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## **Bevordering van arbeidsparticipatie en autonomie van nierpatiënten**

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# Inhoud

<b>Voorwoord</b>	<b>5</b>
<b>1 Samenvatting</b>	<b>7</b>
1.1 Achtergrond	7
1.2 Opzet project	8
1.3 Resultaten deelstudie 1	10
1.3.1 Beschrijving van de onderzoeksgroepen	10
1.3.2 Arbeidsparticipatie, ervaren autonomie en zelfwaardering	11
1.3.3 Ziekte- en behandelingspercepties	12
1.3.4 Stabiliteit ziekte- en behandelingspercepties	14
1.3.5 Ervaren sociale steun en overbescherming	15
1.4 Resultaten deelstudie 2	16
1.4.1 Opzet interventie	16
1.4.2 Pilotstudie interventie	17
1.5 Conclusies	18
<b>2 Beschrijving cursus</b>	<b>23</b>
<b>3 Perceived autonomy and self-esteem in Dutch dialysis patients: the importance of illness and treatment perceptions</b>	<b>27</b>
3.1 Abstract	27
3.2 Introduction	27
3.3 Methods	29
3.4 Results	31
3.5 Discussion	38
<b>4 Pre-dialysis patients' labour participation, perceived autonomy and self-esteem: associations with illness and treatment perceptions</b>	<b>45</b>
4.1 Abstract	45
4.2 Introduction	45
4.3 Methods	48
4.4 Results	50
4.5 Discussion	56

<b>5</b>	<b>Illness and treatment perceptions of end-stage renal disease patients: different stages, different perceptions?</b>	<b>61</b>
5.1	Abstract	61
5.2	Introduction	61
5.3	Methods	64
5.4	Results	66
5.5	Discussion	69
<b>6</b>	<b>The impact of social support and overprotection on dialysis patients' labour participation, autonomy and self-esteem</b>	<b>75</b>
6.1	Abstract	75
6.2	Background and objectives	75
6.3	Methods	76
6.4	Results	80
6.4.1	Dialysis patients' experienced social support and overprotection	80
6.4.2	Associations between experienced social support, overprotection and background characteristics	83
6.4.3	Associations with autonomy, self-esteem and labour participation	86
6.5	Conclusions	92
<b>7</b>	<b>Development of and first experiences with a behavioural self-regulation intervention for ESRD patients and their partners</b>	<b>97</b>
7.1	Abstract	97
7.2	Introduction	97
7.3	Development intervention	99
7.4	Pilot intervention	104
7.5	Discussion	108

## Voorwoord

Dit rapport vormt de eindrapportage van het project ‘Bevordering van arbeidsparticipatie en autonomie van nierpatiënten’, dat in de periode januari 2006 tot en met december 2008 is uitgevoerd. Het project had tot doel inzicht te krijgen in de psychologische factoren die van belang zijn voor het al dan niet verrichten van werk en -meer in het algemeen- het ervaren van autonomie door nierpatiënten (deelstudie 1), en het ontwikkelen en uittesten van een psychologische interventie gericht op het ondersteunen van nierpatiënten bij het behoud van werk en een actief leven (deelstudie 2). Het project is uitgevoerd vanuit het NIVEL in samenwerking met het Hans Mak Instituut, met subsidie van Nierstichting Nederland en Stichting Instituut Gak. Nierstichting Nederland zet zich middels het meerjarenprogramma Patiëntenzorg (voorheen Maatschappelijke Participatie) in voor de verbetering van de kwaliteit van leven van nierpatiënten. Met het programma wordt onder andere beoogd de autonomie van nierpatiënten te versterken door patiënten te ondersteunen en te stimuleren om zowel sociaal als op werkgebied actief te blijven. Het onderhavige project is uitgevoerd in het kader van dit meerjarenprogramma.

Het projectteam bestond uit mevrouw drs. D.L. Jansen (onderzoeker NIVEL), mevrouw dr. M.J.W.M. Heijmans (senior-onderzoeker NIVEL), mevrouw dr. E.W. Boeschoten (nefroloog, directeur Hans Mak Instituut) en mevrouw dr. P.M. Rijken (projectleider NIVEL). Vanuit Nierstichting Nederland werd het project begeleid door mevrouw drs. E. van Cromvoirt (vanaf 1 september 2006) en mevrouw drs. E.C.M. Aarden (tot 1 september 2006). Voor dit project is tevens een begeleidingscommissie in het leven geroepen. De volgende personen hebben deel uitgemaakt van deze commissie: de heer drs. R. Beekman (NVN), de heer drs. ing. V. van Koersveld (NVN), mevrouw drs. N. Plum (NVN), de heer drs. G. Frijstein (bedrijfsarts AMC), de heer M. Mantel (maatschappelijk werker LUMC, Vereniging Maatschappelijk Werk Nefrologie), de heer prof. dr. P.M. ter Wee (nefroloog VUmc, Nederlandse Federatie voor Nefrologie). Op deze plaats willen wij hen graag hartelijk danken voor hun inzet en constructieve inbreng bij de uitvoering van dit project en de totstandkoming van dit rapport. Tevens willen wij alle nierpatiënten, maatschappelijk werkers, verpleegkundigen en artsen danken die hun medewerking hebben verleend aan de uitvoering van het onderzoek en de interventie. Tot slot gaat onze dank uit naar de medewerkers van de Necosad studiegroep, de Prepare studiegroep en het Hans Mak Instituut voor hun bijdrage aan de dataverzameling en dataverwerking.

Het rapport is opgebouwd uit drie delen. Deel 1 bestaat uit een samenvatting van de opzet van het project en de bevindingen van het onderzoek (H 1). In deel 2 wordt een globale beschrijving gegeven van de ontwikkelde psychologische interventie (H 2). Deel 3 bevat de verantwoording van het onderzoek in de vorm van Engelstalige wetenschappelijke artikelen (H 3, 4, 5 en 7) en een Engelstalige notitie (H 6).

Utrecht, maart 2009



# 1 Samenvatting

## 1.1 Achtergrond

In 2005 is Nierstichting Nederland (NSN) in samenwerking met de Nierpatiënten Vereniging Nederland (NVN) en de Vereniging Maatschappelijk Werk Nefrologie (VMWN) gestart met het meerjarenprogramma 'Maatschappelijke participatie'. In dit programma staan de maatschappelijke participatie en autonomie van nierpatiënten centraal. Chronische nierinsufficiëntie wordt gekenmerkt door specifieke ziekte- en behandelingsaspecten. Veel mensen met een chronische nierziekte hebben last van vermoeidheid en beperkte energie. Daarnaast trekt met name de dialysebehandeling een zware wissel op het dagelijks leven van patiënten. Met het programma 'Maatschappelijke participatie' wordt beoogd de uitval van (pre-)dialysepatiënten uit het maatschappelijk leven zoveel mogelijk te voorkomen en de re-integratie van dialysepatiënten en getransplanteerden te bevorderen. In het kader van dit programma wil NSN met name meer inzicht krijgen in de mogelijkheden en knelpunten die mensen met een nierziekte ervaren bij het behoud van werk en bij hun re-integratie op de arbeidsmarkt. Het verrichten van betaald werk is immers één van de belangrijkste manieren om bij het maatschappelijk leven betrokken te blijven. Met de komst van de wet Werk en inkomen naar arbeidsvermogen (Wia) is het meer dan ooit van belang dat mensen met een nierziekte blijven werken. Het hebben van betaald werk is essentieel om voldoende inkomen te genereren en participatie op andere terreinen mogelijk te maken. Bovendien biedt werk extra sociale contacten, mogelijkheden tot zelfontplooiing en draagt het bij aan een gevoel van eigenwaarde. Het is om deze redenen van belang om nierpatiënten te ondersteunen en te helpen bij het zoeken naar mogelijkheden om werk, maar ook andere dagelijkse activiteiten, zoveel als mogelijk te behouden.

Om zicht te krijgen op de stand van zaken met betrekking tot de maatschappelijke participatie van nierpatiënten, heeft het NIVEL in 2003/2004 – met subsidie van NSN – een literatuurstudie uitgevoerd (Heijmans & Rijken, 2004). Uit deze studie kwam naar voren dat patiënten met chronische nierinsufficiëntie op diverse participatieterrainen (betaald werk, sociale participatie en vrijetijdsbesteding, sociale relaties) knelpunten ondervinden. Opvallend was met name de lage arbeidsparticipatiegraad onder nierpatiënten; de percentages werkenden onder de nierpatiënten van 18 tot en met 64 jaar variëren tussen 25 en 40%, terwijl van de algemene Nederlandse bevolking in deze leeftijdsklasse circa tweederde betaald werk verricht. Een belangrijke bevinding daarbij was dat uitval uit het arbeidsproces vaak al in de pre-dialysefase optreedt. Deze fase verwijst naar het traject waarin patiënten worden voorbereid op een nierfunctieervangende behandeling (dialyse of transplantatie), omdat duidelijk is geworden dat een nierfunctieervangende behandeling binnen enige tijd nodig zal zijn.

De literatuurstudie heeft tevens inzicht opgeleverd in de factoren die van belang zijn om uitval uit het arbeidsproces te voorkomen. Uiteraard spelen sociaal-demografische factoren, zoals de leeftijd en de opleiding van de patiënt, en medische factoren, zoals ernst van de nierziekte en soort behandeling, hierbij een rol. Daarnaast spelen externe

factoren, zoals de aard van het werk dat men verrichtte voor of tijdens de ziekte en de houding van de (toenmalige) werkgever of collega's, een belangrijke rol. Aan deze factoren is over het algemeen door de patiënt niet veel te veranderen. Echter, opvallend was dat er ook grote verschillen bestaan in de mate van deelname aan het arbeidsproces tussen nierpatiënten die een vergelijkbare sociaal-demografische en medische achtergrond hebben. Dit betekent dat ook andere factoren van invloed zijn op het behoud van werk en re-integratie van nierpatiënten.

Uit de literatuurstudie kwamen twee psychologische factoren naar voren die samenhangen met het al dan niet verrichten van betaald werk door nierpatiënten. In de eerste plaats is dit de manier waarop de patiënt zelf aankijkt tegen zijn/haar nierziekte en de behandeling en de mogelijkheden die hij/zij daarbij ziet tot het verrichten van werk en andere dagelijkse activiteiten. In de tweede plaats is dit de wijze waarop de naaste omgeving van de patiënt (met name de partner, familie, behandelend arts) omgaat met de patiënt en hem/haar al of niet actief ondersteunt bij pogingen tot het verrichten van activiteiten, waaronder werk. Binnen de gezondheidspsychologie worden hiervoor de termen ziekte- en behandelingspercepties (persoonlijke ideeën die iemand heeft over zijn/haar ziekte en behandeling) en de ervaren sociale steun c.q. overbescherming gebruikt. Deze psychologische factoren zijn met name interessant, omdat deze mogelijk veranderbaar zijn en derhalve aangrijpingspunten bieden ter ondersteuning van de arbeidsparticipatie van nierpatiënten. Zo hebben Petrie en collega's (2002) aangetoond dat de ziektepercepties van patiënten met een recent hartinfarct door middel van een psychologische interventie konden worden veranderd, waardoor de snelheid van werkherwinning door deze patiënten toenam.

## 1.2 Opzet project

De bevindingen uit de literatuur hebben ertoe geleid een project op te zetten, waarin de betekenis van de hiervoor genoemde psychologische factoren voor het verrichten van betaald werk en –meer in het algemeen– het ervaren van autonomie door nierpatiënten nader werd onderzocht. Het project werd uitgevoerd in drie fasen. In de eerste fase werd beschrijvend en verklarend onderzoek verricht naar de rol van psychologische factoren bij de arbeidsparticipatie, ervaren autonomie en zelfwaardering van nierpatiënten (deelstudie 1). De tweede fase van het project betrof de ontwikkeling van een psychologische interventie, in de vorm van een groepscursus, gericht op het in positieve zin beïnvloeden van de psychologische factoren bij nierpatiënten en hun naaste omgeving (voor meer informatie zie Jansen & Rijken, 2008). De derde fase van het project behelsde een procesevaluatie van de ontwikkelde groepscursus, waarbij de cursus op beperkte schaal werd aangeboden en uitgetest op zijn uitvoerbaarheid en eerste ervaringen (deelstudie 2).

De volgende onderzoeksvragen worden in dit rapport beantwoord:

### *Deelstudie 1*

1. Welke ideeën ten aanzien van hun ziekte en behandeling en hun mogelijkheden tot het verrichten van betaald werk hebben (pre-)dialysepatiënten? Zijn er hierbij verschillen naar sociaal-demografische kenmerken en ziekte- en behandelingskenmerken?



2. Zijn de ziekte- en behandelingspercepties van (pre-)dialysepatiënten stabiel over de tijd dan wel aan verandering onderhevig?
3. In welke mate ervaren dialysepatiënten sociale steun dan wel overbescherming door hun partner en behandelend arts? Zijn er hierbij verschillen naar sociaal-demografische kenmerken en ziekte- en behandelingskenmerken?
4. In hoeverre zijn de percepties van de patiënt en de door hem/haar ervaren sociale steun dan wel overbescherming van zijn/haar partner en behandelend arts voorlopers van arbeidsparticipatie, ervaren autonomie en zelfwaardering?

