might be stimulated and unhelpful illness and treatment related beliefs may be prevented or challenged; this might contribute to a greater sense of autonomy and self-esteem as well as to participation in general
- it seems important that such interventions focus particularly on reducing the perceived (negative) impact of dialysis treatment on daily life, in addition to reducing perceived (negative) consequences of the illness and concerns about the illness, as well as increasing perceptions of personal control over the illness
- the best moment to offer interventions to alter unhelpful or maladaptive beliefs in patients with CKD seems to be when people are likely to form their perceptions of illness and treatment, e.g. in the pre-dialysis phase (preferably even before CKD stage 4) or at the start of dialysis treatment

What needs to be investigated further?

- the formation process of CKD patients' illness and treatment perceptions, and the further development of these perceptions over time and phases of the illness, by means of longitudinal research; by comparing patients' perceptions at different points in time, this research can furthermore provide information about *when* patients' perceptions are most variable, and, consequently, most likely susceptible to change
- the course of illness and treatment perceptions in relation to autonomy, self-esteem and employment outcomes, by means of longitudinal research among CKD patients; this research can gain insight into causal relationships

- with respect to research in patients on dialysis, it would be interesting to take into account a broader range of dialysis modality characteristics, such as whether patients dialyze at night; this research can shed light on whether these characteristics have a positive effect on patients' outcomes, for example patients' sense of autonomy

2.4 The joint role of social support and illness perceptions

As stated before, previous research among patients on dialysis has shown that, besides patients' own attitudes towards employment, the attitudes towards work of people in patients' social environment (such as spouses or doctors) play an important role in patients' labour participation: patients who themselves believed that dialysis patients should work, and had this notion reinforced by significant others were more likely to be employed (Braun Curtin et al., 1996). These findings suggest that patients' social environment can support patients in their efforts to carry on with daily activities, which in turn might support patients' sense of autonomy and self-esteem. A prerequisite for providing this support is that the social environment also has positive (realistic) beliefs regarding the illness in relation to being active. A recent study by Grunfeld et al. (2010) among patients with cancer and (unlinked) employers demonstrated that employers in general held more negative illness perceptions of cancer in relation to work than patients. The authors foresaw that such a discrepancy could impact on an employees' management of their work and on employers' responsiveness to the needs of employees.

Self-determination theory, by Deci and Ryan (1985), postulates that social contexts can indeed support a person's basic psychological need for autonomy. According to Williams et al. (2006) autonomy support, in a health related context, refers to practitioners eliciting and acknowledging patients' perspectives, supporting their initiatives, offering choice about treatment options, and providing relevant information, while minimizing pressure and control. Studies have shown that autonomy support has resulted in improved health-related behaviours (see Ryan et al., 2008) and psychological well-being (Deci et al., 2006; Kasser & Ryan, 1999). Studies also provided evidence for relationships between well-being and other types of social support (see Cohen, 2004) and overprotection (Buunk et al., 1996; Thompsom & Sobolew-Shubin, 1993). In patients with ESRD, social support has also been linked to depressive affect and quality of life (see Patel et al., 2005). However, there are studies that did not demonstrate relationships between support and well-being in patient populations (e.g. Buunk et al., 1996; De Ridder et al., 2005).

A possible explanation for the inconsistent findings is that social support is only beneficial for those experiencing adversity, but does not play a role for those without highly stressful demands (stress-buffering hypothesis, see Cohen, 2004). Another explanation is that not all types of support are equally beneficial in face of the demands (Cohen, 2004). Research has shown that emotional support worked in the face of a variety of stressful events, whereas other types of support (e.g. instrumental, informational) responded to specific needs elicited by an event (Cohen, 2004). The main-effect hypothesis of social support, on the other hand, argues that support is beneficial irrespective of whether one is under stress (see Cohen, 2004). In line with this, Ryan and Solky (1996) conclude that autonomy-support not just buffers one from negative outcomes during distress, but actually facilitates development, expression and integration of the self, such as increased self-esteem, self-confidence, achievement, volition, and vitality. Taking this into account, we aimed to investigate the role of emotional support and overprotection in perceived autonomy and self-esteem of patients with ESRD on dialysis. We chose to investigate the relationships in this patient group, since

