

Living with Chronic Kidney Disease
The role of illness perceptions, treatment perceptions
and social support

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Living with Chronic Kidney Disease

Living with Chronic Kidney Disease
The role of illness perceptions, treatment perceptions
and social support

Leven met een chronische nierziekte
De rol van ziektepercepties, behandelpercepties en sociale steun
(met een samenvatting in het Nederlands)

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General introduction

Introduction

This doctoral thesis focuses on the psychological and social aspects of living with Chronic Kidney Disease (CKD). CKD refers to the gradual and permanent loss of kidney function. This implies that the kidneys are losing their essential function to remove waste products and excess fluid from the blood. CKD and the associated medical regimes impose a heavy burden on the daily lives of patients. People with CKD often cannot do their daily activities the way they used to do before they became ill. People need to make changes to their way of life, and adjust to these changes. Seven years ago, NIVEL (Netherlands institute for health services research) conducted a study of the international literature on the consequences of CKD for participation in several domains of life (Heijmans & Rijken, 2004). This study revealed that many patients with CKD experience substantial difficulties in participating in various life domains, such as paid work, sports and other social and leisure activities. As a follow-up on this study, the central question addressed in this thesis is *why some people with CKD do manage to stay active while others do not*. The answer to this question may provide starting points for supporting people with CKD to live their lives the way they want to. This thesis aims to elucidate the role of *psychological factors* in daily functioning of people with CKD. In addition, this thesis focuses on the development and pilot testing of a psychological intervention aimed at assisting patients to maintain or promote their daily activities.

This introductory chapter starts with providing background information on CKD, available treatments, and prevalence and incidence rates. Next, the impact of CKD and its treatment on daily life will be briefly outlined. Subsequently, the objectives and the main research questions of the study will be presented, followed by a description of theories on how psychological factors may impact daily functioning of patients with CKD. The theoretical framework is primarily based upon three theoretical approaches: the Common Sense Model of self-regulation (Leventhal et al., 1980; Leventhal et al., 1984), the Self-Determination Theory (Deci & Ryan, 1985), and the Social Learning Theory (Bandura, 1977a). Furthermore, the research that will be conducted in the scope of this thesis will be briefly

described. This research is guided by the theoretical framework. The chapter ends with the outline of the thesis.

CKD and its treatment

CKD is defined as the presence of kidney damage or decreased level of kidney function for three months or more (NKF-KDOQI, 2002), and can be divided into five stages of increasing severity (Table 1.1). Diabetes and high blood pressure are the leading causes of CKD as well as of cardiovascular disease (NKF-KDOQI, 2002).

Treatments for CKD are based on the stages of the disease. After evaluating and treating the underlying cause of CKD, the treatment focuses on slowing the progression of kidney disease and preventing or treating co-morbid conditions (including cardiovascular disease) and complications (Table 1.1). In CKD stages 1 to 4, treatment usually encompasses pharmacotherapy and diet restrictions. In stage 5 of the disease, end-stage renal disease (ESRD), the kidneys are no longer able to function, and renal replacement therapy - dialysis or kidney transplantation - becomes necessary to maintain life.

Table 1.1: Clinical action plan Chronic Kidney Disease (source: NKF-KDOQI, 2002)

| Stage | Description | GFR | Action ^a |
|-------|---|------------------------------|---|
| | At increased risk for CKD | ≥ 90 (with CKD risk factors) | Screening CKD risk reduction |
| 1 | Kidney damage, with normal or increased GFR | ≥ 90 | Diagnosis and treatment Treatment of co-morbid conditions Slowing progression CVD risk reduction |
| 2 | Kidney damage, with mildly reduced GFR | 60-89 | Estimating progression |
| 3 | Moderately reduced GFR | 30-59 | Evaluating and treating complications |
| 4 | Severely reduced GFR | 15-29 | Preparation for RRT |
| 5 | Kidney failure | < 15 (or dialysis) | RRT |

a) Includes actions from preceding stages.

Abbreviations: GFR, glomerular filtration rate (test to measure level of kidney function); CKD, chronic kidney disease; CVD, cardiovascular disease; RRT, renal replacement therapy.

Renal replacement therapies

Dialysis refers to the treatment for removing wastes or impurities and excess fluid from the blood, which the kidneys can no longer remove. Dialysis is usually initiated when about 90% or more of the kidney function is lost. The dialysis treatment does not take over the kidney function completely, but takes over about 10% of the purifying capacity of healthy kidneys. Dialysis can however not take over the other kidney functions, such as the hormonal functions. There are two main types of dialysis treatment. The first type is *haemodialysis*, where the blood is purified outside the body via a dialysis machine. The dialysis machine contains an artificial kidney that removes waste products and excess fluid from the blood. The patient is connected to the dialysis machine usually about four hours, three times a week. The treatment often is performed during the day at an in-hospital dialysis unit, but can also be carried out at home. There are also increasing opportunities to perform haemodialysis during the night. The second type is *peritoneal dialysis*, where the blood is filtered by means of the patient's peritoneal membrane that lines the abdominal cavity. This procedure is done by

inserting dialysis fluid (dialysate) in the abdominal cavity. The fluid is kept within the abdomen for several hours, and extracts waste products and excess fluid from the blood that flows through the blood vessels in the peritoneal membrane. In peritoneal dialysis, the changes of the dialysis fluid are performed either four or five times each day manually by the patient (Continuous Ambulatory Peritoneal Dialysis (CAPD)), or every night by a machine (cycler) during a 9-hour bed rest (Automated Peritoneal Dialysis (APD)). Peritoneal dialysis can be performed at home, and in case of CAPD it can also be carried out at other places, for example at the workplace (source: Dutch Kidney Foundation, 2011).

Kidney transplantation refers to the operation where a healthy kidney is placed in the patient's body in the lower abdomen. The kidney may come from a deceased or a living donor. While dialysis cannot take over all functions of the kidney, a kidney transplant can. If the kidney is functioning properly, this means that in principle the patient has 50% kidney function. People who have received a kidney transplant have to take medication in order to prevent rejection of the transplanted kidney, and have to stay under control of a doctor. In principle, each patient is eligible for transplantation. The main limiting factor for transplantation is a poor general health condition of the patient. In practice, most patients initially depend on dialysis treatment for their survival, particularly due to a shortage of deceased kidney donors. In the Netherlands, the average waiting time for a deceased donor kidney transplantation is four and half years. Because of the long waiting time, the number of living donor kidney transplantations is increasing (source: Dutch Kidney Foundation, 2011).

Epidemiology of CKD in the Netherlands

In this section we take a closer look at the prevalence and incidence rates of CKD in the Netherlands.

Prevalence rates of CKD

The prevalence rate of CKD refers to the number of people with CKD at a specific moment in the population. According to the Dutch PREVEND study

(De Zeeuw et al., 2005), which used the CKD definition of the NKF-KDOQI (2002), approximately 10% of the Dutch population has some degree of CKD. In 2010, 14,690 people (886 people per million Dutch residents) were receiving renal replacement therapy, i.e. on dialysis treatment or lived with a kidney transplant (CKD stage 5; ESRD). In Table 1.2 the distribution of renal replacement therapies in the Netherlands is presented, by age and for the total patient group. Of those receiving renal replacement therapy, 43% followed dialysis treatment and 57% lived with a kidney transplant. A large majority (82%) of the people treated with dialysis, received haemodialysis. The figures furthermore show that more than half of the patients on dialysis (55%) were 65 years and above, whereas only a quarter of the patients with a transplant were 65 years or older.

Incidence rates of renal replacement therapy

The incidence rate of renal replacement therapy refers to the number of new patients on renal replacement therapy per year. A study by Visser and colleagues (2011) demonstrated that the annual number of new patients that start with renal replacement therapy (adjusted for age and gender) increased from 101.6 in 1998, to 113.3 per million of the Dutch population (pmp) in 2006 (increase of 11.5%). Incidence of renal replacement therapy is the outcome of a complex interplay of many factors that have effects in different directions (Jager & Van Dijk, 2007). The number will, among other factors, be affected by the age and gender distribution in the general population, by the prevalence of underlying causes of ESRD, by the access to and quality of health care, and by successful prevention of mortality due to other diseases which comprise a so-called 'competing risk' for the development of ESRD (Jager & Van Dijk, 2007).

Table 1.2: Distribution of renal replacement therapies in the Netherlands, at January 1st 2010, by age group and total group

| Age group | Type of renal replacement therapy | | | |
|-----------|-----------------------------------|---------------------|-------------------|---------------|
| | Haemodialysis | Peritoneal dialysis | Kidney transplant | |
| 0 - 15 | 24 (0.5%) | 18 (1.6%) | 118 (1.4%) | |
| 16 - 44 | 573 (11.1%) | 163 (14.3%) | 2,095 (24.9%) | |
| 45 - 64 | 1,585 (30.7%) | 457 (40.2%) | 4,105 (48.9%) | |
| 65 - 74 | 1,228 (23.8%) | 260 (22.9%) | 1,643 (19.6%) | |
| ≥ 75 | 1,745 (33.9%) | 239 (21.0%) | 437 (5.2%) | |
| Total | 5,155 (35%) | 1,137 (8%) | 8,398 (57%) | 14,690 (100%) |

Source: Renine Foundation

Epidemiology of CKD in a broader perspective

In this section we look at the prevalence and incidence rates of CKD as reported by studies conducted in the United States as well as Europe.

Prevalence rates of CKD

Studies carried out in Europe (the Netherlands, Spain and Norway) on the prevalence of CKD, showed percentages ranging from 5.1 to 7.0 for stages 1 and 2 combined, from 4.5 to 5.3 for stage 3, and from 0.1 to 0.4 for stage 4 (De Jong et al., 2008). The total prevalence of CKD stages 1-4 reported by these studies ranged from 10.5 to 12.7% (De Jong et al., 2008). Research in the United States, in the period 1999-2004, showed that the prevalence of CKD stages 1 and 2 was 5.0%, stage 3 was 7.7%, and stage 4 was 0.4%, resulting in a total prevalence of CKD stages 1-4 of 13.1% (Coresh et al., 2007). These findings indicate that about one out of ten people suffers from CKD stages 1 to 4 worldwide.

In 2008, the overall prevalence of renal replacement therapy across Europe - among all registries reporting to the ERA-EDTA Registry - was 644 pmp (Stel et al., 2011). The proportion of people on renal replacement therapy receiving dialysis (haemodialysis and peritoneal dialysis) in 2008, ranged from 30 to 93% across Europe (ERA-EDTA Registry, 2010). By the end of 2005, approximately 1,9 million people were receiving renal replacement

therapy (CKD stage 5; ESRD) worldwide, with about three-quarters treated by dialysis and one-quarter by kidney transplant (Grassmann et al., 2006).

Incidence rates of renal replacement therapy

Stel and colleagues (2011) reported an overall incidence rate of renal replacement therapy across Europe of 122 pmp in 2008. A European study by Kramer et al. (2009) on the incidence rates of renal replacement therapy during 1997-2006, demonstrated that the annual rise of the overall incidence rate (adjusted for age and gender) has diminished. Incidence rates of renal replacement therapy vary considerably worldwide (Caskey et al., 2011).

The study by Kramer et al. (2009) furthermore showed that, in Europe, the survival of patients on renal replacement therapy continued to improve between the periods 1997-2001 and 2002-2006. The authors stated that this might not only be due to technical improvements in renal replacement therapy, but also to a better condition of patients starting renal replacement therapy due to increased awareness of the importance to detect and treat patients with CKD to delay its progression.

Impact on daily life

CKD imposes a heavy burden on patients' lives, in particular for patients on dialysis treatment. Patients on dialysis experience multiple symptoms, with pain, fatigue, pruritus (i.e. itchy skin) and constipation in the majority of the patients (Murtagh et al., 2007). Patients are extremely dependent on the dialysis treatment as well as pharmacotherapy, and the dialysis treatment is very time-consuming.

Along with the development of improved survival of patients on dialysis, the quality of the prolonged life - also referred to as health-related quality of life - has gained more attention. Health-related quality of life refers to patients' experiences of the impact of the condition and its treatment on their life, and is a multidimensional concept which includes physical, psychological and social functioning domains (WHO, 1948). Having ESRD (CKD stage 5) and following dialysis treatment obviously have major impact

on patients' functioning, as well as that of their significant others. Patients are confronted with restrictions regarding food and fluid intake, physical symptoms such as lack of energy, as well as tasks, constraints and side-effects associated with the medical treatment. The intense demands associated with both the disease and treatment may cause that work and other daily activities, social contacts, family and partner relationships become subject to pressure, and may also give rise to psychological stressors. Neto et al. (2000) showed that patients' quality of life is already lowered at the initiation of dialysis treatment, which was clearly evidenced in the role limitations due to physical function and emotional function aspects. Various studies demonstrated impaired functioning with respect to physical, mental, and social domains in patients in a later phase of the dialysis treatment, compared to general population samples (e.g. Khan et al., 1995; Merkus et al., 1997; Molsted et al., 2007).

Labour participation

The study of the international literature, conducted by NIVEL, on the consequences of CKD for participation in several domains of life (Heijmans & Rijken, 2004) revealed that it is in particular difficult to combine dialysis treatment with a paid job. Dialysis patients aged below 65 less often perform paid work, compared to general working-age populations (Braun Curtin et al., 1996; De Wit et al., 2001; Theorell et al., 1991; Van Manen et al., 2001), with labour participation rates ranging from about 20 to 40%. It is notable that people who are being prepared for renal replacement therapy (pre-dialysis patients; CKD stage 4) already experience work-related problems. Results from a Dutch study published ten years ago, indicated that many patients resign from their jobs before the start with dialysis treatment: at the start of the treatment only 35% of the patients, aged 18 to 64 years, had a paid job compared to 61% in the general population in 1997, the year the study was carried out (Van Manen et al., 2001). In line with this, a more recent Swedish study among (pre-) dialysis patients demonstrated that 32% of the pre-dialysis patients experienced limited work capacities, and 34% of the patients reported inability to work. In addition, 30% of the pre-dialysis patients reported limitations regarding vacation activities. Among the dialysis patients, 53% experienced limited work capacities, 61% reported

inability to work, and 52% experienced limitations with respect to vacation activities (Ekelund & Andersson, 2007).

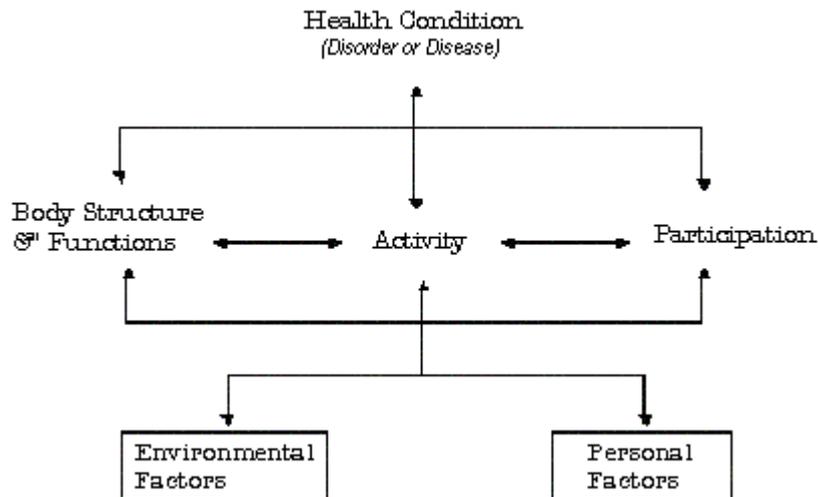
Restrictions on the quantity or quality of daily activities, and the performance of paid work in particular, might impede people's feelings of autonomy and self-esteem. People often regard the performance of paid work as an important activity. It generates income, which in turn makes it possible to participate in other life domains as well. Moreover, work provides extra social contacts, opportunities for self-development and can contribute to people's self-esteem. A review of the literature showed that work is generally good for physical and mental health and well-being, and that unemployment is associated with negative health effects (Waddell & Burton, 2006). Research on the social and behavioural consequences of suffering renal disease are being examined increasingly, however the amount of conducted research on these topics in patients with renal disease is relatively low compared to other patient populations (Kaptein et al., 2010).

In light of the findings from the studies discussed above it is, more specifically, important to gain insight into *why some patients with CKD succeed in keeping high levels of autonomy and self-esteem, and maintaining employment, whereas others do not*. As in the general population, socio-demographic factors, such as age, gender and educational level, play a role in the degree to which patients with CKD participate in for example paid work (Statistics Netherlands - CBS). Furthermore, clinical characteristics might be of influence, such as patients' health condition. Results of the study by Heijmans and Rijken (2004) suggested that psychological factors may play an important role in patients' labour participation and feelings of autonomy as well. In particular the way patients view their illness and treatment, and the extent to which people in patients' social environment support them in their efforts to carry on with daily activities. This was particularly illustrated by Braun Curtin et al. (1996), who showed that patients' perceptions that their health limited the type and amount of work that they could do were negatively associated with employment. In addition, they found that patients who themselves believed that patients on dialysis should work, and had this notion reinforced by significant others (e.g. doctors, family members) were more likely to be employed. These findings are of great

interest since the employed and unemployed patient groups did not differ with respect to objective health indicators. In this thesis we therefore continue to focus on these specific elements.

This focus on the role of personal factors and environmental (or external) factors in daily functioning outcomes is consistent with the International Classification of Functioning, Disability, and Health (ICF) of the World Health Organisation (WHO, 2001; National institute for public health and the environment - RIVM, 2002). According to this classification system, human functioning, including the performance of activities and participation in society, is not only influenced by the individuals' health condition, but also by personal factors (e.g. gender, age, education, personality, lifestyle, experiences and skills) and factors in the physical and social environment in which people live (e.g. home and work environment, personal contacts with family, friends, colleagues, norms, government services, legislation) (Figure 1.1).

Figure 1.1: International Classification of Functioning, Disability, and Health (ICF) (WHO, 2001)



Thus, in order to influence patients' functioning it is, besides focusing on the disease itself, just as important to focus on how patients handle their disease, and on the interaction between patients, their disease and their (social) environment.

Objectives and research questions of the thesis

Previous research shows that, compared to healthy people, people with CKD participate less in various domains of life, particularly the domain of paid work. Restriction of the quantity or the quality of daily activities may have serious drawbacks for people's feelings of autonomy and self-esteem. Recognising the importance of these aspects for people's well-being, it is important to address the question why patients with CKD differ in their levels of perceived autonomy, self-esteem, and in the extent to which they participate in paid work. In this study, psychological factors considered relevant for patients' daily functioning will be examined. Whereas it is not always possible to influence clinical and socio-demographic characteristics, psychological factors are potentially modifiable and therefore might provide starting points for improving outcomes. Consequently, insight into the role of these factors is particularly interesting.

More specifically, this study aims to investigate the association between a) patients' perceptions of their illness and treatment as well as b) patients' experienced social support on the one hand, and patients' perceived autonomy, self-esteem and labour participation on the other hand. This will be investigated by means of several empirical studies. These empirical studies are conducted in pre-dialysis patients (CKD stage 4) and patients on dialysis (CKD stage 5; ESRD), since for these patients the most problems can be expected. A further aim is to develop a psychological intervention - based on the results of the empirical studies and theoretical models - for (pre-) dialysis patients (aged 18-64 yrs) and their partners. This intervention, a group course, aims at maintaining or widening patients' daily activities, including the performance of paid work, and thereby increasing patients' feelings of autonomy and self-esteem. The third objective is to implement the developed psychological intervention on a small scale, and to evaluate

the intervention on feasibility and first experiences (process evaluation), by means of a pilot study. The objectives of this thesis result in **two main research questions**:

- 1) To what extent do (pre-) dialysis patients feel autonomous, experience self-esteem and perform paid work, and to what extent can we explain variation therein from differences in perceptions of illness and treatment and experienced social support?
- 2) What should a psychological intervention look like, that supports participation in daily activities – paid work in particular – as well as perceived autonomy and self-esteem?

Theoretical models

For this study a theoretical framework was developed. The theoretical framework used, is primarily based upon three psychological theoretical models: the Common Sense Model of self-regulation (Leventhal et al., 1980; Leventhal et al., 1984), the Self-Determination Theory (Deci & Ryan, 1985), and the Social Learning Theory (Bandura, 1977a). These three theories offer an explanation of human behaviour, and each highlight different aspects of regulation of human behaviour and behaviour maintenance. Therefore, all three theories will be considered, and discussed separately.

Common Sense Model or Self-regulation model

The Common Sense Model (CSM; Leventhal et al., 1980; Leventhal et al., 1984) - a self-regulation model of health and illness - provides an explanation for different behavioural and emotional responses to acute as well as chronic diseases. According to CSM people make sense of a health threat by developing - in parallel - their own cognitive and emotional representations of that threat, which in turn determine how patients cope with their illness and adjust to their illness. Patients with the same medical condition can have widely different perceptions of their condition (Petrie & Weinman, 2006). This indicates that people with the same medical condition differ with respect to the way they cope with the demands of the illness and adjust to the illness. The representations or perceptions develop from

exposure to a variety of social and cultural sources of information (Cameron & Moss-Morris, 2010), and generally consist of the following components:

- *identity* - beliefs about the illness label and associated symptoms;
- *consequences* - beliefs about effects of the illness on physical, social and psychological well-being;
- *timeline* - beliefs about the expected duration of the illness;
- *control/cure* - beliefs about the extent to which the illness can be controlled or cured through treatment and behaviours;
- *cause* - beliefs about factors or conditions believed to have caused the illness;
- *coherence* - beliefs about how well one understands the illness.

The emotional representations refer to beliefs about the affective responses associated with the illness, for example whether one experiences worry or anxiety in response to the illness. To illustrate: the belief that the illness will have serious consequences for one's work-related activities (illness perception), may induce concern (emotional representation), lead to absence from work or resignation (behavioural response), and feelings of depression (emotional response). The outcomes of the coping behaviours are being appraised, and these appraisals lead to refinements of the representations, and the selection of new coping behaviours (Cameron & Moss-Morris, 2010). Research among patients with various medical conditions has shown that illness perceptions are associated with various (adaptive) outcomes, including role, social and physical functioning, vitality, psychological well-being (Hagger & Orbell, 2003), as well as eating and exercise self-efficacy, attending rehabilitation, and self-management (Petrie et al., 2007).

Medical treatment is often an important part of the disease process. Research has shown that patients' beliefs about their medical treatment (i.e. beliefs about necessity and concerns) also play a role in how patients cope with and adapt to their illness; beliefs about treatment have been associated with adherence and treatment decisions (Horne et al., 2007; Horne & Weinman, 2002).

Previous studies have pointed to the importance of the role of significant others and their illness perceptions for patients' coping with and adaptation to chronic illness. Heijmans et al. (1999) found that dissimilarity of illness

perceptions of chronically ill patients and their spouses has a strong impact on patients' adaptive outcomes, such as physical functioning, social functioning, psychological adjustment and vitality. In addition, research demonstrated that incongruence between chronically ill patients' and general practitioners' ideas about disease-related stressors was associated with a worse health status of the patient and an increase in health-care use (Heijmans et al., 2001).

CSM research in patients with CKD

Several empirical studies have examined the illness perceptions and treatment perceptions of patients with CKD. Studies demonstrated relationships between dialysis patients' illness perceptions and treatment perceptions on the one hand, and several aspects of quality of life on the other hand. Associations were observed between quality of life aspects on the one hand, and perceptions of consequences of the illness and treatment (Fowler & Baas, 2006; Griva et al., 2009; Timmers et al., 2008), emotional response (Covic et al., 2004; Fowler & Baas, 2006; Timmers et al., 2008), timeline (Covic et al., 2004), personal control (Covic et al., 2004; Timmers et al., 2008), and illness identity (Timmers et al., 2008) on the other hand. A Dutch study among patients on dialysis furthermore showed that patients on peritoneal dialysis held more favourable illness perceptions regarding personal control and understanding than patients treated with haemodialysis (Timmers et al., 2008).

Interventions

Petrie and colleagues were one of the first to translate the principles of CSM into a psychological intervention, in order to change maladaptive illness perceptions of patients about their (first) myocardial infarction (Petrie et al., 2002; Petrie et al., 1996). In this (individual) intervention patient's causal beliefs were explored, misperceptions were refuted, and patient's causal model was broadened by including the importance of lifestyle factors. Consequently, patients were provided more avenues for personal control of the disease. Beliefs about personal control were strengthened by trying out lifestyle changes with the help of predesigned personal action plans. Furthermore, highly negative beliefs about the consequences, and the timeline of the myocardial infarction were challenged. Patient's action plan

was reviewed, and patients learned to distinguish harmless from specific symptoms pointing out to a new infarction. RCT study results suggest that the intervention was able to change patients' beliefs about control/cure, timeline and consequences, and resulted in improved functional outcome and an earlier return to work in myocardial infarct patients (Petrie et al., 2002).

Some years ago, a pilot study was published describing the results of a simple intervention to change treatment perceptions of patients on haemodialysis, who used phosphate-binding medication to prevent cardiac disease (Karamanidou et al., 2008). The intervention consisted of a group session in which an information leaflet was discussed with the investigator, and a demonstration of a phosphate binder was given. This brief intervention seemed to be able to improve treatment beliefs and knowledge immediately after the intervention, but this did not result in an increase in medication adherence. The authors suggested that a more comprehensive approach is needed for sustained change in beliefs and behaviours related to treatment.

Self-Determination Theory

Self-determination theory (SDT; Deci & Ryan, 1985) is a model of human motivation. SDT emphasises the importance of *autonomy* for human functioning, and offers a framework for the explanation of behaviour change and maintenance.

Autonomy

SDT considers *autonomy* as one of three basic psychological needs - along with the need for relatedness and the need for competence - that energizes human activity and must be satisfied for long-term psychological health (Deci & Ryan, 2000). 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). Reis et al. (2000) found that daily variations in the satisfaction of the need for autonomy, as well as competence and relatedness, independently predicted daily variations in well-being. In SDT, self-esteem is a by-product of the dynamics of the three basic psychological needs; when the fulfilment of the need for autonomy, or

competence or relatedness is hindered, one's experience of self-worth is also damaged leading to either insecure or low self-esteem (Ryan & Brown, 2003).

Behaviour change and maintenance

The idea of basic psychological needs helps explain the initiation and maintenance of behaviours or activities. According to SDT, successful accomplishment and maintenance of desired behaviours occurs when people are able to satisfy their basic psychological needs, while they pursue and attain the desired activities (see Deci & Ryan, 2000).

One of the requirements for the satisfaction of the needs, 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), and not because it is pressured or coerced by for example one's spouse or health care provider (controlled motivation). Whether people will be autonomous in regulating behaviour can be predicted from individual characteristics (e.g. the extent to which people are self-determined in general) as well as characteristics of relevant social contexts.

Social environments that support a person's autonomy, facilitate more autonomous regulatory processes, and consequently promote effective and maintained behaviour change. 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. In light of this, it is important to note that autonomy is different from independence (Deci & Ryan, 2000). Being independent implies that one does not rely on support from others, while a person who is autonomous can still depend on for example knowledge, guidance and support from others. To be autonomous means to feel volitional or willing to engage in a behaviour, whereas to be independent means to act without reference to or support from another (Ryan, 1993; Ryan & Lynch, 1989, as cited in Williams, 2002).

Support for autonomy has been associated with improved health-related behaviours, such as greater intake of fruits and vegetables, more physical

activity, reductions in smoking, and improved adherence to prescribed medications (see Ryan et al., 2008). Furthermore, positive relationships have been found between autonomy support with respect to various contexts (e.g. work organisations, friendships contexts, and nursing homes) on the one hand, and psychological well-being on the other hand (Baard et al., 2004; Deci et al., 2006; Kasser & Ryan, 1999).

Interventions

Clark and Dunbar (2003) translated the principles of SDT into a family partnership intervention developed for patients with heart failure and their family members. Through this intervention, patients' family members learned to use autonomy-supportive behaviours (opposed to controlling behaviours) to support patients with the required lifestyle changes. Patients learned how to recruit the support they felt was needed in an effective and positive way. Another purpose was to reduce possible negative caregiver outcomes. The intervention was tested by means of a pilot study for effects on improving dietary sodium self-management in persons with heart failure (Dunbar et al., 2005). The study compared the family partnership intervention, combined with an education intervention, with an education intervention for patients and family members. The results indicated that patients who received the family partnership intervention (in combination with education) had greater self-management in dietary sodium behaviours than patients who received education alone (Dunbar et al., 2005).

Following the description of the Common Sense Model and Self-Determination Theory, it is important to address the difference between *personal control* and *autonomy* (Deci & Ryan, 2000). In SDT autonomy refers to acting in accordance with one's own interests or values. Personal control beliefs on the other hand reflect beliefs regarding the extent to which one feels that one can control or influence an outcome, for example one's illness outcomes, with a behaviour.

Social Learning Theory

Social Learning Theory (SLT; Bandura, 1977a, 1977b) also provides a framework for the explanation of behaviour change, and postulates that

most behaviour is learned observationally through modelling. People learn by observing behaviours and behavioural outcomes of others (models).

Within this theory expectations of self-efficacy play an important role in the initiation and retention of new behaviour. Bandura (1977b) defines a self-efficacy expectation as the conviction that one can successfully execute the behaviour required to produce outcomes. These expectations determine whether behaviour will be initiated, how much effort will be expended, and how long it will be sustained in the face of obstacles and aversive experiences (1977b). Sources affecting self-efficacy beliefs are: performance accomplishments, vicarious experiences (or modelling), verbal/social persuasion, and physiological states (Bandura, 1977b). Furthermore, outcome expectancies play a role in the initiation and maintenance of behaviour. According to Bandura (1977b) an outcome expectation is a person's estimate that a given behaviour will lead to certain outcomes. Thus, if people believe that a behavioural action will lead to a (positive) outcome they will adopt that behaviour, but only if they consider themselves able to do so (self-efficacy).

Interventions

Improving patients' self-efficacy beliefs is a key element of the Chronic Disease Self-Management Programme (CDSMP; Lorig et al., 2001). Studies evaluating the CDSMP have demonstrated positive effects on self-efficacy, self-management behaviour, health status, and health care utilisation, although not consistently so in all studies (Elzen et al., 2007). Elzen and colleagues did not yield any evidence for the effectiveness of the CDSMP on the above mentioned outcomes in chronically ill older people in the Netherlands (Elzen et al., 2007, 2008).

It should be noted here that both self-determination theory and social learning theory contain hypotheses with respect to feelings of capability to engage in a behavioural activity (concept of *competence* in self-determination theory, and concept of *self-efficacy* in social learning theory). However, in the self-determination model of change, it is stressed that gaining a sense of competence is facilitated by autonomy (Ryan et al., 2008), and that

competence is only sufficient to ensure adherence when it is accompanied by volition and autonomy (Ryan et al., 2008).

Combining and applying the theories

The theories described above all offer an explanation for initiation and maintenance of (health-related) behaviours. *CSM* explains behavioural outcomes through patients' cognitive and emotional representations of their illness. By means of changing illness perceptions and treatment perceptions, that are negatively related to desired outcomes, into more constructive and positive perceptions, outcomes may be improved. The representations develop from exposure to a variety of social and cultural sources of information, and are refined based upon outcome appraisals. Changing perceptions of illness and treatment therefore might be achieved by means of providing people with positive (realistic) information, and by people's own experiences.

SLT predicts behaviour initiation and maintenance under the condition of positive outcome expectations and self-efficacy expectations, and - as well as *CSM* - stresses that these expectancies are influenced by the social environment and people's personal experiences. For example by: successful personal performances, receiving feedback or encouragements from others, or observing successful outcomes of other people.

SDT stresses the importance of autonomy for optimal human functioning. *SDT* furthermore postulates that for effective and maintained behaviour change to occur, people must be able to satisfy their basic psychological need for autonomy (along with the need for competence and relatedness) while pursuing and attaining the desired activities. According to *SDT*, this need fulfilment can be accomplished by means of personal characteristics and by social contexts that are autonomy-supportive.

Thus, in order to initiate and maintain desired behaviours in people with *CKD* it seems important that patients' perceptions of *CKD* and its treatment do not form barriers or obstacles for the desired behaviours. In addition, it seems important that the desired behaviour is accompanied by the experience of autonomy and self-efficacy.

Empirical studies

Empirical studies were conducted in order to investigate the first (main) research question:

To what extent do (pre-) dialysis patients feel autonomous, experience self-esteem and perform paid work, and to what extent can we explain variation therein from differences in perceptions of illness and treatment, and experienced social support?

The findings will provide insight into whether illness perceptions and treatment perceptions are related to patients' feelings of autonomy, self-esteem and labour participation. We hypothesise that *as patients hold more constructive perceptions of CKD and its treatment, they will perceive more autonomy, self-esteem, and are more likely to be engaged in paid work*. Based upon previous studies among patients with CKD as well as studies among myocardial infarct patients, we particularly expect associations between perceptions of *personal control* and *consequences* on the one hand, and perceived autonomy, self-esteem, and labour participation on the other hand. In view of influencing relevant perceptions of illness and treatment in order to improve outcomes, we aim to gain insight into the illness perceptions and treatment perceptions across the trajectory of CKD in (pre-) dialysis patients. This knowledge is important for determining whether perceptions vary across the illness trajectory and, consequently, whether interventions could potentially target perceptions of patients with CKD stage 4 and 5. It is assumed that illness representations are constantly updated as new illness knowledge and illness experience are acquired (Leventhal et al., 1984). Therefore we hypothesise that *CKD patients' illness perceptions and treatment perceptions change across the CKD trajectory*.