#### *Deelstudie 2*

1. Welke gevolgen heeft implementatie van de groepscursus voor de betrokken zorgverleners binnen de dialysecentra?
2. Wat is de omvang van de instroom in en uitval uit de groepscursus?
3. Welke ervaringen hebben de cursusleiders, deelnemende patiënten en partners met de cursus?
4. Welke resultaten hebben de deelnemende patiënten bij zichzelf waargenomen als gevolg van deelname aan de cursus?

#### *Methode deelstudie 1*

Deelstudie 1 omvatte een beschrijvend en verklarend onderzoek. Door middel van vragenlijstonderzoek onder pre-dialysepatiënten en dialysepatiënten werd onderzocht welke ziekte- en behandelingspercepties deze patiënten hebben, in hoeverre deze percepties aan verandering onderhevig zijn, en in welke mate patiënten steun dan wel overbescherming vanuit hun naaste omgeving ervaren. Vervolgens is nagegaan in welke mate en op welke wijze de genoemde factoren samenhangen met arbeidsparticipatie en het ervaren van autonomie en zelfwaardering.

Voor het onderzoek onder dialysepatiënten werd aangehaakt bij het Overbruggingsproject Pre-Renine-plus, voorheen de Nederlandse Coöperatieve Studie naar de Adequatheid van Dialyse (NECOSAD-2; Termorshuizen et al., 2003; Timmers et al., 2008), dat wordt onderhouden door het Hans Mak Instituut. Vanaf 1997 werden ruim 2000 dialysepatiënten in Necosad-2 geïnccludeerd. Middels het Overbruggingsproject Pre-Renine-plus is een aantal patiënten die deelnamen aan Necosad-2 langer gevolgd om een indruk te kunnen krijgen wat de lange-termijneffecten van de dialysebehandeling zijn. Het Overbruggingscohort bestond ten tijde van de start van het huidige onderzoek uit 248 dialysepatiënten. Aan deze patiënten is in maart-april 2006 een eerste vragenlijst, en in november-december 2006 een tweede vragenlijst gestuurd. De vragenlijst ten behoeve van de eerste meting werd door 166 patiënten ingevuld (netto respons van 67%). Van deze 166 dialysepatiënten hebben 129 patiënten de tweede vragenlijst ontvangen, waarvan 87 de vragenlijst ingevuld hebben geretourneerd (netto respons van 67%).

Voor het onderzoek onder pre-dialysepatiënten werd aangesloten bij de PREdialysis PATients REcord (PREPARE) studie, die wordt uitgevoerd door het Leids Universitair Medisch Centrum in samenwerking met het Hans Mak Instituut. Binnen de Preparestudie wordt onderzocht welke factoren samenhangen met de achteruitgang in nierfunctie bij patiënten met ernstige chronische nierinsufficiëntie. De studie is in augustus 2004 van start gegaan. Eind 2006 deden 196 patiënten met chronisch nierfalen mee aan de studie. De pre-dialysepatiënten die instroomden in de Prepare-studie zijn in het kader van deel-

studie 1 eenmalig bevroegd. Hiertoe ontvingen zij in de periode juli-september 2006 of november-december 2006 een vragenlijst. In totaal vulden 109 pre-dialysepatiënten de vragenlijst in (netto respons van 59%).

Ter beantwoording van de onderzoeksvragen van deelstudie 1 werden kwantitatieve analyses uitgevoerd. Het betreft hier beschrijvende statistiek, variantie-analyse en Chi-square testen (vragen 1 en 3), correlatie-analyse, variantie-analyse (vraag 2), en correlatie-analyse, t-toetsen en regressie-analyse (vraag 4).

### *Methodie deelstudie 2*

Deelstudie 2 behelsde de proces-evaluatie van de ontwikkelde groepscursus. Het raamwerk van de cursus is ontwikkeld op basis van verschillende gezondheidspsychologische theorieën, met name de zelfregulatietheorie van Leventhal en collega's (Leventhal et al., 1984), de sociale leertheorie van Bandura (1977), en de zelfdeterminatietheorie van Deci en Ryan (1985). De invulling van de verschillende cursusonderdelen is gebaseerd op de bevindingen van de eerste deelstudie, aanvullende literatuurstudie over zelfmanagement en zelfregulatieprincipes (e.g. Maes & Karoly, 2005), ervaringen van nierpatiënten, kennis en inzichten van zorgverleners, en ervaringen van andere onderzoekers op het gebied van interventieontwikkeling (Rasgon et al., 1993; 1996; 1997; Varekamp et al., 2006). De ontwikkelde groepscursus is bedoeld voor nierpatiënten, in de leeftijd van 18 tot en met 64 jaar, die worden voorbereid op een nierfunctie vervangende behandeling (pre-dialysepatiënten) of nog niet zo lang geleden zijn gestart met dialyse en voor wie (betaald) werk nog wel een reële optie is. Daarnaast zijn de partners van patiënten welkom om aan de cursus deel te nemen.

In februari 2008 werden vanuit drie dialysecentra, gelegen in de regio Utrecht, 28 patiënten benaderd voor deelname aan de cursus op basis van vooropgestelde selectiecriteria. Van de 28 benaderde patiënten hebben zeven patiënten deelgenomen aan de cursus (respons: 25%), waarvan vijf tezamen met hun partner. De cursus werd in de periode april tot en met juli 2008 uitgetest. De ervaringen van de cursisten (patiënten en deelnemende partners) en betrokken zorgverleners (maatschappelijk werkers, dialyseverpleegkundigen, nefrologen) met de cursus werden na afloop van de cursus bevroegd middels evaluatieformulieren. De ervaringen van de cursusleiders (gezondheidspsycholoog, nefroloog, arbeidsdeskundige) met de cursus werden geëvalueerd aan de hand van individuele gesprekken (voor meer informatie zie Jansen & Rijken, 2008).

## **1.3 Resultaten deelstudie 1**

### **1.3.1 Beschrijving van de onderzoeksgroepen**

#### *Achtergrondkenmerken dialysepatiënten*

Ongeveer twee derde deel van de dialysepatiënten was man (64%). De gemiddelde leeftijd van de patiënten was 67 jaar (range: 32-89 jaar) en de meeste patiënten waren ouder dan 64 jaar (63%). Het percentage ouderen binnen de onderzochte groep dialysepatiënten was hiermee groter in vergelijking met cijfers van de Nederlandse dialysepopulatie in 2006 (49%  $\geq$  65 jaar) (Oppe et al., 2007). Negenendertig procent van de patiënten was laag opgeleid, 44% was midden opgeleid, en 17% was hoog opgeleid. De meeste patiënten waren getrouwd of woonden samen (66%).

Dialysepatiënten kunnen worden behandeld met peritoneaal dialyse (PD) of hemodialyse (HD). Door middel van dialyse wordt het bloed van patiënten kunstmatig gezuiverd. Bij peritoneaal dialyse wordt om het bloed te zuiveren spoelvoeistof in de buikholte gebracht. Hemodialyse gebeurt met behulp van een kunstnier; een apparaat dat het bloed filtert. Een grote meerderheid van de patiënten werd behandeld met hemodialyse (71%). Patiënten dialyseerden gemiddeld 3.6 jaar (range: 0.1-9.0 jaar). De ernst van de gezondheidstoestand van patiënten werd bepaald op basis van de serum albumine waarde. Serum albumine is een belangrijke voorspeller van morbiditeit en mortaliteit bij dialysepatiënten. Hoge serum albumine waarden duiden op een betere gezondheidstoestand. Normaalwaarden liggen rond de 40-50 g/L. De gemiddelde serum albumine waarde van de dialysepatiënten was 36.9 g/L (range: 22.6-45.8 g/L).

#### *Achtergrondkenmerken pre-dialysepatiënten*

Circa twee derde deel van de pre-dialysepatiënten was man (64%). Achtenvijftig procent van de patiënten was ouder dan 64 jaar, hetgeen nog altijd betekent dat ook de pre-dialysepatiënten gemiddeld vrij oud zijn (gemiddeld 64 jaar, range: 19-92 jaar). Van de patiënten was 43% laag opgeleid, eveneens 43% midden opgeleid, en 14% was hoog opgeleid. De meerderheid van de patiënten was getrouwd of samenwonend (64%). De ernst van de gezondheidstoestand van patiënten werd bepaald aan de hand van het aantal comorbide ziekten, oftewel het aantal aandoeningen dat patiënten naast de nierziekte hebben. Hierbij werd gekeken naar de aandoeningen diabetes mellitus type 2, hypertensie, CVA, vaatproblematiek, ischemische hartziekte en hartfalen. Ongeveer een kwart (24%) van de patiënten had geen van de genoemde ziekten naast de nierziekte, 30% had één comorbide ziekte, en 46% had meer dan één comorbide ziekte.

### **1.3.2 Arbeidsparticipatie, ervaren autonomie en zelfwaardering**

Binnen zowel de groep dialysepatiënten als pre-dialysepatiënten die aan deelstudie 1 hebben meegewerkt, is bekeken in welke mate zij deelnemen aan het arbeidsproces, in hoeverre zij het gevoel hebben de dingen te kunnen doen die zij graag willen doen in het leven (ervaren autonomie) en in welke mate zij beschikken over gevoelens van eigenwaarde (zelfwaardering).

#### *Arbeidsparticipatie*

Zevenendertig procent (N=62) van de responderende dialysepatiënten in 2006 was jonger dan 65 jaar en behoorde hiermee tot de potentiële beroepsbevolking. Binnen deze groep verrichtten slechts 15 mensen betaald werk voor tenminste 12 uur per week (definitie van arbeidsparticipatie volgens CBS-norm) met een gemiddelde van 32.4 uur per week (range 12-40 uur), hetgeen neerkomt op een arbeidsparticipatiegraad van 24%. Onderzocht is of er verschillen bestaan in de arbeidsparticipatie tussen patiënten naar sociaal-demografische kenmerken <sup>1</sup> en ziekte- en behandelingskenmerken <sup>2</sup>. De resultaten lieten zien dat patiënten die werkzaam waren voor tenminste 12 uur per week

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<sup>1</sup> Geslacht, leeftijd, opleidingsniveau en burgerlijke staat.

<sup>2</sup> Type dialysebehandeling (hemodialyse (HD)/peritoneaal dialyse (PD)), tijd sinds aanvang van de dialyse, serum albumine waarde (indicator ernst gezondheidstoestand dialysepatiënten), en aantal comorbide ziekten (indicator ernst gezondheidstoestand pre-dialysepatiënten).

gemiddeld genomen jonger waren dan patiënten die minder dan 12 uur per week werkten of niet werkten.

Binnen de pre-dialysegroep lagen de resultaten ten aanzien van arbeidsparticipatie anders. Van deze groep was 42% (N=45) jonger dan 65 jaar. Van de groep jonger dan 65 jaar verrichtten 23 mensen betaald werk voor tenminste 12 uur per week, een arbeidsparticipatiegraad van 51%. Gemiddeld werkte men 34.7 uur per week, met een range van 20 tot 60 uur per week. Ook voor de pre-dialysegroep geldt dat mensen die tenminste 12 uur per week werkten gemiddeld jonger waren dan mensen die minder dan 12 uur per week werkzaam waren of niet werkten.

#### *Ervaren autonomie en zelfwaardering*

Zowel dialyse- als pre-dialysepatiënten hebben gemiddeld genomen gematigde gevoelens van autonomie, wat er op duidt dat zij vanwege hun gezondheidstoestand of anderszins niet vaak het gevoel hebben dat zij de dingen kunnen doen die zij graag willen doen in het dagelijks leven. Ook hier is bekeken in hoeverre er verschillen bestaan in de ervaren autonomie tussen patiënten naar sociaal-demografische kenmerken en ziekte- en behandelingskenmerken. Te zien is dat laag opgeleide dialysepatiënten zich minder autonoom voelen dan hoog opgeleide dialysepatiënten. In de pre-dialysegroep werden geen verschillen gevonden naar achtergrondkenmerken.

Over het algemeen beschikken beide groepen patiënten over een hoge mate van zelfwaardering. Hierbij werden binnen de dialysegroep verschillen gevonden tussen mannen en vrouwen, waarbij mannen een hogere mate van zelfwaardering hebben. Binnen de pre-dialysegroep was een verband waarneembaar tussen zelfwaardering en opleidingsniveau; mensen met een hoog opleidingsniveau hebben een hogere eigenwaarde in vergelijking met midden en laag opgeleiden.