patients on dialysis and their significant others are highly required to actively deal with the illness demands on a daily basis. More specifically, we investigated whether support is more beneficial for patients with specific illness perceptions. Thereby assuming that illness perceptions can function as indicators for whether patients experience adversity from their illness, and for whether they could (additionally) benefit from coping resources provided by their social environment. We looked at two specific illness perceptions, namely perceptions of *personal control* and *concern*. Assuming that for those who believe that they cannot personally control their illness and those who are highly concerned about their illness, the ESRD is likely to be stressful. It is particularly important to gain insight into these relationships in view of interventions focusing on enhancing social support interactions. In addition, this insight is valuable for the purpose of simultaneously intervening on both patients' illness perceptions and experienced support.

2.4.1 Emotional support combined with perceptions of concern and personal control

First of all, we found that, generally taken, dialysis patients now and then experience emotional support from significant others (including general emotional support, e.g. 'being affectionate', and problem-oriented emotional support, e.g. 'giving a nudge in the right direction') (Jansen et al., submitted). The results furthermore showed that the patient group as a whole does not experience significant lack of emotional support. Moreover, the findings of the regression analyses indicated that the extent to which general emotional support is beneficial for patients' sense of autonomy, depends on the way patients perceive their illness. Looking at concern, we found that general emotional support was positively related to autonomy solely in highly concerned patients. However, looking at personal control we did not find such a relationship between general emotional support and autonomy in patients low in control. General emotional support, however, might not be the most relevant type of support in case people feel that they cannot control or influence their illness. Perhaps other types of support, such as informational support, are more relevant under these circumstances. This is in line with the idea that support functions have to match with the stressors or needs faced with (Cohen, 2004). According to Cohen and Wills (1985) informational support that helps one reappraise a stressor as benign or suggests appropriate coping responses would counter a perceived lack of control. In light of our results that patients in the pre-dialysis phase report considerable worry about their disease, the finding that general emotional support is positively associated with autonomy in high concerned patients is particularly interesting. It was notable, that in patients reporting lower levels of concern, the experience of general emotional support was associated with lower levels of perceived autonomy (though this association was not significant). Due to the cross-sectional design of our study this could be explained in two ways, namely that for people with low levels of concern, the experience of more support results in feeling less autonomous, or that people who feel less autonomous generate more support from their social environment. In contrast to autonomy, one's self-esteem always seems to benefit from general emotional support and furthermore suffers from a lack of it, irrespective of illness perceptions. This might reflect satisfaction or dissatisfaction of the general need for belongingness or relatedness which is important for people's self-esteem (Deci & Ryan, 2000; Leary & Baumeister, 2000). It is further notable that emotional support in case of problems showed no associations at all (no main or buffer effects) with autonomy and self-esteem. This type of support is offered in the face of problems and it could be that this support type cannot boost feelings of autonomy and self-esteem, in light of the problems one is faced with.

2.4.2 Overprotection combined with perceptions of concern and personal control

The patient group as a whole experienced little overprotection by significant others. Experienced overprotection appeared to be associated with lower levels of autonomy and self-esteem. This is a plausible finding, since overprotection refers to unwanted and unnecessary help, and therefore likely detracts from one's feelings of autonomy and self-esteem. Moreover, the negative association between overprotection and autonomy appeared to be stronger in patients experiencing more personal control. This finding indicates that experienced overprotection is most harmful for patients' feelings of autonomy, as they experience high levels of personal control over the illness. However, we did not find such a relationship in patients with low levels of concern. People high in personal control over the illness in particular believe that they can manage the illness themselves. The experience of overprotection therefore might have an extra negative impact, because it gives the impression that others believe that one is not capable in managing the illness.