Because of the importance placed on the role of the social environment in patients' outcomes, we are also interested in the role of social support - including overprotection - in patients' feelings of autonomy and self-esteem. When focusing on both *personal* and *external* aspects, it is however important to take into account the possibility that these aspects may interact with each other, and cannot be viewed separately. Insight into this matter is important in view of developing interventions that focus on enhancing social support interactions, and that intervene on support and illness perceptions

simultaneously. The impact of social support, an external coping resource, might be different for people who personally view their illness, and subsequently cope with their illness, differently. This can be illustrated further using the *stress-buffering model*. According to this model social support is only beneficial for physical and psychological well-being, for those experiencing adversity, but does not play a role for those without highly stressful demands (see Cohen & Wills, 1985). We will therefore examine whether the association between social support on the one hand, and feelings of autonomy and self-esteem on the other hand, depends on how patients perceive their illness. Or in other words, is social support more beneficial for patients with specific illness perceptions? We hypothesise that *the strength of the relationships between support and autonomy, and support and self-esteem will depend on patients' illness perceptions*.

The empirical studies were connected to two on-going cohort studies among patients in the pre-dialysis phase and patients in the dialysis phase, PREPARE-2 and NECOSAD-2, respectively. Through these cohort studies, additional data were collected for the present study in 2006. Below a brief description of both cohort studies is provided.

NECOSAD-2

The NETHERLANDS COOPERATIVE Study on the Adequacy of Dialysis phase 2 (NECOSAD-2) is a prospective cohort study, started in 1997, analysing the factors that contribute to the effect of dialysis treatment (both haemodialysis and peritoneal dialysis) (Termorshuizen et al., 2003; Timmers et al., 2008). Inclusion criteria were: being older than 18 years, and having no previous history of renal replacement therapy. Since 1997, more than 2,000 patients on dialysis were recruited on a continuous basis in more than 40 dialysis centres and hospitals in the Netherlands. Within NECOSAD-2 clinical (medical records) and quality of life (self-report) data are collected every six 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.

For the present study, patients on dialysis still being followed in the NECOSAD-2 cohort in January 2006, were invited to participate (N=250).

Twenty-seven hospitals, participating in the NECOSAD-2 study, contributed to the implementation of the current study. These hospitals are situated in the provinces: North Brabant (Den Bosch, Eindhoven); Drenthe (Emmen); Flevoland (Almere); Friesland (Leeuwarden); Gelderland (Arnhem, Doetinchem, Nijmegen); Groningen (Groningen); Limburg (Heerlen, Maastricht, Roermond, Venlo); North Holland (Alkmaar, Amsterdam, Hilversum, Zaandam); Overijssel (Deventer, Enschede); South Holland (Den Haag, Leiden); and Utrecht (Nieuwegein, Utrecht).

PREPARE-2

The PREdialysis PATients REcords-study phase 2 (PREPARE-2) is a multi-centre prospective observational study, started in 2004. The aim of the study is to examine factors associated with deterioration in renal function in patients with severe chronic renal insufficiency. 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 six 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 transplant was within the previous year. 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 participating in the study. Clinical (medical records) and quality of life (self-report) data are collected at inclusion, and every six months thereafter until start of dialysis, transplantation, end of study or death, whichever occurs earliest. 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, all patients who were participating in the PREPARE-2 study during the period July-December 2006 were invited to participate (N=185). Seventeen hospitals, participating in the PREPARE-2 study, contributed to the implementation of the current study. These hospitals are situated in the provinces: North Brabant (Breda, Eindhoven, Roosendaal, Veldhoven); Drenthe (Emmen); Gelderland (Ede); Groningen (Groningen); North Holland (Amsterdam, Haarlem, Zaandam); Overijssel (Zwolle); and South Holland (Den Haag, Gouda, Leiden, Leiderdorp).

Development and pilot phase intervention

Based on the results of the empirical studies and the described theoretical models a psychological intervention for (pre-) dialysis patients and their partners was developed. This intervention aims at maintaining or widening patients' daily activities - including the performance of paid work - and thereby increasing patients' feelings of autonomy and self-esteem. By means of a pilot study the developed psychological intervention was implemented on a small scale, and evaluated on feasibility and initial experiences (process evaluation). The findings provide an answer to the second (main) research question:

What should a psychological intervention look like, that supports participation in daily activities – paid work in particular – as well as perceived autonomy and self-esteem?

Outline of the thesis

The chapters 2 to 6 cover five papers each addressing specific research questions.

Chapter 2 describes the extent to which dialysis patients (CKD stage 5) perceive autonomy and experience self-esteem, and the degree to which they participate in paid work. This chapter furthermore discusses the content of dialysis patients' illness perceptions and treatment perceptions, and the extent to which patients' perceptions of their illness and treatment are associated with autonomy, self-esteem and labour participation. We hypothesise that *as patients on dialysis hold more constructive perceptions of CKD and its treatment (in particular perceptions of personal control and consequences), they will perceive more autonomy, self-esteem, and are more likely to be engaged in paid work.* The data used in this chapter are based upon a cross-sectional study among dialysis patients of the NECOSAD-2 cohort.

Chapter 3 encompasses the results regarding the perceived autonomy, experienced self-esteem, and labour participation reported by patients in the

pre-dialysis phase (CKD stage 4). This chapter furthermore describes the illness perceptions and treatment perceptions of pre-dialysis patients, and the association between these perceptions on the one hand and perceived autonomy, self-esteem and labour participation in pre-dialysis patients on the other hand. We hypothesise that *as pre-dialysis patients hold more constructive perceptions of CKD and its treatment (in particular perceptions of personal control and consequences), they will perceive more autonomy, self-esteem, and are more likely to be engaged in paid work.* The results presented in this chapter are based upon cross-sectional study data collected within the PREPARE-2 study.

Chapter 4 addresses the question whether the illness perceptions and treatment perceptions of (pre-) dialysis patients vary across the CKD trajectory. By investigating these relationships, the dynamics of patients' illness perceptions and treatment perceptions across the illness trajectory can be elucidated. We hypothesise that *CKD patients' illness perceptions and treatment perceptions change across the trajectory of CKD.* The findings are based upon cross-sectional data from pre-dialysis patients (PREPARE-2), and cross-sectional as well as longitudinal data from patients on dialysis (NECOSAD-2).

Chapter 5 examines to what extent patients on dialysis experience social support (including overprotection) from significant others. In addition, this chapter presents the results of the role of experienced support in perceived autonomy and self-esteem of patients on dialysis. More specifically, it addresses the question whether the association between support on the one hand, and autonomy and self-esteem on the other hand, depends on patients' illness perceptions regarding concern about the illness and personal control over the illness. We hypothesise that *the strength of the relationships between support and autonomy, and support and self-esteem will depend on patients' illness perceptions regarding concern and personal control.* The findings are based upon cross-sectional study data collected among dialysis patients of the NECOSAD-2 cohort.

Chapter 6 describes the development of the psychological intervention for (pre-) dialysis patients and their partners, and outlines the framework and

components of the intervention programme. Furthermore, this chapter presents the results of the pilot study on the implementation of the intervention, and evaluation of the intervention on its feasibility and initial experiences.

Lastly, the main findings from this thesis and the implications of these findings are presented and discussed in *Chapter 7*. This chapter furthermore deals with the methodological considerations, and the directions for future research as well as for practice.

2

Perceived autonomy and self-esteem in Dutch dialysis patients: The importance of illness and treatment perceptions

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Abstract

Background

Compared to healthy people, end-stage renal disease (ESRD) patients participate less in paid jobs and social activities. This study explored the perceived autonomy, state self-esteem and labour participation in ESRD patients on dialysis, and the role illness and treatment perceptions play in these concepts.

Methods

Patients completed questionnaires at home or in the dialysis centre (N=166). Data were analysed using bivariate and multivariate analyses.

Results

Labour participation among dialysis patients was low, the average autonomy levels were only moderate, and the average self-esteem level was rather high. On the whole, positive illness and treatment perceptions were associated with higher autonomy and self-esteem, but not with labour participation. Multiple regression analyses demonstrated that illness and treatment perceptions explained 18 to 27% of the variance in autonomy and self-esteem. Perceptions of personal control, less impact of the illness and treatment, and less concern were important predictors.

Conclusions

Our results indicate that dialysis patients' beliefs about their illness and treatment play an important role in their perceived autonomy and self-esteem. Stimulating positive (realistic) beliefs and altering maladaptive beliefs might contribute to a greater sense of autonomy and self-esteem, and to social participation in general. Interventions focusing on these beliefs may assist patients to adjust to ESRD.

Introduction

End-stage renal disease (ESRD) is a chronic condition which is becoming more common worldwide. In this stage of the disease, patients require renal replacement therapy (haemodialysis, peritoneal dialysis, renal transplantation). At the end of 2004, approximately 1,783,000 people worldwide were undergoing treatment for ESRD (Grassmann et al., 2005). In January 2006, 12,038 people in the Netherlands received renal replacement therapy (737 people per million Dutch residents) (Oppe et al., 2007). ESRD is characterized by specific disease aspects and intensive treatment demands. ESRD patients on dialysis experience multiple symptoms, with pain, fatigue, pruritus and constipation in the majority of the patients (Murtagh et al., 2007). In addition, the dialysis treatment is very time consuming and places a large burden on patients' daily lives. Having ESRD and receiving renal replacement therapy has many consequences for different domains of life. Results of a literature study (Heijmans & Rijken, 2004) show that compared to healthy people, renal patients who are being prepared for, or receive renal replacement therapy participate less in paid jobs, sports and other social and leisure activities. A study among Dutch renal transplant patients revealed that in these patients participation in employment and sports is lower than healthy persons (Van der Mei et al., 2007). Thus, having ESRD and undergoing treatment has a negative impact on participation in different domains of life.

Restriction of the number of activities or the quality of activities can have serious drawbacks for a person's feelings of autonomy and self-esteem. According to Deci and Ryan's (1985) Self-determination theory, autonomy is one of people's basic psychological needs, and satisfaction of this need is linked to well-being. Reis et al. (2000) found that perceived autonomy independently predicted daily well-being. State self-esteem refers to the feelings of self-worth depending on a person's experience. Crocker and Wolfe (2001) proposed that good and bad events in domains in which self-esteem is invested raise or lower momentary feelings of self-esteem around a person's trait level of self-esteem. Paradise and Kernis (2002) found that high self-esteem and stable self-esteem were associated with greater psychological well-being. In addition to autonomy and self-esteem, labour

participation is considered important for well-being. A review of the literature showed that there is strong evidence that work is generally good for physical and mental health and well-being, taking into account the nature and quality of work and its social context (Waddell & Burton, 2006). A study among haemodialysis patients showed that, compared to patients without work, working patients have increased self-esteem, higher quality of life, and more positive attitudes towards work (Rasgon et al., 1993).

Little is known about the factors that impede perceived autonomy, (state) self-esteem and labour participation in ESRD patients. Obviously, socio-demographic characteristics like age, and clinical characteristics like severity of the illness are important. Results from the literature study by Heijmans and Rijken (2004) suggest that psychological factors may be important determinants of labour participation and perceived autonomy of renal patients as well. In particular, the way patients perceive their illness might play a role. A study by Braun Curtin et al. (1996) demonstrates that dialysis patients with and without a paid job differed regarding their attitudes towards work. Patients with a job did not feel limited by their illness during the hours they worked, and did not feel limited with respect to the type of work they could do. Patients without work on the other hand, perceived their illness as a barrier to find work. These findings are interesting since both patient groups did not differ with respect to illness severity and treatment modality.

Patients' beliefs about their illness are the central concepts of the Common Sense Model (CSM) (Leventhal et al., 1980; Leventhal et al., 1984). This model suggests that individuals hold certain views about their illness which in turn determine how they respond on a behavioural and emotional level to their illness. Individuals' illness representations include beliefs about symptoms, the causes and prognosis of the illness, the consequences of the illness and the possibilities for control. Research, among patients with various medical conditions, shows that illness perceptions are associated with various outcomes including role, social and physical functioning, vitality, psychological well-being, and self-management (Hagger & Orbell, 2003; Petrie et al., 2007). Besides illness representations, patients' ideas about

treatment also play a role in the way patients cope with their illness (Horne, 2003; Horne et al., 2004).

In the literature, several studies examined the illness and treatment perceptions of renal patients (e.g. Griva et al., 2009; Timmers et al., 2008). Illness and treatment perceptions appeared to be more favourable in transplanted patients compared to dialysis patients (Griva et al., 2009), and peritoneal dialysis (PD) patients held more favourable illness perceptions compared to patients treated with haemodialysis (HD) (Timmers et al., 2008). Furthermore, the studies showed that illness perceptions and treatment perceptions contribute significantly to several aspects of quality of life. More perceived symptoms, more perceived negative consequences and a lower personal control were associated with a lower level of well-being (Timmers et al., 2008).

So far, no studies have been conducted with respect to the role of illness and treatment perceptions in perceived autonomy, self-esteem and labour participation in renal patients. An interesting study among myocardial infarction (MI) patients, however, showed that illness perceptions are related to return to work (Petrie et al., 1996). In particular, perceptions of the duration and the consequences of the illness predicted the speed of return to work. Inspired by these promising results, the aim of the present study was to examine the role of illness and treatment perceptions in perceived autonomy, state self-esteem and labour participation of dialysis patients. The following research questions were formulated:

- 1) To what extent do dialysis patients experience autonomy, and state self-esteem and participate in the work domain, and are there differences in perceived autonomy, state self-esteem and labour participation according to socio-demographic and clinical characteristics?
- 2) To what extent are illness and treatment perceptions in dialysis patients related to perceived autonomy, state self-esteem and labour participation?

Methods

Participants and procedure

Dialysis patients who were participating in the longitudinal Netherlands COoperative Study on the Adequacy of Dialysis phase 2 (NECOSAD-2) (Termorshuizen et al., 2003; Timmers et al., 2008), were invited to participate in the present study. The NECOSAD-2 study was approved by the Medical Ethical Committees of the participating dialysis centres and hospitals. Inclusion criteria were: being older than 18 years, and having no previous history of renal replacement therapy. Since 1997, more than 2,000 dialysis patients were recruited. Within NECOSAD-2 clinical and quality of life data are collected every 6 months. For the present study, an additional survey was conducted in March/April 2006 among the 248 patients still being followed in the NECOSAD-2 cohort. The questionnaires were handed out by the nurses in the dialysis centres. Patients filled in the questionnaires at home or in the dialysis centre and returned them by mail. Out of the 248 patients contacted, 166 patients returned the questionnaire (response rate 67%).

Measures

Outcome variables

Perceived autonomy was assessed with three items derived from the autonomy scale of the CASP-19 (Hyde et al., 2003), which has been used in several studies (Marmot et al., 2003; Taylor et al., 2003). One item 'My health stops me from doing the things I want to do' (reverse scored) was used as an indicator for 'health related autonomy'. The other two items were combined on the basis of their high factor loadings on one factor (both factor loadings: 0.81, variance explained: 66%) to assess 'global autonomy' ('I can do the things that I want to do', 'I feel that I can please myself what I can do'). Items were scored on a 4-point scale (0 = never, 1 = sometimes, 2 = not so often, 3 = often). Global autonomy scores are expressed as average scores based on the two items. Higher scores on both measures signify a higher level of perceived autonomy.

State self-esteem was measured with the Current Thoughts Scale (Heatherton & Polivy, 1991), which comprises 20 items (e.g. 'I am worried

about what other people think of me' (reverse scored)). Items were rated on a 5-point scale (1 = not at all, 2 = a little bit, 3 = somewhat, 4 = very much, 5 = extremely). Scores are summed across individual ratings with higher scores representing a higher level of state self-esteem. The scale has been used in several studies (Baumeister et al., 2005; Chang & Mackenzie, 1998). The Cronbach's alpha for the scale in the current study was 0.88. Labour participation was defined in conformity with Statistics Netherlands (CBS), as performance of paid work for at least 12 hours per week.

Predictor variables

Illness perceptions were assessed using the Brief Illness Perception Questionnaire (Broadbent et al., 2006). This scale is a brief version of the Revised IPQ (Moss-Morris et al., 2002). The scale includes eight items scored on an 11-point scale, ranging from 0 to 10. Each item assesses a cognitive or emotional illness representation dimension. A higher score on the eight dimensions implies greater perceived influence of the illness upon life ('consequences'), a stronger belief in a chronic time course ('timeline'), greater perceived personal control over the illness ('personal control'), greater perceived treatment control over the illness ('treatment control'), greater experience of severe symptoms as a result of the illness ('identity'), greater feelings of concern about the illness ('concern'), better understanding of the illness ('understanding'), and stronger emotional response to the illness ('emotional response'). A ninth open-ended response item assessing the patients' causal representation was not included in the study. The Brief IPQ has proven to be a reliable and valid measure of illness perceptions in a variety of illness populations (Broadbent et al., 2006).

Treatment perceptions were assessed with the Treatment Effects Questionnaire (TEQ; originally developed as the IEQ-Tx by Greenberg and Peterson (2002); adapted by Griva et al. (2009)). The TEQ consists of 20 items (e.g. 'My life revolves around this treatment'), scored on an 8-point scale (0 = strongly disagree to 7 = strongly agree). Scores are summed across individual ratings with higher scores indicating greater perceived disruption from the treatment. The TEQ has been used in a study with ESRD patients (Griva et al., 2009). The Cronbach's alpha for the scale in the current study was 0.91.

Background variables

Socio-demographic characteristics included age, gender, marital status¹ and educational level. Marital status was defined as married/living together versus living alone. Educational level was defined as the highest level of completed education and 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). Clinical characteristics¹ included time on dialysis (in years), type of dialysis treatment (HD/PD), and severity of the health condition. 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 et al., 1993; Churchill et al., 1992; Lowrie & Lew, 1990; Plantinga et al., 2007).

Statistical analysis

Differences between the non-responders and responders regarding socio-demographic and clinical characteristics were tested by means of Student's t and Chi-square tests.

In order to answer the first research question, descriptive statistics were computed to describe the extent to which dialysis patients participate in the work domain and experience autonomy and self-esteem. Relationships between background variables on the one hand and labour participation, perceived autonomy and self-esteem on the other hand were assessed by use of analysis of variance (ANOVA) and Chi-square tests.

In order to answer the second research question, associations between illness perceptions, treatment perceptions and perceived autonomy, self-esteem, labour participation were analysed by means of Pearson's correlation coefficients and Student's t-test. Furthermore, hierarchical multiple linear regression analyses were performed, using the enter method, to examine the effect of illness and treatment perceptions on perceived autonomy and state self-esteem, with adjustment for socio-demographic and clinical characteristics. Three blocks of variables were entered separately; block 1: Socio-demographic variables (age, gender, marital status, educational level); block 2: Clinical variables (time on dialysis, type of dialysis treatment,

¹ These data were derived from the last regular survey carried out under NECOSAD-2.

severity of the health condition); block 3: Illness and treatment perceptions variables. Due to small sample sizes we were not able to perform a regression analysis with regard to labour participation.

Results

Study sample

Characteristics of the total sample are outlined in Table 2.1. Approximately, two thirds of the study sample were male which corresponds with the figures of the population of ESRD patients in the Netherlands (61%) (Renine Foundation, 2005). Around two-thirds of the participants were 65 years or older. Compared to figures of the Dutch dialysis population in 2006 (49% 65 years or older) (Oppe et al., 2007), our sample comprised a higher percentage of older patients. A large majority of respondents (71%) were treated with HD, which is comparable with the percentage HD patients within the Dutch dialysis population (74%) (Renine Foundation, 2005). No significant differences between the study sample and the non-responders were found with regard to gender, age, marital status, type of treatment, time on dialysis and serum albumin level.

Perceived autonomy

The mean global autonomy score of the total sample was 1.60, which indicates that patients do not often experience a sense of autonomy in daily life (Table 2.2). ANOVA analysis showed differences with regard to educational level ($F(2, 146) = 3.29, p=0.040$): high-educated patients had significantly higher scores on global autonomy than low-educated patients. A mean score of 1.21 on the health related perceived autonomy item indicates that patients sometimes experience health related autonomy (Table 2.2). No significant differences were found with respect to socio-demographic and clinical characteristics.

Table 2.1: Socio-demographic and clinical characteristics of the total sample

| | Total Sample | |
|--|-----------------------|---------|
| Gender - N (%) | | |
| Male | 106 | (64) |
| Female | 59 | (36) |
| Age, mean in years (SD) | 66.6 range: 32-89 | (11.69) |
| Age, in groups - N (%)* | | |
| 18-49 years | 16 | (10) |
| 50-64 years | 46 | (28) |
| ≥ 65 years | 104 | (63) |
| Educational level - N (%) | | |
| Low | 61 | (39) |
| Moderate | 68 | (44) |
| High | 27 | (17) |
| Marital status - N (%) | | |
| Married/living together | 104 | (66) |
| Living alone | 53 | (34) |
| Type of treatment - N (%) | | |
| Haemodialysis | 118 | (71) |
| Peritoneal Dialysis | 48 | (29) |
| Time on dialysis, mean in years (SD) | 3.6 range: 0.1-9.0 | (2.34) |
| Time on dialysis, in groups - N (%) | | |
| Up to 2 years | 51 | (31) |
| 2 to 5 years | 76 | (46) |
| 5 to 10 years | 39 | (23) |
| Serum albumin, mean in g/L (SD) ** | 36.9 range: 22.6-45.8 | (4.44) |

* Due to rounding the sum of percentages is > 100%.

** Normal serum albumin values are 40-50 g/L.

State self-esteem

The mean state self-esteem score of the total patient group was 76.47, which indicates a rather high level of state self-esteem (Table 2.2). ANOVA analysis demonstrated that men scored higher on state self-esteem compared to women ($F(1, 152) = 4.05, p=0.046$). No significant differences were found with regard to the other background characteristics.

Labour participation

Sixty-two people were of working age (18–64 years). Fifteen people performed paid work for at least 12 hours per week (24%), which is much lower than the general Dutch population; in 2006, the labour participation rate among the Dutch population aged 15–64 years was 65% (Statistics Netherlands - CBS, 2006). Patients who worked were working for 32.4 hours per week on average (range 12–40 hours). Forty-one people (66%) were not employed (for at least 12 hours per week). The employment status of six people (10%) was unknown. The results of the ANOVA analysis showed that employed patients were significantly younger than unemployed patients ($F(1, 54) = 7.88, p=0.007$). No significant differences were found with regard to the other background variables.

Illness and treatment perceptions

Mean illness perceptions scores indicate that dialysis patients, as a group, consider their illness to be chronic with rather serious consequences, experience quite a few symptoms from the illness, are fairly concerned about their illness, but experience rather little emotional impact from the illness. In addition, patients reported a considerable degree of understanding and consider their illness to be highly controllable with medical treatment but not by self-care. Furthermore, patients experience moderate disruption from the treatment (Table 2.2). Pearson's correlations coefficients between the illness and treatment perceptions were all below 0.60, except for the correlation of emotional response with concern and treatment disruption (Table 2.2). Patients with a stronger illness identity experience more consequences of the illness and treatment, less personal control, more concern and a stronger emotional response. At the same time, they believe to have a better understanding of their illness. As patients experience more impact from the illness and treatment, they experience more severe symptoms, have more concern, have a stronger emotional response and believe they have little personal control. Personal control and treatment control are both correlated with understanding.

Table 2.2: Mean scores, standard deviations (N=154-157) and Pearson's correlations (N=151-156) of illness perceptions, treatment perceptions, perceived autonomy and state self-esteem (total sample)

| | M | (SD) | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-------------------------|-------|---------|---------|--------|--------|-------|---------|---------|-------|---------|---------|
| Consequences | 7.73 | (2.01) | | | | | | | | | |
| Timeline | 9.19 | (1.68) | .07 | | | | | | | | |
| Personal control | 4.91 | (3.20) | -.17* | | | | | | | | |
| Treatment control | 8.28 | (2.03) | .14 | .31*** | .16* | | | | | | |
| Identity | 6.14 | (2.43) | .43*** | -.02 | -.20* | .03 | | | | | |
| Concern | 6.31 | (3.00) | .35*** | -.05 | -.07 | -.01 | .50*** | | | | |
| Understanding | 7.66 | (2.70) | -.01 | .10 | .23** | .23** | .25** | .13 | | | |
| Emotional response | 4.96 | (3.22) | .38*** | -.09 | -.05 | -.07 | .43*** | .71*** | .01 | | |
| Treatment disruption | 63.40 | (25.04) | .43*** | -.04 | -.26** | -.12 | .56*** | .52*** | -.03 | .62*** | |
| Global autonomy | 1.60 | (0.78) | -.24** | .06 | .30*** | .16* | -.28*** | -.24** | .20* | -.20* | -.34*** |
| Health related autonomy | 1.21 | (0.92) | -.39*** | -.06 | .17* | -.04 | -.28** | -.29*** | -.12 | -.41*** | -.40*** |
| State self-esteem | 76.47 | (10.86) | -.26** | .05 | .21* | .18* | -.30*** | -.47*** | .21** | -.52*** | -.60*** |

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

Associations between illness and treatment perceptions and outcome variables Pearson's correlations between illness and treatment perceptions on the one hand and perceived autonomy and state self-esteem on the other hand, show a consistent pattern with stronger beliefs in the seriousness of the illness being associated with lower perceived autonomy and less state self-esteem (Table 2.2). A stronger belief that the treatment disrupts daily life was also associated with low perceived autonomy and low state self-esteem. The dimension timeline was not associated with perceived autonomy and state self-esteem. Within the group of working age, the relationships between labour participation (unemployed vs. employed) and the illness and treatment perceptions were also examined. Greater experience of severe symptoms as a result of the illness was significantly associated with unemployment ($t(41.846) = 2.17, p=0.036$). The other perceptions were not significantly associated with labour participation (Table 2.3).

Table 2.3: Differences in mean illness and treatment perceptions scores between employed and unemployed patients within working age (18-64 yrs)

| | Employed | | Unemployed | | t | df | p |
|----------------------|----------|---------------|------------|---------------|-------|--------|-------|
| | N | M (SD) | N | M (SD) | | | |
| Consequences | 15 | 7.53 (1.68) | 40 | 8.30 (1.98) | 1.330 | 53 | .189 |
| Timeline | 15 | 8.13 (2.56) | 40 | 8.65 (1.96) | .801 | 53 | .427 |
| Personal control | 15 | 5.53 (3.85) | 40 | 4.48 (3.58) | -.957 | 53 | .343 |
| Treatment control | 15 | 7.53 (2.59) | 40 | 8.45 (2.25) | 1.291 | 53 | .202 |
| Identity | 15 | 5.53 (1.55) | 40 | 6.78 (2.58) | 2.173 | 41.846 | .036 |
| Concern | 15 | 6.80 (2.46) | 40 | 6.80 (3.35) | .000 | 53 | 1.000 |
| Understanding | 15 | 7.13 (3.07) | 40 | 8.25 (2.50) | 1.386 | 53 | .172 |
| Emotional response | 15 | 5.27 (2.63) | 40 | 5.65 (3.22) | .411 | 53 | .682 |
| Treatment disruption | 15 | 62.19 (25.29) | 38 | 71.99 (25.29) | 1.271 | 51 | .209 |

Predicting perceived autonomy and state self-esteem

Since emotional response was highly correlated with both concern and treatment disruption and the correlation between concern and treatment disruption was below 0.60 (Table 2.2), we decided not to include the dimension emotional response in the following regression analyses for reasons of multicollinearity. First, regression analysis was conducted with

global autonomy being the outcome variable. The results revealed that the socio-demographic variables (block 1) explained only 4% of the variance in global autonomy (Table 2.4). High educational level appeared to be a significant predictor. In model two the clinical variables were added, increasing the explained variance by only 2%. In addition to a high education, being treated with PD appeared to be a significant predictor. Adding the illness and treatment perceptions to the model (block 3) the percentage of explained variance was increased to 24%. Apart from educational level, a perception of high personal control contributed significantly to the explanation of perceived global autonomy.

Table 2.4: Hierarchical multiple linear regressions models to predict perceived global autonomy in dialysis patients (total sample)

| | Model 1 (block 1) (N=105) Beta | Model 2 (block 1+2) (N=105) Beta | Model 3 (block 1+2+3) (N=105) Beta |
|---|--------------------------------------|--|--|
| Block 1: Socio-demographic characteristics | | | |
| Age in years | -.05 | .03 | -.09 |
| Female (ref: male) | -.06 | -.06 | -.06 |
| <i>Educational level (ref: low)</i> | | | |
| - moderate | .19 | .18 | .21* |
| - high | .28* | .26* | .25* |
| Marital status (ref: married/living together) | .09 | .13 | .09 |
| Block 2: Clinical characteristics | | | |
| Serum albumin | | -.02 | -.07 |
| PD treatment (ref: HD) | | .22* | .10 |
| Time on dialysis in years | | -.07 | -.06 |
| Block 3: Perceptions | | | |
| Consequences | | | -.12 |
| Timeline | | | .14 |
| Personal control | | | .29** |
| Treatment control | | | -.02 |
| Identity | | | -.08 |
| Concern | | | .12 |
| Understanding | | | .12 |
| Treatment disruption | | | -.25 |
| Adjusted R square | .04 | .06 | .24*** |
| F change model | 1.83 | 1.70 | 3.95*** |

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

The results of the regression analysis with health related perceived autonomy being the outcome variable (Table 2.5) demonstrated that only the third model, in which the illness and treatment perceptions were added, explained a substantial amount of variance (18%) with perceptions of less consequences of the illness and less impact of the treatment being the only significant contributors to perceived health related autonomy.

Table 2.5: Hierarchical multiple linear regressions models to predict perceived health related autonomy in dialysis patients (total sample)

| | Model 1 (block 1) (N=105) Beta | Model 2 (block 1+2) (N=105) Beta | Model 3 (block 1+2+3) (N=105) Beta |
|---|--------------------------------------|--|--|
| Block 1: Socio-demographic characteristics | | | |
| Age in years | .05 | .07 | -.13 |
| Female (ref: male) | -.11 | -.11 | .01 |
| <i>Educational level (ref: low)</i> | | | |
| - moderate | .02 | .02 | .04 |
| - high | -.04 | -.04 | -.08 |
| Marital status (ref: married/living together) | .02 | .05 | -.02 |
| Block 2: Clinical characteristics | | | |
| Serum albumin | | .05 | .03 |
| PD treatment (ref: HD) | | .06 | -.10 |
| Time on dialysis in years | | .02 | .12 |
| Block 3: Perceptions | | | |
| Consequences | | | -.26* |
| Timeline | | | .14 |
| Personal control | | | .10 |
| Treatment control | | | .03 |
| Identity | | | -.03 |
| Concern | | | -.01 |
| Understanding | | | -.18 |
| Treatment disruption | | | -.32* |
| Adjusted R square | -.04 | -.06 | .18** |
| F change model | 0.30 | 0.20 | 4.55*** |

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

Finally, we conducted a regression analysis with state self-esteem being the outcome variable. Table 2.6 shows that again the socio-demographic variables (block 1) and the clinical variables (block 2) did not explain any substantial amount of variance. However, in the final model in which the illness and treatment perceptions were included, the percentage of explained variance increased by 27%. Less concern about the illness and less perceived disruption from the treatment appeared to be significant predictors of state self-esteem.

Table 2.6: Hierarchical multiple linear regressions models to predict state self-esteem in dialysis patients (total sample)

| | Model 1 (block 1) (N=105) Beta | Model 2 (block 1+2) (N=105) Beta | Model 3 (block 1+2+3) (N=105) Beta |
|---|--------------------------------------|--|--|
| Block 1: Socio-demographic characteristics | | | |
| Age in years | .02 | .09 | -.02 |
| Female (ref: male) | -.20 | -.21* | -.07 |
| <i>Educational level</i> (ref: low) | | | |
| - moderate | .08 | .10 | .05 |
| - high | .12 | .11 | .08 |
| Marital status (ref: married/living together) | -.09 | -.03 | -.17 |
| Block 2: Clinical characteristics | | | |
| Serum albumin | | .19 | .12 |
| PD treatment (ref: HD) | | .10 | -.09 |
| Time on dialysis in years | | -.09 | -.07 |
| Block 3: Perceptions | | | |
| Consequences | | | -.04 |
| Timeline | | | -.08 |
| Personal control | | | .07 |
| Treatment control | | | .09 |
| Identity | | | .12 |
| Concern | | | -.26* |
| Understanding | | | .13 |
| Treatment disruption | | | -.41** |
| Adjusted R square | .02 | .04 | .31*** |
| F change model | 1.51 | 1.67 | 5.53*** |

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

Discussion

The present study was conducted to examine perceived autonomy, state self-esteem and labour participation in ESRD patients who are on dialysis treatment, and to investigate the extent to which illness and treatment perceptions are related to perceived autonomy, state self-esteem and labour participation in dialysis patients.

The results confirmed previous findings that ESRD patients on dialysis participate less in the work domain (Braun Curtin et al., 1996; De Wit et al., 2001; Van Manen et al., 2001). Only 15 out of the 62 patients of working age indicated to perform paid work for at least 12 hours per week. Furthermore, the average reported levels of perceived autonomy were not very high, which indicates that because of their health condition or otherwise patients feel less autonomous in their lives.

Correlational analyses showed that patients who held more positive beliefs about the illness and treatment experienced more autonomy (both global and health related). The results of the regression analysis confirmed these findings; illness and treatment beliefs explained a large amount of variance in predicting both global and health related perceived autonomy after controlling for socio-demographic and clinical variables. Perceptions of the personal controllability of the illness appeared to be an important predictor of global autonomy; experiencing the ability to personally control the illness is associated with autonomy feelings. In light of these findings it is important to address the difference between the constructs personal control and autonomy, since autonomy is often incorrectly equated with ideas of internal locus of control (Deci & Ryan, 2000; Ryan, 1995). Personal control beliefs reflect individuals' beliefs regarding the extent to which one feels that one can control or influence an outcome, for example one's illness. However, people are autonomous when they act in accord with their authentic interests or integrated values and desires (Chirkov et al., 2003; Deci & Ryan, 1985, 2000; Ryan, 1995). To make the distinction more explicit, a person can feel control over carrying out an exercise programme, but not feel intrinsically motivated, and thus do not act in accordance with his/her own values. Beliefs that the illness and treatment have little impact on life

showed positive associations with health related autonomy after controlling for socio-demographic and clinical variables. Patients who do not feel that the illness and the treatment impede their lives do not feel that their health stops them from doing the things they would like to do.