### **1.3.3 Ziekte- en behandelingspercepties**

*Welke ideeën ten aanzien van hun ziekte en behandeling hebben (pre-)dialysepatiënten? Zijn er hierbij verschillen naar sociaal-demografische kenmerken en ziekte- en behandelingskenmerken?*

Ziekte- en behandelingspercepties zijn de persoonlijke ideeën die iemand heeft over zijn of haar ziekte en behandeling. Deze ideeën hebben betrekking op de ervaren emoties en klachten als gevolg van de ziekte, de oorzaken en het beloop van de ziekte, de gevolgen van de ziekte en de behandeling, en de mogelijkheden om de ziekte zelf of met behulp van een medische behandeling te beïnvloeden.

Over het algemeen beschouwen pre-dialysepatiënten en dialysepatiënten hun nierziekte als een ziekte die niet meer overgaat. Mensen die dialyseren hebben daarnaast het idee dat de nierziekte behoorlijk veel nadelige gevolgen heeft voor hun dagelijks leven, en zij ervaren tamelijk veel lichamelijke klachten van hun nieraandoening. Mensen die worden voorbereid op dialyse geven aan dat hun dagelijks leven in enige mate wordt beïnvloed door de ziekte, maar ondervinden niet veel lichamelijke klachten van de nierziekte. Beide groepen zijn enigszins bezorgd over hun ziekte, maar ervaren tegelijkertijd redelijk weinig emotionele reacties, zoals boosheid en somberheid, als gevolg van hun ziekte.

Daarnaast geven zowel mensen die dialyseren als mensen die dat nog niet doen aan dat zij behoorlijk veel begrip hebben van hun ziekte.

Wat betreft de behandeling hebben dialysepatiënten het idee dat deze een grote positieve invloed heeft op hun ziekte, maar daarentegen hebben zij de overtuiging dat zijzelf tamelijk weinig invloed kunnen uitoefenen op het beloop van hun ziekte. Dit patroon is ook te zien bij de patiënten die voorbereid worden op de dialyse; de behandeling die zij krijgen (veelal medicatie en dieetvoorschriften) heeft volgens hen redelijk wat positieve invloed op de nierziekte, maar ook deze groep ervaart niet veel persoonlijke controle over de ziekte. Tenslotte blijkt dat dialysepatiënten het idee hebben dat de behandeling die zij krijgen tamelijk wat verstoring teweeg brengt in hun dagelijks leven. Pre-dialysepatiënten ondervinden in enige mate impact van hun behandeling op het leven van alledag.

We hebben onderzocht in hoeverre er verschillen bestaan in de percepties tussen patiënten naar achtergrondkenmerken. Binnen de dialysegroep werden verschillende verbanden gevonden met de achtergrondkenmerken. Zo blijken vrouwen meer negatieve emoties te ervaren en bezorgder te zijn over hun ziekte dan mannen.

Verder hebben 65-plussers minder het idee dat de ziekte van invloed is op hun gemoedstoestand in vergelijking met patiënten in de leeftijd van 18 tot en met 49 jaar. Er werd nog een verschil gevonden ten aanzien van leeftijd; naarmate mensen ouder zijn, blijken zij sterker de overtuiging te hebben dat de ziekte chronisch van aard is.

Patiënten die langer dan vijf jaar dialyseren ondervinden door de behandeling meer verstoring in hun dagelijks leven dan degenen die nog geen vijf jaar dialyseren. Mensen die hemodialyse volgen blijken meer verstoring van de behandeling te ervaren in vergelijking met mensen die peritoneaal dialyse volgen, bovendien heeft de laatste groep sterker het idee dat de behandeling helpt. Binnen de pre-dialysegroep werd een verband gevonden met opleidingsniveau; mensen die hoog opgeleid zijn blijken minder het idee te hebben dat de nierziekte hun gemoedstoestand beïnvloedt dan midden en laag opgeleiden.

*In hoeverre zijn de percepties van de patiënt voorspellers van arbeidsparticipatie, ervaren autonomie en zelfwaardering?*

Een breed scala aan ziekte- en behandelingspercepties blijkt samen te hangen met de mate van autonomie en zelfwaardering van (pre-)dialysepatiënten, waarbij positieve percepties gerelateerd zijn aan een hogere mate van ervaren autonomie en zelfwaardering. Voor beide groepen geldt dat mensen die veel lichamelijke klachten toeschrijven aan hun nierziekte en mensen die vinden dat de ziekte en de behandeling een grote negatieve invloed op hun leven hebben, minder autonomie ervaren en een lagere zelfwaardering hebben. Een grotere bezorgdheid en emotionele impact blijken eveneens samen te hangen met een lagere mate van autonomie en zelfwaardering.

De overtuiging dat de behandeling positieve effecten heeft en dat men persoonlijke controle heeft over de nierziekte, hangen juist samen met meer autonomie en een hogere zelfwaardering. Een sterker idee dat men de ziekte begrijpt gaat eveneens gepaard met gevoelens van autonomie en eigenwaarde binnen de dialysegroep, maar niet binnen de pre-dialysegroep.

We hebben vervolgens onderzocht in hoeverre de percepties van patiënten over de ziekte en de behandeling voorspellers zijn van de door hen ervaren autonomie en zelfwaardering. Hierbij werd gecontroleerd voor verschillen tussen patiënten in achtergrondkenmerken. De resultaten laten zien dat de ziekte- en behandelingspercepties een belangrijke bijdrage leveren aan de voorspelling van zowel autonomie als zelfwaardering. Percepties van een hoge mate van persoonlijke controle over de nierziekte, minder impact van de nierziekte en de behandeling op het dagelijks leven, en een lagere mate van bezorgdheid over de ziekte blijken van belang voor het ervaren van autonomie en zelfwaardering door dialysepatiënten. De gedachte dat de behandeling weinig invloed heeft op het dagelijks leven blijkt van belang voor gevoelens van autonomie en zelfwaardering van pre-dialysepatiënten.

Vanwege het geringe aantal patiënten dat deel uitmaakte van de potentiële beroepsbevolking (15 t/m 64 jaar) konden relaties tussen de ziekte- en behandelingspercepties enerzijds en arbeidsparticipatie anderzijds niet worden aangetoond. Desalniettemin, werd een aantal trends gevonden waarbij de verbanden eenzelfde patroon volgen als de verbanden van de percepties met autonomie en zelfwaardering: positieve percepties over de ziekte en de behandeling gaan gepaard met het verrichten van betaald werk.

#### **1.3.4 Stabiliteit ziekte- en behandelingspercepties**

*Zijn de ziekte- en behandelingspercepties van (pre-)dialysepatiënten stabiel over de tijd dan wel aan verandering onderhevig?*

Om deze vraag te kunnen beantwoorden, hebben we allereerst onderzocht in hoeverre de ziekte- en behandelingspercepties van patiënten die worden voorbereid op dialyse (pre-dialysepatiënten), patiënten die minder dan drie jaar dialyseren, en patiënten die drie jaar of langer dialyseren verschillen. De resultaten laten zien dat de percepties van de patiënten variëren over de drie verschillende fasen van het ziekteproces. Zo blijken pre-dialysepatiënten over het algemeen minder het idee te hebben dat hun dagelijks leven wordt verstoord door de ziekte en behandeling in vergelijking met patiënten die dialyseren. Mensen die korter dan drie jaar dialyseren en mensen die nog niet dialyseren blijken minder lichamelijke klachten aan hun ziekte toe te schrijven dan mensen die al drie jaar of langer dialyseren. Daarnaast hebben dialysepatiënten sterker het idee dat hun huidige behandeling een positief effect heeft op het ziektebeloop in vergelijking met mensen die in de pre-dialysefase zitten. Zowel pre-dialyse- als dialysepatiënten hebben de overtuiging dat zijzelf tamelijk weinig invloed kunnen uitoefenen op het beloop van hun ziekte. Tenslotte duiden de resultaten er op dat mensen die dialyseren minder zorgen hebben over de nierziekte dan mensen in de pre-dialysefase, en dat mensen die al langere tijd dialyseren sterker het idee hebben dat zij de ziekte begrijpen.

Tevens hebben we bekeken in hoeverre de ideeën die dialysepatiënten hebben over hun ziekte en behandeling veranderen gedurende een periode van zes maanden. Te zien is dat de ideeën die patiënten hebben over de impact van de behandeling op het dagelijks leven het meest stabiel zijn, gevolgd door de ideeën die mensen hebben over de invloed van de ziekte op de gemoedstoestand. Ideeën over de gevolgen van de ziekte en de mogelijkheden om zelf de ziekte te beïnvloeden blijken het meest te veranderen over een periode van

zes maanden. Ideeën over de mate waarin de behandeling helpt, blijken helemaal niet stabiel te zijn.

Tot slot duiden de resultaten er op dat naarmate mensen langer dialyseren ( $\geq 3$  jaar) zij stabielere percepties hebben, behalve ten aanzien van de gevolgen van de nierziekte en persoonlijke controle.

### **1.3.5 *Ervaren sociale steun en overbescherming***

Behalve ziekte- en behandelingspercepties, hebben we ook onderzocht in hoeverre het ervaren van steun en overbescherming door de naaste omgeving een rol speelt bij het ervaren van autonomie, zelfwaardering en arbeidsparticipatie door nierpatiënten. Dit hebben we alleen bekeken bij de groep die al dialyseerde.

*In welke mate ervaren dialysepatiënten sociale steun dan wel overbescherming door hun partner en behandelend arts? Zijn er hierbij verschillen naar sociaal-demografische kenmerken en ziekte- en behandelingskenmerken?*

De bevindingen laten zien dat de meeste dialyserenden maar af en toe steun ervaren vanuit hun naasten (partner, familie, etc.). Tegelijkertijd wordt dit over het geheel genomen niet als een gemis ervaren. Sociale steun is hierbij opgesplitst in alledaagse emotionele steun, emotionele steun bij problemen, steun in de vorm van gezelschap en totale steun.

Mensen die alleenstaand zijn, blijken minder steun en een groter tekort aan steun te ervaren in vergelijking met mensen die gehuwd zijn of samenwonen. Een betere gezondheidstoestand gaat gepaard met een hogere mate van ervaren alledaagse emotionele steun. Daarnaast blijkt dat mensen die al langer dan vijf jaar dialyseren een grotere, onvervulde behoefte aan gezelschap ondervinden dan mensen die twee tot vijf jaar dialyseren.

Dialysepatiënten hebben over het algemeen niet het gevoel dat ze te veel beschermd worden door hun naasten of artsen. Het ervaren van overbescherming door artsen is hierbij onderverdeeld in ervaren overbescherming door de huisarts en specialist op twee gebieden, te weten overbescherming in de wijze van bejegening en ten aanzien van het ondernemen van activiteiten. Mensen die zich te veel beschermd voelen door mensen uit hun naaste omgeving, voelen zich eveneens overbeschermd in de wijze waarop ze door hun artsen worden bejegend. Bovendien blijkt dat wanneer mensen zich overbeschermd voelen door hun huisarts, zij eveneens te veel bescherming ondervinden bij hun specialist. Kijken we naar subgroepen, dan is te zien dat mensen die laag zijn opgeleid meer het gevoel hebben dat hun huisarts overbeschermd is in zijn bejegening dan hoog opgeleiden. Zowel mensen die alleenstaand zijn als mensen die hemodialyse volgen, hebben sterker het gevoel dat zij overbeschermd worden door hun artsen ten aanzien van het doen van activiteiten in vergelijking tot respectievelijk gehuwden/samenwonenden en peritoneaal dialysepatiënten.

*In hoeverre zijn de door de patiënt ervaren sociale steun dan wel overbescherming van zijn/haar partner en behandelend arts voorspellers van arbeidsparticipatie, ervaren autonomie en zelfwaardering?*

Ervaren sociale steun en overbescherming blijken beiden gerelateerd te zijn aan gevoelens van autonomie en eigenwaarde. Naarmate mensen minder het gevoel hebben dat zij een tekort aan steun ontvangen, en minder het idee hebben dat zij te veel beschermd worden door hun naasten en hun specialist, voelen zij zich autonomer.

Mensen die meer steun van hun naasten ervaren en in mindere mate een gemis aan steun ondervinden, hebben een hogere zelfwaardering. Het gevoel dat men niet wordt overbeschermd door de specialist in de wijze van bejegening en niet wordt overbeschermd door naasten, hangt eveneens samen met een hogere zelfwaardering.

Analyses waarbij is gecorrigeerd voor de verschillen tussen patiënten in achtergrondkenmerken, tonen bovendien aan dat het ervaren van een tekort aan sociale steun en het ervaren van overbescherming een aanzienlijke bijdrage leveren aan de verklaring van zowel autonomie als zelfwaardering. De resultaten laten zien dat de mate van ervaren overbescherming in de bejegening van de specialist en ervaren tekorten aan zowel alledaagse emotionele steun, emotionele steun bij problemen, als gezelschapssteun belangrijke determinanten zijn van het ervaren van autonomie en zelfwaardering.

Voor het al dan niet hebben van betaald werk zijn er duidelijke trends zichtbaar. Mensen die een minder groot tekort aan emotionele ondersteuning ervaren in het geval van problemen, en mensen die minder overbescherming van artsen ervaren als het gaat om het ondernemen van activiteiten zijn vaker werkzaam.