What have we learned from scientific research?

- the role of support (emotional support and overprotection) in patients' perceived autonomy seems to depend on patients' illness perceptions
- the role of support in patients' self-esteem does not seem to depend on the way patients perceive their illness
- the findings suggest that patients' perceptions of their illness provide insight into whether patients actually experience adversity from their illness, and whether they could (additionally) benefit from support provided by their social environment
- the findings point to the relevance of specifying illness related needs, since the results suggest that patients who are worried or experience little personal control regarding their illness do not benefit from the same support interactions, when it comes to their feelings of autonomy

What is important for clinical practice?

- the findings with respect to autonomy, indicate that the provision of support should be tailored to dialysis patients' individual needs, and that patients' needs should be monitored; the findings should be taken into account when developing interventions focused on supporting patients in their efforts to maintain a sense of autonomy and self-esteem

What needs to be investigated further?

- more research is needed to unravel the interaction effects of illness perceptions and (other) types of social support on outcomes related to patients' well-being (including patients' perceived autonomy and self-esteem)
- the relationships between illness perceptions and social support in relation to outcomes should be investigated longitudinally; this research can provide insight into causal relationships
- research should take into account a broader range of social interactions, such as attitudes and provided support of health care providers, employers, and colleagues

3. Development and evaluation of a psychological intervention

We developed a psychological intervention programme for patients who are being prepared for renal replacement therapy (i.e. pre-dialysis patients) and patients on dialysis for a maximum period of twelve months (for details see Jansen et al., 2011). The intervention

assists patients and their partners in integrating the renal disease and treatment into their daily lives, and aims at maintaining or widening patients' daily activities, including paid work, and thereby increasing patients' feelings of autonomy and self-esteem. The intervention also focused on patients' partners, since family members play an important role in patients' recovery from and adjustment to chronic illness, and are also affected by patients' symptomatology, activity restriction, and need for emotional support or physical assistance (Martire, 2005). It can be expected that this is particularly true for patients' spouses. The intervention focused on patients in the mentioned stages for three reasons: 1) patients in the pre-dialysis phase already seem to experience problems from their illness and treatment in their daily lives, and resignation from paid work seems to occur particularly in this stage of the illness as well as the initiation phase of the dialysis treatment; 2) patients' perceptions regarding their illness and treatment are already maladaptive in the pre-dialysis phase; 3) it seems essential to intervene on perceptions in an early stage of the illness process.

Three theoretical models served as a framework for our intervention: the Common Sense Model of self-regulation of health and illness by Leventhal et al. (CSM; 1984); Social Learning Theory by Bandura (1977a); and Self-Determination Theory by Deci and Ryan (SDT; 1985). The content of the intervention is based on the results of our empirical studies among (pre-)dialysis patients, and targets the psychological factors which showed to be associated with perceived autonomy, self-esteem and labour participation. Additionally, knowledge and experiences of experts in the field of research and practice were used. More specifically, the programme focuses on three aspects:

- The first is stimulating positive but realistic beliefs about the illness, treatment, and the opportunities to stay active in both patients and partners - and in so doing, to change unhelpful, maladaptive beliefs. Partners' beliefs are also addressed, because in order to provide support it seems important that the perceptions of the support providers are constructive and not in conflict with patients' perceptions. A study by Broadbent et al. (2009a) among spouses of MI patients indicates that a brief intervention can change spouses' illness perceptions. Spouses in the intervention group had, amongst other aspects, a higher illness understanding compared to the control group, and they had lower anxiety about their spouses' doing physical activity;
- The second aspect is enhancing patients' beliefs in self-efficacy;
- The final aspect concerns stimulating behaviour that supports autonomy in both patients and partners.