Considering the mean state self-esteem score it seems that the majority of the patients did not suffer from low state self-esteem. The regression analysis results revealed that the illness and treatment perceptions contributed substantially to the explanation of state self-esteem. Less concern about the illness and beliefs that the impact of the treatment on life is low were significant predictors of a higher state self-esteem.

It should be noted that a large amount of variance in perceived autonomy and state self-esteem remains still unexplained. Other psychological factors which could be of influence are the extent to which a patient is being supported by people in his immediate surroundings, like his partner, family or doctors. It can be expected that patients who are being stimulated to carry out daily activities participate more than patients who receive little support or who are being overprotected. Research focusing on these aspects is needed.

Not surprisingly, we found a low labour participation among dialysis patients compared to the general Dutch population. The results further showed that as people are younger they participate more in the labour domain, which is consistent with findings in the general Dutch population (Statistics Netherlands - CBS, 2006). Unfortunately, we were not able to demonstrate clear relationships between illness and treatment perceptions and labour participation, defined as performance of paid work for at least 12 hours per week. We also investigated the relationships between number of working hours per week and illness and treatment perceptions by computing correlation coefficients, and on the whole the results were the same. Nonetheless most of these perceptions were consistently related to (un-)employment. Absence of clear relationships might be caused by the small group sizes; the number of patients of working age was very low in this study. Another possible reason for the fact that we did not find significant relationships between illness and treatment perceptions and

labour participation may be the fact that the working age group was relatively old and older people might not value a paid job similarly important than younger people. The domains from which people derive their self-worth (e.g. abilities, achievements) are rather stable, but goals can be chosen moment by moment (Crocker & Park, 2004). Possibly other life goals like doing volunteer work or carry out hobbies become more important and work moves into the background. When trying to increase feelings of autonomy and self-esteem in patients, it therefore seems important to take into account the life domains people find really important, explore their corresponding goals and focus on these goals. For younger renal patients work is probably a more important theme. Research among younger renal patients is recommended to investigate the relationship between illness and treatment perceptions and labour participation more thoroughly.

It is important to note that the present study had a cross-sectional design, which means that no conclusions can be drawn with respect to the causality of the found relationships. Thus, it is not clear whether the positive representations of the illness and treatment are a cause or a result of greater feelings of autonomy and self-esteem. Longitudinal research is necessary to investigate the direction of these relationships. Notwithstanding this limitation, our results demonstrate that especially feelings of personal control over the illness, feelings that the illness and treatment do not have that much impact on life, and less concern about the illness are important factors for autonomy and state self-esteem of ESRD patients. Another issue to note is the usage of single-item measures in this study in order to minimise the burden on respondents. Single-item measures are sometimes viewed as less psychometrically sound than multiple-items. However, several studies demonstrate that single-item measures and their multiple counterparts are comparable (Gardner et al., 1998; McKenzie & Marks, 1999). Moreover, Gardner et al. (1998) show that a well-developed single item measure can be appropriate in avoiding common methods variance, which is often a problem with psychological measures that require respondent self-reports of attitudes, beliefs, perceptions, and the like.

The present study suggests that it may be important that paying attention to the perceptions of renal patients of their illness and the treatment should be integrated in the standard care these patients receive. Patients with the same medical condition differ in their perceptions of their illness and treatment (Weinman et al., 1996). For this reason patients' personal beliefs about personal control, the impact of the illness and treatment on daily life and feelings of concern should be explored. Stimulating (realistic) positive beliefs and identifying and challenging negative or unhelpful beliefs might contribute to a greater sense of autonomy and self-esteem as well as to social participation in general. Petrie et al. (2002) demonstrated that illness perceptions of patients with a first myocardial infarction (MI) could be changed by a psychological intervention, which started when the patients were still in hospital, and resulted in improved functional outcome and earlier return to work. Although ESRD might be far more disruptive than MI, the results from the present study suggest that ESRD patients' beliefs are important for perceived autonomy and self-esteem, and other study results show that these beliefs can be changed (Karamanidou et al., 2008; Petrie et al., 2002). There is no reason why similar interventions would not work for renal patients. In the Netherlands, psychological support is not yet a primary area of attention in renal care. It is therefore important that psychological interventions are developed and tested.

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3

Pre-dialysis patients' perceived autonomy, self-esteem and labour participation: Associations with illness perceptions and treatment perceptions

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Abstract

Background

Compared to healthy people, patients with Chronic Kidney Disease (CKD) participate less in paid jobs and social activities. The aim of the study was to examine a) the perceived autonomy, self-esteem and labour participation of patients in the pre-dialysis phase, b) pre-dialysis patients' illness perceptions and treatment perceptions, and c) the association of these perceptions with autonomy, self-esteem and labour participation.

Methods

Patients (N=109) completed questionnaires at home. Data were analysed using bivariate and multivariate analyses.

Results

The results showed that the average autonomy levels were not very high, but the average level of self-esteem was rather high, and that drop out of the labour market already occurs during the pre-dialysis phase. Positive illness and treatment beliefs were associated with higher autonomy and self-esteem levels, but not with employment. Multiple regression analyses revealed that illness and treatment perceptions explained a substantial amount of variance in autonomy (17%) and self-esteem (26%). The perception of less treatment disruption was an important predictor.

Conclusions

Patient education on possibilities to combine CKD and its treatment with activities, including paid work might stimulate positive (realistic) beliefs and prevent or challenge negative beliefs. Interventions focusing on these aspects may assist patients to adjust to CKD, and ultimately prevent unnecessary drop out of the labour market.

Introduction

Chronic renal failure, also referred to as end-stage renal disease (ESRD; chronic kidney disease (CKD) stage 5), is a permanent condition which requires renal replacement therapy (peritoneal dialysis, haemodialysis or transplantation) to maintain life. At the end of 2005, approximately 1,9 million people were receiving renal replacement therapy worldwide (Grassmann et al., 2006). In January 2006, 12,038 people in the Netherlands received renal replacement therapy (737 people per million Dutch residents) (Oppe et al., 2007). ESRD is associated with specific disease and treatment aspects. Patients with ESRD often experience physical symptoms such as fatigue, pain, cramps and itching (Thong et al., 2009). Furthermore, patients are extremely dependent on treatment and the treatment itself - dialysis in particular - places substantial behavioural and psychosocial demands on the patient.

Neto et al. (2000) showed that the quality of life of ESRD patients is already lowered at the initiation of dialysis treatment, which was clearly evidenced in the role limitations due to physical function and emotional function aspects. Various studies demonstrated lowered quality of life of patients with ESRD in a later phase of the dialysis treatment compared to general population samples (Khan et al., 1995; Merkus et al., 1997; Merkus et al., 1999; Mittal et al., 2001; Timmers et al., 2008). Results of a literature study revealed that people with chronic renal insufficiency experience difficulties in participating in various domains of life, such as paid work, sports and other social and leisure activities (Heijmans & Rijken, 2004). It seems in particular difficult to combine dialysis treatment with a paid job: several studies found labour participation rates around 24% in dialysis patients aged below 65 (Braun Curtin et al., 1996; Jansen et al., 2010; Theorell et al., 1991). It is notable that people with CKD who are being prepared for renal replacement therapy (pre-dialysis patients; CKD stage 4) already experience work-related problems. Results from a Dutch study showed that patients mainly drop out the labour market before the start with dialysis treatment: at the start of the treatment only 35% of the patients, aged 18 to 64 years, had a paid job compared to 61% in the general population in 1997, the year the study was carried out (Van Manen et al., 2001). 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 dialysis patients reported stressors with respect to work and leisure time (Ekelund & Andersson, 2007).

Restrictions on labour participation can have serious drawbacks for a person's well-being. Work is generally good for physical and mental health and well-being, and unemployment is associated with negative health effects (Waddell & Burton, 2006). Moreover, participation in general is important for feelings of autonomy and self-esteem. According to Self-Determination Theory (SDT) autonomy is one of the basic psychological needs for optimal functioning (Deci & Ryan, 1985). Reis et al. (2000) found that variations in the fulfilment of autonomy independently predicted variability in daily well-being. Factors in the person or situation that facilitate autonomy are thus expected to enhance well-being, whereas factors that detract from fulfilment of this need will undermine well-being. In the SDT view, self-esteem is a derivative or by-product of need dynamics. 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). The feelings of self-worth depending on a person's experience, is referred to as state self-esteem. Research showed that high as well as stable self-esteem are associated with greater psychological well-being (Paradise & Kernis, 2002).

In light of these findings it is important to uncover the factors that influence feelings of autonomy, self-esteem and labour participation in patients with CKD. Socio-demographic factors (e.g. age, educational level) and medical factors (e.g. severity of the health condition, type of treatment) obviously determine the extent to which patients with CKD participate in paid jobs. Besides these factors, psychological factors may be important for labour participation and perceived autonomy as well, in particular the way patients view their illness and treatment (Heijmans & Rijken, 2004). Braun Curtin et al. (1996) demonstrated that employed dialysis patients did not feel limited by their health in the hours they worked or the kind of work in which they could engage. Unemployed patients on the other hand, perceived their

illness as a barrier to work. These findings are important since both patient groups did not differ with respect to objective health indicators.

Patients' beliefs about their illness are the central concepts of the Common Sense Model (CSM), which is a self-regulation model of health threat (Leventhal et al., 1980; Leventhal et al., 1984). This model aims to explain patients' responses to illness from the cognitive representations patients hold of their medical condition. Five domains of illness representations have been identified: (1) the identity or label (e.g. 'renal disease') with associated emotions ('it makes me afraid') and symptoms ('tiredness', 'itching'); (2) timeline, reflecting patients' expectations about the duration of the condition and its characteristic course (acute, chronic, or episodic); (3) cause, reflecting patients' ideas about how one gets the disease (e.g. by stress or bad luck); (4) beliefs about the cure or controllability of the disease; and (5) patients' expectations about the physical, social, economic and emotional consequences of the disease. The CSM predicts that these cognitions are directly related to coping and via coping to adaptive outcomes, such as quality of life. Furthermore, as treatment constitutes a major part of the experience of any chronic illness, it should be anticipated that patients also develop their beliefs regarding treatment or engage in treatment appraisals and evaluations that complement illness perceptions (Horne, 2003; Horne & Weinman, 1999, 2002). Recent studies found relationships between dialysis patients' illness representations and well-being (Timmers et al., 2008), mortality (Van Dijk et al., 2009), and dialysis and renal transplant patients' representations of their illness and treatment and health related quality of life (Griva et al., 2009).

Our research team recently conducted a study among patients on dialysis (Jansen et al., 2010), and the results showed that patients' illness and treatment perceptions significantly contributed to the explained variance in both perceived autonomy and state self-esteem, after controlling for socio-demographic and clinical characteristics. Beliefs about greater personal control over the disease, less perceived impact of the illness and treatment on daily life, and less concern about the illness were important determinants. Contrary to our expectations, no significant associations were found between illness perceptions, treatment perceptions and labour

participation. This may be caused by the fact that the working age group (18-64 years) of dialysis patients was small (N=62). An additional explanation might be that patients who are on dialysis do not value a paid job as that important anymore, i.e. performing paid work does not contribute to their feelings of autonomy and self-esteem. Patients in this stage of the illness are aware of the fact that they are seriously ill, and therefore other life domains might have become more important. The aim of the present study was to investigate the associations of the illness perceptions and treatment perceptions with perceived autonomy, self-esteem and labour participation among pre-dialysis patients. It is expected that the associations with employment are stronger in this group of patients compared to patients on dialysis, since paid work is presumably more important and relevant to patients in an earlier phase of the illness. The following research questions were formulated:

- 1) To what extent do pre-dialysis patients experience autonomy, and state self-esteem, and to what degree do these patients participate in the work domain?
- 2) Which perceptions do pre-dialysis patients have of their illness and treatment?
- 3) To what extent are illness perceptions and treatment perceptions of pre-dialysis patients related to perceived autonomy, state self-esteem and labour participation?

Methods

Participants and procedure

Pre-dialysis patients, who were participating in the PREPARE-2 study, were invited to participate in the present cross-sectional study. PREPARE-2 is a 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. Patients with stage 4 CKD (severe CKD) aged 18 years or older who were treated by a nephrologist and recently (within the previous six months) referred to pre-dialysis care were eligible for inclusion. All patients had to be suitable for renal replacement therapy. Patients with chronic transplant dysfunction

were excluded from the study if the transplant was within the previous year. Clinical (medical records) and quality of life (self-report) data are collected at inclusion and every six months thereafter until start of dialysis, transplantation, end of study or death, whichever occurs earliest. 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 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 completed a paper questionnaire at home. Of those patients who received the questionnaire (N=185), 109 returned the questionnaire (response rate 59%).

Measures

Perceived autonomy

Perceived autonomy was assessed with three items derived from the autonomy scale of the CASP-19 (Hyde et al., 2003). One item 'My health stops me from doing the things I want to do' (reverse scored) was used as an indicator for 'health related autonomy'. The other two items were combined on the basis of their high factor loadings on one factor (both factor loadings: 0.86, variance explained: 74%) to assess 'global autonomy' ('I can do the things that I want to do', 'I feel that I can please myself what I can do'). Items were scored on a 4-point scale (0 = never, 1 = sometimes, 2 = not so often, 3 = often). Global autonomy scores are expressed as average scores based on the two items. Higher scores on both measures signify a higher level of perceived autonomy.

State self-esteem

State self-esteem was measured with the Current Thoughts Scale (Heatherton & Polivy, 1991), which comprises 20 items (e.g. 'I am worried about what other people think of me' (reverse scored)). Items were rated on a 5-point scale (1 = not at all, 2 = a little bit, 3 = somewhat, 4 = very much, 5 = extremely). Scores are summed across individual ratings with higher scores representing a higher level of state self-esteem. The Cronbach's alpha for the scale in the current study was 0.86. The scale has proven to be

psychometrically sound and has a high degree of construct validity (Heatherton & Polivy, 1991).

Labour participation

Labour participation was defined in conformity with Statistics Netherlands (CBS), as performance of paid work for at least 12 hours per week. A full-time employment in the Netherlands consists usually of 36 working hours. It should be noted 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. In addition people were asked to indicate whether performing paid work was of personal importance on a 7-point scale (1 = not important at all to 7 = extremely important).

Illness perceptions

Illness perceptions were assessed using the Brief Illness Perception Questionnaire (Broadbent et al., 2006), which is a brief version of the Revised IPQ (Moss-Morris et al., 2002). The questionnaire includes eight items scored on an 11-point scale, ranging from 0 to 10. Each item assesses a cognitive or emotional illness representation dimension. A higher score on the eight dimensions implies greater perceived influence of the illness upon life ('consequences'), a stronger belief in a chronic time course ('timeline'), greater perceived personal control over the illness ('personal control'), greater perceived treatment control over the illness ('treatment control'), greater experience of severe symptoms as a result of the illness ('identity'), greater feelings of concern about the illness ('concern'), better understanding of the illness ('understanding'), and a stronger emotional response to the illness ('emotional response'). A ninth open-ended response item assessing the patients' causal representation was not included in the study. The Brief IPQ has proven to be a reliable and valid measure of illness perceptions in a variety of illness populations (Broadbent et al., 2006).

Treatment perceptions

Treatment perceptions were assessed with the Treatment Effects Questionnaire (TEQ; originally developed as the IEQ-Tx by Greenberg and Peterson (2002); adapted by Griva et al. (2009)). The TEQ consists of 20 items

(e.g. 'My life revolves around this treatment'), scored on an 8-point scale (0 = strongly disagree to 7 = strongly agree). Scores are summed across individual ratings with higher scores indicating greater perceived disruption from the treatment. The TEQ has been used in a study with ESRD patients (Griva et al., 2009). The Cronbach's alpha for the scale in the current study was 0.94.

Background variables

Background characteristics included age, gender, living status (living with versus without a partner), 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 number of co-morbid diseases (based on the presence of diabetes mellitus type 2, hypertension, cerebrovascular accident, vascular problems, ischemic heart disease, and heart failure).

Statistical analysis

Descriptive statistics were computed to describe the extent to which pre-dialysis patients experience autonomy and state self-esteem, participate in the work domain, and rate work as personally important. Relationships of the background characteristics with autonomy, state self-esteem and labour participation were assessed by use of analysis of variance (ANOVA) and Chi-square tests.

Descriptive statistics were computed to describe patients' illness and treatment perceptions. Relationships of the background characteristics with illness and treatment perceptions were assessed by means of ANOVA. Associations between illness perceptions and treatment perceptions on the one hand and autonomy, state self-esteem and labour participation on the other hand were analysed by means of Pearson's correlation coefficients and Student's t-test. Furthermore, multiple linear regression analyses were performed, using the enter method, to examine the relationship between illness and treatment perceptions on the one hand and perceived autonomy and state self-esteem on the other hand, controlling for background characteristics. Two blocks of variables were entered separately; block 1: Background variables (age, gender, educational level, number of co-morbid

diseases); block 2: Illness and treatment perceptions variables. To perform regression analyses, the missing values on the co-morbidity variable were replaced by the mean number of co-morbid diseases computed over the total study group.

Results

Patients

Characteristics of the total study group are outlined in Table 3.1. Approximately two-thirds of the patients were male. Patients had a mean age of 64 years (SD=14.9 years). The patients' number of co-morbid conditions ranged from 0 to 5, with 46% of the patients suffering from two or more co-morbid conditions. Differences between the responders and the non-responders with respect to age, gender, and number of co-morbid diseases were examined and no significant differences were found.

Perceived autonomy

The mean global autonomy score of the total sample was 1.9 (SD=0.8, range scores = 0-3, N=100), and the mean score on the health related autonomy item was 1.4 (SD=1.0, range scores = 0-3, N=101). No significant differences in autonomy scores were found according to age, gender, educational level, living status and number of co-morbid diseases.

State self-esteem

The mean state self-esteem score of the total patient group was 78.2 (SD=10.3, range scores = 46-98, N=104). ANOVA analysis showed that high educated patients had higher state self-esteem compared to patients with a low and moderate educational level ($F(2, 100) = 3.50, p=0.03$). No associations were found between state self-esteem and the other background characteristics.

Table 3.1: Background characteristics of participating patients

| | Total group | |
|--|--------------------------|------|
| Gender - N (%) | | |
| Male | 69 | (64) |
| Female | 39 | (36) |
| Unknown | 1 | |
| Age, mean in years (SD) | 64.3(14.9), range: 19-92 | |
| Age, in groups - N (%) | | |
| 18 - 49 years | 21 | (20) |
| 50 - 64 years | 24 | (22) |
| ≥ 65 years | 63 | (58) |
| Unknown | 1 | |
| Educational level - N (%) | | |
| Low | 46 | (43) |
| Moderate | 45 | (43) |
| High | 15 | (14) |
| Unknown | 3 | |
| Living status - N (%) | | |
| Living with a partner | 69 | (64) |
| Living without a partner | 38 | (36) |
| Unknown | 2 | |
| Number of co-morbid diseases, mean (SD) | 1.5(1.2), range: 0-5 | |
| Number of co-morbid diseases, in groups - N (%) | | |
| No co-morbid diseases | 23 | (24) |
| One co-morbid disease | 28 | (30) |
| Two or more co-morbid diseases | 44 | (46) |
| Unknown | 14 | |

Labour participation

Among the total group of patients, forty-five people were of working age (18-64 years), with a mean age of 50 years (10.7 years). Twenty-three patients (51%) performed paid work for at least 12 hours per week. Patients who worked (at least 12h per week) were working for 34.7h per week on average (range: 20-60h per week). The majority worked in the 'industry, mineral extraction, construction' sector (N=4), 'services provision' sector (N=4), 'health and welfare' sector (N=4), and the 'commercial' sector (N=3). Eighteen people aged 18 to 64 years (40%) were not employed (for at least

12h per week) and the employment status of four people (9%) was unknown. Of those who were not employed, 15 people indicated that they were employed in the past (for at least 12h per week). Most of them had worked in the 'industry, mineral extraction, construction', 'commercial' and 'health and welfare' sector (N=12). The results of the ANOVA analysis showed that among the patients of working age, employed patients were significantly younger than unemployed patients ($F(1, 39) = 4.19, p=0.047$). No significant differences were found with regard to the other background variables.

Working-age patients' mean importance rating score with respect to performing paid work was 5.1 (2.4), which indicates that patients regard paid work as considerably important. Unemployed patients rated the importance of performing paid work with a mean score of 3.4 (2.3) and employed patients' mean importance score was 6.7 (0.6).

Illness and treatment perceptions

Mean illness perceptions scores indicate that pre-dialysis patients believe that their illness is chronic (timeline). Furthermore, patients experience a moderate amount of physical symptoms from their illness (identity), and believe their illness affects their daily life to a rather large extent (consequences). On the other hand, patients experience rather little disruption of daily life from their current treatment (in most cases medication and diet restrictions). Patients are fairly concerned about their illness; however, do not believe strongly that their illness affects them emotionally. In addition, patients believe that they understand their illness rather well, and consider their illness to be positively influenced by the treatment they receive (treatment control), yet believe that they themselves have rather little control over their illness (personal control) (Table 3.2). ANOVA analysis showed that patients in the different age groups differed with respect to their beliefs about the timeline of the illness (Welch $F(2, 29.35) = 4.36, p=0.02$). Games-Howell post hoc-tests, however, did not point to significant differences between two or more groups in particular. High educated patients believe that their emotional state is less affected by their illness compared to low and moderate educated patients ($F(2, 100) = 3.31, p=0.04$). No differences were found with respect to gender, living status and number of co-morbid diseases.

The Pearson's correlation coefficients between the illness perceptions and treatment perceptions are depicted in Table 3.3. As patients experience a large impact from the illness on daily life, they believe that their treatment disrupts their life, experience more physical complaints from the illness, believe they have little personal control over the illness, are worried about their illness and feel that their illness affects them emotionally. As patients experience disruption from the treatment, they experience more consequences and symptoms from the illness, feel that their illness cannot be controlled by medical treatment, are concerned about their illness and experience a large emotional impact due to the illness. Personal and treatment control beliefs are positively interrelated and both associated with less concern.

Table 3.2: Mean scores and standard deviations of illness and treatment perceptions of pre-dialysis patients (total group)

| Illness and treatment perceptions | N | Range scale | Range scores | M (SD) |
|-----------------------------------|-----|-------------|--------------|-------------|
| Consequences | 105 | 0-10 | 0-10 | 6.7 (2.5) |
| Timeline | 104 | 0-10 | 0-10 | 9.3 (1.7) |
| Personal control | 103 | 0-10 | 0-10 | 4.7 (2.9) |
| Treatment control | 103 | 0-10 | 0-10 | 6.8 (2.9) |
| Identity | 103 | 0-10 | 0-10 | 5.2 (2.9) |
| Concern | 104 | 0-10 | 0-10 | 6.9 (2.7) |
| Understanding | 102 | 0-10 | 0-10 | 7.3 (3.1) |
| Emotional response | 104 | 0-10 | 0-10 | 5.0 (3.1) |
| Treatment disruption | 94 | 0-140 | 0-125 | 38.8 (25.9) |

Associations between independent and dependent variables

Pearson's correlation coefficients between illness perceptions and treatment perceptions and perceived autonomy and state self-esteem showed that stronger positive beliefs about the illness and treatment are related to higher levels of perceived autonomy and state self-esteem (Table 3.3). Within the working-age group, the associations between the illness and treatment representations and labour participation were investigated by means of Student's t-test and the results demonstrated no significant associations (Table 3.4).

Table 3.3: Pearson's correlations between illness perceptions, treatment perceptions and perceived autonomy, state self-esteem (total group)

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|-------------------------|---------|------|--------|-------|---------|---------|------|---------|---------|
| 1. Consequences | | | | | | | | | |
| 2. Timeline | .11 | | | | | | | | |
| 3. Personal control | -.33** | -.05 | | | | | | | |
| 4. Treatment control | -.17 | .06 | .44*** | | | | | | |
| 5. Identity | .65*** | .07 | -.18 | -.16 | | | | | |
| 6. Concern | .59*** | .09 | -.30** | -.20* | .49*** | | | | |
| 7. Understanding | .13 | -.01 | .18 | .21* | .23* | .03 | | | |
| 8. Emotional response | .58*** | .04 | -.20* | -.14 | .44*** | .62*** | .24* | | |
| 9. Treatment disruption | .45*** | .01 | -.10 | -.23* | .47*** | .45*** | .12 | .56*** | |
| Global autonomy | -.36*** | .00 | .22* | .29** | -.37*** | -.30** | -.01 | -.37*** | -.42*** |
| Health related autonomy | -.44*** | -.12 | .16 | .15 | -.34*** | -.28** | -.02 | -.24* | -.21 |
| State self-esteem | -.39*** | .04 | .20* | .21* | -.37*** | -.44*** | .03 | -.49*** | -.48*** |

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

Table 3.4: Differences in mean illness and treatment perceptions scores between employed and unemployed patients of working age (18-64 years)

| | Employed | | Unemployed | | t | df | p |
|----------------------|----------|-------------|------------|-------------|--------|--------|------|
| | N | M (SD) | N | M (SD) | | | |
| Consequences | 22 | 6.7 (2.3) | 18 | 6.8 (2.9) | .129 | 38 | 0.9 |
| Timeline | 22 | 8.5 (2.6) | 18 | 8.6 (2.3) | .071 | 38 | 0.9 |
| Personal control | 21 | 4.9 (2.8) | 18 | 3.7 (3.2) | -1.229 | 37 | 0.23 |
| Treatment control | 21 | 6.8 (2.0) | 18 | 5.6 (3.5) | -1.331 | 26.072 | 0.20 |
| Identity | 22 | 5.1 (2.9) | 18 | 5.4 (3.2) | .365 | 38 | 0.72 |
| Concern | 22 | 7.0 (2.8) | 18 | 7.0 (2.7) | .051 | 38 | 0.9 |
| Understanding | 21 | 7.1 (3.0) | 18 | 7.1 (3.2) | -.032 | 37 | 0.9 |
| Emotional response | 22 | 5.6 (2.7) | 18 | 4.5 (3.2) | -1.123 | 38 | 0.27 |
| Treatment disruption | 21 | 34.7 (22.9) | 17 | 44.3 (31.3) | 1.095 | 36 | 0.28 |

Regression analysis was conducted with global autonomy being the dependent variable. The results showed that the background variables accounted for only 3% of the variance in global autonomy (Table 3.5). In this model, fewer co-morbid diseases were significantly associated with higher levels of global autonomy. Adding the illness and treatment perceptions to the model (block 2) the percentage of explained variance significantly increased to 20%. None of the included variables reached the level of significance, though less perceived treatment disruption was close to significance ($p=0.054$). The results of the regression analysis with health related perceived autonomy being the dependent variable, demonstrated that the background variables and illness and treatment perceptions variables did not explain any substantial amount of variance (adjusted $R^2=3.5\%$; data not shown).

Finally, we performed regression analysis with state self-esteem being the dependent variable. The results showed that the background variables explained 5% of the variance. In the second model, in which the illness and treatment perceptions were added, the percentage of explained variance increased by 26%, to 31%, with less perceived treatment disruption being the only significant predictor of state self-esteem (Table 3.6).

Table 3.5: Multiple linear regression models for the association between the independent variables and perceived global autonomy in pre-dialysis patients (total group)

| | Model 1 (block 1) (N=88) Beta | Model 2 (block 1+2) (N=88) Beta |
|--|-------------------------------------|---------------------------------------|
| Block 1: Background characteristics | | |
| Age in years | .14 | .02 |
| Gender (ref: male) | .01 | -.04 |
| <i>Educational level</i> (ref: low) | | |
| - moderate | -.06 | -.07 |
| - high | .03 | -.07 |
| Number of co-morbid diseases | -.27* | -.17 |
| Block 2: Perceptions | | |
| Consequences | | -.06 |
| Personal control | | .08 |
| Treatment control | | .12 |
| Identity | | -.22 |
| Concern | | .19 |
| Emotional response | | -.14 |
| Treatment disruption | | -.25 |
| Adjusted R ² | 0.03 | 0.20** |
| F change model | 1.51 | 3.52** |

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

Table 3.6: Multiple linear regression models for the association between the independent variables and state self-esteem in pre-dialysis patients (total group)

| | Model 1 (block 1) (N=91) Beta | Model 2 (block 1+2) (N=91) Beta |
|--|-------------------------------------|---------------------------------------|
| Block 1: Background characteristics | | |
| Age in years | .18 | .07 |
| Gender (ref: male) | -.06 | -.08 |
| <i>Educational level</i> (ref: low) | | |
| - moderate | .00 | -.04 |
| - high | .18 | .09 |
| Number of co-morbid diseases | -.16 | -.05 |
| Block 2: Perceptions | | |
| Consequences | | .07 |
| Personal control | | .18 |
| Treatment control | | -.06 |
| Identity | | -.18 |
| Concern | | -.11 |
| Emotional response | | -.13 |
| Treatment disruption | | -.31* |
| Adjusted R ² | 0.05 | 0.31*** |
| F change model | 1.88 | 5.57*** |

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

Discussion

The first aim of the study was to investigate the extent to which pre-dialysis patients experience feelings of autonomy and self-esteem, and participate in the work domain. Secondly, we wished to explore the content of patients' illness and treatment perceptions, and whether these perceptions are related to patients' perceived autonomy, state self-esteem and labour participation.

The mean age of the study group (64 years) and the gender distribution (64% male) corresponds with pre-dialysis patients and patients starting dialysis in the Netherlands (Renine Foundation, 2005; Voormolen et al., 2007). By comparing the mean scores on the autonomy measures of the total group with the answer scale, the results indicate that patients feel less autonomous

because of their health condition or otherwise. In spite of this, most patients reported a high level of self-esteem. The autonomy and self-esteem levels of the pre-dialysis patients are slightly higher than the reported levels by patients on dialysis (Jansen et al., 2010).

Looking at the mean illness and treatment perceptions levels of pre-dialysis patients it is noticed that patients are quite worried about their illness (M=6.9), and believe that they themselves have rather little control over their illness (M=4.7). To compare, patients on dialysis reported mean levels of 6.3 on the 'concern' dimension and 4.9 on the 'personal control' dimension (Jansen et al., 2010). In a study by Broadbent et al. (2006) people with diabetes and people with asthma reported higher mean levels of personal control (M=6.7). Feelings of personal control are important for dialysis patients' quality of life (Covic et al., 2004; Timmers et al., 2008). Personal control over the illness refers to the feeling that one can influence the course of the illness and one can fit the disease and treatment into daily life. In order to manage their illness pre-dialysis patients obviously are dependent on treatment. However, this does not indicate that there are no possibilities for personal control. It is of great importance that pre-dialysis patients practise self-care behaviours, such as following diets and performing daily exercise in order to optimise their health condition (Sijpkens et al., 2008). However, patients in this stage of the illness 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.

On the whole, the correlation analyses demonstrated that as patients hold more positive beliefs about their illness and their current treatment, they perceive more autonomy (both global and health related) and have a higher self-esteem. In light of these findings, it is important to point out the difference between the construct of personal control and the construct of autonomy, since autonomy is often incorrectly equated with ideas of internal locus of control (Deci & Ryan, 2000; Ryan, 1995). Beliefs about personal control reflect individuals' beliefs regarding the extent to which one feels that one can control or influence an outcome, for example one's illness.

However, people are autonomous when they act in accord with their authentic interests or integrated values and desires (Chirkov et al., 2003; Deci & Ryan, 1985, 2000; Ryan, 1995). To make the distinction more explicit, a person can experience control over carrying out a walking programme, but not feel intrinsically motivated, and thus do not act in accordance with his/her own values.

The regression analyses revealed that the illness and treatment perceptions explain a substantial amount of variance in predicting both global autonomy and state self-esteem after controlling for background characteristics. These results illustrate that less perceived disruption from the treatment upon life is a significant predictor of state self-esteem. The findings furthermore suggest that less perceived impact of the treatment upon life is an important determinant of global autonomy as well. Treatment in the pre-dialysis phase in most cases includes taking pharmacotherapy and following a diet. Although these treatments are far less disruptive than dialysis treatment, the findings show that treatment already is a significant theme in this stage of the illness. Illness representations are considered to be constantly updated as new experiences and knowledge are acquired (Leventhal et al., 1984). 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 more occupied with treatment in general, both their current treatment as well as their future treatment.

It should be noted that a large amount of variance remained unexplained. This indicates that other factors are of influence as well, for example the extent to which people in the patient's close environment, like the patient's partner or care providers support the patient. Moreover, health related perceived autonomy could not be predicted by the illness perceptions and treatment perceptions. An explanation for this finding might be that patients are inclined to interpret 'health' as 'physical health'. At this stage of the illness, the renal disease - in most cases - will however not be associated with severe physical symptoms, which is also reflected by the mean score on the 'identity' dimension.

Because of the relatively old age of the study group (M=64 years), only 45 patients (42%) were of working age (18-64 years). Fifty-one percent of the patients aged between 18 and 64 years performed paid work for at least 12 hours per week, which is a higher percentage compared to dialysis patients; 24% (Jansen et al., 2010), though considerably lower than that of the general Dutch population between the ages of 15-64 years; 65% (Statistics Netherlands - CBS, 2006). Thus, as suggested by Van Manen et al. (2001), drop out of the labour market already occurs before patients start with dialysis treatment. Furthermore, the results show that, despite of their health condition, patients of working age place relatively high importance on carrying out a paid job. These findings point to the importance and necessity of work-related assistance in an early stage of the illness process. We wish to mention here that the average age of the working-age group (18-64 years) was rather high (50 years), and 53% of the working-age group was 50 years or older. To put this into perspective, in 2006, 32% of the Dutch people aged 20-64 years were 50-64 years (Statistics Netherlands - CBS, 2006). Notwithstanding that, our results suggest that labour participation in pre-dialysis patients is indeed lower than in the general population. Because of the small number of patients aged 18-64 years, we could not investigate the relationships between patients' perceptions of their illness and current treatment on the one hand, and employment on the other hand more thoroughly. The findings, however, do show some trends: employed patients perceive their treatment as less disruptive and their illness as better controllable by self-care and medical care than unemployed patients.