## **1.4 Resultaten deelstudie 2**

### **1.4.1 Opzet interventie**

Gedurende de periode juli-december 2007 werd een groepscursus ontwikkeld waarmee wordt aangegrepen op de psychologische factoren waarvan uit deelstudie 1 is gebleken dat deze samenhangen met de ervaren autonomie, zelfwaardering en arbeidsparticipatie van mensen met een nierziekte. De interventie had tot doel het behoud dan wel het vergroten van dagelijkse activiteiten van patiënten, waaronder het verrichten van betaald werk, en daarmee het versterken van de autonomie en eigenwaarde van patiënten. Door vroegtijdig te interveniëren, kan worden verwacht dat uitval uit het arbeidsproces en vermindering van andere dagelijkse bezigheden wordt voorkomen.

De ontwikkelde groepscursus was bedoeld voor patiënten in de leeftijd van 18 tot en met 64 jaar, die werden voorbereid op de dialyse of die maximaal één jaar dialyseerden en voor wie (betaald) werk nog wel een reële optie was. De cursusgroep bestond uit minimaal vijf patiënten en hun eventuele partners. De cursus was opgebouwd uit zes tweewekelijkse bijeenkomsten van elk 2,5 uur, en één terugkombijeenkomst drie maanden na afloop van de zesde bijeenkomst. Het cursusmateriaal voor de deelnemende patiënten en partners bestond uit een handboek met daarin individuele en groepsopdrachten, en praktische en theoretische informatie. De cursus werd in de pilotfase geleid door een gezondheidspsycholoog aan de hand van een gedetailleerd draaiboek in samenwerking met een arts gespecialiseerd in nierziekten (nefroloog) en een arbeidsdeskundige van de NVN.



Het raamwerk van de interventie is met name gebaseerd op de zelfregulatietheorie van Leventhal en collega's (1984), de sociale leertheorie van Bandura (1977) en de zelf-determinatietheorie van Deci en Ryan (1985). In de eerste drie cursusbijeenkomsten wordt ingegaan op het stimuleren van positieve ideeën en het veranderen van negatieve ideeën en mispercepties over de ziekte en behandeling bij zowel patiënten als hun partners. En wordt inzicht gegeven in de beschikbare mogelijkheden om betaald werk te verrichten en actief te blijven in combinatie met de nierziekte en dialyse. In de laatste drie bijeenkomsten ligt de focus op het bevorderen van de persoonlijke effectiviteit van de patiënt ten aanzien van het uitvoeren van werk en andere dagelijkse activiteiten. In de vierde bijeenkomst wordt daarnaast extra aandacht besteed aan de relatie tussen vermoeidheid en (in)activiteit en het omgaan met vermoeidheidsklachten en beperkte energie. Tijdens de vijfde bijeenkomst is er speciale aandacht voor de rol van de naaste omgeving, gericht op het bevorderen van autonomie-ondersteunend gedrag bij zowel patiënten als partners. Binnen de cursus worden verschillende technieken gebruikt om de van belang zijnde factoren te beïnvloeden, zoals mondelinge en schriftelijke voorlichting, groepsdiscussie, modeling, zelfmonitoring, zelfobservatie, het ondernemen van activiteiten aan de hand van persoonlijke actieplannen, en feedback krijgen en geven (zie Hoofdstuk 2 voor een globale cursusbeschrijving).

#### **1.4.2 Pilotstudie interventie**

In de maanden april-juli 2008 werd de cursus aangeboden aan patiënten van drie dialysecentra, gelegen in de regio Utrecht. Daarbij werd de cursus uitgetest op zijn uitvoerbaarheid en eerste ervaringen.

*Welke gevolgen heeft implementatie van de groepscursus voor de betrokken zorgverleners binnen de dialysecentra? Wat is de omvang van de instroom in en uitval uit de groepscursus?*

De bereidheid onder de centra om hun medewerking te verlenen aan de uitvoering van de groepscursus en de studie was groot. De uitvoering van de cursus binnen een klinische setting verliep succesvol. De betrokken zorgverleners (maatschappelijk werkers, nefrologen, dialyseverpleegkundigen) rapporteerden geen nadelige gevolgen van hun medewerking aan de uitvoering van de cursus. De centra waren in staat om voldoende potentiële kandidaten te selecteren en te benaderen; in totaal werden 28 patiënten benaderd voor deelname. Van de 28 benaderde patiënten hadden tien patiënten zich voor de cursus aangemeld. Aandachtspunten bij de instroom van patiënten waren de lage respons onder de benaderde patiënten, en met name onder jong-volwassenen. Uit de redenen voor non respons bleek dat deze niet specifiek gerelateerd waren aan het doel van de cursus. Het lijkt vooral belangrijk dat de cursus goed kan worden ingepast in de dagelijkse bezigheden van de patiënt. Van de tien patiënten die zich hadden aangemeld, hebben zeven patiënten daadwerkelijk deelgenomen aan de cursus, waarvan vijf tezamen met hun partner. De overige drie patiënten zijn uitgevallen vanwege gezondheidsgerelateerde redenen zonder dat zij cursusbijeenkomsten hebben bijgewoond.

Bij aanvang van de cursus dialyseerden drie van de zeven deelnemende patiënten. De overige vier patiënten werden voorbereid op een nierfunctievervangende behandeling. Zes patiënten hadden betaald werk en één patiënt was werkloos/werkzoekend. Van de deelnemende patiënten is niemand tussentijds gestopt.

*Welke ervaringen hebben de cursusleiders, deelnemende patiënten en partners met de cursus?*

De cursusleiders en deelnemers waren over de gehele linie positief over de opzet van de cursus. Verder gaven deelnemers aan veel te hebben gehad aan de geboden informatie van zowel de cursusleiding als medecursisten en de verschillende cursusopdrachten, met name de persoonlijke actieplannen. Eén patiënt gaf hierbij aan dat het werken met de persoonlijke actieplannen energie en rust opleverden. Een andere deelnemende patiënt was van mening dat de cursus inzicht gaf in hoe 'gezond' je nog bent en hoeveel en wat je allemaal nog wel kunt doen.

De cursusleiders hadden positieve ervaringen met het groepsproces en het overbrengen van de cursusinhoud. Uit de evaluatie kwamen tevens enkele aandachts- en verbeterpunten naar voren. Deze punten hebben onder andere betrekking op het tijdstip van de cursus, de grootte en samenstelling van de cursusgroep, de informatievoorziening binnen de cursus en de cursusopdrachten. De voorkeur van patiënten voor cursustijden is zeer persoonlijk, doordat patiënten verschillen wat betreft de tijden waarop zij dialyseren, werken etc. Voor toekomstige cursussen is het aan te bevelen om voor iedere cursusgroep de cursustijden af te stemmen op de wensen van de deelnemers. Ten aanzien van de grootte van de cursusgroep werd geadviseerd om in grotere groepen te werken, zodat het groepsproces en daarmee het leerproces worden bevorderd. Hierbij wordt gestreefd naar groepen van minimaal acht patiënten (al of niet met partner). In het geval van grotere groepen wordt aanbevolen om de cursus standaard te laten begeleiden door twee cursusleiders. Daarnaast werd het van belang geacht dat patiënten in een zo vroeg mogelijk stadium van het ziekteproces deelnemen aan de cursus, zodat preventief kan worden gewerkt, en dat inclusie voor de cursus wordt verbreed naar alle dialysepatiënten. Verder werd aanbevolen om binnen de bijeenkomsten meer ruimte te creëren voor aansluiting bij de individuele behoeften en situaties van patiënten en de algemene informatieverstrekking binnen de bijeenkomsten te beperken. Ten aanzien van de cursusopdrachten werd geadviseerd meer tijd in te ruimen voor de voor- en nabespreking van de opdrachten en om vooral als (sub-)groep aan de slag te gaan met de opdrachten.

*Welke resultaten hebben de deelnemende patiënten bij zichzelf waargenomen als gevolg van deelname aan de cursus?*

De zelf geobserveerde resultaten als gevolg van de cursus van de deelnemende patiënten waren bemoedigend. Eén patiënt liet weten een baan te hebben gevonden en over het algemeen actiever te zijn geworden. Verder rapporteerden patiënten dat zij geleerd hebben beter hun energie en tijd te verdelen, hun naaste omgeving te betrekken bij hun ziekte, dat zij zich meer bewust zijn geworden van de mogelijke consequenties van hun ziekte en beter voorbereid zijn op eventuele complicaties (voor meer informatie zie Jansen & Rijken, 2008).

## **1.5 Conclusies**

De bevindingen ten aanzien van arbeidsparticipatie bevestigen het beeld uit de literatuur dat uitval uit het werk al gedurende de pre-dialysefase optreedt en zich voortzet in de dialysefase. Uit gegevens van een Nederlandse studie naar de arbeidssituatie van dialyse-

patiënten in 1997 kan worden afgeleid dat er al een grote uitval uit het arbeidsproces is vóór aanvang van de dialyse, dus in het pre-dialysetraject (Van Manen et al., 2001). De resultaten laten zien dat bij aanvang van de dialyse 35% van de patiënten (18-64 jaar) betaald werk had ten opzichte van 61% van de algemene Nederlandse beroepsbevolking in dat jaar. Eén jaar na dialyse werkte nog 28% van de patiënten. Van de patiënten die bij aanvang van de dialyse nog werk hadden, viel circa 20% uit in het eerste jaar van dialyse (in 1997/1998). De gegevens van Van Manen et al. betreffen het al dan niet hebben van betaald werk, ongeacht het aantal uren.

De arbeidsparticipatiegraad onder de pre-dialysepatiënten in de leeftijd van 18 tot en met 64 jaar (51%) was niet heel laag in vergelijking met de algemene Nederlandse bevolking van 15 tot en met 64 jaar, van wie circa tweederde tenminste 12 uur per week betaald werk verricht (CBS, 2006). Deze patiënten staan over het algemeen ook nog redelijk aan het begin van het pre-dialysetraject. Met name de arbeidsparticipatiegraad onder dialysepatiënten in de leeftijd van 18 tot en met 64 jaar (24%) is veel lager dan onder de algemene Nederlandse beroepsbevolking. De arbeidsparticipatiegraad onder dialysepatiënten is ook erg laag in vergelijking tot de percentages bij andere groepen somatisch chronisch zieken (gemiddeld circa 40%; Van den Brink-Muinen et al., 2007). Deze resultaten duiden op het belang en de noodzaak van werkgerelateerde ondersteuning en begeleiding in een vroeg stadium van het ziekteproces. Bovendien rapporteren beide patiëntgroepen gemiddeld genomen gematigde niveaus van ervaren autonomie in het dagelijks leven. Ondanks dit beschikken patiënten over het algemeen over een hoge mate van zelfwaardering.

De ideeën die patiënten hebben over de ziekte en behandeling laten zien dat zowel pre-dialyse- als dialysepatiënten over het algemeen weinig persoonlijke controle over de ziekte ervaren. Daarnaast valt op dat dialysepatiënten over het algemeen veel invloed van de ziekte ervaren op het dagelijks leven.

De wijze waarop pre-dialyse- en dialysepatiënten tegen hun ziekte en behandeling aankijken, hangt samen met de mate van zelfwaardering en autonomie die zij ervaren. Deze relaties vertonen een vast patroon, waarbij positieve ideeën over de ziekte en behandeling gerelateerd zijn aan het gevoel de dingen te kunnen doen die men wil doen en een gevoel van eigenwaarde. De gedachte dat men persoonlijke controle heeft over de ziekte, de ziekte en behandeling een geringe invloed hebben op het leven en minder bezorgdheid over de ziekte, blijken belangrijke voorspellers te zijn van gevoelens van autonomie en zelfwaardering van dialysepatiënten. Het idee dat de behandeling weinig verstoring teweeg brengt in het dagelijks leven blijkt een belangrijke voorspeller te zijn van ervaren autonomie en zelfwaardering van pre-dialysepatiënten. Voor het al dan niet verrichten van betaald werk door (pre-)dialysepatiënten werden overeenkomstige patronen gevonden.

De bovengenoemde bevindingen zijn interessant, te meer omdat de resultaten aantonen dat de ziekte- en behandelingspercepties van patiënten variëren over de verschillende fasen van het ziekteproces (predialysefase, dialysefase < 3 jaar, dialysefase ≥ 3 jaar), en dat de meeste percepties van de dialysepatiënten ook over de tijd lijken te veranderen, hetgeen er op duidt dat ze mogelijk beïnvloedbaar zijn. Dit is in overeenstemming met de resultaten van interventiestudies die aantoonen dat cognities van patiënten met verschillende ziekteachtergronden veranderbaar zijn (Karamanidou et al., 2008; Moss-

Morris et al., 2007; Petrie et al., 2002). De resultaten laten verder zien dat percepties van dialysepatiënten stabiel zijn naarmate mensen langer dialyseren ( $\geq 3$  jaar). Deze bevindingen ondersteunen het belang van vroegtijdig interveniëren.