The intervention was pilot tested on feasibility and evaluated on initial experiences of participants, course leaders and health care providers involved (for details see Jansen et al., 2011). The intervention as implemented in the pilot phase, consisted of a group course for a minimum of five patients aged 18-64 years and their partners. Patients from three different dialysis centres were invited to participate via the social workers working in the centres. The course comprised six 2.5-hour sessions every two weeks, and one return session after three months, led by a health psychologist in cooperation with a nephrologist and an employment expert familiar with patients with CKD. Social workers of the participating dialysis centres were also present at one or more sessions. Course material for participants included a handbook which contains assignments and practical and theoretical information. Material for the course leaders included a detailed manual for delivering the course.

3.1 Components of the intervention programme

For the first three sessions the method developed by Petrie et al. (2002) was followed. In these sessions, information is provided about the illness and treatment in relation to the performance of daily activities, paid work in particular. This specific information is given by a nephrologist and an employment expert. Beliefs patients hold about their illness, treatment, and about the importance and attainability of activities related to work and private life are explored and discussed within the group. Special attention is given to perceptions which seem important for patients' feelings of autonomy, self-esteem, and labour participation. These include perceptions of consequences (particularly beliefs that activities including working cannot be combined with dialysis treatment), and beliefs about personal control (particularly beliefs that one cannot influence the course of the illness and one cannot fit the illness and dialysis treatment into daily life). Negative beliefs and misperceptions are challenged, and positive (realistic) beliefs are stimulated. Hereby, broadening participants' views on the opportunities available. Furthermore, the sessions focus on reducing existing concerns about the illness by means of addressing questions and providing information. Techniques that are used to influence beliefs are observational learning techniques, such as didactic teaching, written material, examples of personal stories from peers, and group discussion about personal experiences, wishes and perceived opportunities. The choice for the applied techniques stems from the Common Sense Model (CSM) of illness representations and Social Learning Theory. Illness perceptions are formed on the basis of personal and observed encounters with illness, as well as information from for example medical sources, friends, the Internet, and fellow patients (Kaptein et al., 2008). Social Learning Theory postulates that human beings learn by observing attitudes, behaviours and behavioural outcomes of others (Bandura, 1977a). Furthermore, participants are asked to set a main goal and related sub goals, with respect to employment and private life by the end of the third session. Patients have to evaluate these goals on personal importance and attainability, hereby taking into account the importance of autonomous motivation for the initiation and maintenance of behaviours (see Deci & Ryan, 2000), and the importance of perceived self-efficacy (see Bandura, 1977a, 1977b) or perceived competence (see Deci & Ryan, 2000) for behaviour change. Subsequently, the chosen goals are discussed within the group and adjusted if necessary, and participants learn how to develop action plans in order to reach the sub goals, and ultimately their main goals. From the third session onwards, the participants develop and carry out an action plan every two weeks, helped by their partners.

Changing maladaptive perceptions and stimulating constructive perceptions regarding illness and treatment are first steps towards behaviour change. Support for self-efficacy (Bandura, 1977a, 1977b) and support for autonomy (Deci & Ryan, 1985) are necessary to actually perform the intended behaviour. In sessions four to six, the focus is on these aspects. Beliefs in self-efficacy in relation to activities, including employment, are explored and enhanced using techniques such as self-monitoring, guided mastery of skills through the two-weekly action plans and feedback on progress, modelling of self-management behaviours and problem-solving strategies. These techniques are based on Social Learning Theory, which argues that personal experiences, modelling, social persuasions and physiological states are sources for affecting self-efficacy beliefs (Bandura, 1977b). In the context of self-efficacy, attention is furthermore given to fatigue. Fatigue is a common complaint in patients with chronic kidney disease, and might interfere with the performance of daily activities (Bonner et al., 2010). Patients are asked to keep a fatigue diary in order to

gain insight into existing fatigue complaints and its patterns. The experiences are discussed and advice is given, so that a framework is provided for structuring and prioritising activities and for making the activities more accessible. In so doing, the threshold for carrying out activities is lowered and beliefs of self-efficacy are supported. Resulting in a greater chance of successful implementation of the action plans.