A limitation of this study is the replacement of the missing values on the variable co-morbidity with the mean value of the total study group. Mean substitution preserves the mean of a variable's distribution; however, mean substitution typically distorts other characteristics of a variable's distribution (i.e., variance, median) (Little & Rubin, 1989). In spite of this, we decided to substitute the missing values by the mean in order to be able to make maximal use of the data from all our cases. Another issue to note is the use of single-item measures in order to minimise the burden on respondents. Single-item measures are sometimes seen as less psychometrically sound than multiple items. However, several studies show that single-item measures and their multiple counterparts are comparable (Gardner et al.,

1998; McKenzie & Marks, 1999). Moreover, Gardner et al. (1998) demonstrate that a well-developed single item measure can be appropriate in avoiding common methods variance, which is often a problem with psychological measures that require respondent self-reports of attitudes, beliefs, perceptions, and the like. Furthermore, it is noteworthy that the present study had a cross-sectional design, which means that no conclusions can be drawn regarding the causality of the observed relationships. Notwithstanding this limitation, our results suggest that the beliefs pre-dialysis patients hold about their illness and treatment are important factors for patients' sense of (global) autonomy and self-esteem. Finally, it should be noted that the study sample was rather small (N=109), as well as the working-age sample (N=45). Consequently, there was little statistical power to demonstrate relationships between perceptions and labour participation in particular. Future research should take this issue into account. It would be worthwhile to investigate these relationships once again in a larger sample of pre-dialysis patients.

Conclusions

In light of the findings it seems important that patients with severe CKD are educated by a multi-professional team, comprising of nephrologists, dialysis nurses as well as employment experts and social workers, on the possibilities to combine CKD and its treatment with daily activities, including work. By means of education, positive (realistic) beliefs might be stimulated and negative 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. This education should take place as soon as possible. Research suggests that interventions to change cognitions should focus on patients in an early stage of the illness process (Petrie et al., 2002). The best moment to offer interventions to alter maladaptive beliefs in patients with CKD seems to be in the pre-dialysis phase (preferably even before CKD stage 4) or at the start of renal replacement therapy, in which patients are most prone to influences. In the Netherlands, psychological support is not yet a primary area of attention in pre-dialysis care and renal

care in general. It is therefore important that interventions which focus on these psychological concepts are developed (Jansen et al., 2011).

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4

Illness perceptions and treatment perceptions of patients with Chronic Kidney Disease: Different phases, different perceptions?

This chapter was submitted as:

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Abstract

Objectives

Elucidate the dynamics of CKD (Chronic Kidney Disease) patients' illness perceptions and treatment perceptions across the illness trajectory, by investigating whether these perceptions vary across: 1) time on dialysis, 2) treatment type, in both pre-dialysis patients (CKD stage 4) and patients on peritoneal dialysis (PD) or haemodialysis (HD) (CKD stage 5), and 3) an 8-month interval in patients on dialysis (CKD stage 5).

Design and methods

Mixed cross-sectional and longitudinal design, using self-report questionnaires (BIPQ, TEQ). One hundred five pre-dialysis and 161 dialysis patients; of the 161 dialysis patients, 87 patients filled in the questionnaires again after an 8-month interval. Associations between the different phases of the illness trajectory on the one hand, and illness and treatment perceptions on the other hand were investigated using pooled-cross sectional analyses, controlled for background characteristics and dependency of multiple observations within individuals.

Results

Perceptions of *treatment disruption* and *illness understanding* vary between patients as a function of time on dialysis ($p < 0.1$, $p < .05$, respectively). Furthermore, among dialysis patients, perceptions of illness and treatment vary within persons over an 8-month interval, with *treatment control* and *personal control* showing the lowest correlations. Finally, patients on different treatments vary in perceptions of *illness consequences* ($p < .05$), *treatment disruption* ($p < .01$), and *treatment control* ($p < .05$).

Conclusions

Findings suggest that (stage 4 and 5) CKD patients' perceptions of illness and treatment vary across the illness trajectory. The study offers starting points for interventions to target CKD patients' illness and treatment perceptions, aimed at improving adaptive outcomes.

Introduction

Chronic Kidney Disease (CKD) refers to the progressive and irreversible loss of kidney function. In CKD stage 1 (kidney damage, with normal or increased kidney function) to stage 4 (severe reduction in kidney function), treatment is focused on slowing the progression of kidney disease and preventing or treating complications and co-morbid conditions (NKF-KDOQI, 2002). Treatment in these stages usually encompasses pharmacotherapy and diet restrictions. Research carried out in the United States (NHANES), the Netherlands (PREVEND study), Spain (EPIRCE study) and Norway (HUNT study), demonstrated prevalence rates of CKD stages 1 to 4 from 10.5 to 13.1% (Coresh et al., 2007; De Jong et al., 2008). In CKD stage 5 (end-stage renal disease (ESRD)), the kidneys are no longer able to function and, renal replacement therapy (RRT) - dialysis or kidney transplantation - becomes necessary to maintain life. At the end of 2005, about 1,9 million people were receiving RRT worldwide; about three quarters being treated by dialysis and one quarter by kidney transplant (Grassmann et al., 2006).

Dialysis is an artificial way of blood purification, which is an essential function of the kidneys. There are two main dialysis types. The first is haemodialysis (HD), where the blood is purified outside the body via a dialysis machine which contains an artificial kidney that removes waste products and excess fluid from the blood. The patient is connected to the dialysis machine usually about four hours, three times a week. The second type is peritoneal dialysis (PD), where the blood is filtered by means of the patient's peritoneal membrane that lines the abdominal cavity. This procedure is done by inserting dialysis fluid (dialysate) in the patient's abdominal cavity, which extracts waste products and excess fluid from the blood that flows through the blood vessels in the peritoneal membrane. In peritoneal dialysis, the changes of the dialysis fluid are performed either four or five times each day manually by the patient (Continuous Ambulatory Peritoneal Dialysis (CAPD)), or every night by a machine (cycler) during a 9-hour bed rest (Automated Peritoneal Dialysis (APD)) (Dutch Kidney Foundation, 2011).

CKD imposes a heavy burden on patients' daily life, in particular for patients on dialysis. The quality of life of patients in the earlier stages of CKD, i.e. before the start of RRT, is already impaired compared to general population samples, with the most pronounced impairment found with respect to physical functioning (Korevaar et al., 2000; Molsted et al., 2007). Several studies demonstrated lowered quality of life in patients on dialysis regarding physical, social and mental functioning, compared to general population samples (e.g. Khan et al., 1995; Merkus et al., 1997; Molsted et al., 2007).

Research in various chronically ill populations has shown that illness perceptions, i.e. the way people give meaning to their illness, account for a substantial part of individual differences in outcomes such as quality of life, functional status, and psychological well-being (e.g. Aalto et al., 2006; Hagger & Orbell, 2003; Heijmans, 1999; Helder et al., 2002; Scharloo et al., 2000). The Common Sense Model of self-regulation of health and illness (CSM; Leventhal et al., 1984) predicts that the cognitive and emotional representations patients hold of their medical condition are directly related to coping and via coping to adaptive outcomes (Hagger & Orbell, 2003; Moss-Morris et al., 2002). The CSM is a dynamic model: outcomes of behaviours generated by the representations are appraised on an on-going basis, which may result in the modification of the representations (Wearden & Peters, 2008). Research has shown that people also develop beliefs about the necessity and concerns towards their medical treatment, and has demonstrated that these treatment beliefs are related to adherence and treatment decisions (Horne et al., 2007; Horne & Weinman, 2002).

In recent years, studies have explored the illness perceptions and treatment beliefs of patients with CKD on dialysis and their associations with quality of life (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 over the illness, less perceived (negative) consequences (of both the illness and treatment), and fewer negative emotional reactions to the illness are generally associated with better quality of life outcomes in patients on dialysis. Studies also have demonstrated associations between depression on the one hand, and illness perceptions (Chilcot, 2010; Griva et

al., 2010) and treatment perceptions (Griva et al., 2010) on the other hand in patients on dialysis.

Knowing that illness perceptions and treatment perceptions of patients on dialysis are closely related to patients' adaptive outcomes, raises a new interesting question: *whether these perceptions can be influenced in order to improve adaptive functioning.*

For the purpose of designing a psychological intervention aimed at altering (unhelpful) perceptions in patients who are being prepared for RRT (pre-dialysis patients; CKD stage 4) or who are undergoing dialysis (CKD stage 5; ESRD), we wished to gain insight into the illness perceptions and treatment perceptions across the CKD trajectory, in pre-dialysis patients and patients on dialysis. This knowledge is important for determining whether perceptions vary across the illness trajectory and, consequently, whether interventions could potentially target perceptions of patients with CKD stage 4 and 5. More specifically, we aimed to investigate whether patients' illness and treatment perceptions vary:

- as a function of treatment type, in both pre-dialysis patients (CKD stage 4), and patients on peritoneal dialysis (PD) or haemodialysis (HD) (CKD stage 5),
- as a function of time on dialysis treatment in both pre-dialysis patients and patients on PD and HD,
- over an 8-month interval in patients on dialysis (both PD and HD).

It is assumed that illness representations are constantly being updated as new illness knowledge and illness experience are acquired (Leventhal et al., 1984). Two interesting longitudinal studies have provided insight into how perceptions of illness in patients with CKD on dialysis change over time. Covic et al. (2006) investigated the illness perceptions and quality of life of patients on HD with low co-morbidity over a two-year period. Their findings showed that, over this two-year follow-up, patients 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) revealed a similar trajectory for illness understanding in dialysis patients over their first year on dialysis: over a one year follow-up, patients' understanding increased. In addition, patients perceived fewer

somatic symptoms from their illness over time. Previous research in other patient populations also demonstrated longitudinal changes in illness perceptions, as well as associated changes in 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 status and medical treatment bring about changes in illness perceptions as well as in treatment beliefs. In this study the illness and treatment perceptions of 41 patients pre to post kidney transplantation (i.e., still on dialysis compared to six months after transplantation) were compared. The findings showed that after the kidney transplantation, patients expressed different perceptions, including less illness and treatment disruptiveness and stronger control beliefs, than before the transplantation. Cross-sectional studies also have demonstrated differences in illness and treatment perceptions between patients who receive different treatments for CKD stage 5 (Griva et al., 2010; Griva et al., 2009; 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 techniques and demands.

The aim of the present study was to gain insight into the illness perceptions and treatment perceptions across the CKD trajectory, in pre-dialysis patients (CKD stage 4) and patients on dialysis (CKD stage 5). By also focusing on patients with CKD stage 4 the present study can, together with the knowledge offered by previous studies, provide a more complete picture of the dynamics of CKD patients' illness and treatment perceptions. We formulated the following research questions:

- 1) Do patients who receive different treatments (pre-dialysis, HD, PD treatment) differ in their illness and treatment perceptions, taking into account several background characteristics?;
- 2) Do patients who are on dialysis treatment for different lengths of time differ with respect to their illness and treatment perceptions, taking into account several background characteristics?;

- 3) Do the illness and treatment perceptions that patients on dialysis hold at two points in time (with an 8-month interval) vary, taking into account several background characteristics?

Methods

Data for the present study were collected in two large multi-centre studies in the Netherlands: the PREdialysis PATients REcords study phase 2 (PREPARE-2) and the NETHERlands COoperative Study on the Adequacy of Dialysis phase 2 (NECOSAD-2).

Sample of pre-dialysis patients

PREPARE-2 study is a multi-centre 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 participating 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 six months) referred to pre-dialysis care were eligible for inclusion in PREPARE-2. All patients had to be suitable for RRT. Patients with chronic transplant dysfunction were excluded from the study if the transplant was within the previous year. Clinical (medical records) and quality of life (self-report) data are collected at inclusion and every six months thereafter until start of dialysis, transplantation, end of study or death, whichever occurs earliest. 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 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.

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 RRT. Clinical (medical records) and quality of life (self-report) data are collected every six 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 among these patients in March/April 2006 and eight months later (November 2006). Patients filled in the questionnaires at home or in the dialysis centre and returned them by mail. At the start of the present study, 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 first additional questionnaire (response rate 67%). Eight months later, 129 of these 166 respondents again received the additional questionnaire, which was returned by 87 persons (response rate 67%). The 37 persons who did not receive the questionnaire for the second time dropped out 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.

Measures

Illness perceptions and treatment perceptions were assessed with the Brief Illness Perception Questionnaire (BIPQ; Broadbent et al., 2006), and the Treatment Effects Questionnaire (TEQ, originally developed as the IEQ-Tx by Greenberg & Peterson, 2002; adapted by Griva et al., unpublished). The Brief IPQ consists of eight items that are scored on an 11-point scale, ranging from 0 to 10, each assessing a cognitive or emotional illness representation dimension (illness consequences; timeline (expected duration of the illness);

personal control; treatment control; identity (physical symptoms associated with the illness); concern; understanding; emotional response). The open-ended question about what patients think are the three most important causes of their illness was not used in this study, since in view of a chronic disease it is less relevant to intervene on causal beliefs. The TEQ was used to assess patients' perceptions of the disruption associated with treatment rather than the illness. The TEQ consists of 20 items. Items are scored on an 8-point scale ranging from 0 to 7 (strongly disagree - strongly agree). Scores are 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.

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 co-morbid conditions (i.e. the presence of diabetes mellitus type 2, hypertension, cerebrovascular accident, vascular problems, ischemic heart disease, and heart failure) was recorded. The 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.

With respect to patients on dialysis, the type of dialysis treatment (HD or PD), and dialysis treatment duration (in years) were collected. 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 et al., 1993; Plantinga et al., 2007). The data regarding dialysis patients' living status and clinical characteristics were derived from the last known regular NECOSAD-2 measurement at the time of the implementation of the current study.

Statistical analysis

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

By means of pooled cross-sectional analyses (Snijders & Bosker, 1999) we examined whether patients who are being prepared for RRT (pre-dialysis patients) and patients who are on dialysis treatment for different lengths of time vary in their perceptions of the illness and treatment (for pre-dialysis patients time on dialysis treatment was set to value 0) (research question 2). We tested for linear and quadratic associations of time on dialysis, since for example it could be possible that perceptions initially improve due to experiences with the treatment, but become less favourable at a later point in time due to complications (quadratic association). By means of the pooled cross-sectional analyses we examined simultaneously whether patients who follow different treatments (pre-dialysis, HD, PD treatment) vary in their illness and treatment perceptions (research question 1). In all analyses we controlled for gender, age, living status, and educational level.

The pooled cross-sectional analysis combines multiple measurements. In so doing, the data provided by the sample of pre-dialysis patients (one measurement within PREPARE-2) and the sample of 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 eight months¹)) can be combined in one analysis, resulting 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.

Since we have multiple observations over time for a part of the dialysis patient group, it is also important to take the dependency of these observations into account when analysing the data. The observations are clustered within individuals. To control for the correlation between

¹ For dialysis patients who provided data at point 2, time on dialysis was allowed to vary over time.

measurements within individuals, we modelled for both measurements a separate variance and a covariance between the measurements. The correlation provides an indication of whether dialysis patients' illness and treatment perceptions vary over time (8-month interval) (research question 3).

For the potential systematic difference between measurement one (within PREPARE-2 and NECOSAD-2) and measurement two (within NECOSAD-2) we put an indicator variable in the model that captures the potential deviation of measurement two average from measurement one. The analyses were performed using MLwiN software.

Results

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

Responding and non-responding dialysis patients on the first measurement did not differ with respect to age, gender, living status, type of treatment, time on dialysis, and serum albumin level. Patients invited for the second measurement did not differ with respect to the above mentioned characteristics compared to those not invited. Patients who responded to the second measurement did not differ from the non-responders, except for living status. Responders were more often married/living together with a partner than non-responders ($p < .05$).

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 outlined in Table 4.1. The two groups (pre-dialysis and dialysis group) were compared with respect to age, gender, living status and educational level. No significant differences were observed.

Table 4.1: Socio-demographic and clinical characteristics of the samples

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

* Normal serum albumin values are 40-50 g/L.

Illness perceptions and treatment perceptions

Table 4.2 displays the mean illness perceptions and treatment perceptions scores of the pre-dialysis sample and the dialysis sample. On the whole,

patients report 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 are quite worried about their illness (*concern*), this is particularly true for pre-dialysis patients. Patients do not believe strongly that their illness affects them emotionally (*emotional response*). Dialysis patients perceive quite a few physical symptoms from their illness (*identity*), whereas pre-dialysis patients perceive a moderate amount of symptoms. Furthermore, the mean scores indicate that patients believe that their illness affects their daily life (*consequences*) to a rather large extent, this is especially true for patients on dialysis. In addition, the mean scores indicate a moderate level of perceived *treatment disruption* in patients on dialysis, and a mild level of perceived disruption from the current treatment in pre-dialysis patients. Lastly, patients believe strongly that their illness will last for a long time (*timeline*), and believe that they understand their illness (*coherence*) rather well.

Table 4.2: Mean (SD) illness perceptions (BIPQ) and treatment perceptions (TEQ) scores of pre-dialysis patients and dialysis patients

| | Pre-dialysis patients (N=94-105) | Patients on dialysis at point 1 (N=154-156) |
|--------------------------------------|-------------------------------------|--|
| | M (SD) | M (SD) |
| BIPQ - 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 - Identity (0 - 10) | 5.2 (2.9) | 6.1 (2.4) |
| BIPQ - Concern (0 - 10) | 6.9 (2.7) | 6.3 (3.0) |
| 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 disruption (0 - 140) | 38.8 (25.9) | 63.4 (25.0) |

Note: A higher score on the dimensions implies greater perceived consequences, timeline, personal control, treatment control, identity, concern, understanding, emotional response, treatment disruption.

Perceptions of illness and treatment across the CKD trajectory

Type of treatment (research question 1)

Patients on HD perceive more treatment disruption compared to patients in the pre-dialysis phase (Table 4.3), and compared to patients on PD ($p=.01$, not shown in Table).

Patients on HD as well as patients on PD perceive more illness consequences compared to patients in the pre-dialysis phase (Table 4.4). Furthermore, patients on HD and PD believe more strongly that their treatment controls the illness than patients who receive a pre-dialysis treatment (Table 4.4). Patients on PD and HD do not differ with regard to both these dimensions.

Time on dialysis (research question 2)

The results of the pooled cross-sectional analyses reveal a quadratic association between time on dialysis and perceived illness understanding (Table 4.3). Figure 4.1 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 to patients who just started dialysis, and patients who are on dialysis for long lengths of time. This pattern is observed in both HD and PD patients.

The results furthermore demonstrate a linear association between time on dialysis and perceived treatment disruption (Table 4.3). Figure 4.2 shows that patients who are on dialysis for longer lengths of time perceive their treatment as more disruptive to daily life compared to 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 HD and PD patients.

Table 4.3: Association time on dialysis, type of treatment and perceptions of treatment disruption, concern, understanding, emotional response, controlled for background characteristics and multiple observations within individuals (final model), total sample (N=235-245)

| | Treatment disruption Estimate (SE) | Concern Estimate (SE) | Understanding ^a Estimate (SE) | Emotional response Estimate (SE) |
|--|---------------------------------------|--------------------------|---|-------------------------------------|
| Random effects (individual level) | | | | |
| Variance measurement one | 602 (55.76) | 7.53 (0.68) | 7.83 (0.71) | 9.33 (0.85) |
| Variance measurement two | 609.2 (84) | 6.31 (0.97) | 5.63 (0.87) | 6.76 (0.99) |
| Covariance measurement one/two | 479.4 (61.05) | 3.95 (0.73) | 3.72 (0.71) | 5.34 (0.82) |
| Correlation measurement one/two | 0.79 | 0.57 | 0.56 | 0.67 |
| Fixed effects | | | | |
| Constant | 37.95 (2.58) | 6.84 (0.27) | 2.76 (0.28) | 4.85 (0.30) |
| Measurement 2 | -4.39 (1.86)* | -0.68 (0.26)** | 0.33 (0.26) | -0.62 (0.25)* |
| Time on dialysis (in years) | 2.22 (0.85)** | -0.13 (0.09) | -0.75 (0.33)* | -0.03 (0.10) |
| Time on dialysis (in years) squared | | | 0.07 (0.04)* | |
| HD (ref: pre-dialysis) | 21.41 (4.80)*** | 0.19 (0.51) | 1.23 (0.71) | 0.61 (0.56) |
| PD (ref: pre-dialysis) | 7.94 (5.42) | 0.17 (0.57) | 0.51 (0.80) | -0.02 (0.63) |
| Female (ref: male) | 3.77 (3.44) | 0.85 (0.36)* | -0.47 (0.37) | 0.88 (0.40)* |
| Age in years | -0.31 (0.13)* | -0.02 (0.01) | -0.00 (0.01) | -0.05 (0.01)** |
| Married/living together with a partner (ref: living without partner) | 5.61 (3.50) | 0.51 (0.37) | 0.68 (0.37) | 0.18 (0.40) |
| Moderate education (ref: low) | -1.70 (3.51) | -0.71 (0.37) | 0.30 (0.37) | -0.31 (0.41) |
| High education (ref: low) | -0.55 (4.71) | -0.97 (0.49)* | -0.07 (0.49) | -0.87 (0.54) |

^a Scores are recoded so that higher scores indicate lower levels of understanding; * p < 0.05; ** p < 0.01; *** p < 0.001
 Note: In case no significant quadratic association was observed, the results of the analyses are presented in which solely the linear association was tested

Figure 4.1: Quadratic association between time on dialysis and perception of understanding (high understanding scores signify low levels of perceived understanding)

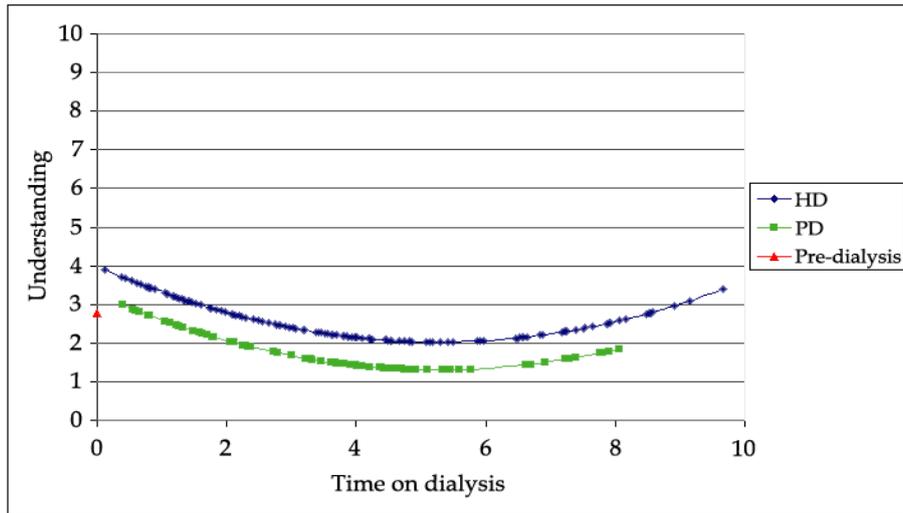
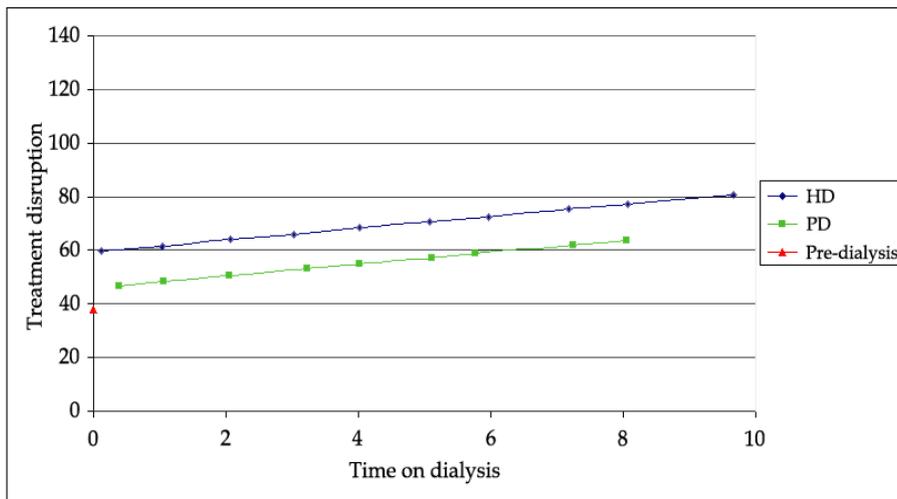


Figure 4.2: Linear association between time on dialysis and perception of treatment disruption (high treatment disruption scores signify high levels of perceived treatment disruption)



8-month interval (research question 3)

The results of the pooled cross-sectional analyses also provide insight into the extent to which perceptions vary within patients on dialysis over an interval of eight months. This insight can be gained by examining the correlation coefficients between the perceptions measured at time point one and time point two. The correlations between the perceptions of patients on dialysis at measurement one and measurement two are not that strong (Table 4.3 and 4.4), indicating that the perceptions vary over an interval of eight months. This is especially true for the perception of personal control over the illness ($r=0.37$), and the perception of treatment control over the illness ($r=0.31$). The correlation between the perceptions of treatment disruption at two points in time shows the highest value ($r=0.79$).

Association between background characteristics and perceptions of illness and treatment

Since we controlled for several background characteristics, the results of the analyses also provide insight into the relationships between these characteristics on the one hand and illness perceptions and treatment perceptions on the other hand. The results show that as patients are older they perceive less treatment disruption, a less strong emotional response, more treatment control and a greater timeline. Compared to men, women perceive more concern, a stronger emotional response, and more physical symptoms (identity). Lastly, high educated patients perceive less concern than patients with a low educational level.

Table 4.4: Association time on dialysis, type of treatment and perceptions of illness consequences, timeline, personal control, treatment control, identity, controlled for background characteristics and multiple observations within individuals (final model), total sample (N=243-245)

| | Consequences Estimate (SE) | Timeline Estimate (SE) | Personal control ^a Estimate (SE) | Treatment control ^a Estimate (SE) | Identity Estimate (SE) |
|---|-------------------------------|---------------------------|--|---|---------------------------|
| Random effects (individual level) | | | | | |
| Variance measurement one | 4.92 (0.45) | 2.45 (0.22) | 9.04 (0.82) | 5.79 (0.53) | 6.50 (0.59) |
| Variance measurement two | 3.33 (0.52) | 2.19 (0.33) | 8.00 (1.26) | 6.12 (0.97) | 5.71 (0.89) |
| Covariance measurement one/two | 2.00 (0.44) | 1.32 (0.25) | 3.12 (0.94) | 1.81 (0.67) | 3.21 (0.66) |
| Correlation measurement one/two | 0.50 | 0.57 | 0.37 | 0.31 | 0.53 |
| Fixed effects | | | | | |
| Constant | 6.68 (0.22) | 9.35 (0.16) | 5.30 (0.30) | 3.13 (0.24) | 5.18 (0.25) |
| Measurement 2 | -1.16 (0.21)*** | 0.08 (0.15) | 0.34 (0.34) | 0.78 (0.30)* | -0.63 (0.26)* |
| Time on dialysis (in years) | -0.03 (0.07) | -0.03 (0.05) | -0.13 (0.10) | -0.06 (0.08) | 0.09 (0.08) |
| HD (ref. pre-dialysis) | 1.39 (0.40)*** | -0.07 (0.29) | 0.52 (0.55) | -0.93 (0.45)* | 0.79 (0.48) |
| PD (ref. pre-dialysis) | 0.96 (0.45)* | -0.03 (0.33) | -0.48 (0.62) | -1.54 (0.50)** | 0.66 (0.53) |
| Female (ref. male) | -0.18 (0.28) | 0.12 (0.21) | -0.27 (0.39) | -0.26 (0.32) | 0.72 (0.34)* |
| Age in years | -0.01 (0.01) | 0.04 (0.01)*** | -0.02 (0.01) | -0.02 (0.01)* | -0.01 (0.01) |
| Married/living together with a partner (ref. living without partner) | 0.03 (0.29) | -0.20 (0.21) | 0.65 (0.39) | -0.15 (0.32) | 0.40 (0.34) |
| Moderate education (ref. low) | 0.06 (0.29) | -0.06 (0.21) | 0.27 (0.40) | -0.23 (0.32) | -0.16 (0.34) |
| High education (ref. low) | -0.30 (0.38) | -0.16 (0.28) | 0.59 (0.52) | -0.63 (0.42) | -0.64 (0.46) |

a Scores are recoded so that higher scores indicate lower levels of personal control and treatment control; * p < 0.05; ** p < 0.01; *** p < 0.001
 Note: In case no significant quadratic association was observed, the results of the analyses are presented in which solely the linear association was tested

Discussion

The aim of the present study was to gain insight into whether (pre-) dialysis patients' perceptions of illness and treatment vary across the CKD trajectory. According to Leventhal et al. (1984), illness perceptions are constantly updated as new experience and knowledge are acquired.

Firstly, the results showed that the perception of *illness understanding* and of *treatment disruption* vary between patients as a function of time on dialysis treatment (quadratic and linear association, respectively). Our finding that the perception of *understanding* varies across the illness trajectory is in line with the (longitudinal) research findings of Covic et al. (2006) and Chilcot (2010). Both studies demonstrated improvements in dialysis patients' perception of understanding, either over a two-year period (Covic et al.) or over the first year on dialysis (Chilcot). The latter finding also corresponds with the nature of the observed association in our study with respect to patients during the first years on dialysis (Figure 4.1). Our study also provided insight into the perceived illness understanding in patients who were on dialysis for longer lengths of time, and revealed a decline in perceived illness understanding among these patients. A possible explanation for this decline may be that the medical situation of these patients is becoming more complex.

In addition, our results suggest that dialysis patients' perceptions of *personal control* and *treatment control* in particular vary within persons over an interval of eight months. An explanation for the fact that we did not find variations in personal and treatment control as a function of time on dialysis treatment based upon the first approach may be that there are differences between the two approaches with respect to the power to detect relationships. The observed variation in *treatment control* over time is also in accordance with the Covic study that revealed improvements regarding this perception after a two-year period. Though the study by Chilcot did not reveal 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.

The studies by Covic and Chilcot both revealed changes in illness perceptions which we did not observe in our study (i.e. perceptions of emotional reaction and physical symptoms). Furthermore, our study revealed variations in perceptions that were not observed in the studies by Covic and Chilcot (i.e. perception of personal control). The different findings might have been caused by the different research designs that were used. Another reason may be that patients in these studies were exposed to other conditions which may have influenced their perceptions. In the Covic study, for example, it is 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., 2010).

The results of our study 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 believe more strongly that their treatment controls the illness than patients who receive pre-dialysis treatment. Dialysis is a life-saving treatment. Consequently, treatment control has a different meaning for patients on dialysis than for patients in the pre-dialysis phase, who use medication or follow a diet and are much less dependent on their treatment compared to patients on dialysis. Another explanation for the different treatment control scores is that pre-dialysis patients are aware of the fact that, soon, their current treatment will no longer suffice. Furthermore, patients on HD and PD perceive more illness consequences compared to patients in the pre-dialysis phase. These differences are plausible, since the dialysis phase is characterized by specific disease aspects and intensive and time-consuming treatment demands. Lastly, patients on HD perceive more disruption from their treatment in life relative to 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 (the clinical characteristics of patients in the pre-dialysis phase and dialysis phase did not match), and due to the cross-sectional design, this disruption cannot be simply attributed to HD. We conducted an extra analysis to investigate whether patients on HD and PD differ regarding their serum albumin levels (an indicator of patients' health condition), and did not observe significant differences. Knowing that people

on HD (in most cases) have to go to the hospital three times a week for half a day, it is however likely that HD causes greater interference with daily life than PD. A study by Timmers et al. (2008) revealed that patients on PD perceived more personal control and had a better understanding of their illness than patients on HD. Griva et al. (2009) did not observe significant differences in any of the illness perceptions between patients on HD and PD, or differences in perceptions of treatment disruption. There are however several ways to perform HD as well as PD, which may explain the different findings. Another study by Griva et al. (2010) did take into account several HD and PD modalities, and observed significant differences in perceptions of treatment disruption between people on CAPD and APD. Following this, it seems worthwhile that future research takes into account a wider variety of dialysis modalities when investigating patients' illness perceptions and treatment perceptions and associated outcomes.

With respect to the dynamics of illness and treatment perceptions, it can be expected that, opposed to beliefs about understanding and emotional response which might change as part of the natural adaptation process to a chronic illness, beliefs about for example personal control need to be directly challenged in order to change (e.g. through treatments or interventions). Following this, it seems appropriate to note that the effect of experiences 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.

In terms of developing interventions, it seems important that interventions for (pre-) dialysis patients primarily focus on reducing the perceived negative impact of (dialysis) treatment and illness on daily life, improving beliefs about *personal control* and improving the *emotional response*, since these perceptions have been associated with quality of life outcomes in patients on dialysis (Covic et al., 2004; Fowler & Baas, 2006; Griva et al., 2009; Timmers et al., 2008), and results of the present and previous studies indicate that these perceptions are dynamic. Targeting these beliefs by means of an intervention may have potential to improve these outcomes. Moreover, it is notable that both pre-dialysis patients and patients on dialysis, on average, reported relatively low levels of perceived personal

control. In addition, patients on dialysis in particular perceived rather serious consequences of their illness.

Our study does not provide information about *when* patients' perceptions are varying the most, and therefore are possibly most prone to influences. An illness perception intervention study by Petrie et al. (2002) to alter maladaptive illness perceptions of patients with a first myocardial infarction suggests that it is important to intervene in an early phase of the illness process. It seems likely that patients' perceptions may be more apt to change, when these perceptions are not very well established yet. Moreover, it can be expected that patients in these earlier phases of the illness have more energy and time to take part in an intervention than patients in the advanced phases of the illness. It is therefore recommended to intervene on perceptions as early as possible, preferably when people are likely to form their perceptions (e.g. in the pre-dialysis phase (preferably even before CKD stage 4) or at the start of dialysis treatment).