De manier waarop de patiënt door zijn/haar omgeving wordt ondersteund blijkt eveneens erg belangrijk te zijn. Over het algemeen kan worden gesteld dat een ervaren gemis aan (positieve) steun vanuit de naaste omgeving en beschermende, betuttelende en controlerende vormen van ondersteuning vanuit zowel naasten als artsen, gepaard gaan met een lage mate van ervaren autonomie, zelfwaardering en een hoge uitval uit het arbeidsproces binnen de groep dialysepatiënten.

Om de arbeidsparticipatie en de grip op het eigen leven van nierpatiënten te vergroten lijkt het, gezien de bevindingen, zinvol om door middel van een interventie de ideeën van patiënten over hun ziekte en behandeling en de wijze waarop de omgeving met hen omgaat te verhelderen en te beïnvloeden. Om die reden werd besloten een groepscursus te ontwikkelen en uit te testen, die gericht is op verandering van deze psychologische factoren. Het algemene doel van de cursus is het bevorderen van het behoud c.q. toename van het verrichten van (betaald) werk en andere activiteiten en vergroting van de ervaren autonomie door mensen met een nierziekte. De focus van de cursus ligt op drie aspecten, te weten:

- 1) het stimuleren van positieve ideeën over de ziekte, behandeling en de mogelijkheden om actief te blijven bij zowel patiënten als hun partners, en het veranderen van negatieve ideeën en mispercepties,
- 2) het bevorderen van de persoonlijke effectiviteit van de patiënt ten aanzien van het uitvoeren van werk en andere activiteiten,
- 3) het stimuleren van gedrag dat autonomie ondersteunend is bij zowel patiënten als partners.

De cursus werd op kleine schaal uitgetest op zijn uitvoerbaarheid en eerste ervaringen met de cursus van zowel de cursisten, cursusleiders als de betrokken zorgverleners. De uitkomsten van de pilotstudie waren bemoedigend. De bevindingen duiden er op dat een benadering waarbij cognitieve, gedragsmatige, en contextuele aspecten worden geïntegreerd veelbelovend is. Verder onderzoek waarbij de cursus, nadat deze is aangepast op grond van de geboden aanbevelingen, op grotere schaal zal worden aangeboden binnen de reguliere zorg moet aantonen of de cursus daadwerkelijk effectief is. Dat wil zeggen, leidt tot minder uitval uit het arbeidsproces en vergroting van de ervaren autonomie.

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## 2 Beschrijving cursus

Het doel van de cursus is als volgt geformuleerd:

*het bevorderen van behoud c.q. toename van het verrichten van (betaald) werk en andere dagelijkse activiteiten en vergroting van de ervaren autonomie (grip krijgen en houden op het eigen leven).*

De doelgroep bestaat uit nierpatiënten, in de leeftijd van 18 t/m 64 jaar, die worden voorbereid op een nierfunctievervangende behandeling of die nog niet zo lang geleden met dialyse zijn gestart én voor wie (betaald) werk nog wel een reële optie is. Daarnaast zijn de partners van patiënten welkom om aan de cursus deel te nemen.

De cursus heeft de vorm van een groepscursus, bestaande uit zes tweewekelijkse bijeenkomsten en een terugkombijeenkomst drie maanden na afloop van de cursus. Elke bijeenkomst duurt 2,5 uur. De groep bestaat uit minimaal vijf patiënten, al of niet met hun partners (maximaal 12 deelnemers per groep).

Het eerste deel van de cursus (bijeenkomst 1 t/m 3) is gewijd aan het exploreren en veranderen van de ziekte- en behandelingspercepties van patiënten en hun partners. Het tweede deel (bijeenkomst 4 t/m 6) gaat in op het vergroten van de persoonlijke effectiviteit van de patiënten. In bijeenkomst 4 wordt daarnaast extra aandacht besteed aan het omgaan met vermoeidheidsklachten en beperkte energie. In bijeenkomst 5 zal eveneens worden ingegaan op de rol van de naaste omgeving.

### *Cursusleiding*

In de pilotfase werd de cursus geleid door een gezondheidspsycholoog in samenwerking met een nefroloog (bijeenkomst 1) en een arbeidsdeskundige (bijeenkomst 2, 6 en de terugkombijeenkomst). Toekomstige cursussen zullen standaard door twee maatschappelijk werkers, die werkzaam zijn binnen de dialysecentra, worden begeleid. Maatschappelijk werkers zullen worden getraind om de cursus te gaan geven.

### *Cursushandboek*

Voor de deelnemers aan de cursus is een handboek ontwikkeld. Dit handboek bevat:

1. een globale beschrijving van de cursus met tijdspad en cursusdata (en locatie);
2. algemene informatie over nierziekten en dialyse;
3. hoofdstukken die parallel lopen aan de bijeenkomsten van de cursus. Elk hoofdstuk bevat ervaringsverhalen van patiënten, theoretische en praktische informatie, invulopdrachten en 'huiswerk'.

### *Cursusbijeenkomsten*

Onderstaand volgt een korte beschrijving van de bijeenkomsten:

#### Bijeenkomst 1: 'Dialyse, wat betekent dit voor mij en mijn werk?' Deel 1

Doel: Geven van enige algemene voorlichting over nierziekten en dialyse, exploreren van de ziekte- en behandelingspercepties van de deelnemers en ingaan op mispercepties en negatieve gedachten. Deze bijeenkomst wordt geleid in samenwerking met een nefroloog.

In deze eerste bijeenkomst ontvangen patiënten en hun partners enige algemene informatie over nierziekten en dialyse. Deze informatie wordt gegeven door een nefroloog. Vervolgens worden de ziekte- en behandelingspercepties van patiënten en hun partners geëxploreerd aan de hand van twee korte vragenlijsten, die de deelnemers als voorbereiding op de bijeenkomst thuis hebben ingevuld. Het gaat hierbij met name om het verhelderen van de percepties ten aanzien van de symptomen die deelnemers toeschrijven aan de nierziekte en de percepties over de gevolgen van de nierziekte en de behandeling voor het dagelijks leven. De ziekte- en behandelingspercepties worden in de groep besproken. Speciale aandacht wordt gegeven aan mispercepties en negatieve gedachten. Bij het weerleggen van mispercepties kan de nefroloog een rol spelen door het verstrekken van juiste informatie. Het gaat erom dat patiënten en hun partners zelf het idee hebben dat er ook met dialyse nog veel mogelijk is, waaronder het behoud van werk of het doen van andere dagelijkse activiteiten.

### Bijeenkomst 2: 'Dialyse, wat betekent dit voor mij en mijn werk?' Deel 2

Doel: Exploreren van de ideeën die deelnemers hebben over de haalbaarheid en belangrijkheid van activiteiten, waaronder werk. Geven van voorlichting over werken met een nierziekte en ingaan op mispercepties en negatieve gedachten. Deze bijeenkomst wordt geleid in samenwerking met een arbeidsdeskundige.

In deze bijeenkomst wordt ingegaan op de door de deelnemers gescoorde belangrijkheid en haalbaarheid van verschillende activiteiten, waaronder het verrichten van werk. Dit gebeurt naar aanleiding van een huiswerkopdracht. Problemen en/of mogelijkheden die de deelnemers zien op het gebied van werk of op het gebied van andere activiteiten zullen worden besproken. Vervolgens geeft de arbeidsdeskundige voorlichting over werken met een nierziekte. Er zal onder andere worden ingegaan op de mogelijkheden die er zijn op het gebied van werk, zoals werkaanpassing, (om)scholing en re-integratie. Na de voorlichting is er gelegenheid om vragen te stellen en zal er worden ingegaan op de persoonlijke ervaringen en wensen van de deelnemers op het gebied van werk. Er zal hierbij aandacht zijn voor mispercepties en negatieve gedachten. Bij het weerleggen van mispercepties zal met name de arbeidsdeskundige een rol spelen door het verstrekken van juiste informatie.

### Bijeenkomst 3: 'Denken én doen'

Doel: Vergroten van controlegedachten en ontwikkelen van een persoonlijk actieplan.

In de derde bijeenkomst wordt nader ingegaan op de ideeën die patiënten en hun partners hebben over met name de controleerbaarheid van de ziekte en de gevolgen van de ziekte en de behandeling voor hun dagelijks leven. De cursusleider geeft hierbij informatie over de relatie tussen gebeurtenissen (krijgen van een nierziekte, starten met de behandeling), gedachten, gevoelens en gedragingen, en het belang van het omzetten van niet-helpende gedachten naar meer helpende gedachten. Vervolgens worden door de cursusleider algemene voorbeelden gegeven van hoe mensen er toch in slagen om bepaalde dingen die zij belangrijk vinden te blijven doen. De cursusleider gaat daarbij na welke ideeën de deelnemers zelf hebben om datgene wat zij belangrijk vinden te blijven doen. Op deze wijze worden de wensen en mogelijkheden die patiënten en hun partners hebben ten aanzien van het verrichten van werk en/of andere dagelijkse activiteiten inzichtelijk



gemaakt. Dit wordt besproken naar aanleiding van de huiswerkopdrachten die patiënten hebben moeten maken en waarbij werd gevraagd welk doel ze op het gebied van werk en op privé-gebied bereikt willen hebben na afloop van de cursus en waarbij ze hebben aangegeven in hoeverre ze dit haalbaar achten. Indien nodig kunnen de deelnemers de doelen onder begeleiding van de cursusleider nog aanpassen of aanscherpen. Na de pauze leren zij hoe ze de doelen in stapjes kunnen bereiken en wordt hen geleerd hoe ze een persoonlijk actieplan kunnen opstellen. De bedoeling is dat de deelnemers voor beide doelen een actieplan formuleren wat zij de komende twee weken thuis in praktijk gaan brengen.

#### Bijeenkomst 4: 'Moe, maar toch actief'

Doel: Evalueren van de persoonlijke actieplannen en inzicht geven in relatie vermoeidheid – activiteit.

De deelnemers vertellen aan het begin van deze vierde bijeenkomst om de beurt in welke mate ze de door hen gestelde (sub)doelen in de afgelopen twee weken hebben bereikt. Ze geven aan hoe makkelijk of moeilijk dat ging, tegen welke barrières ze aanliepen, welke factoren de uitvoering vergemakkelijkten, in hoeverre ze zich gesteund voelden door hun omgeving bij het uitvoeren van het doel, wat ze ervan geleerd hebben en wat ze eventueel nu anders zouden doen. De andere deelnemers worden uitgenodigd om (na degene wiens doel besproken wordt) na te denken over andere mogelijkheden, hoe de volgende keer om te gaan met de ervaren barrières en tips mee te geven. De cursusleider gaat in op enkele aspecten, zoals het stellen van realistische doelen en omgaan met conflicterende doelen. Na de pauze wordt het onderwerp 'Omgaan met vermoeidheid' besproken aan de hand van geboden informatie door de cursusleider en de ervaringen van deelnemers. Hierbij komen onderwerpen aan bod, zoals angst voor inspanning, de al of niet aanwezige relatie tussen inspanning en vermoeidheid en hoe men efficiënt met de beschikbare energie om kan gaan. De bijeenkomst wordt weer afgesloten met het maken van persoonlijke actieplannen voor de komende twee weken, die voortbouwen op de eerder gestelde doelen (werk doel én privé doel).

#### Bijeenkomst 5: 'Actief zijn is teamwork'

Doel: Evalueren van de persoonlijke actieplannen, inzicht geven in de manier waarop de patiënt en zijn naaste omgeving met elkaar communiceren en het leren genereren en geven van autonomiebevorderende sociale steun (patiënten die zonder een partner deelnemen wordt gevraagd om een familielid of vriend mee te nemen naar deze bijeenkomst).

De bijeenkomst begint met het terugkijken op de afgelopen twee weken: In hoeverre is men in staat geweest de gestelde (sub)doelen te bereiken? De deelnemers geven aan hoe makkelijk of moeilijk dat ging, tegen welke barrières ze aanliepen, welke factoren de uitvoering vergemakkelijkten en in hoeverre ze zich gesteund voelden door hun omgeving bij het uitvoeren van het doel. Vervolgens wordt aangehaakt bij dit laatste aspect: de rol die de naaste omgeving van de patiënt speelt. De deelnemende patiënten hebben als huiswerk een aantal vragen beantwoord over de mate waarin zij sociale steun c.q. overbescherming vanuit hun naaste omgeving ervaren en de mate waarin zij zelf om onder-

steuning vragen. De deelnemende partners (familieleden/vrienden) hebben een aantal vragen beantwoord over de mate waarin zij de patiënt ondersteunen en de manier waarop. Tevens is aan hen een aantal vragen gesteld over de mate waarin zij zich zorgen maken over de patiënt en zich zelf gesteund voelen. Naar aanleiding van de opdrachten worden ervaringen van patiënten en partners (familieleden/vrienden) besproken. Na de pauze geeft de cursusleider informatie over hoe men om steun kan vragen en wat autonomie-ondersteunend gedrag is en wat niet. De bijeenkomst wordt weer afgesloten met het maken van persoonlijke actieplannen voor de komende twee weken.