Our study findings showed that the experience of overprotection was associated with lower levels of autonomy and self-esteem, and highlight the importance of promoting autonomy-supportive behaviours. Autonomy-support is enhanced by means of discussing supportive and unsupportive behaviours, by exchanging ways to provide support, to prevent overprotection and to ask for support in an adequate way. These elements were partly derived from the family partnership intervention of Clark and Dunbar (2003). Moreover, autonomy-supportive behaviours in patients and partners are encouraged by means of the implementation of the developed action plans, which enable patients to carry out activities that they personally value with support from their social environment (partners or family members, friends). Furthermore, our findings indicated that the extent to which general emotional support is beneficial and overprotection is harmful for patients' sense of autonomy depends on the way patients view their illness (i.e. perceptions regarding concern and personal control). This suggests that the provision of support has to be tailored to patients' individual illness-related needs and patients' needs have to be monitored. This knowledge should be taken into account when stimulating supportive interactions. In session six, the focus is on the development of an action plan for an employment goal for the next three months, which is personally important and attainable. Patients develop the action plan together with their partners, under guidance of the course leader and employment expert. The plans are discussed within the group, and advice is given on which steps to take and how to contact relevant parties, such as employers and company doctors. During the return session, the outcome of the action plans regarding the employment goal are discussed and evaluated within the group, under guidance of the course leader and employment expert. The participants discuss what the course has given to them, paying attention to how one can maintain or widen the goals that have been achieved.

3.2 Evaluation of the intervention programme

The developed psychological intervention was theory driven. The three theories, providing a framework for our intervention, all focus on different aspects important for self-regulatory processes, including cognitive, emotional, behavioural and contextual aspects. An important component within the intervention is the focus on goals or activities which patients themselves choose and value, i.e. autonomous motivation (instead of controlled motivation), which is associated with greater behavioural persistence and more effective performance (see Deci & Ryan, 2000). According to Michie et al. (2008) there are three main reasons for advocating the use of theory in designing interventions: 1) interventions are likely to be more effective if they target causal determinants of behaviour and behaviour change; 2) theory can be tested and developed by evaluations of interventions only if those interventions and evaluations are theoretically informed; 3) theory-based interventions facilitate an understanding of what works and thus a basis for developing better theory across different contexts, populations and behaviours. Within our intervention we have combined three theories. It could be argued that the number of theoretical frameworks and corresponding components used is relatively high. Behaviour change and its maintenance are however complex processes, and several aspects seem to underlie these processes. We

believe that the components provided by the separate theories are all important for behaviour change, and complement each other well. Another important aspect of our intervention is the multidisciplinary aspect, pooling the knowledge of experts including nephrologists, employment experts, social workers, and peers. The contribution of the employment expert was particularly greatly appreciated by both participants and involved social workers, and should therefore be an integral part of the course.

The intervention mainly has a proactive character. It focuses on prevention of the development of negative beliefs with respect to the illness, treatment and opportunities to stay active in both patients and partners. It stresses anticipating possible future problems due to changing conditions with respect to treatment, physical condition, work situation, and ultimately prevention of unnecessary resignation from paid work and other daily activities.

The participating three dialysis centres endorsed the necessity of this type of assistance. Together the centres approached enough patients eligible for participation (N=28), however the rate of participation was lower than expected (7 participating patients and 5 participating partners). The reasons for not responding indicated that it is important for the course to be fitted into participants' daily schedules. It is therefore advised to be flexible with respect to scheduling future courses (in terms of days / times / locations). Preferences for course times seem to be very personal, since patients differ regarding dialysis and work schedules. One could think of giving the intervention to participants at the dialysis centre while they are on dialysis, or adapting dialysis or work schedules in cooperation with health care providers or employers. It was further notable that no participants younger than 30 years took part, although some were approached. More efforts are needed to reach these younger patients by emphasising that besides employment, attention is given to education and training.