A limitation of the present study is the partial cross-sectional design. A longitudinal study, preferably among patients in the earlier stages of CKD, would make it possible to investigate the 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, and, consequently, most likely prone to influences. In addition, it is important that future research focuses on whether changes in perceptions of patients with CKD are associated with changes in adaptive outcomes, for example quality of life or participation outcomes. Furthermore, it is important to note that the size of our data set imposed restrictions on the analyses that could be performed. We were for example not able to investigate whether associations between time on dialysis and perceptions are different for people who follow different treatments. It is recommended that future research focuses on this aspect. Furthermore, it should be emphasised that the aim of the present study was to examine whether perceptions vary across the CKD trajectory, rather than to detect factors explaining as much variation as possible. In view of future research, it would however be interesting to investigate which clinical

characteristics explain dynamics in patients' illness and treatment perceptions.

To conclude, the study findings suggest that perceptions of illness and treatment, that are relevant for CKD patients' outcomes, vary across the CKD trajectory. This study therefore offers starting points for the development of interventions to target illness and treatment perceptions of patients with CKD, aimed at improving adaptive outcomes. By giving realistic information and providing tools for fitting the illness and the (future) dialysis treatment into daily life, it may be prevented that illness and treatment perceptions become obstacles for successful adaptation to CKD. Connecting to this, it seems also important that the (future) dialysis treatment matches patients' personal preferences and situations. Consequently illness perceptions and particularly treatment perceptions may be more favourable for adaptation.

Acknowledgements

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5

The role of social support in dialysis patients' feelings of autonomy and self-esteem: Is support more beneficial for patients with specific illness perceptions?

This chapter was submitted as:

Jansen Daphne L, Rijken Mieke, Kaptein Ad A, Boeschoten Elisabeth W, Dekker Friedo W, and Groenewegen Peter P. The role of social support in dialysis patients' feelings of autonomy and self-esteem: Is support more beneficial for patients with specific illness perceptions?

Abstract

Background

Patients with end-stage renal disease (ESRD) on dialysis often experience difficulty performing daily activities. This study focuses on the role of social support in perceived autonomy and self-esteem of patients on dialysis. We examined whether the effects of various types of support depend on patients' concerns and perceived personal control regarding their illness.

Methods

One hundred sixty-six Dutch patients on dialysis completed written questionnaires. Main and interaction effects of support, concern and personal control on autonomy and self-esteem were examined, controlled for background characteristics, using linear regression analyses.

Results

General emotional support was positively related to autonomy in highly concerned patients ($p < 0.05$). This relationship turned negative in patients with low concern levels ($p = 0.054$). Overprotection was negatively associated with autonomy ($p < 0.05$), and this association was stronger in patients experiencing more personal control ($p < 0.01$). Furthermore, a positive main effect of general emotional support ($p < 0.05$) and negative main effects of lack of this support type ($p < 0.01$) and overprotection ($p < 0.01$) on self-esteem were observed.

Conclusions

The role of support in patients' autonomy appears to depend on patients' illness perceptions, whereas the role of support in patients' self-esteem does not. The results indicate that patients' personal views about their illness can provide insight into whether patients could benefit from support. The findings should be taken into account when developing interventions to support patients' autonomy and self-esteem.

Introduction

End-stage renal disease (ESRD, Chronic Kidney Disease stage 5) results when kidney function has deteriorated and is no longer adequate to sustain life. In this stage of the disease, renal replacement therapy - dialysis or transplantation - becomes inevitable. In 2008, the overall prevalence of renal replacement therapy for ESRD across Europe - among all registries reporting to the ERA-EDTA Registry - was 644 per million population (Stel et al., 2011). Dialysis in particular is burdensome and intrusive. Patients on dialysis experience multiple symptoms, with pain, fatigue, pruritus (i.e. itchy skin) and constipation in the majority of the patients (Murtagh et al., 2007). Moreover, the dialysis treatment is very time-consuming. Studies have demonstrated that patients with ESRD on dialysis experience impaired physical, mental, and social functioning compared to general population samples (e.g. Khan et al., 1995; Merkus et al., 1997; Molsted et al., 2007). Results of a Swedish study demonstrated that more than 50% of the dialysis patients reported stressors with respect to work and leisure time (Ekelund & Andersson, 2007).

Restrictions on the quantity and quality of daily activities might impede people's feelings of autonomy. A recent study showed that patients on dialysis, on average, have moderate feelings of autonomy which indicates that they do not often feel that they can do the things they wish to do in everyday life, because of their health condition or otherwise (Jansen et al., 2010). According to Deci and Ryan's Self-Determination Theory (SDT; 1985) autonomy is one of the basic psychological needs for optimal functioning. 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).

Recognising the importance of quality of life of patients on dialysis, it is interesting to know why patients, who have a comparable clinical status, differ in the extent to which they feel autonomous and experience self-esteem. By gaining insight into this matter, starting points can be generated for promoting patients' feelings of autonomy and self-esteem. It is then also important to focus on potentially modifiable factors. Previous research

suggests that patients' social environment plays an important role, by supporting patients in their efforts to carry on with daily activities (Heijmans & Rijken, 2004), which in turn might support patients' sense of autonomy. Support may, however, also undermine patients' feelings of autonomy as well as their self-esteem, in case the support is perceived as controlling or overprotective. The autonomy supportive approach involves listening fully, providing choice, and encouraging self-initiation of behaviours, whereas a controlling context refers to pressuring one to think, feel, or behave in specific ways (Williams et al., 1998, as cited in Clark & Dunbar, 2003).

Significant relationships have been found between different types of support and well-being: autonomy support in various contexts and psychological well-being (Baard et al., 2004; Deci et al., 2006; Kasser & Ryan, 1999), social support and general well-being (for an overview see Cohen & Wills, 1985; Sarason et al., 1997), and overprotection and psychological well-being (Buunk et al., 1996; Joekes et al., 2007; Thompson & Sobolew-Shubin, 1993). Studies in patients with ESRD also have demonstrated associations between social support and depressive affect, quality of life (Patel et al., 2005) and even mortality (Thong et al., 2007).

However, some studies did not demonstrate relationships between support and well-being in patient populations (e.g. Buunk et al., 1996; De Ridder et al., 2005). The question arises why social support sometimes does and sometimes does not work. According to the stress-buffering model, social support is only beneficial for those suffering adversity but does not play a role for those without highly stressful demands (Cohen, 2004). Moreover, as already mentioned support can be provided in different ways and not all types of support may be equally beneficial in face of the demands. Cohen (2004) found that, when types of perceived support were broken down, emotional support (i.e. expression of empathy, caring, reassurance, and trust and providing opportunities for emotional expression and venting) 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.

Opposed to the stress-buffering model, the main-effect model of social support argues that support is beneficial irrespective of whether one is under stress (see Cohen & Wills, 1985). Likewise, Ryan and Solky (1996) conclude - on the basis of a review of the literature - that autonomy support does not just buffer 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.

According to Lazarus and Folkman (1984) stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being. Having a chronic illness can be viewed as a potentially stressful life event. Tjihuis et al. (1995) investigated the stress-buffering effect of social support on duration and disabilities of illness in a sample of chronic ill people, taking the illness itself as a stressor. Their results did not reveal systematic buffer effects. The authors concluded that the diseases studied might not be severe or threatening enough for the buffer effect to function. The way people view their illness might be a valuable indication of the extent to which people experience their illness as a stressful event, and consequently for whether or not support could be helpful. Patients' beliefs about their illness are the central concepts of Leventhal's Common Sense Model (CSM; Leventhal et al., 1980; 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. The cognitive illness representations encompass five main dimensions: identity beliefs (illness label and associated symptoms), causal beliefs (factors or conditions believed to have caused the illness), timeline beliefs (expected duration of the illness), beliefs about control or cure (extent to which the illness can be controlled or cured through treatment and behaviours), and beliefs about consequences (expected effects of an illness on physical, social and psychological well-being). At the same time that symptoms or other cues trigger the activation and development of cognitive illness representations, they can also induce emotional responses, such as fear and worry (Cameron & Moss-Morris, 2004).

In particular for those who believe that they cannot personally control their illness and those who are highly concerned about their illness, life with end-stage renal disease is likely to be stressful. The question we address in the present study is: What is the role of social support, including overprotection, in ESRD patients' feelings of autonomy and self-esteem, and does the association depend on patients' levels of concern and perceived personal control? Or in other words, is social support more beneficial for some than for others?

Emotional support and autonomy

Based on the stress-buffering model, we expect a positive relationship between emotional support (including general emotional support, e.g. 'are affectionate towards you', and problem-oriented emotional support, e.g. 'give you a nudge in the right direction') on the one hand and autonomy on the other hand, but only in patients who report high concern and low personal control. Furthermore, we expect a negative relationship between lack of these types of support and autonomy in people with high levels of concern and low levels of personal control. We thus predict that patients with low levels of concern and high levels of personal control are not dependent on emotional support to act according to their wishes and values, and thus will not benefit from this kind of support or be harmed by a lack of it. Consequently, we do not expect any main effects of emotional support on autonomy. This latter hypothesis follows from the idea that the experience of emotional support is not a universal necessity for experiencing a sense of autonomy, and that experiencing a sense of autonomy may be more related to autonomy-supporting interactions rather than to the experience of emotional support.

Emotional support and self-esteem

In line with the previous hypotheses, we hypothesise a positive relationship between problem-oriented emotional support and self-esteem, and a negative relationship between lack of this type of support and self-esteem, in patients who report high concern and low personal control. So here too, we expect no main effects of support on self-esteem. We however expect that general emotional support is positively related to self-esteem in all patients, and that a lack of this kind of support is negatively associated with self-esteem. This assumption follows from the general emphasis of self-esteem theories on the importance of perceptions of belongingness and relatedness to people's self-esteem (Deci & Ryan, 2000; Leary & Baumeister, 2000). Experienced general emotional support might reflect satisfaction of the general need for belongingness or relatedness, and therefore contribute to people's self-esteem. In addition, we expect that these relationships will be stronger in patients who report high levels of concern and low levels of personal control.

Overprotection and autonomy, self-esteem

Finally, we expect a negative association between experienced overprotection on the one hand and autonomy and self-esteem on the other hand in all patients. Negative main effects are expected since overprotection refers to unwanted and unnecessary help, which is likely to detract from one's feelings of autonomy and self-esteem. In addition, we hypothesise that this relationship will be stronger in people who report low levels of concern and high levels of personal control. This latter hypothesis results from the assumption that these patients are less in need of help in order to maintain their sense of autonomy and self-esteem and unwanted, unnecessary help will therefore have an aggravating impact. Summarised, this brings us to the following hypotheses:

- 1) General and problem-oriented emotional support and a lack of these support types are related to autonomy (positive and negative relationships resp.), in patients who report high levels of concern and low levels of personal control (buffering effects).
- 2a) Problem-oriented emotional support and a lack of this support type are related to self-esteem (positive and negative relationships resp.), in

patients who report high levels of concern and low levels of personal control (buffering effects).

- 2b) General emotional support and a lack of this support type are related to self-esteem (positive and negative relationships resp.) in all patients (main effects), and these relationships are stronger in patients who report high levels of concern and low levels of personal control (buffering effects).
- 3) Overprotection is negatively related to autonomy and self-esteem in all patients (main effects), and these relationships are stronger in patients who report low levels of concern and high levels of personal control (buffering effects).

These hypotheses were tested in a study among patients with ESRD on dialysis, since this patient group and their significant others are required to actively deal with the illness demands on a daily basis.

Methods

Study sample

Patients on dialysis who participated in the longitudinal Netherlands Cooperative Study on the Adequacy of Dialysis phase 2 (NECOSAD-2; Termorshuizen et al., 2003; Timmers et al., 2008), were invited to participate in the present study. The NECOSAD-2 study was approved by the Medical Ethical Committees of the participating dialysis centres and hospitals. Inclusion criteria were: being older than 18 years, and having no previous history of renal replacement therapy. Since 1997 more than 2,000 dialysis patients were recruited. Within NECOSAD-2 clinical and quality of life data are collected every six months. For the present study, an additional survey was conducted in March/April 2006 among the 248 patients still being followed in the NECOSAD-2 cohort. The questionnaires were handed out by the nurses in the dialysis centres. Patients filled in the questionnaires at home or in the dialysis centre and returned them by mail. Out of 248 patients contacted, 166 patients returned the questionnaire (response rate 67%).

Measures

Dependent variables

Perceived autonomy was assessed with two items derived from the autonomy scale of the CASP-19 (Hyde et al., 2003). The two items were combined on the basis of their high factor loadings on one factor (both factor loadings: 0.81, variance explained: 66%) to assess 'global autonomy' ('I can do the things that I want to do', 'I feel that I can please myself what I can do'). Items were scored on a 4-point scale (0 = never, 1 = sometimes, 2 = not so often, 3 = often). Global autonomy scores are expressed as average scores based on the two items. Higher scores signify a higher level of perceived autonomy.

State self-esteem was measured with the Current Thoughts Scale (Heatherton & Polivy, 1991), which comprises 20 items (e.g. 'I am worried about what other people think of me' (reverse-scored item)). Items were rated on a 5-point scale (1 = not at all, 2 = a little bit, 3 = somewhat, 4 = very much, 5 = extremely). Scores are summed across individual ratings with higher scores representing a higher level of state self-esteem. The Cronbach's alpha (i.e. internal consistency) for the scale in the current study was 0.88.

Independent variables

Social support was measured with the scales 'daily-oriented emotional support' and 'problem-oriented emotional support' of the Social Support List-Interactions and Discrepancies (Van Sonderen, 1993). This is a self-report questionnaire that has been designed and validated in the Netherlands. The Social Support List-Interactions measures the experienced amount of support received from people in the close environment, such as members of the family, friends, etc. The Social Support List-Discrepancies measures the experienced discrepancy between the desired amount of social support and the received amount of support from the close environment.

The Interaction scales 'daily-oriented emotional support' and 'problem-oriented emotional support' consist of four items (e.g. 'Does it ever happen to you that people cuddle/hug you?') and eight items (e.g. 'Does it ever happen to you that people perk you up or cheer you up?') respectively. The items are all answered on a four-point scale (1 = seldom or never, 2 = now

and then, 3 = regularly, 4 = very often). Scores are summed across items, with higher scores indicating greater levels of experienced support.

The Discrepancy scales 'daily-oriented emotional support' and 'problem-oriented emotional support' consist of four and eight items respectively. Respondents are asked to indicate to what extent the behaviour, the reaction of the people they have contact with, deviates from the desired behaviour and reaction. These items are also answered on a four-point scale (1 = I miss it, I would like it to happen more often, 2 = I don't really miss it, but it would be nice if it happened a bit more often, 3 = just right, I would not want it to happen more or less often, 4 = it happens too often, it would be nice if it happened less often). The scores on the Discrepancy scales are recoded in such a way that high scores indicate a greater experienced lack of support. Scores are summed across items to obtain a total scale score. The internal consistency of the Interaction and Discrepancy scales in this study varied from 0.82 to 0.93. Hereafter, we will refer to 'general emotional support' instead of 'daily-oriented emotional support'.

Overprotection by significant others was measured using the Overprotection Scale for Adults (OPSA; Thompson & Sobolew-Shubin, 1993), which is a validated self-report questionnaire. This scale measures the patient's perceptions concerning overprotection by members of the family and friends. The scale consists of 18 items (e.g. 'The people around me do not let me do the things I could do myself'). All items are answered on a four-point scale (1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree). Scores are summed across items to obtain a total score. A high score on this scale is indicative of a high level of experienced overprotection. The internal consistency of the scale in this study was 0.85.

Concern about the illness and perceived personal control over the illness were assessed using the Brief Illness Perception Questionnaire (B-IPQ; Broadbent et al., 2006). This measure is an abbreviated version of the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002) and consists of nine items each assessing one cognitive or emotional illness representation dimension, including the dimension 'concern' and the dimension 'personal control'. The items are scored on an 11-point scale,

ranging from 0 to 10. A higher score on the dimension 'concern' implies greater feelings of concern about the illness, and a higher score on the dimension 'personal control' indicates a greater perceived personal control over the illness. The B-IPQ has proven to be a reliable and valid measure of illness perceptions in a variety of illness groups (Broadbent et al., 2006).

Background variables

Demographic characteristics included age, gender, marital status¹ (married/living together vs. not married/living alone), and 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)).

Clinical characteristics¹ included time on dialysis (in years), type of dialysis treatment (haemodialysis (HD)/peritoneal dialysis (PD)), and severity of the health condition. 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 et al., 1993; Churchill et al., 1992; Plantinga et al., 2007).

Statistical analyses

Descriptive statistics were used to describe the background characteristics of the study sample. Differences between the non-responders and responders regarding socio-demographic and clinical characteristics were tested by means of Student's T and Chi-square tests.

Descriptive statistics were computed to describe the extent to which dialysis patients experience support and overprotection by their significant others. Interrelationships between the illness perception and support variables were assessed by means of Pearson correlation analyses in order to detect potentially multicollinearity problems.

¹ These data were derived from the last known regular NECOSAD-2 measurement at the time of the implementation of the current study.

Multiple linear regression analyses were performed, using the enter method, to examine the main and interaction effects of the support and illness perception variables on perceived autonomy and self-esteem. In order to take possible confounders into account, relevant socio-demographic and clinical characteristics were included in the analyses as control-variables.

We conducted separate regression analyses for each of the five support types combined with either the illness perception 'concern' or 'personal control', resulting in ten regression analyses for each criterion variable (autonomy or self-esteem). Three blocks of variables were entered separately; block 1: socio-demographic variables (age, gender, educational level) and clinical variables (type of dialysis treatment, severity of the health condition); block 2: illness perception variable and support variable; block 3: cross-product term of the illness perception variable and support variable. Prior to entering the illness perception and support variables and their cross-product term into the regression analyses, the variables were centred by subtracting the mean score from respondents' raw scores and the product was calculated based upon the centred variables (Aiken & West, 1991). Centring the continuous variables ensures that the interpretation of effects will occur at a meaningful value of the continuous variable (i.e., the mean, which has a value of 0 with centred variables) and reduces multicollinearity (West et al., 1996). A significant increase in explained variance in the criterion variable as a result of adding the cross-product term to the model, as well as a significant regression coefficient of the product term, indicate an interaction effect. For the present study an interaction effect implies that the relationship between support and autonomy/self-esteem varies with the level of concern/personal control.

Results

Study sample

Characteristics of the total sample are outlined in Table 5.1. Approximately, two thirds of the study sample were male, which corresponds with the figures of the population of ESRD patients in the Netherlands (61%) (Renine Foundation, 2005). Around two thirds of the participants were 65 years or

older. Compared to figures of the Dutch dialysis population in 2006 (49% 65 years or older) (Oppe et al., 2007), our sample comprises a higher percentage of older patients. A large majority of respondents (71%) were treated with HD, which is comparable with the percentage HD patients within the Dutch dialysis population in 2005 (74%) (Renine Foundation). No significant differences between the study sample and the non-responders were found with regard to gender, age, marital status, type of treatment, time on dialysis, and serum albumin level.

Experienced support

The mean sum scores of the study sample on the social support Interaction scales indicate that patients now and then experience support (Table 5.2). Scores found by Van Sonderen (1993) among patients with cancer (N=399) were slightly higher on the scale general emotional support (M=10.5), and slightly lower on the scale problem-oriented emotional support (M=18.1). Scores of the healthy control group (N=220) in the study of Van Sonderen were somewhat lower for both scales (general emotional support: M=9.8; problem-oriented emotional support: M=15.0).

Table 5.1: Socio-demographic and clinical characteristics of the total sample

| | Total Sample | |
|--|-----------------------|---------|
| Gender - N (%) | | |
| Male | 106 | (64) |
| Female | 59 | (36) |
| Age, mean in years (SD) | 66.6 range: 32-89 | (11.69) |
| Age, in groups - N (%)* | | |
| 18-49 years | 16 | (10) |
| 50-64 years | 46 | (28) |
| ≥ 65 years | 104 | (63) |
| Educational level - N (%) | | |
| Low | 61 | (39) |
| Moderate | 68 | (44) |
| High | 27 | (17) |
| Marital status - N (%) | | |
| Married/living together | 104 | (66) |
| Not married/living alone | 53 | (34) |
| Type of treatment - N (%) | | |
| Haemodialysis | 118 | (71) |
| Peritoneal Dialysis | 48 | (29) |
| Time on dialysis, mean in years (SD) | 3.6 range: 0.1-9.0 | (2.34) |
| Time on dialysis, in groups - N (%) | | |
| Up to 2 years | 51 | (31) |
| 2 to 5 years | 76 | (46) |
| 5 to 10 years | 39 | (23) |
| Serum albumin, mean in g/L (SD) ** | 36.9 range: 22.6-45.8 | (4.44) |

* Due to rounding the sum of percentages is > 100%.

** Normal serum albumin values are 40-50 g/L.

When we consider the mean scores on the Discrepancy scales, it shows that the patient group as a whole does not experience significant lack of support (Table 5.2). Van Sonderen (1993) found slightly lower scores on the discrepancy scales among patients with cancer (lack of general emotional support: M=5.2; lack of problem-oriented emotional support: M=10.0) and the healthy control group (lack of general emotional support: M=5.5; lack of

problem-oriented emotional support: M=10.5). In general, dialysis patients experience a low level of overprotection by significant others (Table 5.2).

Table 5.2: Alpha's, mean scores and standard deviations of experienced (lack of) emotional support and experienced overprotection, total sample

| | Items | α | Range scale scores | M (SD) | Range scores respondents | N |
|--|-------|----------|--------------------|--------------|--------------------------|-----|
| Social Support Interactions | | | | | | |
| General emotional support | 4 | .82 | 4-16 | 9.98 (2.61) | 4-15 | 158 |
| Problem-oriented emotional support | 8 | .92 | 8-32 | 18.69 (5.12) | 8-32 | 155 |
| Social Support Discrepancies (lack) | | | | | | |
| General emotional support | 4 | .86 | 4-12 | 5.85 (2.32) | 4-12 | 157 |
| Problem-oriented emotional support | 8 | .93 | 8-24 | 11.49 (4.02) | 8-24 | 156 |
| Overprotection by significant others | 18 | .85 | 18-72 | 34.50 (7.46) | 18-60 | 147 |

Relationships between support and illness perceptions

The Pearson's correlation coefficients between the support and illness perceptions are small. With respect to concern, three significant correlations can be observed. As patients report higher levels of concern about their illness, they report higher levels of problem-oriented emotional support ($r=.22$, $p<.01$), lack of general emotional support ($r=.16$, $p<.05$), and experience more overprotection ($r=.22$, $p<.01$). Personal control is not significantly related to support (data not shown).

Combined relationships of support and concern with criterion variables

The results with respect to the regression analyses in which the support and concern variables are entered, do not demonstrate any significant main effects of general emotional support (Table 5.3) or problem-oriented emotional support (data not shown) on autonomy. With respect to self-esteem the results show that Model 2, in which the general emotional support and concern variables are added, accounts for a significant increase

in explained variance compared to the first model, in which only the background characteristics are entered ($\Delta_{m1,2}R^2$ adjusted=18.3%, $p=.000$), and also reveal a significant positive main effect of general emotional support on self-esteem (Table 5.3, Model 2 and 3). No main effects of problem-oriented emotional support on self-esteem are observed (data not shown).

Table 5.3: Regression models for the relationship of concern - support with global autonomy and self-esteem (N=108)

| | Autonomy | | Self-esteem | |
|-----------------------------------|-------------------|-------------------|-------------------|-------------------|
| | Model 2 B (SE) | Model 3 B (SE) | Model 2 B (SE) | Model 3 B (SE) |
| Concern | - 0.05 (0.03) | -0.05 (0.03) | - 1.50 (0.31)*** | - 1.50 (0.31)*** |
| General emotional support | 0.01 (0.03) | 0.01 (0.03) | 0.73 (0.36)* | 0.72 (0.36)* |
| Concern*general emotional support | - | 0.02 (0.01)* | - | 0.11 (0.11) |

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

B= Unstandardized Coefficient; SE= Standard Error.

Note: Controlled for gender, age, educational level (dummy variable: low-moderate, low-high), serum albumin, type of treatment (HD/PD).

Furthermore, the results demonstrate a significant interaction effect ($p=.02$) of concern and general emotional support on autonomy (Table 5.3, Model 3). This result indicates that the relationship between general emotional support and autonomy varies with the level of concern. The addition of the product term to the model also leads to a significant contribution in explained variance ($\Delta_{m2,3}R^2$ adjusted= 4.3%, $p=.02$), compared to the model without the product term (Model 2). Next, we examined the nature of the association between general emotional support and autonomy in patients with different concern scores. The B coefficient of general emotional support presented in Table 5.3 (Model 3) is indicative for people who have mean concern levels (concern score= 0, since the concern variable is centred²).

² This is illustrated by the following regression equations:

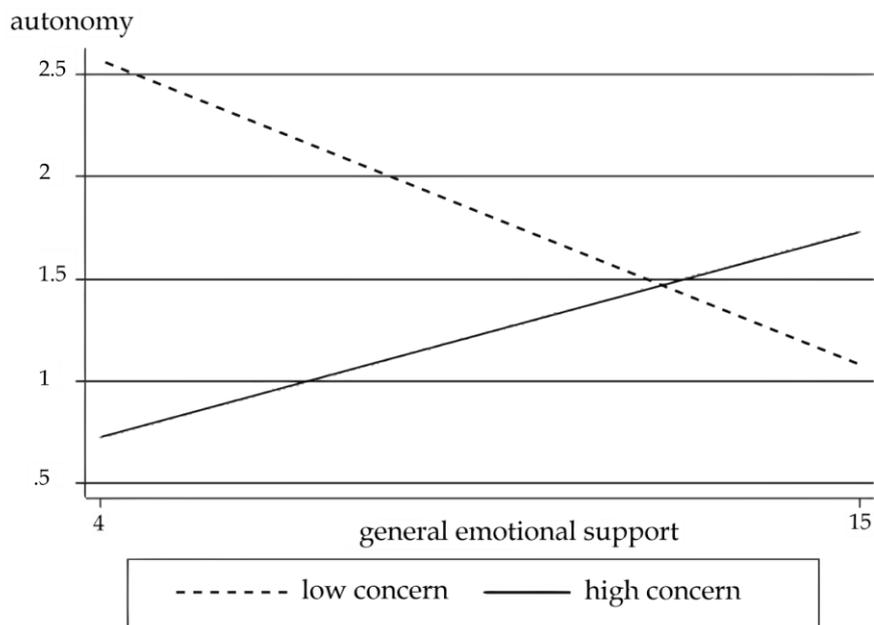
$$Y=B^0 + 0.01X (\text{general emotional support}) + -0.05 Z (\text{concern}) + 0.02 XZ$$

$$Y=B^0 + 0.01X (\text{general emotional support}) + -0.05 0 (\text{concern}) + 0.02 X0$$

$$Y=B^0 + 0.01X (\text{general emotional support})$$

The B coefficient reflects a weak positive, though not significant, association between general emotional support and autonomy. In Figure 5.1 the relationship is plotted for the highest and lowest concern scores. The results reveal a positive relationship between general emotional support and autonomy in people reporting high levels of concern, and this relationship appears to be significant ($B=0.09$, $p=.046$). Furthermore, the results demonstrate a negative association in people reporting low levels of concern, and this association is close to significant ($B=-0.13$, $p=.054$).

Figure 5.1: Association between general emotional support and autonomy for the highest level and lowest level of concern about the illness (for mean age, male, low educational level, mean serum albumin level, HD treatment)



We also examined the separate and joint effects of lack of support and concern. The results do not demonstrate significant relationships between lack of general emotional support (Table 5.4) and lack of problem-oriented emotional support (not shown in table) on the one hand and autonomy on the other hand. The results with respect to self-esteem reveal that the second model, in which the lack of general emotional support variable and concern variable are added, accounts for a significant increase in explained variance, compared to the model containing solely the background characteristics ($\Delta m_{1,2}R^2$ adjusted = 25.3%, $p=.000$), and also show a negative significant main effect of lack of general emotional support on self-esteem (Table 5.4, Model 2 and 3). These findings correspond with the previous finding that general emotional support is positively related to self-esteem (Table 5.3). Lack of problem-oriented emotional support is not associated with self-esteem (data not shown).

Finally, we looked at the separate and combined effects of overprotection and concern. The results with respect to autonomy demonstrate that Model 2 significantly contributes to the explained variance in comparison with the first model ($\Delta m_{1,2}R^2$ adjusted = 5.2%, $p=.03$), and reveal a negative significant main effect of overprotection on autonomy (Table 5.4, Model 2 and 3). With respect to self-esteem, the results show that the second model accounts for a significant increase in explained variance, compared to the model containing solely the background characteristics ($\Delta m_{1,2}R^2$ adjusted = 21.3%, $p=.000$), and that overprotection is significantly negatively associated with self-esteem (Table 5.4, Model 2 and 3).

Table 5.4: Regression models for the relationship of concern - lack of support, and concern-overprotection with global autonomy and self-esteem (N=104-107)

| | Autonomy | | Self-esteem | |
|---|-------------------|-------------------|-------------------|-------------------|
| | Model 2 B (SE) | Model 3 B (SE) | Model 2 B (SE) | Model 3 B (SE) |
| Concern | - 0.04 (0.03) | - 0.05 (0.03) | - 1.54 (0.31)*** | - 1.56 (0.31)*** |
| General emotional support, lack | - 0.03 (0.04) | - 0.02 (0.04) | - 1.50 (0.41)*** | - 1.46 (0.43)** |
| Concern*general emotional support, lack | - | - 0.02 (0.01) | - | - 0.06 (0.16) |
| Concern | - 0.04 (0.03) | - 0.04 (0.03) | - 1.35 (0.32)*** | - 1.28 (0.33)*** |
| Overprotection | - 0.02 (0.01)* | - 0.02 (0.01)* | - 0.36 (0.13)** | - 0.37 (0.13)** |
| Concern*overprotection | - | 0.00 (0.00) | - | 0.04 (0.04) |

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

B= Unstandardized Coefficient; SE= Standard Error.

Note: Controlled for gender, age, educational level (dummy variable: low-moderate, low-high), serum albumin, type of treatment (HD/PD).

Combined relationships of support and personal control with criterion variables

Next, we investigated the associations between general emotional support and problem-oriented emotional support, combined with personal control beliefs, on the one hand and autonomy and self-esteem on the other hand. The results do not reveal any significant main effects of these types of support or interaction effects of these support types and personal control (data not shown).

No significant main or interaction effects regarding lack of general emotional support (Table 5.5) or lack of problem-oriented emotional support (data not shown) on perceived autonomy are present either. The results regarding self-esteem, demonstrate that the second model, in which the lack of general emotional support variable and personal control variable are added, accounts for a significant increase in explained variance compared with the first model ($\Delta_{m1,2}R^2$ adjusted = 13.4%, p=.000), and again reveal a negative significant main effect of lack of general emotional support on self-

esteem (Table 5.5, Model 2 and 3). No further effects of lack of support on self-esteem were observed.

Finally, we investigated the separate and combined effects of overprotection and personal control. The results demonstrate a significant negative main effect of overprotection on autonomy, as well as a significant interaction effect ($p=.03$) of personal control and overprotection on autonomy (Table 5.5, Model 3). Model 3, in which the product term is added, accounts for a significant increase in explained variance ($\Delta_{m2,3}R^2$ adjusted = 3.2%, $p=.03$). The interaction effect indicates that the association between overprotection and autonomy depends on patients' reported personal control levels. Subsequently, we examined the nature of the associations. The B coefficient of overprotection presented in Table 5.5 (Model 3) shows a negative significant relationship between overprotection and autonomy in people with average personal control levels. In Figure 5.2 the relationship is plotted for the highest and lowest personal control scores. The B coefficients related to the highest and lowest personal control scores demonstrate a significant negative relationship between overprotection and autonomy in people with high levels of personal control ($B=-0.06$, $p=.003$) and a weak positive, though not significant, relationship in people with low levels of personal control ($B=0.01$, $p=.604$).

With respect to the dependent variable self-esteem, the results show that Model 2, in which the overprotection and personal control variables are added separately, leads to a significant increase in explained variance, compared with Model 1 ($\Delta_{m1,2}R^2$ adjusted = 12.7%, $p=.000$), and also reveal a negative significant main effect of overprotection on self-esteem (Table 5.5, Model 2 and 3).

Table 5.5: Regression models for the relationship of personal control - lack of support, and personal control - overprotection with global autonomy and self-esteem (N=104-107)

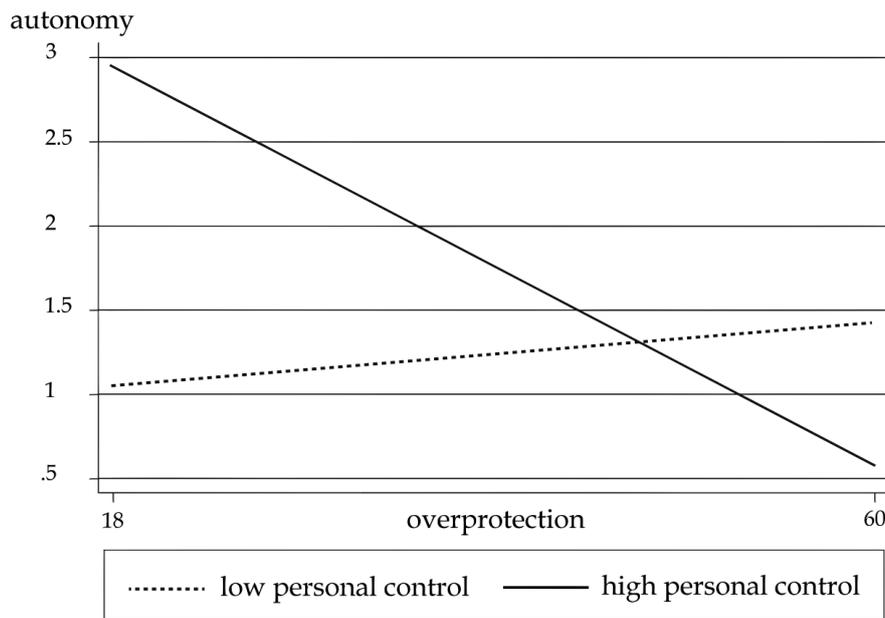
| | Autonomy | | Self-esteem | |
|--|-------------------|-------------------|-------------------|-------------------|
| | Model 2 B (SE) | Model 3 B (SE) | Model 2 B (SE) | Model 3 B (SE) |
| Personal control | 0.09 (0.02)*** | 0.08 (0.02)*** | 0.80 (0.29)** | 0.79 (0.30)** |
| General emotional support, lack | - 0.02 (0.04) | - 0.02 (0.04) | - 1.40 (0.44)** | - 1.40 (0.45)** |
| Personal control*general emotional support, lack | - | - 0.01 (0.01) | - | - 0.02 (0.13) |
| Personal control | 0.09 (0.02)*** | 0.08 (0.02)*** | 0.72 (0.30) * | 0.71 (0.30)* |
| Overprotection | - 0.02 (0.01)* | - 0.02 (0.01)* | - 0.42 (0.13)** | - 0.42 (0.13)** |
| Personal control*overprotection | - | - 0.01 (0.00)* | - | - 0.01 (0.04) |

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

B= Unstandardized Coefficient; SE= Standard Error.