#### Bijeenkomst 6: 'Met dialyse aan het werk'

Doel: Het geven van advies bij het opstellen van een persoonlijk actieplan gericht op behoud van werk c.q. re-integratie. Deze bijeenkomst wordt geleid in samenwerking met een arbeidsdeskundige.

De bijeenkomst begint met het bespreken van de persoonlijke actieplannen van de afgelopen twee weken: In hoeverre is men in staat geweest de gestelde (sub)doelen te bereiken? De deelnemers geven aan hoe makkelijk of moeilijk dat ging, tegen welke barrières ze aanliepen, welke factoren de uitvoering vergemakkelijkten. Er wordt daarbij vooral ingegaan op in hoeverre de patiënten zich gesteund voelden door hun naaste omgeving bij het uitvoeren van de plannen en in hoeverre het de partners van patiënten gelukt is om steun te geven. De cursusleider en arbeidsdeskundige geven vervolgens informatie over het opstellen van een actieplan voor het bereiken van een werk gerelateerd doel en gaan in op specifieke vragen of problemen van patiënten. Daarnaast worden tips gegeven voor het voorbereiden en voeren van gesprekken met bijvoorbeeld een werkgever of bedrijfsarts. Na de pauze wordt besproken welk doel patiënten de komende drie maanden willen bereiken in relatie tot het verrichten van betaald werk. Hierbij wordt geëxploreerd hoe belangrijk patiënten het vinden om hun doel te bereiken en hoe haalbaar het doel voor hen is. Dit doel hebben zij als huiswerkopdracht vooraf geformuleerd en kunnen zij nu nog aanpassen of aanscherpen. Dit gebeurt in interactie met de cursusleider en de arbeidsdeskundige. De deelnemers wordt vervolgens gevraagd hiervoor een persoonlijk actieplan voor de komende drie maanden op te stellen, waarbij zij ook de tussenstappen moeten benoemen. Bijvoorbeeld, welke stappen gaan zij in maand 1, 2 en 3 zetten? Patiënten worden geïnformeerd over de mogelijkheid om, wanneer zij daaraan behoefte hebben, ondersteuning te vragen aan de arbeidsdeskundigen van de NVN.

#### Terugkombijeenkomst (drie maanden na afronding cursus)

Doel: Bekrachtiging van uitgevoerde en voorgenomen activiteiten, voorkomen van terugval bij patiënten die voor de cursus nauwelijks actief waren. Deze terugkombijeenkomst wordt geleid in samenwerking met een arbeidsdeskundige.

In deze bijeenkomst zal worden teruggekomen op de uitvoering van het persoonlijke actieplan dat patiënten in de laatste bijeenkomst hebben opgesteld. Ook zal er aandacht worden geschonken aan hoe datgene wat de deelnemers hebben bereikt in de toekomst kan worden vastgehouden of verder kan worden uitgebouwd.

### **3 Perceived autonomy and self-esteem in Dutch dialysis patients: the importance of illness and treatment perceptions<sup>3</sup>**

#### **3.1 Abstract**

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.

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

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.

#### **3.2 Introduction**

End-stage renal disease (ESRD) is a chronic condition which is becoming more common worldwide. In this stage of the disease, patients have to start with 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, Gioberge, Moeller, & Brown, 2005). In January 2006, 12.038 people in the Netherlands received renal replacement therapy (737 people per million Dutch residents) (Oppe, Treur, Barendregt, & de Charro, 2007). ESRD is characterised 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, Addington-Hall, & Higginson, 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

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<sup>3</sup> Geaccepteerd voor publicatie in het tijdschrift *Psychology and Health* (Jansen, Rijken, Heijmans, & Boeschoten).

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 self-determination theory autonomy is one of people's basic psychological needs, and satisfaction of this need is linked to well-being (Deci & Ryan, 1985). Reis and colleagues found that perceived autonomy independently predicted daily well-being (Reis, Sheldon, Gable, Roscoe, & Ryan, 2000). State self-esteem refers to the feelings of self-worth depending on a person's experience. Crocker and Wolfe 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 (Crocker & Wolfe, 2001). 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 with 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 of 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 and colleagues (Braun Curtin, Oberly, Sacksteder, & Friedman, 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, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steele, 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, Jago, & Devcich, 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, Jayasena, Davenport, Harrison, & Newman, 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, Weinman, Sharpe, & Buckley, 1996). In particular perceptions about 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?

### **3.3 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 2000 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 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, Wiggins, Higgs, & Blane, 2003), which has been used in several studies (Marmot, Banks, Blundell, Lessof, & Nazroo, 2003; Taylor, Brice, Buck, & Prentice-Lane, 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: .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, DeWall, Ciarocco, & Twenge, 2005; Chang & Mackenzie, 1998). The Cronbach's alpha for the scale in the current study was .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, Petrie, Main, & Weinman, 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 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 .91.

#### *Background variables*

Socio-demographic characteristics included age, gender, marital status<sup>4</sup> 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 characteristics included time on dialysis (in years), type of dialysis treatment (HD/ PD)<sup>4</sup>, and severity of the health condition<sup>4</sup>. Severity of the health condition was determined by the level of serum albumin. Serum albumin is an important predictor of patient morbidity and mortality in dialysis patients (Blake, Flowerdew, Blake, & Oreopoulos, 1993; 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, 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.

### **3.4 Results**

#### *Study sample*

Characteristics of the total sample are outlined in table 3.1. Approximately, two thirds of the study sample were male which corresponds with the figures of the population of ESRD patients in the Netherlands (61%) (Stichting Renine, 2005). Around two thirds of the participants were 65 years or older. Compared with figures of the Dutch dialysis population in 2006 (49% 65 years or older) (Oppe et al., 2007), our sample comprised a

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<sup>4</sup> These data were derived from the last regular survey carried out under NECOSAD-2

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%) (Stichting Renine, 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.

Table 3.1: 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.

### ***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 3.2). ANOVA analysis showed differences with regard to educational level ( $F(2, 146) = 3.29, p = .040$ ): 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 3.2). No significant differences were found with respect to socio-demographic and clinical characteristics.



### ***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 3.2). ANOVA analysis demonstrated that men scored higher on state self-esteem compared to women ( $F(1, 152) = 4.05, p = .046$ ). No significant differences were found with regard to the other background characteristics.

### ***Labour participation***

Sixty-two people were of working age (18-64 yrs). 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 grade among the Dutch population aged 15-64 years was 65% (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 ( $F(1, 54) = 7.88, p = .007$ ). 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 3.2).

Pearson's correlation coefficients between the illness and treatment perceptions were all below .60, except for the correlation of emotional response with concern and treatment disruption (table 3.2). Patients with a stronger illness identity experience more consequences from 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 3.2: 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***							
Identity	6.14 (2.43)	.43***	-.02	.16*						
Concern	6.31 (3.00)	.35***	-.05	-.07	.03					
Understanding	7.66 (2.70)	-.01	.10	.23**	-.01	.50***				
Emotional response	4.96 (3.22)	.38***	-.09	-.05	.23**	.25**	.13			
Treatment disruption	63.40 (25.04)	.45***	-.04	-.26**	-.07	.43***	.71***	.01		
					-.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 3.2). 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 ( $t(41.846) = 2.17, p = .036$ ). The other perceptions were not significantly associated with labour participation (table 3.3).

Table 3.3: 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	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 .60 (table 3.2), we decided not to include the dimension emotional response in the following regression analyses for reasons of multi-collinearity.

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 3.4). 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.

The results of the regression analysis with health related perceived autonomy being the outcome variable (table 3.5) 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 3.4: Hierarchical multiple linear regression models to predict perceived global autonomy in dialysis patients (total sample).

	<b>Model 1</b> (block 1) (N=105) Beta	<b>Model 2</b> (block 1+2) (N=105) Beta	<b>Model 3</b> (block 1+ 2+3) (N=105) Beta
<b>Block 1: Socio-demographic characteristics</b>			
Age in years	-.05	.03	-.09
Female (ref: male)	-.06	-.06	-.06
Educational level (ref: low)			
- Moderate	.19	.18	.21*
- High	.28*	.26*	.25*
Marital status (ref: married/living together)	.09	.13	.09
<b>Block 2: Clinical characteristics</b>			
Serum albumin		-.02	-.07
PD treatment (ref: HD)		.22*	.10
Time on dialysis in years		-.07	-.06
<b>Block 3: Perceptions</b>			
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.

Table 3.5: Hierarchical multiple linear regression models to predict perceived health related autonomy in dialysis patients (total sample).

	<b>Model 1</b> (block 1) (N=105) Beta	<b>Model 2</b> (block 1+2) (N=105) Beta	<b>Model 3</b> (block 1+2+3) (N=105) Beta
Block 1: Socio-demographic characteristics			
Age in years	.05	.07	-.13
Female (ref: male)	-.11	-.11	.01
Educational level (ref: low)			
- 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 3.6 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 3.6: Hierarchical multiple linear regression models to predict state self-esteem in dialysis patients (total sample).

	<b>Model 1</b> (block 1) (N=105) Beta	<b>Model 2</b> (block 1+2) (N=105) Beta	<b>Model 3</b> (block 1+2+3) (N=105) Beta
Block 1: Socio-demographic characteristics			
Age in years	.02	.09	-.02
Female (ref: male)	-.20	-.21*	-.07
Educational level (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

### 3.5 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, Polder, Jager, & Charro, 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 about 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, Ryan, Kim, & Kaplan, 2003; Deci & Ryan, 1985, 2000; Ryan, 1995). To make the distinction more explicit, a person can feel control over carrying out an exercise program, 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 focussing 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 (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 to 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 minimize 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 (e.g. Gardner, Cummings, Dunham, & Pierce, 1998; McKenzie & Marks, 1999). Moreover, Gardner and colleagues (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 about 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, Petrie, Moss-Morris, & Horne, 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 and colleagues (Petrie, Cameron, Ellis, Buick, & Weinman, 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, Weinman, & Horne, 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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## 4 Pre-dialysis patients' labour participation, perceived autonomy and self-esteem: associations with illness and treatment perceptions<sup>5</sup>

### 4.1 Abstract

Compared to healthy people, patients with end-stage renal disease (ESRD) participate less in paid jobs and social activities. The aim of the present study was to examine a) the labour participation, perceived autonomy and self-esteem of ESRD patients in the pre-dialysis phase, b) patients' illness and treatment perceptions, and the role these perceptions play in labour participation, perceived autonomy and self-esteem.

Patients completed questionnaires at home (N=109). Data were analysed using bivariate and multivariate analyses. The results showed that drop out of the labour force already takes place during the pre-dialysis phase. The average autonomy levels were not very high, and the average level of self-esteem was rather high. On the whole, positive illness and treatment beliefs were associated with higher autonomy and self-esteem levels, but not with labour participation. Multiple regression analyses revealed that illness and treatment perceptions explained a substantial amount of variance in autonomy (15%) and self-esteem (27%). The perception of less treatment disruption was an important predictor.

It seems important to inform pre-dialysis patients about the available possibilities to combine ESRD and its treatment with activities, including paid work, in order to stimulate positive (realistic) beliefs and prevent or challenge negative beliefs. Interventions focusing on these aspects may assist patients to adjust to ESRD.

### 4.2 Introduction

Chronic renal failure, also referred to as end-stage renal disease (ESRD), 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 (Grassman, Gioberge, Moeller, & Brown, 2006). In January 2006, 12,038 people in the Netherlands received renal replacement therapy (737 people per million Dutch residents) (Oppe, Treur, Barendregt, & de Charro, 2007). ESRD is associated with specific disease and treatment aspects. Patients with ESRD often experience physical symptoms such as fatigue, pain, cramps and itching. Furthermore, patients are extremely dependent from treatment and the treatment itself, dialysis in particular, places substantial behavioural demands on the patient. A study by Neto and colleagues (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 in patients with ESRD in a later

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<sup>5</sup> Zal ter publicatie worden aangeboden (Jansen et al.).

phase of the dialysis treatment compared to general population samples (e.g. Khan et al., 1995; Merkus et al., 1997; 1999; Mittal et al., 2001).

Results of a literature study revealed that people with ESRD 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 ESRD and dialysis treatment with a paid job (e.g. Braun Curtin, Oberly, Sacksteder, & Friedman, 1996; Jansen, Rijken, Heijmans, & Boeschoten, in press; Theorell, Konarski-Svensson, Ahlmen, & Perski, 1991). It is notable that people who are being prepared for dialysis (pre-dialysis patients) already experience problems with regard to employment. In the Netherlands, patients enter this stage of preparation as soon as their renal function decreased to 20%. Results from a Dutch study showed that patients mainly drop out the labour force before the start with dialysis treatment; at the start of the dialysis 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).