Another issue is that patients may not always see the need for a proactive approach. In particular, those patients who have not experienced any problems in the past. The involved course leaders however stressed that it is important that patients are referred to the course as early as possible, preferably even before CKD stage 4, in order to work preventatively. These patients often have no insight into the consequences of the illness and treatment for their daily life. As a result they are not able to anticipate necessary adjustments in order to prevent problems with employment. Therefore this group of patients are likely to benefit the most from the assistance offered in the course. Thus, there is a perceived need for widening the target group to the earlier stages of CKD (e.g. CKD stage 3). Following this, it seems appropriate to stress the importance of participating in the course, in view of future changes regarding the physical condition, treatment, and employment situation. Patients on dialysis in the more advanced stages of CKD stage 5 were not included in the pilot study. These patients may, however, also benefit from the practical assistance provided during the course. Any existing problems with daily functioning could be addressed. Moreover, possible future changes in circumstances regarding patients' physical condition, treatment modality, or work may bring about new problems.

Furthermore, it seems important that, besides social workers, more different health care providers (e.g. nephrologists, dialysis nurses) are involved in highlighting the course among patients so that the course becomes more integrated into regular care. Naturally, the individual needs of the patients must remain the starting point and taken into consideration at all times. Patients can be too overwhelmed by all the demands imposed by the illness and treatment, and may feel that they are not able to participate in the course on top of all the

other tasks they have to undertake. This may particularly be the case for people who have to start with the dialysis treatment at short notice, or for people who just started with the dialysis treatment. It is then advised that health care providers continue to follow these patients and offer the course again at a later point in time. Furthermore, it would be helpful for health care providers if they have an instrument at their disposal, by which they at a given time can get insight into the most vulnerable patients, i.e. the patients who could benefit the most from the assistance provided by the course and consequently should be included in the course. Connecting to this, it is also important to reflect on whether the course should be offered to all eligible patients, or only to those who may benefit the most from it. Implementation of these types of interventions requires efforts from health care providers and requires financial resources. The health care providers involved in the pilot study reported no unfavourable consequences from their cooperation with the course. Moreover, in the long run, health care providers, especially social workers, might experience favourable consequences, since an intervention of this kind may prevent problems, or anticipates problems, which social workers normally encounter in their regular care.

Regarding the process and content of the intervention, there are both strengths and points for improvement to mention. Important elements within the course included group discussion, giving examples of practice, and didactic teaching. These elements were strategies to broaden participants' views on the available opportunities and, in so doing, to promote positive realistic beliefs. This was also endorsed by one of the participants, who stated that the course gave insight into how "healthy" you still are, and what and how much you still can do. The focus on influencing patients' perceptions can be regarded as an important ingredient of the intervention, and we advise to maintain these elements. The focus on influencing beliefs was also the reason for choosing a group format instead of an individual format, since peer modelling and peer support are useful strategies to influence beliefs. All participants held positive attitudes towards the group element, indicating that they valued the opportunity to exchange knowledge and experiences and had learned from it. The mixture of experiences and information of both patients who were being prepared for dialysis and patients on dialysis was particularly highly valued. The course leaders also indicated that there was a lot of open discussion, cooperation and mutual interest, and thought that it was important to increase the opportunities for discussion and cooperation in order to improve the group process and, in turn, the learning process. This should be achieved by increasing the number of participating patients to at least eight. However, when working with larger groups it is essential to have two main course leaders so that the process with respect to both content and the group will be warranted. A prerequisite for a successful group process, however, is that a trustful, confidential atmosphere is created from the first moment by means of an extensive group introduction, and occasionally putting participants together in smaller groups. Participants are asked to share their feelings and thoughts and these should be reviewed in a non judgmental way.