Note: Controlled for gender, age, educational level (dummy variable: low-moderate, low-high), serum albumin, type of treatment (HD/PD).

Figure 5.2: Association between overprotection and autonomy for the highest level and lowest level of personal control over the illness (for mean age, male, low educational level, mean serum albumin level, HD treatment)



Discussion

In the literature on social support there are two main hypotheses on the role of social support in well-being (Cohen & Wills, 1985). The first hypothesis proposes that social support is related to well-being only (or primarily) for persons under stress ('stress-buffering'). Cohen and colleagues (2000) discuss several pathways through which social support influences individual responses to stressful life events. One of these pathways is that support may alleviate the impact of stress appraisal by providing a solution to the problem, by reducing the perceived importance of the problem, or by providing a distraction from the problem. The second hypothesis argues that social support positively influences well-being irrespective of whether

persons face stressful events ('main effect'). This study provides evidence for the existence of stress-buffering effects of support on autonomy, by taking patients' illness representations as stress indicators. Furthermore, we found main effects of support on self-esteem. Below we will discuss the results on the basis of the formulated hypotheses.

Emotional support and autonomy

The findings suggest that the experience of general emotional support is beneficial for patients' autonomy, but only in patients with high levels of concern. These results are in accordance with our hypothesis and in line with the stress-buffering hypothesis. We did not expect to find a relationship between emotional support and autonomy in people with low levels of concern. Remarkably, the results demonstrated a negative, close to significant, association between general emotional support and autonomy in people with low levels of concern. Cohen and Wills (1985) state that a pure buffering effect exists when the mean health outcome level for low- and high-support subjects is not significantly different under low stress (but quite different under high stress), and that this indicates that support is relevant only for subjects under stress. Our study findings with respect to autonomy indicate that support is, in a negative sense, also significant for people under low stress (i.e. low levels of concern).

Based upon our findings, people with low levels of personal control do not seem to benefit from general emotional support when it comes to their sense of autonomy. Cohen and Wills (1985) emphasise that support functions have to match with the stressors faced with. Tijhuis et al. (1995) also concluded that social support should be asked specifically, in relation to specific events. People who experience worries, an emotional response, seem to benefit from support that focuses on emotions, and therefore indicates a good match between the event and the type of support investigated. General emotional support, however, might not be the most relevant type of support in case people feel that they cannot influence their illness. Perhaps informative support for managing the illness and treatment and integrating the illness and treatment into daily life is more relevant under these circumstances. In contrast to our expectations, no interaction effect was found of problem-oriented emotional support and illness perceptions on autonomy. The

results did not show main effects either. This type of support is only offered in more problematic situations. It could be that this support type cannot boost feelings of autonomy, in light of the problems one is faced with.

Furthermore, we expected a negative relationship between lack of support and autonomy in patients who experience high levels of concern and low levels of personal control. However, no interaction effects were observed and no main effects were observed here either. Thus, people who experience high and low levels of lack of support do not differ in their feelings of autonomy, not even when they are worried about their illness or when they feel that they cannot personally control their illness. This suggests that an experienced lack of support is not harmful to patients' sense of autonomy, which is a notable finding.

Emotional support and self-esteem

As expected, our findings indicate that people's self-esteem benefits from general emotional support and suffers from a lack of it, regardless of their illness perceptions regarding concern and personal control. This, as stated before, might reflect satisfaction or dissatisfaction of the general need for belongingness or relatedness which is related to feelings of self-esteem. Unlike our expectations, these relationships were however not stronger in patients who reported higher levels of concern and lower levels of personal control. This might reflect a certain limit to the boosting effect of this kind of support, i.e. to derive self-esteem through social resources. Contrary to our expectations, no interaction effects were observed of (lack of) problem-oriented emotional support and illness perceptions on self-esteem. Also here the absence of a positive association between problem-oriented emotional support and self-esteem could be explained by the fact that the problematic situation itself predominates. And also in line with the results regarding autonomy, lack of problem-oriented emotional support does not seem to be harmful to one's self-esteem.

Overprotection and autonomy, self-esteem

We found significant negative associations between overprotection on the one hand and autonomy and self-esteem on the other hand, as hypothesised. In addition, we hypothesised that these relationships would be stronger in people who reported lower levels of concern and higher levels of personal control since these people are less in need of help, let alone unwanted and unnecessary help. This hypothesis was partly confirmed. With respect to autonomy, we found a significant interaction effect indicating that the relationship between overprotection and autonomy varies with the level of personal control. Overprotection seems to have an aggravating impact on autonomy in patients with stronger beliefs that they can personally control their illness. We however did not observe a significant interaction effect of overprotection and concern on autonomy. This again may have to do with the linkage of the type of event with the type of support. 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.

It is noteworthy that the present study had a cross-sectional design, which means no conclusions can be drawn with respect to the causality of the observed relationships. For example, a negative relationship between support and autonomy may indicate that experiencing little support results in feeling more autonomous, or that people with a stronger sense of autonomy generate less support from their social environment. Notwithstanding this limitation, our results show that experienced support by patients on dialysis is associated with their feelings of self-esteem, and that illness representations regarding concern and personal control interfere with the relationship between experienced support and feelings of autonomy in patients on dialysis. We were able to reveal significant interaction effects, despite the rather small study sample which reduces the statistical power to demonstrate relationships.

With respect to the measurement methods, we like to emphasise that illness perceptions and experienced support were measured via self-reporting, which means that the constructs are assessed from the patients' perspectives. In the first case this is logical, since it concerns patients' personal beliefs

about their illness. Received support can however also be measured from the provider's perspective or by observation. However, the interpretation and experience of the patients themselves are the most important and relevant for the outcomes under study.

Implications

The findings from our study indicate that emotional support is not necessarily beneficial for dialysis patients' sense of autonomy. General emotional support seems to be helpful for patients who are highly concerned about the illness, and the results suggest that it might even be detrimental in case patients are not worried. In addition, the findings indicate that experienced overprotection is most harmful to patients' feelings of autonomy as they experience high levels of personal control over the illness. The results suggest that the provision of support should be tailored to dialysis patients' individual needs. In contrast to autonomy, one's self-esteem always seems to benefit from general emotional support and to suffer from a lack of it, as well as from overprotection. We suggest taking these findings into account when developing interventions focused on supporting patients in their efforts to maintain a sense of autonomy and self-esteem. Future research would benefit from using a longitudinal design which would allow statements about causality, and generate recommendations for interventions.

Our findings also point to the value of patients' beliefs about their illness as indicators for the extent to which social support could be beneficial. Patients' personal views about 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. We recommend investigating these relationships in other chronic ill patient groups as well.

Furthermore, the results point to the relevance of specifying illness related needs. The results indicate that people who are worried about their illness or who experience little personal control over their illness do not benefit from the same types of support. Regarding these findings, we want to emphasise that our findings only cover the roles of emotional support and

overprotection aspects in perceived autonomy and self-esteem. Other types of support exist (e.g. esteem support, instrumental support, informative support) and these support types, combined with the illness perceptions, might deliver different outcomes with respect to autonomy and self-esteem. In addition, the support types and illness perceptions we investigated in the present study might show different relationships with other well-being outcomes, such as vitality or relatedness. More research is needed that focuses on illness perceptions in combination with other support types and/or other aspects of well-being.

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6

The development of and first experiences with a behavioural self-regulation intervention for end-stage renal disease patients and their partners

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Abstract

Objectives

This article describes the development of an intervention programme for patients with end-stage renal disease (ESRD) and their partners. The programme is based on theories of self-regulation, social learning, and self-determination aimed at maintaining and increasing patients' activities, including paid work, and sense of autonomy.

Methods

The intervention was evaluated on its feasibility and first experiences among a group of 12 patients and partners.

Results and conclusion

Results show that the intervention is feasible. The outcomes observed by the patients themselves are encouraging. The findings show that an approach in which cognitive, emotional, behavioural, and contextual aspects are integrated is promising. Areas of attention for developing and implementing interventions are discussed.

Introduction

End-stage renal disease (ESRD) refers to the point at which a patient with renal failure can no longer survive on existing kidney function and must undergo renal replacement therapy. At the end of 2005, about 1,9 million people were receiving renal replacement therapy worldwide, with about three quarters treated by dialysis and one-quarter by kidney transplant (Grassmann et al., 2006). ESRD patients on dialysis experience multiple symptoms such as pain, fatigue, pruritus and constipation (Murtagh et al., 2007). In addition, they experience impaired physical, mental, and social functioning compared to the general population (e.g. Khan et al., 1995; Merkus et al., 1997; Merkus et al., 1999; Mittal et al., 2001).

The combination of dialysis and employment seems particularly difficult. Dialysis patients aged 18–64 years work less compared to the general working age population (Braun Curtin et al., 1996; Theorell et al., 1991; Van Manen et al., 2001). It is notable that many renal patients resign from their jobs during the period in which they are being prepared for renal replacement therapy. In a Dutch study only 35 percent of the ESRD patients of working age were still employed at the start of dialysis, compared to 61 percent in the general population (Van Manen et al., 2001). A review of the literature shows that work is generally beneficial to people's physical and mental health and well-being, and unemployment is associated with negative health effects (Waddell & Burton, 2006).

A literature study by Heijmans and Rijken (2004) revealed two psychological factors that may be closely linked to employment in ESRD patients, in addition to disease and socio-demographic characteristics: the patient's perceptions of illness and treatment, and social support including over-protection. These psychological factors, which have not been studied systematically, are interesting as they could be altered (Moss-Morris et al., 2007; Petrie et al., 2002). Therefore, we investigated how ESRD patients' cognitive representations of their illness and treatment and the type of support that they experience are associated with participation in employment, feelings of autonomy, and self-esteem. In 2006 questionnaires were sent to 248 dialysis patients and 185 patients being prepared for

dialysis. The response rate was 67% and 59%, respectively. We found that perceptions of illness and treatment contributed significantly to the variance in perceived autonomy and self-esteem, after controlling for socio-demographic and clinical characteristics. Beliefs about personal control over the illness, less perceived impact of the illness and its treatment, and less concern about the illness were the most important predictors of perceived autonomy and self-esteem (Jansen et al., 2010; Jansen et al., 2010). With respect to employment status, consistent bivariate relationships with perceptions of the illness and treatment were observed in both patient groups. However, these relationships did not reach statistical significance due to the low number of working age patients. Furthermore, the results showed that social support by significant others, and overprotection by significant others and doctors, made an important contribution to the explained variance in perceived autonomy and self-esteem in dialysis patients. In addition, unemployment was related to perceived overprotection by doctors (Jansen et al., 2009).

Development of intervention

We decided to develop a psychological intervention which targeted these factors in order to maintain or widen ESRD patients' daily activities, including paid work, and to increase patients' feelings of autonomy. The content of the intervention is based on the results of our empirical study and three theoretical models: self-regulation theory, by Leventhal and colleagues (Leventhal et al., 1980; Leventhal et al., 1984); social learning theory, by Bandura (1977a); and self-determination theory, by Deci and Ryan (1985).

Self-regulation theory

Illness perceptions are a key component of Leventhal's Common Sense Model of self-regulation of health and illness (Leventhal et al., 1980; Leventhal et al., 1984). According to this model, people make sense of a health threat by developing their own cognitive representation of that threat. These representations generally contain the following factors:

- the name of the illness and the range of symptoms that the patient believes are associated with the condition;

- beliefs about the cause of the illness and how long it will last;
- beliefs about the personal consequences of the condition for the patient and their family; and
- the extent to which the illness is amenable to personal control or to control through treatment (Petrie et al., 2007).

These representations determine how patients respond to their illness on a behavioural and emotional level. Besides representations of illness, patients' beliefs about treatment also play a role in how they cope with their illness (Horne, 1997, 2003). Research has shown that positive perceptions of illness and treatment are associated with various patient outcomes (Hagger & Orbell, 2003; Petrie & Weinman, 1997; Petrie et al., 2007). Studies among ESRD patients demonstrate that their illness representations and treatment beliefs are associated with health-related quality of life (Griva et al., 2009; Timmers et al., 2008). Petrie and colleagues (Petrie et al., 2002; Petrie et al., 1996) were one of the first to translate the principles of self-regulation theory into a hospital intervention in order to change perceptions of illness after myocardial infarction. The results of a randomised controlled trial (RCT) study showed that the intervention produced improved functional outcome and an earlier return to work. A recent pilot study demonstrated that a simple intervention to change haemodialysis patients' perceptions of phosphate-binding medication improved their beliefs and knowledge about their treatment immediately after the intervention, in comparison to a control group (Karamanidou et al., 2008).

Social learning theory

According to Bandura's (1977a, 1997) social learning theory, human beings learn by observing how other people behave. The use of peer modelling, and peer support are approaches grounded in this theory. Central concepts within this theory are self-efficacy and expectations of outcome. Self-efficacy is a person's belief in their own ability to perform a particular behaviour successfully, and outcome expectations are beliefs about the effectiveness of the behaviour. These cognitive processes play an important role in the acquisition and retention of new behaviour. Improving patients' belief in self-efficacy is a key element of the Chronic Disease Self-Management Programme (Lorig et al., 2001): results from a RCT study showed that at six

months and two years after the start of the programme, the participants experienced an increase in self-efficacy, well-being, health behaviours, and physical health status in comparison to the control group (Lorig et al., 2001; Lorig et al., 1999).

Self-determination theory

Self-determination theory emphasises the importance of autonomy for an individual's well-being (Deci & Ryan, 1985). One is autonomous to the degree that one experiences choice, willingness, and personal endorsement of one's actions. According to self-determination theory, the successful accomplishment of desired behaviours occurs when people themselves view this behaviour as important, and not because the behaviour is achieved through pressure or coercion by others.

Contexts that support autonomy facilitate more autonomous regulatory processes, and thus promote an effective change in behaviour. Support for autonomy in various contexts has been associated with psychological well-being and improved health behaviours (Baard et al., 2004; Deci et al., 2006; Kasser & Ryan, 1999; Williams et al., 2006; Williams et al., 1998). Patients' family members are probably the most important actors within the patients' social context: they play an important role in a patient's adjustment to the illness (Martire, 2005). Clark and Dunbar (2003) translated the principles of self-determination theory into a family partnership intervention, in which the family members of heart failure patients learned how to develop behaviours that support autonomy, and the patients learned how to achieve the support they felt was needed in an effective and positive way. The results of an experimental pilot study demonstrated that patients who received this family partnership intervention showed greater self-management in dietary sodium behaviours than patients who received a minimal intervention (Dunbar et al., 2005).

The three theories discussed above all focus on different aspects, and a combination of the theories might be promising. A study by Chatzisarantis et al. (2008) provides support for the merit of integrating theories when explaining behaviour change. They show that the construct of perceived autonomy support in self-determination theory helps to identify the

influences that others exert on intentions. They suggest that it may be worthwhile to include this idea in Ajzen's (1991) theory of planned behaviour. For this reason, we integrated the three theories described above into the development of our intervention.

Outline intervention

The intervention was a course for a minimum of five patients aged 18–64 years who were being prepared for dialysis, or were on dialysis for less than one year, and their partners. The course comprised six 2.5-hour sessions every two weeks, and one return session after three months. Course material for participants included a handbook which contained assignments and practical and theoretical information. The course focused on changing both misperceptions and negative perceptions of illness and treatment, increasing belief in self-efficacy, and stimulating social support. It was delivered by a health psychologist in cooperation with a nephrologist and an employment expert.

Content sessions

For the first three sessions we followed the method developed by Petrie et al. (2002, 1996). In the first session, information is given about the illness and treatment by a nephrologist. Next, the illness and treatment perceptions of the participants are explored and discussed in order to recognise different beliefs and coping strategies.

In the second session, the participants' beliefs about the importance and attainability of activities related to work and private life are explored and discussed. Topics such as work adjustments and employment legislation are addressed by an employment expert. Questions, personal experiences and wishes are discussed, and perceived opportunities encouraged if attainable. In both the first and second sessions, special attention is given to ideas about consequences: particularly beliefs that activities including employment cannot be combined with dialysis. Negative beliefs and misperceptions are challenged by highlighting positive beliefs, giving practical examples, and addressing personal stories of ESRD patients which are described throughout the course book, thus broadening participants' views on the opportunities available.

In the third session, special attention is given to beliefs about personal control and information provided on the relationship between events (for example starting with treatment), beliefs, feelings, and behaviour, and on the importance of turning negative thoughts into constructive ones. In preparation for this session, all the patients are asked to think of one employment and one private life goal: for example, collecting for charity or starting a walking programme. They are asked, then, to evaluate these goals based on personal importance and attainability. The patients' goals are discussed within the group and adjusted if necessary. Subsequently, patients divide their main goals into sub goals and learn how to develop an action plan in order to reach these goals and ultimately their main goals. From this third session onwards, the patients develop and carry out an action plan every two weeks, helped by their partners. In these three sessions, observational learning techniques are used, such as didactic teaching, written material, examples of personal stories from peers, and group discussion.

Changing inadequate perceptions is a first step towards behavioural change, but support for self-efficacy and autonomy is 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 two-weekly action plans and feedback on progress, modelling of self-management behaviours and problem-solving strategies.

In session four, special attention is given to fatigue. In preparation for the session the patients keep a daily fatigue diary to gain insight into existing complaints about fatigue and its patterns. Experiences are discussed and information is given on how to manage time and energy in an adequate way by structuring and setting priorities.

In session five, attention is paid particularly to the role of the social network. The patients who participate without a partner are invited to bring along a family member or friend. Supportive and unsupportive behaviours are discussed, together with ways to ask for support. Partners, family members,

or friends learn to give support and to prevent overprotection, and the patients learn how to ask for support in an adequate way.

In session six, the participants develop an action plan for an employment goal for the next three months. Advice is given on which steps to take and how to contact relevant parties, such as employers and company doctors. In preparation for this session, all the patients are asked to think of an employment goal, and to check whether this is attainable and important to them. During the session the patients' goals are discussed and adjusted if necessary. Subsequently, they develop a plan together with their partners under the guidance of the employment expert and the health psychologist. They then discuss their plans within the group.

During the return session, the outcome of their action plans related to employment is evaluated within the group under the guidance of the health psychologist 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.

Pilot intervention

In the months from April to August 2008 the intervention was piloted, testing whether it was feasible and initial experiences. During this period patients and their partners received a course in three dialysis centres situated in the centre of the Netherlands. In February 2008, patients were recruited by the social workers based in the participating dialysis centres on the basis of a range of criteria. These comprised the following, where the patient: is experiencing decreased renal function and renal replacement therapy is inevitable (ESRD); is being prepared for dialysis, or receiving dialysis for a maximum period of 12 months; is aged 18-64 years; is able to speak Dutch sufficiently; is able to perform work; has sufficient intellectual capacities to participate in the course and study; and is not undergoing psychological, psychotherapeutic or psychiatric treatment. All the meetings were held in one of the three centres. Feasibility and experiences were investigated through evaluation forms and interviews.

Implementing the intervention

The social workers were positive about the organization of the course. Two social workers stated that recruiting the participants resulted in a minimal burden. For the other two it was a substantial burden, but manageable. Neither they, nor the other health care providers, nephrologists and dialysis nurses, received an increase in requests for information and support from participating patients. The social workers stated that the number and nature of their contacts with the participants remained the same throughout the course.

Recruitment and retention

Twenty-eight eligible patients were selected and received information on the course and the study; ten of them signed up. Reasons for not responding were mostly due to not being able to fit the course into one's daily schedule. Three patients dropped out without attending any meetings because of health reasons, resulting in seven patients participating. All participating patients lived with a partner, and five of them took part with their partner. There were four men and three women with a mean age of 48.7 years. Six patients performed paid work (M=21.8 hrs. per week; SD=11.3, range 4.5–40), and one patient was unemployed. No patients withdrew during the course. Among the participating partners were two men and three women.

Acceptability

Course participants' views

The majority of the participants were satisfied with the length, number, and frequency of the meetings, although experiences varied with regard to the times at which the course was held. All participants liked to work in a group. The mixture of experiences and information of both pre-dialysis and dialysis patients was highly valued. The participants rated all the meetings (considerably) useful according to a three-point scale: 'useful', 'considerably useful', and 'not useful'. The meetings which were indicated most often as useful were those in which the action plan was introduced, the topic of fatigue addressed and focus placed on developing an action plan for a long-term employment goal. According to a majority of the participants the various aspects of living with ESRD received sufficient attention. However, the need for information differed between the participants. Some reported

that they were interested in more information on certain addressed topics, such as dialysis and employment legislation, while others were not. Furthermore, two participating partners wanted more attention given to the role of partners and the exchange of partners' experiences.

Action plans were important elements within the course. The great majority considered the action plans as useful (7/9) and the number of plans as good (9/10). Five out of ten participants appreciated the degree of difficulty posed by the action plans.

However, an equal part thought that it was difficult. Notwithstanding this, most considered the action plans to be practical (6/10). Furthermore, the participants stated that all the assignments within the course were useful. The fatigue diary and the action plans were regarded as most helpful. One partner responded that thinking about ways to help their partner to cope with the illness was very useful.

The participants largely indicated that the course leaders addressed individual needs, situations, and questions adequately and were much involved with the group (Table 6.1).

Table 6.1: Participants' experiences with course leaders (N=11)

| | Not at all | Some- what | Quite a lot | Very much |
|--|---------------|---------------|----------------|--------------|
| Were your personal situation and needs considered? | 0 | 1 | 7 | 3 |
| Was there attention for your questions and needs? | 0 | 1 | 4 | 6 |
| Was the provided feedback clear? | 0 | 1 | 6 | 4 |
| Was the information provided clear? | 0 | 1 | 7 | 3 |
| Was there involvement with respect to the group? | 0 | 0 | 6 | 5 |

Course leaders' views

According to the course leaders, the participants preferred to work in groups, as this provided much discussion, cooperation, motivation, and mutual interest. They would like to see larger groups that would enable greater opportunities for cooperation and discussion. In order to monitor the group process and course content, it is proposed that two main course

leaders deliver the course. The course leaders had good experiences with course feasibility and delivery, and indicated that course content corresponded with the participants' personal needs and situations. In order to optimize this link, it was felt that general information should be reduced while participants' personal contribution promoted. Furthermore, it was advised that there should be more opportunities for partners to exchange experiences. The participants sometimes had difficulty doing the exercises: therefore, it is recommended that work on the various exercises should be conducted mainly in subgroups. In addition, more time should be spent on the discussion before and after the exercises, in particular the action plans. The course leaders stated that the group composition was good, although they stress that it is important to maximize efforts to include patients shortly after diagnosis. In this phase of the illness, 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 is likely to benefit the most from the assistance offered in the course.

Perceived outcomes

The patients were asked if they were able to work on their goals during the course. One responded that he had been able to do a lot of work on his goals; three indicated that they had worked on their goals quite a lot, and another three stated that they were able to work on their goals to some extent. Several patients observed changes in their personal situations. One patient stated: 'I have found a job, do more at home and I have become more active in general.' Several patients indicated that by using the action plans and fatigue diaries they were able to divide their time and energy better during the day. Furthermore, the answers showed that some patients had learned to integrate their social environment into their illness and treatment. For example, one said: 'I am more aware of the fact that you have to explain the illness and its limitations to everyone, and have to keep your employer informed about the situation.' Most patients (4/7) indicated that they are planning to put the things they have learned into practice in the future.

Participants valued the course with an average grade of 7.6 on a scale from 1 to 10. All participants recommended the course to other patients and their partners. Examples of accompanying statements are as follows:

The course gives insight into how 'healthy' you still are, and what, and how much, you still can do.

A wonderful way to learn what you should do to stay in work. By means of a good personal action plan you build energy into your daily life. You know how you would like to reach for your goals, and that gives you peace of mind.

Discussion

The first aim of this study was to develop a psychological intervention to assist ESRD patients and their partners in integrating renal disease and treatment into their daily activities, primarily work, and thereby increasing their autonomy. The focus of the intervention can be divided into three aspects.

The first was to stimulate positive but realistic beliefs about the disease, treatment, and the opportunities to stay active in both patients and partners – and in so doing, to change maladaptive beliefs.

The second was to increase patients' self-efficacy.

The final aspect was to stimulate behaviour that supports autonomy in both patients and partners.

The second aim of this study was to test how feasible the intervention was and to evaluate the first experiences of the participants, course leaders and health care providers involved.

We were successful in developing an intervention which addressed the cognitive, emotional, behavioural, and contextual aspects important for patients' self-regulatory processes. Furthermore, implementation of the intervention in a clinical setting was successful. The participating dialysis centres were strongly supportive of the intervention, since all the three centres endorsed the necessity of this type of assistance. The cooperation

with the three dialysis centres worked well, in that together the centres approached enough potential participants; however, the rate of participation was lower than expected. The reasons for not responding indicate that it is important for the course to be fitted into participants' daily lives. In future, consideration should be given to where and when the meetings are held and how participants can get there. When we compare the patients approached with those who actually participated, we found that no patients younger than 30 took part, although some were approached. More efforts are needed to reach this group. It is advisable to emphasize that besides employment, attention is given to education and training. None of the seven participating patients withdrew from the course, which indicates that all patients regarded the course as useful.

On the whole, the participants and course leaders were positive about the course format. Participants were less satisfied about the times at which the course was held. Preference for course times seems to be very personal, since patients' dialysis and work schedules differ. These findings highlight the importance of flexibility in scheduling future courses. One could think of giving the intervention to patients at the dialysis centre while they are on dialysis, or adapting dialysis or work schedules in cooperation with health care providers or employers.

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 beliefs. This was endorsed by one of the patients, who stated that the course gave insight into how 'healthy' you still are, and what and how much you still can do. We chose a group format instead of an individual format, since peer modelling and peer support are useful strategies to influence beliefs about illness, treatment and self-efficacy. All participants held positive attitudes towards the group element, and indicated that they valued the opportunity to exchange knowledge and experiences and had learned from it. However, a group could inhibit the expression of difficulties and emotions. Consequently, it is important to create a trusted atmosphere by means of an extensive introduction around

the group and occasionally putting participants together to work in smaller groups.

The course leaders indicated that there was a lot of open discussion, cooperation and mutual interest, and thought that it was important to increase these opportunities in order to improve the group process and, in turn, the learning process. This should be done by increasing the number of 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.

The course leaders stress that more effort is needed to include patients shortly after diagnosis, in order to assist them during the early phase of the illness and to work preventatively. Moreover, research suggests that interventions to change cognition should focus on patients at an early stage of the illness (Petrie et al., 2002). The fact that various disciplines, and consequently knowledge, come together in an early phase of the illness, can be seen as a great advantage of the course. The topics addressed within the course appeared to be relevant to all the participants. However, one area for attention is how the information given is tailored to individual preferences. The differences in these preferences may be partly caused by the differences in participants' stages of illness and/or treatment. Therefore, the amount of general information should be reduced and more time spent on exploring and discussing individual needs for information: this can be done throughout the course or by organizing separate question times. Furthermore, it was suggested that more opportunities should be created for partners to exchange experiences with respect to how they deal with their partners' illness. Partners 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 need for support.

The participants' attitudes towards the exercises were good, particularly the fatigue diary and action plans. These exercises aimed to provide a framework for ways to structure activities and make them more accessible, thus lowering the threshold for carrying them out and consequently promoting patients' belief in self-efficacy. Patients indicated that these exercises meant they were more able to divide their time and energy during

the day, and one patient stated that creating plans to reach goals gave him peace of mind. However, some participants encountered difficulties with the exercises: it is recommended that this problem should be tackled by working in small groups, paying more attention to discussion and giving more examples, so that participants are able to relate to them better. In addition, patients' self-observed results from the course were encouraging.

The health care providers reported no unfavourable consequences of their cooperation with the course. Moreover, in the long run, health care providers, especially social workers, might experience favourable consequences, since it can be expected that an intervention of this kind prevents problems, or anticipates problems, which social workers normally encounter in their regular care.

Conclusion

The current study meets the emerging need for research regarding development and evaluation of self-regulatory based interventions aimed at improving patient outcomes (Petrie et al., 2007) and ESRD patients outcomes in particular (Griva et al., 2009; Timmers et al., 2008). Further research is needed to evaluate the actual effectiveness of the course, both in the short term and the long run. It needs to ask whether the course leads to fewer patients dropping out of the employment market and results in increased feelings of autonomy. Findings from this pilot study are encouraging and suggest that an approach driven by theory in which cognitive, emotional, behavioural, and contextual aspects are integrated is promising. The maintenance of paid employment and reintegration are complex processes. A positive attitude, social support as well as a belief in self-efficacy, are needed. Many reintegration programmes use action plans by which goals are reached in small steps, but for these plans to be effective it is of great importance that the patients themselves support these goals. They should be autonomous rather than controlled. The study revealed factors that are important for the development and implementation of psychological interventions in general, and identified challenges for future interventions.

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7

General discussion

This chapter is based on:

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Introduction

Chronic Kidney Disease (CKD) draws heavily on patients' daily functioning. The disease, medical 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 (dialysis or kidney transplantation) often experience difficulties in participating in various domains of life, such as paid work, sports and other social and leisure activities (Heijmans & Rijken, 2004). For CKD patients on dialysis it seems particularly difficult to perform paid work and it is notable that patients who are being prepared for renal replacement therapy (pre-dialysis patients) already experience work-related problems.

Restrictions on the number or quality of daily activities, including performing 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, these studies aimed to investigate the role of perceptions of illness and treatment and experienced social support in perceived autonomy, self-esteem and labour participation in both pre-dialysis patients and patients on dialysis (haemodialysis and peritoneal dialysis). A further aim was to develop a psychological intervention programme - for (pre-) dialysis patients (aged 18-64 years) and their partners - aimed at supporting patients' participation in daily activities, including paid work, and feelings of autonomy and self-esteem. The third objective was to implement the developed intervention on a small scale, and to test the intervention on feasibility and initial experiences (process evaluation).

In this final chapter we will provide an overview of the key findings from our studies and we will reflect upon the findings. In the next section, the key findings from our empirical research on this topic will be discussed in the context of previous research and existing theories. In the third section the development and pilot phase of the psychological intervention programme will be described, and areas of attention for the development and implementation of interventions in general will be addressed. We will end

by discussing the methodological considerations, and directions for future research as well as practice.

Review key findings empirical research

In this section we provide an overview of the main findings from 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 national multi-centre studies among pre-dialysis patients (PREPARE-2 study) and 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.

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 has demonstrated that both high self-esteem and stable self-esteem are associated with greater psychological well-being (Paradise & Kernis, 2002).

The findings from our studies, presented in **chapter 2** and **chapter 3**, demonstrated that both patients in the pre-dialysis phase and patients on dialysis, on average, have moderate feelings of autonomy. This indicates that patients 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. Our research

did not provide insight into the stability of patients' self-esteem. A Dutch study by Abma et al. (2007) revealed that people with renal disease 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.

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.

In **chapter 3** we have investigated pre-dialysis patients' labour participation. In 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. 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 included 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 years.

In **chapter 2**, we have investigated the labour participation of patients on dialysis. Within the sample of 166 dialysis patients, 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). 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 7.1). It should be noted that the studies vary with respect to the labour participation definitions and age ranges used.

Table 7.1: Labour participation rates of working-age patients on dialysis

| 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 |

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 were important determinants (see Heijmans & Rijken, 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

engaged in paid work 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 yrs.) 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 and that the groups were small (small N's). Notwithstanding that, our results suggest that labour participation in (pre-) dialysis patients is indeed lower than in the general Dutch population. We also have compared the (pre-) dialysis patients' employment rates for the group aged below 55 yrs. and the group aged 55-64 yrs. with rates of the general population by age (Table 7.2). The employment rates among patients on dialysis still lag behind. The employment rate of pre-dialysis patients aged 55-64 yrs. appears to be comparable with the employment rate of the general population aged 55-64 yrs. The employment rate among patients aged below 55 yrs. is however considerably lower compared to the employment rates in the general population aged between 25 and 54 yrs.

Table 7.2: Labour participation (paid job \geq 12 hrs. per week) in the Dutch general population, the sample of pre-dialysis patients (N=45) and patients on dialysis (N=62) of working age in 2006

| | 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% |

* Source: Statistics Netherlands - CBS

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 paid jobs in the pre-dialysis phase. These findings are in line with the findings from the study by Van Manen et al. (2001) among 659 dialysis patients aged 18-64 yrs. 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 has 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 four months after dialysis start.

These results point to the importance of work-related support at an early stage of the illness process. Research indicates that renal patients themselves also report to have problems related 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 & Andersson, 2007).

Key points

- 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 regarding work and leisure time.