Restrictions with regard to participation in the work domain can have serious drawbacks for people's well-being. A review of the literature demonstrated that there is strong evidence 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). Moreover, participation in general is important for feelings of autonomy and self-esteem. According to Deci and Ryan's (1985) Self-Determination Theory (SDT) autonomy is one of the basic psychological needs for optimal functioning. A study by Reis, Sheldon, Gable, Roscoe and Ryan (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 should undermine well-being. In the SDT view, self-esteem is a derivative or by product of need dynamics. When autonomy need fulfilment 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 shows that positive self-esteem is important for well being; Paradise and Kernis (2002) found that high self-esteem and stable self-esteem are associated with greater psychological well-being.

In light of these findings it is important to uncover the factors which undermine labour participation, feelings of autonomy and self-esteem in patients with ESRD, in order to create solutions for the experienced obstacles to participation. Socio-demographic factors, such as age and educational level and medical factors such as severity of the health condition and type of treatment obviously determine the extent to which patients with ESRD 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. Patients without work on the other hand, perceived their illness as a barrier to work. These findings are

interesting 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, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steele, 1984). This model postulates that individuals hold certain views about their illness, which in turn determine how patients cope with their illness and adjust to their illness. These representations are categorised in five dimensions: beliefs about the symptoms from the illness, the timeline of the illness (whether the illness is thought of as acute or chronic), the cause of the illness, the consequences of the illness for life, and the possibilities to control/cure the illness. Horne and colleagues extended the self-regulation model with beliefs about treatment (Horne & Weinman, 1999; 2002; Horne, 2003). Two recent studies found relationships between dialysis patients' illness representations and well-being (Timmers et al., 2008) and dialysis and renal transplant patients' representations about their illness and treatment and health related quality of life (Griva, Jayasena, Davenport, Harrison, & Newman, 2009). Our research team recently conducted a study on the relationship between illness and treatment perceptions on the one hand and employment, perceived autonomy and state self-esteem on the other hand in patients on dialysis (Jansen et al., in press). The results showed that the 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 and treatment perceptions and labour participation. This latter finding might be caused by the fact that the working-age group (15 to 64 years) of dialysis patients in our study was small (N=62). An additional explanation might be that patients who are already 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 replicate the study among patients who are being prepared for dialysis, and to examine a) the labour participation, perceived autonomy and self-esteem of pre-dialysis patients, and b) the content of pre-dialysis patients' perceptions of their illness and treatment, and whether these perceptions are related to labour participation as well as perceived autonomy and self-esteem. It is expected that the associations of illness and treatment perceptions with labour participation are stronger in this group of patients compared to patients already on dialysis, since paid work is presumably a more important and relevant activity in patients who are in an earlier phase of the illness. The following research questions were formulated:

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

## 4.3 Methods

### *Participants and procedure*

Pre-dialysis patients who were participating in the PREPARE-2 study, were invited to participate in the present study. PREPARE-2 is a prospective observational study, started in 2004 and which is now operating in 25 pre-dialysis outpatient clinics in community and university hospitals throughout The Netherlands. 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. Patients with stage IV chronic kidney disease (severe chronic kidney disease) 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. 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 to 123 patients and in November-December to another 62 newly recruited patients. Patients completed a paper questionnaire at home. Of the 185 patients who received the questionnaire, 109 returned the questionnaire (response rate 59%).

### *Measures*

#### *Outcome variables*

Perceived autonomy was assessed with three items derived from the autonomy scale of the CASP-19 (Hyde, Wiggins, Higgs, & Blane, 2003), which has been used in several studies (Marmot, Banks, Blundell, Lessof, & Nazroo, 2003; Taylor, Brice, Buck, & Prentice-Lane, 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 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 (e.g. Baumeister, DeWall, Ciarocco, & Twenge, 2005; Chang & Mackenzie, 1998). The Cronbach's alpha for the scale in the current study was 0.86. 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, Petrie, Main, & Weinman, 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 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 0.94.

### *Background variables*

Background characteristics included age, gender, living status, educational level and number of comorbid diseases. Living status was defined as living with versus living without a partner. 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). Number of comorbid diseases was based on the presence of diabetes mellitus type 2, hypertension, cerebrovascular accident (cva), vascular problems, ischemic heart disease, and heart failure.

### *Statistical analysis*

Descriptive statistics were computed to describe the extent to which pre-dialysis patients participate in the work domain and experience autonomy and state self-esteem. Relationships between background variables on the one hand and autonomy, state self-esteem and labour participation on the other hand 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 between background variables on the one hand and illness and treatment perceptions on the other hand were assessed by means of analysis of variance (ANOVA). Associations between illness perceptions, treatment perceptions and autonomy, state self-esteem and 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, controlling for background characteristics. Two blocks of variables were entered separately; block 1: Background variables (age, gender, living status, educational level, number of comorbid diseases); block 2: Illness and treatment perceptions variables.

## 4.4 Results

### *Study sample*

Characteristics of the total sample are outlined in table 4.1. Approximately two-thirds of the study sample were male which corresponds with the figures of the population of ESRD patients in the Netherlands (61%; Stichting Renine, 2005). Patients had a mean age of 64 years. Patients' comorbid conditions ranged from 0 to 5, with 46% of the patients suffering from two or more comorbid conditions. Differences between the study sample and the non-responders with respect to age, gender, and number of comorbid diseases were examined and no significant differences were found.

Table 4.1: Socio-demographic and clinical characteristics of the total sample.

	Total sample	
Gender – N (%)		
- male	69	(64)
- female	39	(36)
- unknown	1	
Age, mean in years (SD)	64.27 (14.85), 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 comorbid diseases, mean (SD)	1.47 (1.20), range: 0-5	
Number of comorbid diseases, in groups – N (%)		
- no comorbid diseases	23	(24)
- one comorbid disease	28	(30)
- two or more comorbid diseases	44	(46)
- unknown	14	

### *Perceived autonomy*

The mean global autonomy score of the total sample was 1.90 (SD=0.84), which indicates that pre-dialysis patients do not that often experience a sense of autonomy in daily life. The mean score on the health related autonomy item (M=1.42, SD=0.96) indicates that

patients sometimes experience health related autonomy. No significant differences in autonomy scores were found according to age, gender, educational level, living status and number of comorbid diseases.

### ***State self-esteem***

The mean state self-esteem score of the total patient group was 78.21 (SD=10.34), which indicates that patients have a rather high level of state self-esteem. ANOVA analysis showed that high educated patients had higher state self-esteem compared to patients with a low and moderate educational level ( $F(2, 100) = 3.50, p = .034$ ). No associations were found between state self-esteem and age, gender, living status and number of comorbid diseases.

### ***Labour participation***

Of the total group of patients, only forty-five people appeared to be of working age (18-64 years), with a mean age of 49.6 years (SD= 10.72 years). Twenty-three people (51%) performed paid work for at least 12 h per week, which is lower compared to the general Dutch population. In 2006 the labour participation grade among the Dutch population aged 15 to 64 years was 65% (CBS, 2006). Patients who worked (at least 12 h per week) were working for 34.7 h per week on average (range 20-60 h per week). Eighteen people aged 18 to 64 years (40%) were not employed (for at least 12 h per week) and the employment status of four people (9%) was unknown. The results of the ANOVA analysis showed that among the patients of working age, employed patients were significantly younger than unemployed patients ( $F(1, 39) = 4.19, p = .047$ ). No significant differences were found with regard to the other background variables.

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

Mean illness perceptions scores indicate that pre-dialysis patients believe that their illness is chronic. Furthermore, patients experience a moderate amount of physical symptoms from their illness and believe their illness affects their daily life to a rather large extent. 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, though, believe that their illness does not affect 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, yet believe that they themselves have rather little control over their illness (table 4.2). ANOVA analysis showed that patients in the different age groups differed with respect to their beliefs about the timeline of the illness (Welch  $F(2, 29.353) = 4.36, p = 0.022$ ). However, Games-Howell post hoc-tests did not reveal any differences between the groups. High-educated patients believed that their emotional state was less affected by their illness compared to low- and moderate-educated patients ( $F(2, 100) = 3.31, p = 0.041$ ). No differences were found with respect to gender, living status and number of comorbid diseases.

Table 4.2: Mean scores and standard deviations of illness and treatment perceptions of pre-dialysis patients (total sample).

	N	Range scale	M (SD)
<i>Illness and treatment perceptions</i>			
Consequences	105	0-10	6.71 (2.52)
Timeline	104	0-10	9.29 (1.74)
Personal control	103	0-10	4.67 (2.94)
Treatment control	103	0-10	6.82 (2.86)
Identity	103	0-10	5.24 (2.91)
Concern	104	0-10	6.90 (2.69)
Understanding	102	0-10	7.27 (3.14)
Emotional response	104	0-10	4.97 (3.15)
Treatment disruption	94	0-140	38.82 (25.93)

The Pearson's correlation coefficients between the perceptions are outlined in table 4.3. 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.

#### ***Associations independent variables and outcome variables***

Pearson's correlation coefficients between illness and treatment perceptions and perceived autonomy and state self-esteem on the whole show that stronger positive beliefs about the illness and treatment are related to higher levels of perceived autonomy and state self-esteem (table 4.3). 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 4.4).

Table 4.3: Pearson's correlations coefficients between illness perceptions, treatment perceptions and perceived autonomy, state self-esteem (total sample).

	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 4.4: 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	6.73 (2.29)	18	6.83 (2.92)	.129	38	.898
Timeline	22	8.50 (2.58)	18	8.56 (2.33)	.071	38	.944
Personal control	21	4.86 (2.83)	18	3.67 (3.22)	-1.229	37	.227
Treatment control	21	6.81 (2.02)	18	5.56 (3.54)	-1.331	26.072	.195
Identity	22	5.09 (2.94)	18	5.44 (3.17)	.365	38	.717
Concern	22	6.95 (2.84)	18	7.00 (2.72)	.051	38	.959
Understanding	21	7.14 (3.02)	18	7.11 (3.16)	-.032	37	.975
Emotional response	22	5.55 (2.74)	18	4.50 (3.15)	-1.123	38	.268
Treatment disruption	21	34.67 (22.90)	17	44.29 (31.26)	1.095	36	.281

### ***Predicting perceived autonomy and state self-esteem***

To perform regression analyses, the missing values on the variable comorbidity were replaced by the mean number of comorbid diseases, in order to be able to make maximal use of the data of all our cases. First, regression analysis was conducted to predict global autonomy. The results showed that the background variables accounted for only 2% of the variance in global autonomy (table 4.5). In this model, less comorbid diseases appeared to be a significant predictor of global autonomy. Adding the illness and treatment perceptions to the model (block 2) the percentage of explained variance was significantly increased to 17%. The comorbid disease variable was no longer significant and none of the other included variables reached the level of significance, though less perceived disruption from treatment was close to significance ( $p=0.058$ ). The results of the regression analysis with health related perceived autonomy being the outcome variable demonstrated that the background variables and illness and treatment perceptions variables did not explain any substantial amount of variance (data not shown).

Table 4.5: Hierarchical multiple linear regression models to predict perceived global autonomy in pre-dialysis patients (total sample).

	<b>Model 1</b> (block 1) (N=87) Beta	<b>Model 2</b> (block 1+2) (N=87) Beta
Block 1: Background characteristics		
Age in years	0.14	0.01
Gender (ref: male)	- 0.00	- 0.04
Educational level (ref: low)		
- moderate	- 0.07	- 0.06
- high	0.03	- 0.07
Living status (ref: living with a partner)	- 0.06	0.01
Number of comorbid diseases	- 0.27*	- 0.17
Block 2: Perceptions		
Consequences		- 0.06
Timeline		0.02
Personal control		0.08
Treatment control		0.12
Identity		- 0.21
Concern		0.19
Understanding		- 0.02
Emotional response		- 0.14
Treatment disruption		- 0.26
Adjusted R square	0.02	0.17*
F change model	1.28	2.58*

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

Finally, we performed regression analysis in order to predict state self-esteem. The results showed that the background variables explained 4% of the variance. In the second model, in which the illness and treatment perceptions were added, the percentage of explained variance increased by 27%, with less perceived disruption from the treatment being the only significant contributor to state self-esteem (table 4.6).

Table 4.6: Hierarchical multiple linear regression models to predict state self-esteem in pre-dialysis patients (total sample).

	<b>Model 1</b> (block 1) (N=90) Beta	<b>Model 2</b> (block 1+2) (N=90) Beta
Block 1: Background characteristics		
Age in years	0.18	0.03
Gender (ref: male)	- 0.07	- 0.07
Educational level (ref: low)		
- moderate	- 0.01	- 0.02
- high	0.18	0.10
Living status (ref: living with a partner)	- 0.03	0.06
Number of comorbid diseases	- 0.16	- 0.05
Block 2: Perceptions		
Consequences		0.07
Timeline		0.12
Personal control		0.19
Treatment control		- 0.10
Identity		- 0.20
Concern		- 0.10
Understanding		0.10
Emotional response		- 0.14
Treatment disruption		- 0.32*
Adjusted R square	0.04	0.31***
F change model	1.59	4.55***

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

## 4.5 Discussion

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

Fifty-one percent of the working age pre-dialysis patients performed paid work for at least 12h per week, which is a higher percentage compared to dialysis patients (e.g. Braun Curtin et al., 1996; Jansen et al., in press), though lower than that of the general Dutch working-age population (65% CBS, 2006). Thus, as suggested by the results of the study by Van Manen et al. (2001), drop out of the labour force already occurs before patients start with dialysis treatment. These findings emphasize the importance and necessity of work related assistance in an early stage of the illness process. Moreover, the average reported levels of perceived autonomy were not very high, which shows that patients feel less autonomous because of their health condition or otherwise. In spite of this, most patients have a high level of self-esteem.