The topics addressed (e.g. dialysis, employment legislation) within the course appeared to be relevant to all participants. However, an area for attention is how the information given, is tailored to individual preferences. The differences in these preferences may be partly caused by differences in participants' stages of illness and/or treatment. Therefore, the amount of orally presented, discussed general information should be reduced. This information can be offered in the form of written information or on a website instead. On the other hand more time should be spent on exploring and discussing individual needs for information. This can be done throughout the course or by organising separate question times.

The attitudes of the participants towards the exercises were good, particularly the fatigue diary and the action plans. These exercises were tools to enhance beliefs about self-efficacy. Participants indicated that these exercises meant they were more able to divide their time and energy during the day, and one participant stated that creating plans to reach goals gave peace of mind. Based on these experiences, it seems important to preserve these exercises as part of the course. However, some participants encountered difficulties with the exercises: it is recommended tackling this problem by working in small groups, paying more attention to discussion of the exercises and giving more examples regarding the interpretation of the exercises, so that participants are able to relate to them better. It is furthermore advised to reduce the number of action plans.

An advantage of the course was the involvement of partners and attention for the role of the social environment. These aspects were appreciated by both patients and partners. However, increased attention is needed for partners and how they cope with the illness. Participating partners themselves indicated that more opportunities should be created for partners to exchange experiences with respect to how they deal with their partners' illness. Partners for example could work in separate groups occasionally, so that they can talk about their experiences more freely. Clark and Dunbar (2003) stress the importance of taking into account family members' experiences and their own needs for support.

Lastly, patients' self-observed results were encouraging. One patient reported that he found a job and generally became more active. Patients reported that they were able to divide their time and energy better during the day, they learned to involve their social environment in their illness and treatment, and they were more aware of the possible consequences of their illness and were better prepared for possible complications.

What have we learned?

- findings from the pilot study are encouraging and suggest that a theory driven multiple approach - focusing on cognitive, emotional, behavioural, and contextual aspects - is promising
- on the whole it can be concluded that the ingredients of the intervention all have value, however, the total course programme appears very intensive and parts of the sessions should be shortened
- issues that deserve attention are the need for larger course groups, two main course leaders, tailoring information to individual needs, increasing opportunities for discussion, and increasing attention for the needs of the participating partners
- a successful implementation process in regular care is not easy to achieve, despite the efforts of motivated health care providers; many conditions must be met in order to implement interventions successfully

What is important for clinical practice?

- the study elucidated factors that need specific attention when implementing interventions of this kind: the need for insight into patient groups that could benefit from the intervention, awareness of the importance of a proactive approach, early referral, flexibility in scheduling interventions, the need for broad support and cooperation among health professionals for organising and embedding interventions into regular care, the importance of the direct involvement of a multidisciplinary team of experts (i.e. employment expert, social worker, nephrologist, dialysis nurse)

What needs to be investigated further?

- the study meets the emerging need for research regarding development and evaluation of self-regulatory based interventions aimed at improving patient outcomes and CKD patient outcomes in particular; future research needs to evaluate whether the developed and refined intervention leads to lower rates of job resignation, increased feelings of autonomy, and whether the benefits outweigh the efforts, both in the short-term and in the long run
- research needs to address the question at which point in time (i.e. which illness phases) interventions of this kind should be offered to patients
- instruments should be developed by which health care providers can identify patients who could benefit from this type of intervention
- implementation of interventions requires a specific and separate route, which identifies success factors and bottlenecks and takes into account all necessary conditions

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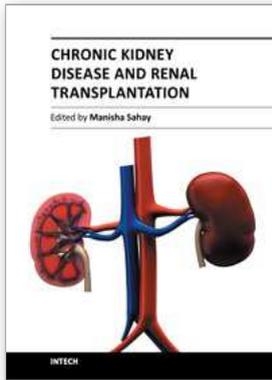
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