The role of perceptions of illness and treatment

One of the objectives of our studies has been to investigate (pre-) dialysis patients' illness perceptions and treatment perceptions in relation to employment and - more generally - perceived autonomy and self-esteem. Findings from two previous studies inspired us to investigate these relationships. Firstly, 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. Secondly, a study by Petrie et al. (1996), among myocardial

infarction (MI) patients, that showed that illness perceptions were related to return to work. Particularly 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, 2010). CSM postulates that both cognitive and emotional representations determine how patients cope with their illness and adapt to their illness. The cognitive representations generally consist of beliefs about the illness *identity, cause, timeline, personal control over the illness, treatment control over the illness, illness consequences, and coherence*. Emotional representations refer to beliefs about the extent to which one is emotionally affected by the illness, e.g. whether one experiences fears or worries.

Two important aspects of illness perceptions are: firstly, that patients' beliefs about their condition are often at variance from those who are treating them; secondly, that 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 positive perceptions of the curability/controllability of the illness 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 have provided evidence that perceptions of illness are associated with eating and exercise self-efficacy in patients with coronary

heart disease, attending rehabilitation in MI patients, and self-management behaviour in patients with diabetes (see Petrie et al., 2007).

Besides representations of illness, patients' beliefs about their medical treatment (i.e. beliefs about necessity for and concerns about treatment) also play a role in how patients cope with and adapt to their illness. Studies have demonstrated that beliefs about treatment are related to adherence and treatment decisions (Horne et al., 2007; Horne & Weinman, 2002).

Content of CKD patients' illness and treatment perceptions

Taking a look at the findings from our studies among pre-dialysis patients and patients on dialysis (**chapter 2** and **chapter 3**) it is notable that both patient groups, on average, have relatively low levels of perceived personal control over the illness. 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 to 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 about 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 showed 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 required to monitor food and fluid intake and to take multiple medications, in addition to following a generally healthy lifestyle (Braun Curtin et al., 2005). However, the extreme dependence on the dialysis treatment might predominate, and overshadow the extent to which one can influence the course of the illness themselves. For pre-dialysis patients it is of great importance to practise self-

care behaviours as well, 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 had 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 they have 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 on 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 patients and peritoneal dialysis patients showed that patients on peritoneal dialysis experienced more personal control, compared to haemodialysis patients.

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 over the illness, less perceived (negative)

consequences (of both the illness and treatment) on life, and less perceived negative emotional reactions to the illness generally are 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.

Studies also have demonstrated associations between depression on the one hand, and illness perceptions (Chilcot, 2010; Griva et al., 2010), and treatment perceptions (Griva et al., 2010) on the other hand in patients on dialysis. 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.

Illness and treatment perceptions - autonomy and self-esteem

In our studies (**chapter 2** and **chapter 3**) we have investigated whether differences in patients' illness perceptions and treatment perceptions are associated with variation in perceived autonomy and self-esteem. We did this by means of multiple regression analyses in which we controlled for differences in socio-demographic and clinical characteristics. The results demonstrated that the illness and treatment perceptions explained a substantial amount of variance in autonomy and self-esteem, after controlling for background characteristics.

With respect to pre-dialysis patients (**chapter 3**) the results showed that little perceived disruption in life due to treatment 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 indicate that the way patients perceive their treatment is already significant 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 and future treatment.

With respect to patients on dialysis (**chapter 2**) the results showed that the perception of high 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 to global autonomy feelings. Furthermore, the results showed that beliefs that the illness and treatment have little negative impact on daily life are positively associated with autonomy (health-related measure). Thus, patients who believe that the illness and treatment do not impede their lives, feel that their health does not stop them from doing the things they would like to do. Lastly, perceptions of little concern about the illness and little treatment disruption are significant contributors to a high 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.

Illness and treatment perceptions – labour participation

We also have examined the relationship 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 12 hours per week) on the other hand within the working-age group (18-64 years) (**chapter 2** and **chapter 3**).

We were not able to demonstrate distinct relationships between perceptions

of illness and treatment and labour participation. However, the results of the bivariate analyses showed some trends. Employed dialysis patients perceive less severe physical symptoms from the illness, less impact from the illness, greater personal control, and less disruption from the treatment compared to unemployed patients. It is noteworthy that employed dialysis patients also reported less treatment control and less understanding compared to unemployed patients. This might indicate that employed patients are less focused on, or occupied with factors that lie outside their control or reach. Employed pre-dialysis patients perceive their illness as better controllable by self-care and medical care, and their treatment as less disruptive than unemployed patients. However, employed patients reported a stronger (negative) emotional response to the illness compared to 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 that illness perceptions regarding the duration and the consequences of the illness were associated with 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 longer, 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, but that it is not clear how strong this relationship is and which illness perception dimensions are most useful.

The absence of distinct relationships in our sample of pre-dialysis and dialysis patients might have been 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). Kidney 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 into 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.

To summarize, on the whole our results show that perceptions of high personal control over the illness, little (negative) impact of the illness and its treatment on daily life, and little concern about the illness are the most important contributors to perceived autonomy and self-esteem. With respect to labour participation similar trends were observed, i.e. beliefs about greater personal control and less impact of the illness and treatment are 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 findings from previous studies. These studies showed that perceptions of higher personal control, less (negative) consequences of the illness and treatment, and a lower emotional response generally were associated with better quality of life outcomes in patients on dialysis.

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 functioning. We have investigated the illness perceptions and treatment perceptions across the CKD trajectory, in pre-dialysis patients and patients on dialysis (**chapter 4**). This knowledge is important for determining whether perceptions vary across the illness trajectory and, consequently, whether interventions could potentially target perceptions of patients with CKD stage 4 and 5. More specifically, we have investigated whether illness and treatment perceptions vary:

- as a function of treatment type (i.e. pre-dialysis, haemodialysis, peritoneal dialysis treatment);
- as a function of time on dialysis treatment (for pre-dialysis patients the value regarding time on dialysis was set to zero years);
- over an eight-month interval, in patients on dialysis.

We analysed the data by means of pooled cross-sectional analyses, in which we combined data from the measurement among pre-dialysis patients and two measurements among dialysis patients. Because of the multiple observations over time for a part of the dialysis patient group, we controlled for the correlation between the measurements within individuals. We furthermore controlled for socio-demographic characteristics.

Firstly, the results of the analyses demonstrated an association between time on dialysis and the perception of *illness understanding*. This association indicates that patients who just started dialysis perceive less understanding of the illness than pre-dialysis patients; patients who are on dialysis for a moderate amount of time perceive more understanding compared to patients who just started dialysis and patients who are on dialysis for long lengths of time (quadratic association). A possible explanation for this decline in perceived illness understanding among patients who are on dialysis for longer lengths of time may be that the medical situation of these patients became more complex. Secondly, the analyses revealed an association between time on dialysis and the perception of *treatment disruption*, indicating that patients who are on dialysis for longer lengths of time perceive their treatment as more disruptive to daily life compared to

patients who are not yet on dialysis or who are on dialysis for a shorter time. These study findings indicate that perceptions of treatment disruption and understanding vary between patients as a function of time on dialysis. Our finding that the perception of *understanding* varies across the illness trajectory is in line with the (longitudinal) research findings of Covic et al. (2006) and Chilcot (2010). Both studies demonstrated improvements in dialysis patients' perception of understanding, either over a two-year period (Covic et al.) or over the first year on dialysis (Chilcot). The latter finding also corresponds with the nature of the observed association in our study with respect to patients during their first years on dialysis.

The results of the analyses also have 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 the lowest correlations with respect to perceptions of *personal control* and *treatment control*, suggesting that these perceptions particularly vary within patients over time (over an interval of eight months). The fact that we did not find variations in personal and treatment control as a function of time on dialysis treatment based upon the first approach may be the result of differences between the two approaches with respect to the power to detect relationships. The observed variation in *treatment control* over time is also in accordance with the Covic study that revealed improvements regarding this perception after a two-year period. Though the study by Chilcot did not reveal changes in control scores (over the first year of dialysis), the results did reveal that the variability in personal control scores varies over time, suggesting that there was more divergence as time went by.

The studies by Covic and Chilcot both revealed changes in illness perceptions which we did not observe in our study (i.e. perceptions of emotional reaction and physical symptoms). Furthermore, our study revealed variations in perceptions that were not observed in the studies by Covic and Chilcot (i.e. perception of personal control). The different findings might have been caused by the fact that different research designs were used, or because patients in these studies were exposed to other conditions which may have influenced their perceptions, for example the availability of psychological support.

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 haemodialysis and peritoneal dialysis perceive more consequences of their illness compared to pre-dialysis patients. These differences are plausible, since the dialysis phase is characterized by specific disease aspects and intensive and time-consuming treatment demands. Furthermore, patients on haemodialysis perceive more treatment disruption compared to pre-dialysis patients and patients on peritoneal dialysis. 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 haemodialysis treatment. However, it is likely that haemodialysis causes greater interference with daily life than peritoneal dialysis, because people on haemodialysis in many cases have to go to the hospital three times a week for half a day in order to receive their treatment. Lastly, patients on haemodialysis and peritoneal dialysis believe more strongly that their treatment controls the illness than patients who receive a pre-dialysis treatment. Dialysis is a life-saving treatment, and this may 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. Another explanation for the different treatment control scores is that pre-dialysis patients are aware of the fact that, soon, their current treatment will no longer suffice. Previous studies have demonstrated other or no differences between haemodialysis and peritoneal dialysis patients' illness perceptions (Griva et al., 2009; Timmers et al., 2008). There are however several ways to carry out haemodialysis and peritoneal dialysis, which may explain the different findings. It seems worthwhile to take into account more dialysis modality characteristics when investigating patients' illness and treatment perceptions and associated outcomes (cf. Griva et al., 2010).

To conclude, our study findings suggest that certain illness and treatment perceptions of (pre-) dialysis patients 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. It is however appropriate to note here that the effect of (changes in) medical treatment or clinical state on patients' illness and treatment perceptions may have

different magnitudes, than the effect of a psychological intervention on perceptions.

One of the perceptions that varies across the illness trajectory is the perception of treatment disruption. It seems important that interventions focus 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. Targeting treatment disruption perceptions by means of an intervention may have potential to improve these outcomes. In addition, perceptions of illness concern, illness consequences, and personal control over the illness are associated with autonomy and self-esteem. The current study findings indicate that the latter two perceptions are dynamic as well. Moreover, patients in the pre-dialysis phase and/or dialysis phase, on average, reported unfavourable scores with respect to these illness perceptions.

Leventhal et al. 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). Looking at the relationships between the illness and treatment perceptions found in our study, it is noticed that pre-dialysis patients' perceptions of greater treatment disruption are associated with beliefs that the treatment cannot control the illness. Dialysis patients' perceptions of greater treatment disruption are, on the other hand, associated with beliefs that they themselves cannot control the illness. 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 is notable that pre-dialysis patients' perception of little personal control is associated with higher levels of concern and emotional impact. It is therefore advisable to, besides enhance personal control beliefs, reduce feelings of concern regarding the illness and treatment to more 'realistic standards'. 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).

Our study findings do not provide insight into *when* patients' illness and treatment perceptions are varying the most. In addition, our findings suggest that some perceptions of illness are more stable than others. It is therefore recommended to intervene on perceptions as early as possible, preferably when people are likely to form their perceptions. It seems likely that patients' perceptions may be more apt to change, when these perceptions are not very well established yet. 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.

Key points

- Patients in the pre-dialysis phase and dialysis phase, on average, have relatively low levels of perceived personal control over the illness; pre-dialysis patients, generally, are quite worried about their illness; patients on dialysis, on average, experience rather serious consequences of their illness in daily life.
- On the whole, perceptions of high personal control, little (negative) impact of the illness and its treatment, and little concern are 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, and peritoneal dialysis treatment).

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 about 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 have provided evidence for relationships between well-being and other types of social support (see Cohen, 2004) and overprotection (Buunk et al., 1996; Thompson & Sobolew-Shubin, 1993). In patients with ESRD, social support also has 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 have aimed to investigate the role of emotional support and overprotection in perceived autonomy and self-esteem of patients on dialysis (**chapter 5**). We have chosen 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 have 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 have 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, life with 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.

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'). The results furthermore showed that the patient group as a whole does not experience significant lack of emotional support. Moreover, the findings from the regression analyses (controlled for background characteristics) indicated that the extent to which general emotional support is beneficial for patients' sense of autonomy, depends on how patients perceive their illness. Looking at concern, we found that general emotional support is 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 findings that patients in the pre-dialysis phase reported considerable worry about their disease, the finding that general emotional support is positively associated with autonomy in high concerned patients, is particularly interesting. It is notable, that in patients reporting lower levels of concern, the experience of general emotional support is 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 to suffer from a perceived lack of it, irrespective of illness perceptions. This might reflect (dis-) satisfaction of the general need for belongingness or relatedness which is important for people's self-esteem (Deci & Ryan, 2000; Leary & Baumeister, 2000). It is also 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.

Overprotection combined with perceptions of concern and personal control

The patient group as a whole experiences little overprotection by significant others. As patients experience more overprotection they feel less autonomous and have lower levels of 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 appears to be stronger in patients experiencing more personal control. This finding indicates that experienced overprotection is most harmful to patients' feelings of autonomy, as they perceive high 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 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.

Key points

- The role of support (emotional support and overprotection) in patients' perceived autonomy seems to depend on patients' illness perceptions, whereas the role of support in patients' self-esteem does not.
- 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.
- The findings highlight the importance of reducing overprotective interactions, and promoting autonomy-supportive interactions.

Development and evaluation of a psychological intervention

We have 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 (**chapter 6**). 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 above-mentioned stages for three reasons:

- patients in the pre-dialysis phase already seem to experience problems in their daily lives as a result of the illness and treatment, 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;
- patients' perceptions of their illness and treatment are already maladaptive in the pre-dialysis phase;
- it seems essential to intervene on patients' perceptions in an early stage of the illness process

Three theoretical models have 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 (SLT; 1977a), and Self-Determination Theory by Deci and Ryan (SDT; 1985). The content of the intervention has been based on the results of our empirical studies among (pre-) dialysis patients, and targets the psychological factors which have been shown to be associated perceived autonomy, self-esteem, and labour participation. Additionally, knowledge and experiences of experts in the field of research and practice, and knowledge and experiences of kidney patients 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. (2009) 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 initial experiences of participants, course leaders and health care providers involved (**chapter 6**). 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 contained assignments and practical and theoretical information. Material for the course leaders included a detailed manual for delivering the course.

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. 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 and Social Learning Theory. According to the Common Sense Model, 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 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, 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, 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 CKD, 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.

Our study findings showed that the experience of overprotection is 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 role of social support in perceived autonomy depends on how 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 has to be taken into account when stimulating supportive interactions.

In session six, the focus is on the development of an action plan for a (personally important and attainable) employment goal for the next three months. 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.

Evaluation of the intervention programme

Framework of the intervention

The developed psychological intervention is theory driven. The three theories, providing a framework for our intervention, all focus on different aspects that are 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.

Implementation of the intervention

The three participating dialysis centres endorsed the necessity of the type of assistance. The rate of participation among patients and partners however was lower than expected. Based on the reasons for not responding, it is advisable to be flexible with respect to scheduling future courses (in terms of days, times, locations). 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 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. 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 with respect to any existing problems or possible future changes in circumstances.

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 who just started with dialysis. 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. 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 of 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, or anticipate problems, which social workers normally encounter in their regular care.

Process and content of the intervention

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. The course leaders also indicated that there was a lot of open discussion, cooperation and mutual interest, and reckoned that it was important to increase the opportunities for these elements 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 and that there is extra attention given to the atmosphere within the group.

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, and 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 towards the fatigue diary and the action plans. These exercises were tools to enhance self-efficacy beliefs. 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. Furthermore, it is advisable to reduce the number of action plans.

An advantage of the course was the involvement of partners, and attention to the role of the social environment. These aspects were appreciated by both patients and partners. 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. 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.

Key points

- 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 to 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.

Methodological considerations

The empirical studies, part of this thesis, were carried out within two national cohort studies: the NECOSAD-2 cohort study among patients on dialysis, and the PREPARE-2 cohort study among pre-dialysis patients. Connecting to these multi-centre cohort studies, provided us with the opportunity to examine psychological and medical characteristics in patients on haemodialysis, peritoneal dialysis as well as patients prepared for renal replacement therapy throughout the Netherlands. The multi-centre aspect of our study is a great strength, since it increases the generalizability of the study results. The focus on patients who are being prepared for renal replacement therapy is another great strength of the present study, since to date most of the psychological research in patients with CKD has focused on dialysis patients. Moreover, previous psychological research in patients with CKD has mainly focused on health-related quality of life outcomes. The current research addressed outcomes other than quality of life, namely perceived autonomy, self-esteem and labour participation. Hereby extending the scope to other aspects important for patients' well-being. In addition, the present study meets the emerging need for research regarding development and evaluation of self-regulatory based interventions, aimed at improving patient outcomes (Petrie et al., 2007) and ESRD patient outcomes in particular (Griva et al., 2009; Kaptein et al., 2010; Timmers et al., 2008).

It should be noted that at the time of the implementation of our empirical study in patients on dialysis, the NECOSAD-2 cohort already existed for a long period of time. Patients were recruited on an on-going basis until January 2007, but the cohort was also subject to an outflow of patients due to mortality or transplantation. This outflow might have resulted in a selection of patients with a more favourable health condition and consequently a bias. Outflow from the cohort was no issue, however, for the PREPARE-2 study. At the time of the implementation of our empirical study among pre-dialysis patients, the PREPARE-2 study was still in its initial phase. No bias was observed when comparing patients who did and did not participate in the empirical studies, based on several background characteristics (age, gender, marital/living status, type of dialysis treatment, time on dialysis, serum albumin level/number of chronic diseases).

With respect to the two study samples, it should furthermore be mentioned that the samples were rather small, which reduced the statistical power to demonstrate relationships or effects. Moreover, the samples consisted of patients who were relatively old. Moderately or severely decreased kidney function is a rare condition among younger adults, but common among older people (Coresh et al., 2003). Consequently, the number of working-age patients (aged 18-64 years) was rather small. This imposed restrictions when analysing the associations between illness perceptions and treatment perceptions on the one hand, and labour participation on the other hand.

The multiple regression analyses conducted - in order to investigate the relationships between perceptions of illness and treatment, social support on the one hand, and autonomy and self-esteem on the other hand - have been corrected for several factors which could confound the associations under investigation. However, it should be noted that there are potentially relevant personal and environmental factors that have not been included, such as personal goals or motivations, financial or living circumstances, available facilities to participate, etc. This is also reflected by the findings that substantial amounts of variance have remained unexplained.

The cross-sectional design of the empirical studies has limited the conclusions of this thesis. Cross-sectional data provide information on associations between variables, but not on causal relationships between variables. Thus, it is not clear whether patients' perceptions of illness and treatment, and experienced social support are a cause or a result of patients' perceived autonomy, self-esteem and patients' labour participation.

Recommendations

Recommendations for research

- Research needs to investigate the formation process of CKD patients' illness perceptions and treatment perceptions, and the further development of these perceptions across the illness trajectory. Longitudinal research among patients with CKD can provide insight into these processes. By comparing patients' perceptions at different points in

time, this type of research can furthermore generate information about when patients' perceptions are most variable and, consequently, most likely prone to influences.

- The associations between perceptions of illness and perceptions of treatment on the one hand, and autonomy, self-esteem and labour participation on the other hand requires further research, in order to gain insight into the causal relationships. Future (longitudinal) research should focus on whether changes in illness and treatment perceptions generate changes in these outcomes. It is then also important to investigate these relationships in a sample of younger patients with CKD, so that associations with employment can be investigated more thoroughly. In addition to this, it is recommended to shift the focus of this research to patients in an earlier stage of CKD (i.e. CKD stage 3).
- In order to reduce the perceived negative impact of dialysis treatment it seems essential that patients choose the dialysis modality that best suits their personal characteristics and daily lives. Therefore, future research should focus on developing and testing decision aids that assist patients in making deliberative choices between all dialysis treatment options.
- 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, self-esteem and employment).
- Research on the role of social support in the adaptation to chronic illness should, besides support from significant others such as spouses or family members, take into account a broader range of social interactions. It is strongly recommended to take into account attitudes of and provided support by health care providers and employers.
- It is advisable to gain insight into a wider range of personal characteristics as well as environmental characteristics of CKD patients who do and do not participate in paid work and/or other daily activities. Characteristics that are interesting to take into account are personal goals or motivations, financial circumstances, attitudes of employers, colleagues, health care providers, and available facilities in the living, work, and health care environment. This kind of research can provide input for developing profiles of vulnerable and less vulnerable patients, and for developing

instruments by which patients that are most eligible for participation in supportive interventions can be identified.

- 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 dialyse at night, or whether patients are actively involved in their (haemo)dialysis treatment (by preparing the machine, monitoring the blood pressure etc.). This type of research can shed light on whether these characteristics have a positive effect on patients' sense of autonomy and patients' well-being.
- Future research needs to evaluate whether the developed and refined psychological 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.
- Lastly, it is advisable that research focuses on developing psychometrically sound instruments by which CKD patients' perceived autonomy can be assessed.

Recommendations for practice

Based on our findings, it is strongly recommended that patients with CKD are being supported in their efforts to carry out paid work, and - more generally - in their autonomy in an early phase of the illness process. By doing so, unnecessary drop out of paid work and other daily activities might be prevented. The findings indicate that negative personal beliefs about the illness and treatment, and the experience of overprotection from significant others form obstacles for patients' perceived autonomy and self-esteem. All together, the findings point to the importance of (multidisciplinary) self-management support, for patients and their significant others, on combining CKD and its treatment with daily activities, including paid work. By giving realistic information and providing tools and support for fitting the illness and (future) treatment into daily life, unhelpful illness and treatment related beliefs - in both patients and significant others - as well as overprotective interactions may be prevented or challenged. In doing so, successful adaptation to CKD can be facilitated.

More specifically, it is essential that interventions focus 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 to more realistic standards, as well as increasing perceptions of personal control over the illness. Connecting to this, it seems also important that patients are supported in making a deliberate choice for a (future) dialysis treatment that matches their preferences and best fits into their daily lives.

Next to targeting perceptions of illness and treatment, it is important to promote autonomy-supportive interactions between patients and their social environment. Patients should be encouraged to select the goals or activities that they personally value, and their significant others should be stimulated to support them in achieving these goals. By promoting autonomy-supportive behaviours in both patients and their significant others, overprotective interactions may be prevented. When stimulating supportive interactions it seems, however, essential that the provision of support is tailored to patients' individual illness-related needs. Besides targeting illness perceptions, treatment perceptions and support interactions it seems important to strengthen patients' self-efficacy regarding the performance of their desired activities.

The best moment to offer interventions to assist patients with CKD and their significant others seems to be when people are likely to form their perceptions of the illness and treatment, and perceptions are not very well established yet, e.g. in the pre-dialysis phase (preferably even before CKD stage 4) or at the start of dialysis treatment.

Recommendations for implementation

Based upon the findings from the evaluation of the intervention programme, we would like to dedicate a separate section to implementation of interventions into regular clinical care. The evaluation study elucidated factors that need specific attention when implementing the types of psychological group interventions as developed in this study.

Firstly, it is important to raise the awareness of the necessity of a proactive approach among patients as well as their health care providers, and connecting to this, to refer patients to supportive interventions as early as

possible. By focusing on anticipating and preventing problems in patients who are most vulnerable, the most benefits could be gained for both patients and healthcare providers, in terms of patients' outcomes and outcomes related to health care costs and efforts. Connecting to this, it seems essential to have insight into the patient groups that could benefit the most from the intervention. It is desirable that instruments are being developed by which health care providers can identify these groups of patients. Research and practice therefore should focus on developing profiles of patients who are most eligible for participation in interventions.

In terms of organising interventions, it is important that health care providers (or other people in patients' social environment, for example employers) are flexible in scheduling interventions (in terms of days, times, locations). In so doing, meeting the preferences of participants as much as possible and increasing chances for attendance.

Lastly, broad support and cooperation among health professionals (in renal care) for organising and embedding interventions in regular care is a prerequisite for successful implementation, in addition to the direct involvement of a multidisciplinary team of experts (i.e. social workers, employment experts, nephrologists, dialysis nurses).

Our findings suggest that implementation of psychological group interventions requires a specific and separate route. Before conducting research aimed at testing the effects of interventions on a large scale, research should focus on identifying success factors and bottlenecks for implementation, taking into account all necessary conditions for implementation. In so doing, preventing factors impeding the evaluation of the effects of the intervention. Francke et al. (2008) conducted a systematic meta-review on factors which influence the implementation of clinical guidelines for health care professionals. Their findings have shown that besides characteristics of the guidelines themselves (e.g. complexity), characteristics of professionals (e.g. awareness of the existence and familiarity with its content), patients (e.g. co-morbidity), and the environment (lack of support from peers or superiors, insufficient staff and time) may influence implementation. It seems worthwhile to take all these

factors into account as well when implementing psychological interventions, as developed in the present study. Consequently, research on the implementation of psychological interventions should be conducted in close collaboration with health care providers, management teams of health care organisations, and patients themselves.

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Summary

Summary

Introduction

Chronic Kidney Disease (CKD) refers to the gradual and permanent loss of kidney function. This means that the kidneys are losing their essential function to remove waste products and excess fluid from the blood. CKD is divided into five stages of increasing severity. When the kidneys are no longer able to function (CKD stage 5; end-stage renal disease (ESRD)), people require renal replacement therapy: haemodialysis, peritoneal dialysis, or kidney transplantation. Because of a shortage of kidney donors, most patients initially depend on dialysis treatment.

CKD and the associated treatments, dialysis in particular, impose a heavy burden on the daily lives of patients. Along with the development of improved survival of patients on dialysis, the quality of the prolonged life has gained more attention. Previous research has demonstrated that many people with CKD experience substantial difficulties in doing their daily activities. It seems particularly difficult to combine dialysis treatment with a paid job. It is however notable that patients who are being prepared for renal replacement therapy (pre-dialysis patients; CKD stage 4) already experience work-related problems. Restrictions on the number or quality of daily activities, the performance of paid work in particular, might impede people's feelings of autonomy and self-esteem. Recognising the importance of these aspects for people's well-being it is important to address the question *why some people with CKD succeed in keeping high levels of autonomy and self-esteem, and in maintaining paid employment, whereas others do not.*

Previous research implies that personal factors and environmental factors (or 'external factors') are determinants of human functioning, in addition to disease-related factors. The research described in this thesis has focused on psychological factors considered relevant for (pre-) dialysis patients' daily functioning. Whereas it is not always possible to influence clinical and socio-demographic characteristics, psychological factors are potentially modifiable. Therefore they might provide starting points for improving patient outcomes. The aim of the research described in this thesis has been to examine the role of patients' perceptions of their illness and treatment, and

the role of experienced social support in perceived autonomy, self-esteem and participation in paid work; and to develop and test a psychological intervention focused on maintaining employment (and other daily activities), and feelings of autonomy and self-esteem in people with CKD. The objectives of this thesis resulted in two main research questions:

- 1) To what extent do (pre-) dialysis patients feel autonomous, experience self-esteem, and perform paid work, and to what extent can we explain variation therein from differences in perceptions of illness and treatment and experienced social support?
- 2) What should a psychological intervention look like, that supports participation in daily activities - paid work in particular - as well as perceived autonomy and self-esteem?

The introductory chapter of this thesis (chapter 1) provides background information on CKD, available treatments, and epidemiology of CKD. Furthermore, this chapter briefly describes the impact of CKD and the (dialysis) treatment on daily life. After the introduction of the objectives and main research questions of this thesis, the theoretical framework on how psychological factors may impact daily functioning of patients with CKD is presented. This framework consists of three theoretical models: the *Common Sense Model* of self-regulation of health and illness, the *Social Learning Theory*, and the *Self-Determination Theory*. Lastly, the research that has been conducted in the scope of the thesis - in the period 2006-2011 - is briefly described.

Moderate levels of autonomy and low labour participation rate

Chapter 2 and chapter 3 discuss the perceived autonomy and self-esteem of (pre-) dialysis patients, and the degree to which patients participate in paid work for at least 12 hours per week (definition of labour participation as applied by Statistics Netherlands - CBS). The findings are based upon cross-sectional data from 166 patients on dialysis (CKD stage 5) of the NECOSAD-2 cohort, and 109 pre-dialysis patients (CKD stage 4) who participated in the PREPARE-2 study.

The results show that pre-dialysis patients and patients on dialysis, on average, have moderate feelings of autonomy. This indicates that patients 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, patients have rather high mean levels of self-esteem. Pre-dialysis patients and dialysis patients of working age (18-64 years) less often have a paid job compared to the general Dutch working-age population (51% and 24%, respectively versus 65% in 2006).

The finding that the labour participation rate is already low in pre-dialysis patients indicates that patients already resign from their paid jobs before they start with renal replacement therapy. These outcomes are in line with findings from previous studies. This development is alarming since previous research has shown that occupational status in the phase before dialysis treatment is an important predictor of employment during the dialysis phase. The results point to the importance of assisting patients in maintaining employment and other activities at an early stage of the illness process.

Perceptions of illness and treatment play a role in autonomy and self-esteem

Chapter 2 and chapter 3 furthermore describe (pre-) dialysis patients' personal beliefs about their illness and treatment, and the extent to which these so-called illness perceptions and treatment perceptions are associated with patients' perceived autonomy and self-esteem and participation in paid employment.

It is particularly notable that both pre-dialysis patients and patients on dialysis, on average, report relatively low levels of perceived personal control over the illness. In addition, the results show that, generally, dialysis patients believe that their illness has rather serious consequences on their daily life; and that pre-dialysis patients are quite worried about their illness.

The findings from the multiple regression analyses, controlled for differences in socio-demographic and clinical characteristics between patients, demonstrate that illness perceptions and treatment perceptions explain a substantial amount of variance in autonomy and self-esteem. On

the whole, positive perceptions of the (personal) controllability of the illness and of the consequences the illness and treatment have on daily life as well as little concern about the illness are important contributors to a higher perceived autonomy and self-esteem of patients. In both pre-dialysis patients and patients on dialysis, the perception that the treatment causes a low degree of disruption in daily life appears to be associated with higher levels of perceived autonomy and self-esteem. The results do not reveal distinct relationships between illness perceptions and treatment perceptions on the one hand and labour participation on the other hand. Nevertheless, the bivariate analyses do show a number of trends that point in the same direction as the above described associations. The absence of distinct relationships might have been caused by the small group sizes.

Our findings are in line with the findings from previous studies examining the relationships between illness and treatment perceptions and quality of life outcomes in patients on dialysis. Based on the findings it is likely that positively influencing illness and treatment perceptions can contribute to perceived autonomy and self-esteem as well as to prevention of early resignation from paid employment in patients with CKD.

Patients' illness and treatment perceptions change across the illness trajectory

Chapter 4 addresses the question whether illness perceptions and treatment perceptions of (pre-) dialysis patients vary across the trajectory of CKD, and consequently whether interventions could potentially target perceptions of patients with CKD stage 4 and 5. We explored this question by investigating the extent to which perceptions:

- are dependent on the type of treatment (pre-dialysis, haemodialysis, and peritoneal dialysis treatment);
- are dependent on time on dialysis treatment (for pre-dialysis patients the value regarding time on dialysis was set to 0 years);
- are varying across an 8-month interval in patients on dialysis.

Cross-sectional data from pre-dialysis patients (PREPARE-2) and cross-sectional as well as longitudinal data from patients on dialysis (NECOSAD-

2) were used. We analysed the data by means of pooled cross-sectional analyses, in which we combined data from the measurement among pre-dialysis patients and two measurements among dialysis patients (with an 8-month interval). Since a part of the dialysis group took part in multiple measurements, we controlled for the correlation between these measurements within individuals. We furthermore controlled for socio-demographic characteristics.

Firstly, the results demonstrate an association between time on dialysis and the perception of *illness understanding*. This association indicates that patients who just started dialysis have lower levels of perceived illness understanding than pre-dialysis patients; patients who are on dialysis for a moderate amount of time have higher levels of understanding compared to patients who just started dialysis, and patients who are on dialysis for long lengths of time (quadratic association). Secondly, the findings reveal a relationship between time on dialysis and the perception of *treatment disruption*, indicating that patients who are on dialysis for longer lengths of time perceive their treatment as more disruptive to daily life compared to patients who are not yet on dialysis or who are on dialysis for a shorter time (linear association). Furthermore, perceptions of illness and treatment of patients on dialysis vary within individuals over an 8-month interval, with *treatment control* and *personal control* showing the highest levels of variation. These findings are partly in line with findings from two previous (longitudinal) studies among first-year dialysis patients (both haemodialysis and peritoneal dialysis) and established haemodialysis patients. Lastly, our findings show that patients, who receive different treatments for their kidney disease, vary in their perceptions of *illness consequences*, *treatment disruption*, and *treatment control*.

Our findings suggest that illness and treatment perceptions of patients with CKD (stage 4 and 5) change across the illness trajectory, and offer starting points for the development of interventions to target illness and treatment perceptions of patients with CKD aimed at improving patient outcomes. It should be noted, however, that the effect of (changes in) medical treatment or clinical state on perceptions may have different magnitudes than the effect of an intervention on perceptions.

It seems important that interventions focus on reducing patients' perceived negative impact of treatment on daily life. Since our findings suggest that the belief that treatment causes great disruption to daily life is associated with lower levels of perceived autonomy and self-esteem in both pre-dialysis patients and dialysis patients. In addition, perceptions of illness concern, illness consequences, and personal control over the illness are associated with perceived autonomy and self-esteem. Based upon our findings, these perceptions also (partly) appear to change across the illness trajectory.

Our study findings do not provide insight into *when* patients' illness perceptions and treatment perceptions are varying the most, and consequently into the moment at which perceptions are possibly most prone to influences. Research among myocardial infarct patients points to the importance of intervening on perceptions in an early stage of the illness process, when perceptions of illness (and treatment) are not very well established yet.

The association between social support and autonomy depends on illness perceptions, the association between support and self-esteem does not

Chapter 5 describes the extent to which patients on dialysis experience social support – including overprotection – from significant others, and the role of experienced support in feelings of autonomy and self-esteem. We examined whether the association between support on the one hand, and autonomy and self-esteem on the other hand, depends on how patients perceive their illness. We focused on 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, life with CKD is likely to be stressful and support could be (extra) beneficial. The findings are based upon cross-sectional data from 166 dialysis patients of the NECOSAD-2 cohort.

On the whole, dialysis patients now and then experience emotional support from significant others. The patient group as a whole however does not experience significant lack of emotional support or overprotection from significant others.

The findings from the multiple regression analyses (controlled for socio-demographic and clinical characteristics) reveal that the experience of emotional support is solely positively related to perceived autonomy in patients who are highly concerned about the illness. This indicates that patients who are worried benefit the most from emotional support. This type of support also seems relevant in case patients are highly concerned about the illness, and is possibly less meaningful in case patients believe they have little control over the illness. This is in line with the idea offered by previous research that support functions have to match with the stressors or needs faced with. The finding that a higher level of experienced emotional support is associated with a higher level of perceived autonomy in patients who are very concerned, is particularly interesting in light of our results showing that patients in the pre-dialysis phase are considerably worried about their illness.

In contrast to autonomy, one's self-esteem always seems to benefit from emotional support and to suffer from a perceived lack of it, irrespective of how one perceives the illness. This might reflect (dis-) satisfaction of the general need for belongingness or relatedness, which is considered as important for people's self-esteem.

Furthermore, it appears that as patients feel more overprotected by their significant others, they feel less autonomous and have a lower self-esteem. Moreover, the negative association between overprotection and autonomy appears to be stronger in patients who believe that they can personally control their illness.

These findings highlight the importance of matching the support type with the personal needs of patients. In addition, it is important to reduce overprotective interactions between patients and their significant others, and to promote autonomy-supportive interactions.

Chapter 6 describes the development of a psychological intervention programme for kidney patients and their partners. The chapter outlines the framework and components of the intervention programme. Furthermore, this chapter presents the results of a pilot study in which the intervention was tested.

Development psychological intervention

The intervention – a group course – aims to assist patients (aged 18-64 years) who are being prepared for renal replacement therapy or who are on dialysis for a short length of time, and their partners, to integrate the kidney disease and treatment into their daily activities, primarily work; and thereby increasing patients' feelings of autonomy and self-esteem. Through early intervention, it can be expected that drop out of employment and other daily activities is prevented.

Three theoretical models served as a framework for the intervention: the *Common Sense Model* of self-regulation of health and illness, the *Social Learning Theory*, and the *Self-Determination Theory*. Several aspects seem to underlie the complex process of behaviour change and its maintenance. We believe that the components provided by the separate theories are all important for this process.

The content of the intervention is based on the results of the previously described empirical studies among (pre-) dialysis patients, and focuses on the psychological factors which have been shown to be associated with perceived autonomy, self-esteem, and labour participation. Additionally, knowledge and experiences of experts in the field of research and practice, and knowledge and experiences of kidney patients were used.

The intervention is characterized by a multidisciplinary and proactive approach, and more specifically focuses on three aspects:

- stimulating positive but realistic beliefs about the illness, treatment, and the opportunities to stay active in both patients and partners;
- enhancing patients' self-efficacy with respect to the performance of work and other daily activities;
- stimulating social interactions that are autonomy-supportive between patients and partners.

Within the course, various techniques are used to target perceptions of illness, perceptions of treatment, self-efficacy, and social support, such as didactic teaching, examples of personal stories from peers, group discussion, and guided mastery of skills through action plans.

Evaluation psychological intervention

The intervention was tested on feasibility and initial experiences of participants (seven patients and five partners), course leaders (health psychologist, nephrologist and employment expert), and health care providers (social workers, nephrologists, dialysis nurses) involved.

Findings from the pilot study are positive, and suggest that a theory driven multiple approach - focusing on cognitive, emotional, behavioural, and contextual aspects - is feasible and possibly effective. On the whole it can be concluded that the ingredients of the intervention all have value, however, the total course programme appears very intense.

A successful implementation process of the intervention in regular care is, however, not easy to achieve despite the efforts of motivated health care providers. Based upon the findings, attention points with respect to the content and process of the intervention, as well as the implementation of interventions of this kind are discussed in chapter 6.

Lastly, in chapter 7 the main findings from this thesis and the implications of these findings are being presented and discussed. Furthermore, this chapter deals with the methodological considerations, and directions for future research and practice. The following pages provide an overview of important methodological considerations and recommendations.

Methodological considerations

The empirical studies were connected to multi-centre cohort studies which provided us with the opportunity to examine psychological and medical characteristics in both patients on haemodialysis, peritoneal dialysis as well as pre-dialysis patients throughout the Netherlands. This is a great strength of our research. Another strength of the present research is that it addressed outcomes other than the frequently used health-related quality of life outcomes, namely perceived autonomy, self-esteem and labour participation. In addition, the present study meets the emerging need for research regarding development and evaluation of self-regulatory based interventions, aimed at improving patient outcomes. Methodological limitations are the possible selection-bias of the sample of dialysis patients resulting from outflow of the cohort, and the rather small research samples.

Lastly, the cross-sectional design of the empirical studies limits the conclusions of this thesis.

Recommendations for future research

It is recommended that future research investigates the extent to which changes in illness perceptions and treatment perceptions of patients with CKD are associated with changes in patients' sense of autonomy, self-esteem and labour participation. Furthermore, it is recommended to shift the focus of this type of research to samples of younger patients in an earlier stage of CKD. In addition, there is a need for research on the development of psychometrically sound instruments, by which CKD patients' perceived autonomy can be assessed.

In terms of research on the role of social support, it is important that research focuses on a broader range of social interactions, such as attitudes of and provided support by health care providers and employers.

Furthermore, it is advisable to take into account other characteristics of patients and their environment, such as personal motivations of patients and available facilities in the work and health care environment. With respect to research in patients on dialysis, it would then also be interesting to take into account more dialysis modality characteristics.

In terms of interventions, research is needed that investigates the effects of the developed and refined intervention both in the short term and in the long run. Lastly, it is advisable to conduct research on the development and evaluation of decision aids that assist patients in making deliberative choices between dialysis treatment options, for a treatment that best fits their personal situation.

Recommendations for future practice

It is strongly recommended that future practice offers (multidisciplinary) self-management support, to patients and their significant others, for combining CKD and its treatment with daily activities, including paid work. It is recommended offering this support in an early phase of the illness process, preferably even before CKD stage 4. By giving realistic information and providing tools and support for fitting the illness and (future) treatment into daily life, helpful illness and treatment related beliefs – in both patients and their significant others – may be strengthened. In doing so, successful

adaptation to CKD can be facilitated. Connecting to this, it seems also important that patients are supported in making a deliberate choice for a (future) dialysis treatment that matches their personal preferences and best fits into their daily lives.

Recommendations for implementation

Implementation of psychological group interventions, as developed in this study, requires a specific and separate route. Before conducting research aimed at testing the effects of interventions on a large scale, it is strongly advised to identify success factors and bottlenecks for implementation by means of research. This research should preferably be conducted in close collaboration with health care providers, management teams of health care organisations, and patients themselves.

Samenvatting (Summary in Dutch)

Samenvatting

Inleiding

Chronische nierziekte (ook wel chronische nierinsufficiëntie of chronisch nierfalen genoemd) verwijst naar de geleidelijke vermindering en het blijvende verlies van de nierfunctie. Dit betekent dat de nieren hun essentiële functie om afvalstoffen en overtollig vocht uit het bloed te verwijderen, verliezen. Chronische nierziekte wordt onderverdeeld in vijf stadia van toenemende ernst. Wanneer de nieren niet langer meer in staat zijn om te functioneren (stadium 5 chronische nierziekte; eindstadium nierfalen) moet worden overgegaan tot een nierfunctievervangende therapie: hemodialyse, peritoneaal dialyse of niertransplantatie. Door een tekort aan nierdonoren zijn de meeste patiënten in eerste instantie aangewezen op een dialysebehandeling.

Chronische nierziekte en de bijbehorende behandelingen, dialyse in het bijzonder, trekken een zware wissel op het dagelijks leven van patiënten. Door de verbeterde overleving van dialysepatiënten is de aandacht gegroeid voor de kwaliteit van het verlengde leven. Uit eerder onderzoek blijkt dat veel mensen met chronische nierziekte aanzienlijke problemen ondervinden bij het doen van hun dagelijkse activiteiten. Het lijkt vooral moeilijk om de dialysebehandeling te combineren met een betaalde baan. Het is echter opvallend dat patiënten die worden voorbereid op een nierfunctievervangende therapie (pre-dialysepatiënten; stadium 4 chronische nierziekte) reeds problemen ervaren bij hun betaalde werk. Beperkingen in de hoeveelheid of de kwaliteit van dagelijkse activiteiten, het verrichten van betaald werk in het bijzonder, kunnen het gevoel van autonomie en eigenwaarde van mensen verminderen. Gezien het belang van deze aspecten voor het welzijn van mensen, is het belangrijk de vraag te stellen *waarom sommige mensen met chronische nierziekte erin slagen een hoge mate van autonomie en eigenwaarde te behouden en betaald werk te blijven doen, terwijl dat anderen niet lukt.*

Eerder onderzoek impliceert dat persoonlijke factoren en omgevingsfactoren (of 'externe factoren') determinanten zijn van het functioneren van mensen, in aanvulling op ziektegerelateerde factoren. Het onderzoek beschreven in

dit proefschrift heeft zich geconcentreerd op psychologische factoren die als relevant worden beschouwd voor het dagelijks functioneren van (pre-) dialysepatiënten. Waar het niet altijd mogelijk is om klinische en sociaal-demografische kenmerken te beïnvloeden, zijn psychologische factoren potentieel veranderbaar. Hierdoor leveren ze mogelijk aanknopingspunten voor het verbeteren van patiëntuitkomsten. Het in dit proefschrift beschreven onderzoek had tot doel de rol van percepties van patiënten over hun ziekte en behandeling en de rol van de door hen ervaren sociale steun bij ervaren autonomie, eigenwaarde en arbeidsparticipatie te onderzoeken. Het onderzoek had tevens tot doel een psychologische interventie te ontwikkelen en uit te testen, die gericht is op het behoud van werk (en andere dagelijkse activiteiten) en gevoelens van autonomie en eigenwaarde van mensen met een nierziekte. De doelstellingen van dit proefschrift resulteerden in twee hoofdonderzoeksvragen:

- 1) In welke mate voelen (pre-) dialysepatiënten zich autonoom, ervaren zij een gevoel van eigenwaarde, en hebben zij betaald werk, en in welke mate kan variatie hierin worden verklaard door verschillen in percepties over de ziekte en behandeling en ervaren sociale steun?
- 2) Hoe moet een psychologische interventie eruit zien, die deelname aan dagelijkse activiteiten ondersteunt – betaald werk in het bijzonder – alsmede de ervaren autonomie en eigenwaarde?

Het introductie hoofdstuk van dit proefschrift (hoofdstuk 1) biedt achtergrondinformatie over chronische nierziekte, beschikbare behandelingen en de epidemiologie van chronische nierziekte. Verder beschrijft dit hoofdstuk kort de impact van chronische nierziekte en de (dialyse-) behandeling op het dagelijks leven. Na de introductie van de doelstellingen en de hoofdonderzoeksvragen van dit proefschrift, wordt het theoretische kader over hoe psychologische factoren van invloed kunnen zijn op het dagelijks functioneren van patiënten met chronische nierziekte uiteengezet. Dit kader bestaat uit drie theoretische modellen: het *'Common Sense Model'* van zelfregulatie van gezondheid en ziekte, de *Sociale Leertheorie*, en de *Zelfdeterminatie Theorie*. Tot slot wordt kort het onderzoek beschreven dat voor dit proefschrift, in de periode 2006-2011, is uitgevoerd.

Gematigde niveaus van autonomie en lage arbeidsparticipatiegraad

Hoofdstuk 2 en hoofdstuk 3 gaan in op de ervaren autonomie en het gevoel van eigenwaarde van (pre-) dialysepatiënten, en de mate waarin patiënten participeren in betaalde arbeid voor minstens 12 uur per week (definitie van arbeidsparticipatie, zoals toegepast door het Centraal Bureau voor de Statistiek - CBS). De bevindingen zijn gebaseerd op cross-sectionele gegevens van 166 dialysepatiënten (stadium 5 chronische nierziekte) van het NECOSAD-2 cohort, en 109 pre-dialysepatiënten (stadium 4 chronische nierziekte) die deelnamen aan de PREPARE-2 studie.

De resultaten laten zien dat pre-dialysepatiënten en patiënten die dialyse ondergaan, gemiddeld genomen, gematigde gevoelens van autonomie ervaren. Dit betekent dat patiënten niet vaak het gevoel hebben dat ze de dingen kunnen doen die ze willen doen in het dagelijks leven, vanwege hun gezondheidstoestand of anderszins. Desondanks beschikken patiënten over het algemeen over een vrij hoge mate van eigenwaarde. Pre-dialysepatiënten en dialysepatiënten die tot de beroepsbevolking behoren (18 t/m 64 jaar) hebben minder vaak betaald werk dan de algemene Nederlandse beroepsbevolking (respectievelijk 51% en 24% versus 65% in 2006).

De bevinding dat ook bij pre-dialysepatiënten de arbeidsparticipatiegraad al lager is, duidt erop dat patiënten al vóór de start met een nierfunctie-ervangende behandeling uit het arbeidsproces treden. Deze uitkomsten bevestigen het beeld uit eerdere studies. Deze ontwikkeling is zorgwekkend, omdat eerder onderzoek heeft aangetoond dat de werkstatus in de fase voorafgaand aan de dialyse een belangrijke voorspeller is van het hebben van werk tijdens dialyse. De resultaten wijzen erop dat het belangrijk is om reeds in een vroeg stadium van het ziekteproces ondersteuning te bieden bij het behoud van werk en andere activiteiten.

Percepties over ziekte en behandeling spelen een rol bij autonomie en eigenwaarde

Hoofdstuk 2 en hoofdstuk 3 gaan daarnaast in op de ideeën die (pre-) dialysepatiënten hebben over hun ziekte en behandeling, en de mate waarin deze zogenoemde ziektepercepties en behandelpercepties samenhangen met de door patiënten ervaren autonomie, eigenwaarde en hun deelname aan betaalde arbeid.

In de bevindingen valt het vooral op dat zowel pre-dialysepatiënten als dialysepatiënten over het algemeen relatief lage niveaus van ervaren persoonlijke controle over de ziekte rapporteren. Daarnaast komt naar voren dat, gemiddeld genomen, dialysepatiënten het idee hebben dat hun ziekte vrij ernstige gevolgen heeft voor hun dagelijks leven, en dat patiënten in de pre-dialysefase vinden dat zij behoorlijk bezorgd zijn over hun nierziekte.

Uit de bevindingen van de meervoudige regressie analyses, gecontroleerd voor verschillen in sociaal-demografische en klinische kenmerken tussen patiënten, blijkt dat de ziektepercepties en behandelpercepties een aanzienlijke hoeveelheid variatie in autonomie en eigenwaarde verklaren. Over het geheel genomen dragen positieve percepties over de (persoonlijke) controleerbaarheid van de ziekte, over in hoeverre de ziekte en behandeling gevolgen hebben voor het dagelijks leven, alsook het idee weinig zorgen over de ziekte te hebben in belangrijke mate bij aan de door patiënten ervaren autonomie en eigenwaarde. Voor zowel pre-dialysepatiënten als dialysepatiënten blijkt het idee dat de behandeling een geringe verstoring teweegbrengt in het dagelijks leven gepaard te gaan met een hogere mate van ervaren autonomie en gevoel van eigenwaarde. Er komen geen duidelijke relaties tussen ziektepercepties en behandelpercepties enerzijds en arbeidsparticipatie anderzijds naar voren. Niettemin laten de bivariante analyses wel een aantal trends zien die in dezelfde richting wijzen als de bovengenoemde verbanden. Het ontbreken van duidelijke relaties is mogelijk veroorzaakt door de kleine onderzoeksgroepen.

Onze resultaten zijn in lijn met bevindingen van eerdere studies naar de relatie tussen ziekte- en behandelpercepties en kwaliteit van leven bij dialysepatiënten. Op basis van de bevindingen is het aannemelijk dat

positieve beïnvloeding van de ziekte- en behandelpercepties kan bijdragen aan de ervaren autonomie en het gevoel van eigenwaarde van nierpatiënten, alsmede aan het voorkomen van vroegtijdige uitval uit het arbeidsproces.

Percepties van patiënten over de nierziekte en behandeling veranderen over het ziekte-traject

Hoofdstuk 4 behandelt de vraag of ziektepercepties en behandelpercepties van (pre-) dialysepatiënten variëren over het traject van de chronische nierziekte, en hiermee samenhangend de vraag of percepties van patiënten met een chronische nierziekte (stadium 4 en 5) door interventies kunnen worden beïnvloed. We hebben dit onderzocht door na te gaan in hoeverre deze percepties:

- afhankelijk zijn van de soort behandeling (pre-dialyse, hemodialyse en peritoneaal dialyse behandeling);
- afhankelijk zijn van de dialyseduur (voor pre-dialysepatiënten werd de dialyseduur ingesteld op 0 jaar);
- variëren over een interval van 8 maanden bij dialysepatiënten.

Voor deze studie werden cross-sectionele data van pre-dialysepatiënten (PREPARE-2) en cross-sectionele en longitudinale gegevens van dialysepatiënten (NECOSAD-2) gebruikt. We hebben de data geanalyseerd met gepoolde cross-sectionele analyses, waarbij de gegevens van de meting bij pre-dialysepatiënten en de twee metingen bij dialysepatiënten (met een interval van 8 maanden) werden samengevoegd. Omdat een deel van de dialysegroep aan meerdere metingen heeft deelgenomen, hebben we gecontroleerd voor de correlatie tussen deze metingen binnen personen. Daarnaast hebben we gecontroleerd voor sociaal-demografische kenmerken.

Ten eerste laten de resultaten een relatie zien tussen dialyseduur en de perceptie over *begrip van de ziekte*. Dit verband duidt erop dat patiënten die net zijn begonnen met de dialyse een lagere mate van begrip over de ziekte ervaren dan pre-dialysepatiënten; patiënten die dialyseren voor een middellange duur ervaren een hogere mate van begrip in vergelijking met patiënten die net zijn begonnen met dialyse en patiënten die al lange tijd dialyseren (kwadratisch verband). Ten tweede laten de bevindingen een verband zien tussen dialyseduur en de perceptie over *de verstoring van de*

behandeling, dat erop wijst dat patiënten die langere tijd dialyseren de behandeling als meer verstorend ervaren voor het dagelijks leven in vergelijking met patiënten die nog niet dialyseren of die kortere tijd dialyseren (lineair verband). Daarnaast veranderen de ziekte- en behandel-percepties van dialysepatiënten binnen individuen over een interval van 8 maanden. Waarbij de meeste verandering te zien is bij percepties over in hoeverre de ziekte kan worden *gecontroleerd* door het eigen handelen of door de behandeling. Deze uitkomsten zijn deels in overeenstemming met de bevindingen van twee eerdere (longitudinale) studies onder patiënten die nog niet lang dialyseren (hemodialyse en peritoneaal dialyse) en onder (niet nieuwe) hemodialysepatiënten.

Tot slot blijkt uit de bevindingen van onze studie dat patiënten die verschillende behandelingen voor hun nierziekte krijgen, variëren in hun percepties over de *gevolgen van de ziekte*, de *verstoring van de behandeling* en de *controle van de behandeling* over de ziekte.

De uitkomsten duiden erop dat ziekte- en behandelpercepties van patiënten met chronische nierziekte (stadium 4 en 5) veranderen over het ziekte-traject, en bieden aanknopingspunten voor het ontwikkelen van interventies om percepties van patiënten met chronische nierziekte over de ziekte en behandeling te beïnvloeden, met als doel verbetering van patiëntuitkomsten. Hierbij moet worden aangetekend dat het effect van (veranderingen in) de medische behandeling of klinische toestand op percepties van een andere orde kan zijn dan het effect van een interventie op percepties.

Het lijkt van belang dat interventies zich richten op het reduceren van de door patiënten ervaren negatieve impact van de behandeling op het dagelijks leven. De uitkomsten van ons onderzoek wijzen er namelijk op dat het idee dat de behandeling veel verstoring teweegbrengt in het dagelijks leven, gepaard gaat met een lagere mate van ervaren autonomie en gevoel van eigenwaarde bij zowel pre-dialysepatiënten als dialysepatiënten. Daarnaast zijn percepties over bezorgdheid over de ziekte, gevolgen van de ziekte voor het leven en persoonlijke controle over de ziekte gerelateerd aan ervaren autonomie en eigenwaarde. Deze percepties lijken op grond van de bevindingen van het huidige onderzoek ook voor een deel te veranderen over het ziekte-traject.

Onze bevindingen bieden geen inzicht in *wanneer* ziekte- en behandel-percepties van patiënten het meest veranderen, en derhalve in het moment waarop percepties mogelijk het meest vatbaar zijn voor beïnvloeding. Onderzoek onder hartpatiënten heeft aanwijzingen opgeleverd dat het belangrijk is om in een zo vroeg mogelijk stadium van ziekte te interveniëren op percepties, wanneer percepties over de ziekte (en de behandeling) zich nog niet hebben bestendigd.

De relatie tussen sociale steun en autonomie hangt af van ziektepercepties, de relatie tussen steun en eigenwaarde niet

Hoofdstuk 5 beschrijft in hoeverre patiënten die dialyseren steun ervaren – inclusief overbescherming – vanuit hun naaste omgeving, en welke rol deze ervaren ondersteuning speelt bij gevoelens van autonomie en eigenwaarde. Daarbij is nagegaan of het verband tussen steun enerzijds en autonomie en eigenwaarde anderzijds afhangt van de wijze waarop patiënten tegen hun ziekte aankijken. We richtten ons op twee specifieke ziektepercepties, namelijk de perceptie over *persoonlijke controle* en over *bezorgdheid*. Hierbij gingen we ervan uit dat voor mensen die het idee hebben dat ze hun ziekte niet zelf kunnen beheersen en voor mensen die veel bezorgdheid over hun ziekte ervaren, het leven met eindstadium nierfalen stressvol is en ondersteuning een (extra) gunstig effect zou kunnen hebben. De bevindingen zijn gebaseerd op cross-sectionele gegevens van 166 dialysepatiënten van het NECOSAD-2 cohort.

Dialysepatiënten ervaren over het algemeen zo nu en dan emotionele steun van hun naasten. De patiëntgroep als geheel ervaart echter geen groot tekort aan emotionele steun en ondervindt evenmin overbescherming door naasten.

De resultaten van de meervoudige regressie analyses (gecontroleerd voor sociaal-demografische en klinische kenmerken) laten zien dat het ervaren van emotionele steun uitsluitend positief samenhangt met het ervaren van autonomie bij patiënten die vinden dat zij zeer bezorgd zijn over hun ziekte. Dit duidt erop dat bezorgde patiënten het meest baat hebben bij emotionele ondersteuning. In het geval dat patiënten erg bezorgd zijn over de ziekte, lijkt dit type ondersteuning ook relevant. Deze vorm van ondersteuning is

wellicht minder betekenisvol in het geval patiënten het idee hebben dat zij weinig invloed op hun ziekte kunnen uitoefenen. Dit is in overeenstemming met het idee – geboden door eerder onderzoek – dat steun moet aansluiten bij de stressoren of behoeften waarmee mensen worden geconfronteerd. De bevinding dat een hogere mate van ervaren emotionele steun gepaard gaat met een hogere mate van ervaren autonomie bij patiënten die veel zorgen ervaren, is vooral interessant in het licht van de bevinding dat patiënten in de pre-dialysefase aanzienlijk bezorgd zijn over hun ziekte.

In tegenstelling tot autonomie, lijkt iemands gevoel van eigenwaarde altijd gebaat bij emotionele ondersteuning en te lijden onder een ervaren tekort daaraan, ongeacht de manier waarop men tegen de ziekte aankijkt. Dit weerspiegelt mogelijk de (dis-) satisfactie van de universele behoefte om ergens bij te horen en zich verbonden te voelen, wat als belangrijk wordt gezien voor iemands eigenwaarde.

Verder blijkt dat naarmate patiënten zich meer overbeschermd voelen door hun naasten, zij zich minder autonoom voelen en een lagere eigenwaarde hebben. Bij patiënten die het idee hebben hun nierziekte zelf te kunnen controleren, blijkt het negatieve verband tussen overbescherming en autonomie bovendien sterker te zijn.

De bevindingen wijzen erop dat het van belang is dat ondersteuning aansluit bij de persoonlijke behoeften van patiënten. Daarnaast is het van belang om overbeschermende interacties tussen patiënten en hun naasten te verminderen, en autonomie-ondersteunende interacties te bevorderen.

Hoofdstuk 6 beschrijft de ontwikkeling van een psychologisch interventieprogramma voor nierpatiënten en hun partners. Het hoofdstuk schetst het kader en de componenten van het programma. Verder gaat het hoofdstuk in op de resultaten van een pilot-studie waarin de interventie werd uitgetest.

Ontwikkeling psychologische interventie

Het interventieprogramma – een groepscursus – heeft tot doel patiënten (in de leeftijd van 18 t/m 64 jaar) die voorbereid worden op een nierfunctievervangende therapie of die nog niet zo lang dialyseren, en hun partners, te ondersteunen bij het inpassen van de nierziekte en de behandeling in hun dagelijkse activiteiten, in het bijzonder hun werk. En aan de hand hiervan gevoelens van autonomie en eigenwaarde van patiënten te versterken. Door vroegtijdige interventie kan naar verwachting uitval uit het arbeidsproces en wegvallen van andere dagelijkse activiteiten worden voorkomen.

Drie theoretische modellen vormen een raamwerk voor de interventie: het *'Common Sense Model'* van zelfregulatie van gezondheid en ziekte, de *Sociale Leertheorie*, en de *Zelfdeterminatie Theorie*. Aan het complexe proces van gedragsverandering en behoud van gedrag lijken verschillende aspecten ten grondslag te liggen. Wij zijn van mening dat de componenten van de afzonderlijke theorieën allen van belang zijn voor dit proces. De inhoud van de interventie is gebaseerd op de resultaten van de eerder beschreven empirische studies onder (pre-) dialysepatiënten, en richt zich op de psychologische factoren die samenhangen met ervaren autonomie, eigenwaarde en arbeidsparticipatie. Daarnaast zijn kennis en ervaringen van deskundigen uit het onderzoeksveld en de praktijk, en kennis en ervaringen van nierpatiënten gebruikt.

De interventie wordt gekenmerkt door een multidisciplinaire en proactieve aanpak, en richt zich meer specifiek op drie aspecten:

- het stimuleren van positieve maar realistische ideeën over de ziekte, behandeling en de mogelijkheden om actief te blijven bij zowel patiënten als partners;
- het bevorderen van de persoonlijke effectiviteit ten aanzien van het uitvoeren van werk en andere dagelijkse activiteiten bij patiënten;
- het stimuleren van sociale interacties die autonomie-ondersteunend zijn tussen patiënten en partners.

Binnen de cursus worden verschillende technieken gebruikt om percepties over de ziekte en de behandeling, persoonlijke effectiviteit en sociale steun te

beïnvloeden, zoals didactische werkvormen, voorbeelden van persoonlijke verhalen van lotgenoten, groepsdiscussie, en begeleide training van vaardigheden door middel van het uitvoeren van actieplannen.

Evaluatie psychologische interventie

De interventie werd getest op uitvoerbaarheid en eerste ervaringen van deelnemers (zeven patiënten en vijf partners), betrokken cursusleiders (gezondheidspsycholoog, nefroloog en arbeidsdeskundige) en zorgverleners (maatschappelijk werkers, nefrologen, dialyseverpleegkundigen).

De bevindingen van de pilot-studie zijn positief, en duiden erop dat een theoriegestuurde meervoudige aanpak – gericht op cognitieve, emotionele, gedragsmatige en contextuele aspecten – uitvoerbaar en mogelijk effectief is. Over het algemeen kan worden geconcludeerd dat alle ingrediënten van de interventie waardevol zijn, maar dat het totale cursusprogramma erg intensief is. Ondanks de inzet van gemotiveerde zorgverleners, blijkt het echter niet eenvoudig om de interventie succesvol te implementeren in de reguliere zorg. Op basis van de bevindingen worden in hoofdstuk 6 aandachtspunten benoemd voor zowel de inhoud en het proces van de interventie als voor de implementatie van dit soort interventies.

Tot slot worden in hoofdstuk 7 de belangrijkste bevindingen van dit proefschrift en de implicaties van deze bevindingen gepresenteerd en besproken. Daarnaast gaat dit hoofdstuk in op de methodologische overwegingen en richtingen voor toekomstig onderzoek en de praktijk. Op de volgende pagina's wordt een overzicht gegeven van belangrijke methodologische overwegingen en aanbevelingen.

Methodologische overwegingen

De empirische studies werden aangesloten bij cohort studies waaraan meerdere Nederlandse dialysecentra hebben meegewerkt. Deze aansluiting bood ons de mogelijkheid om psychologische en medische kenmerken te onderzoeken bij zowel hemodialysepatiënten, peritoneaal dialysepatiënten, als pre-dialysepatiënten door heel Nederland. Dit is een sterk punt van ons onderzoek. Een ander sterk punt is dat het andere uitkomsten dan de vaak gebruikte gezondheidsgerelateerde kwaliteit van leven aan de orde stelt, te weten ervaren autonomie, gevoel van eigenwaarde en arbeidsparticipatie. Daarnaast komt de huidige studie tegemoet aan de opkomende behoefte aan onderzoek naar de ontwikkeling en evaluatie van interventies gebaseerd op principes van zelfregulatie, met als doel het verbeteren van patiëntuitkomsten. Methodologische beperkingen zijn de mogelijke selectiebias van de steekproef van dialysepatiënten als gevolg van een kleiner wordend cohort, en de vrij kleine onderzoeksgroepen. Ten slotte beperkt de cross-sectionele opzet van de empirische studies de conclusies van dit proefschrift.

Aanbevelingen voor toekomstig onderzoek

Het verdient aanbeveling te onderzoeken in hoeverre veranderingen in ziekte- en behandelpercepties van patiënten met chronische nierziekte gepaard gaan met veranderingen in gevoelens van autonomie, eigenwaarde en arbeidsparticipatie. Verder is het nodig om de focus van dit type onderzoek te verschuiven naar groepen jongere patiënten die zich in een eerder stadium van chronische nierziekte bevinden. Daarnaast is er behoefte aan onderzoek naar de ontwikkeling van psychometrisch degelijke instrumenten, waarmee de door mensen met een chronische nierziekte ervaren autonomie kan worden gemeten.

Met het oog op onderzoek naar de rol van sociale steun, is het belangrijk dat onderzoek zich op een breder scala van sociale interacties richt, zoals de houding van en geboden steun door zorgverleners en werkgevers.

Daarnaast wordt geadviseerd om ook andere kenmerken van patiënten en hun omgeving in beschouwing te nemen, zoals persoonlijke drijfveren van patiënten en beschikbare faciliteiten op het gebied van werk en gezondheidszorg. Voor onderzoek bij dialysepatiënten zou het dan ook

interessant zijn om rekening te houden met meer kenmerken van de verschillende dialysemodaliteiten.

Op het gebied van interventies is onderzoek nodig naar de effecten van de ontwikkelde en aangepaste psychologische interventie op zowel de korte als de lange termijn. Ten slotte is het aan te raden onderzoek te doen naar de ontwikkeling en evaluatie van beslissingshulpmiddelen die patiënten helpen bij het maken van een weloverwogen keuze tussen de verschillende dialyseopties, voor een behandeling die het beste past bij hun persoonlijke situatie.

Aanbevelingen voor de toekomstige praktijk

Voor de praktijk wordt aanbevolen om (multidisciplinaire) zelfmanagement ondersteuning te bieden aan patiënten en hun naasten bij het combineren van de chronische nierziekte en de behandeling met dagelijkse activiteiten, inclusief betaald werk. Aangeraden wordt deze ondersteuning in een vroeg stadium van het ziekteproces aan te bieden, bij voorkeur vóór stadium 4 chronische nierziekte. Door realistische informatie te geven en hulpmiddelen en steun te bieden bij het inpassen van de ziekte en de (toekomstige) behandeling in het dagelijks leven, kunnen helpende ziekte- en behandelpercepties – bij zowel patiënten als naasten – versterkt worden. Hierdoor kan een succesvolle aanpassing aan chronische nierziekte worden gefaciliteerd. In aansluiting hierop lijkt het ook van belang dat patiënten worden ondersteund bij het maken van een weloverwogen keuze voor een (toekomstige) dialysebehandeling, die het beste past bij hun persoonlijke voorkeuren en hun dagelijks leven.

Aanbevelingen voor implementatie

Implementatie van psychologische groepsinterventies, zoals ontwikkeld in deze studie, vereisen een specifiek en apart traject. Voordat grootschalig effectonderzoek wordt gedaan naar interventies, wordt geadviseerd om via onderzoek de succesfactoren en de knelpunten voor implementatie te identificeren. Dit onderzoek zou bij voorkeur in nauwe samenwerking met zorgverleners, managementteams van gezondheidszorgorganisaties en patiënten zelf moeten worden uitgevoerd.

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Curriculum Vitae

Daphne Louise Jansen was born in Oss, the Netherlands, on January the 22nd 1981. After finishing her secondary education (VWO) in 1999 at the Titus Brandsma Lyceum in Oss, she studied Psychology at the Radboud University Nijmegen (formerly Catholic University of Nijmegen) and specialised in Social Psychology. From August 2003 until August 2004 she worked as a research assistant at the department of Social Psychology of the Radboud University Nijmegen. In May 2004, she obtained her Master's degree in Social Psychology with a thesis on contingent self-esteem, and the reliability and validity of the Dutch global and domain-specific contingency scales. In January 2006 she started working at NIVEL, Netherlands institute for health services research. At NIVEL she worked on several studies related to social participation and self-management in people with a chronic illness or disability, including the research underlying this thesis.

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