Looking at the mean illness and treatment perceptions of pre-dialysis patients it is noticed that patients are quite worried about their illness and believe that they themselves have rather little control over their illness. Personal control over the illness refers to the feeling that one can influence the course of one's illness and one can fit the disease and treatment into one's daily life. Of course, patients with ESRD are handed over to treatment in order



to manage their illness. However, this does not indicate that there are no possibilities for personal control. In the pre-dialysis phase it is of great importance that patients practice self-care behaviours, such as following diets and performing daily exercise in order to optimise their health condition (Sijpkens, Berkhout-Byrne, & Rabelink, 2008). However, patients in this stage of the illness got the news that they have to start with dialysis treatment in the near future, which indicates that despite of their self-care activities they were not able to remain sufficient renal function. This knowledge might have an effect on patients' personal control beliefs. Studies have demonstrated that feelings of personal control are important for ESRD patients' quality of life (Covic, Seica, Gusbeth-Tatomir, Gavrilovici, & Goldsmith, 2004; Timmers et al., 2008).

On the whole, the correlational analyses conducted in this study demonstrated that as patients held more positive beliefs about their illness and their current treatment they perceived more autonomy (both global and health related) and had a higher self-esteem. Contrary to our expectations, the total sample of pre-dialysis patients appeared to be relatively old, with only 45 patients (42%) of working age. Consequently, we could not investigate the relationships between ESRD patients' perceptions of their illness and current treatment on the one hand and employment on the other hand more thoroughly. Though, the findings showed a number of trends in the expected direction; employed patients perceived their treatment as less disruptive and their illness as better controllable by self-care and medical care than unemployed patients. The regression analyses revealed that the illness and treatment perceptions explained a substantial amount of variance in predicting both global autonomy and state self-esteem after controlling for background characteristics. The results showed that the perception that the current treatment does not disrupt daily life that much was a significant predictor of state self-esteem and the findings furthermore suggested 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 medication and following a diet. Though 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, thus both their current treatment as well as their future treatment.

It should be noted that a large amount of variance in perceived global autonomy and state self-esteem remained unexplained. Moreover, health related perceived autonomy could not be predicted by the illness and treatment perceptions. This indicates that other factors are of influence as well, such as for example the extent to which people in the patient's close environment, like the patient's partner or doctors, support the patient. 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.

The present study had a few limitations. The missing values on the variable comorbidity were replaced with the mean value. 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).

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 found 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. In light of these study findings it seems essential that patients in the pre-dialysis phase are provided with information about the implications of ESRD and its treatments. By showing patients the available possibilities to combine ESRD and its treatment with daily activities, including work, positive (realistic) beliefs are stimulated and negative beliefs are prevented or challenged, which might contribute to a greater sense of autonomy and self-esteem as well as to participation in general. Research suggests that interventions to change cognitions should focus on patients in an early stage of the illness process (Heijmans et al., submitted; Petrie et al., 2002). The best moment to offer interventions to alter maladaptive beliefs in patients with ESRD seems to be in the pre-dialysis phase or at the start of dialysis in which patients are most susceptible to change (Heijmans et al., submitted). 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 and tested.

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## 5 Illness and treatment perceptions of end-stage renal disease patients: different stages, different perceptions?<sup>6</sup>

### 5.1 Abstract

The aim of the present study was 1) to assess the illness perceptions and treatment perceptions of patients with end-stage renal disease (ESRD) in different stages of the treatment process, and 2) to examine changes in illness perceptions and treatment perceptions of patients with ESRD over time.

A sample of pre-dialysis patients (n=109), patients up to three years on dialysis (n= 69), and patients longer than three years on dialysis (n=97) completed the Brief Illness Perception Questionnaire and the Treatment Effects Questionnaire. Demographic and clinical data were also collected. Pre-dialysis patients believed their illness and treatment to be far less disruptive and felt less dependent from treatment than patients who were already on dialysis. At the same time, pre-dialysis patients were more concerned about their ESRD and were more puzzled about their disease than patients who were on dialysis for a number of years. The illness perceptions and treatment perceptions of dialysis patients become more definite the longer patients are on dialysis.

The beliefs that patients hold about their illness and treatment seem to be related to the phase of illness and, therefore, to the type of treatment patients are in. The best moment to offer interventions to alter maladaptive beliefs in patients with ESRD seems to be in the pre-dialysis phase or at the start of dialysis where patients are most susceptible to change.

### 5.2 Introduction

End-stage renal disease (ESRD) is a chronic condition caused by an irreversible decline in kidney function, which is severe enough to be fatal in the absence of renal replacement therapy (dialysis or transplantation). The number of ESRD patients is growing due to the aging of our population, the increasing incidence rates of related conditions such as diabetes, hypertension and renal vascular disease especially in the elderly, better treatment options of these related conditions, and a more liberal entry into dialysis and transplant programmes (Stengel et al., 2003; Stewart et al., 1994). At the end of 2005, about 1,9 million people were receiving renal replacement therapy worldwide; about three quarters being treated by dialysis and one quarter by kidney transplant (Grassman, Gioberge, Moeller et al., 2006). ESRD is a serious illness which imposes a heavy burden on the patient's life, especially for those who are on dialysis. Qualitative investigations have shown that dialysis is commonly perceived as extremely demanding, burdensome and disruptive across personal, work, family and social facets of life (Gregory et al., 1998; Krespi et al., 2004). However, research has also shown that the impact of ESRD can vary greatly from patient to patient even in those with the same illness severity or

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<sup>6</sup> Zal ter publicatie worden aangeboden aan het tijdschrift *Journal of Psychosomatic Research* (Heijmans et al.).

treatment modality (Cameron et al., 2000; Griva, Jayasena, Davenport et al., 2008). Some patients experience their ESRD as extremely burdensome as expressed in a worse health related quality of life, while others perceive it as something they can cope with.

Research in other chronically ill populations has demonstrated that illness perceptions, i.e. the way people give meaning to their illness, account for a substantial part of these individual differences in outcomes such as functional status, psychological well-being and quality of life (e.g. Aalto et al., 2006; Hagger & Orbell, 2003; Helder et al., 2002; Heijmans et al., 1999; Scharloo, Kaptein, Weinman et al., 2002). Illness perceptions are the essential components of Leventhal's self-regulation model of illness (SRM), which aims to explain patients' responses to illness from the cognitive representations patients hold about 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) patient's expectations about the physical, social, economic and emotional *consequences* of the disease. The SRM 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 & Weinman, 1999; Horne & Weinman, 2002; Horne, 2003).

During the last years, several studies have been conducted exploring the illness perceptions of ESRD patients and their associations with patient outcomes (Christensen, Moran, Wiebe et al., 2002; Covic, Seica, Gusbeth-Tatomir et al., 2004, Krespi, Bone, Ahmad et al., 2004; Pucheu, Consoli, D'Auzac et al., 2004; Fowler & Baas, 2006; see Timmers et al., 2008 for details). These studies generally show that more perceived control and a perception of fewer (negative) consequences are associated with better outcomes in haemodialysis patients. In a recent study of Timmers, Thong, Dekker et al. (2008), the illness perceptions of haemodialysis (HD) patients were compared to those of peritoneal dialysis (PD) patients. The results show that PD patients experience more personal control and have a better understanding of their illness than HD patients. Moreover, especially perceptions of more control, less consequences and less symptoms were associated with a better health related quality of life. To date, only two recent studies investigated the treatment perceptions of patients with ESRD. Griva, Jayasena, Davenport et al. (2009) compared the treatment perceptions of ESRD patients with different treatment modalities (dialysis and transplantation). They found that patients on dialysis experienced their treatment as more disruptive than transplant recipients. A higher treatment disruptiveness was associated with a worse quality of life. In another study, Griva, Davenport, Harrison et al. (2008) compared the illness perceptions and treatment perceptions of 41 ESRD patients pre to post kidney transplantation (i.e., still on dialysis compared to six months after transplantation). Post kidney transplantation patients expressed lower illness and treatment disruptiveness. Moreover, quality of life

improvements after transplantation were significantly associated with changes in identity, consequences and treatment disruption beliefs. So, beliefs regarding treatment are likely to be of particular importance in ESRD since treatment differs significantly across the different phases of the illness (pre-dialysis, dialysis, transplantation), both technically and in procedures as well as in the demands they impose upon patients.

Knowing that illness perceptions and treatment perceptions of patients on dialysis are closely related to patient outcomes raises a new interesting question: whether these patients' perceptions can be influenced in order to improve adaptive functioning. Only during recent years, the concept of illness perceptions has been incorporated into interventions to improve patient outcomes. Studies on persons with chronic pain provide evidence that altering patients' cognitions may be an important component of the effects of multidisciplinary pain programs. Reductions in pain catastrophizing have consistently been associated with improvements in pain severity, pain interference and depression (Moss-Morris, Humphrey, Johnson et al., 2007). Petrie, Cameron, Ellis and colleagues (2002) developed an intervention to alter illness perceptions of patients with a first myocardial infarction (MI). In this intervention causal beliefs were explored, misperceptions were refuted, and beliefs of personal control were strengthened by teaching the patient to distinguish harmless fatigue from specific symptoms pointing out to a new infarction, and trying out lifestyle changes with the help of predesigned personal action plans. The results showed that return to work was generally faster in patients having received the intervention as compared to controls. Recently, a pilot study was published describing the results of a simple intervention to change treatment beliefs of haemodialysis patients who used phosphate-binding medication to prevent cardiac disease (Karamanidou, Weinman & Horne, 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 immediately after the intervention, but this did not result in an increase in medication adherence. The authors suggest that a more comprehensive intervention targeting the specific beliefs related to behaviour change may be needed to improve adherence.

Petrie and colleagues (2002) stress the importance to intervene in an early stage of the illness process; in fact, their intervention started already when the patients were still in hospital. It seems likely that patient's perceptions may be more apt to change, when these perceptions are not very well established yet. Nevertheless, until now there has been hardly any research on how illness perceptions and treatment perceptions in ESRD patients change over time and during the different phases of illness. Only the study by Griva, Davenport, Harrison et al. (2008) suggests that changes in clinical status and treatment bring about changes in illness perceptions and treatment perceptions. For the purpose of designing psychological interventions aimed at altering maladaptive patients' perceptions on ESRD and dialysis, we wished to gain insight into the illness and treatment perceptions in different phases of the illness. We focussed on patients being prepared for dialysis treatment, patient in their first three years on dialysis, and patients who were on dialysis for a longer period of time. Our research questions were:

1. Do the illness perceptions and treatment perceptions of patients with ESRD differ in different stages of the treatment process (based on duration of the (pre-)dialysis trajectory)?
2. Do the illness perceptions and treatment perceptions of patients with ESRD on dialysis change over time (six months), and is this change/stability of patients' perceptions related to the stage of the treatment process?

### 5.3 Methods

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

#### *Sample of dialysis patients*

NECOSAD-2 is a longitudinal study on a total of some 2,000 dialysis patients who were recruited on a continuous basis since 1997 for this study in 38 dialysis centres and hospitals in The Netherlands. Inclusion criteria were: aged 18 years or older, and having no previous history of renal replacement therapy. Clinical (medical records) and quality of life data were collected every six months.

In January 2006, there were still 250 patients on dialysis participating in the study. Data for the present study were collected by means of an additional survey in these patients in March/April 2006 and six months later. Patients filled in the questionnaires at home or in the dialysis centre and returned them by mail. At the start of this study, one patient from the cohort had died and one patient had 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%). Six months later, 129 of these 166 respondents received the second additional questionnaire, which was returned by 87 persons (response rate 67%). The 37 persons who did not receive the second questionnaire dropped out for different reasons: change of address, being transplanted, unwilling, or deceased.

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

Predialysis patients came from the PREPARE-2 study, a prospective observational study in 25 predialysis outpatient clinics in community and university hospitals throughout the Netherlands. Clinical (medical records) and quality of life data are collected at inclusion and every six months thereafter until start of dialysis, transplantation, death or end of study, whichever occurs earliest. Patients with stage IV chronic kidney disease 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.

The study was approved by the institutional review boards of all participating hospitals. All patients gave written informed consent.



For the present study, data were collected in 2006 by means of an additional survey sent in two phases to all newly recruited patients: in the period July-September to 123 patients and in November-December to 62 patients. Patients filled in the questionnaire at home. Of the 185 patients having received the questionnaire, 109 returned the questionnaire (response rate 59%) and 101 questionnaires were eligible for analysis, the other eight had too many missing answers. In the pre-dialysis sample there were no possibilities for an additional survey.

### *Measures*

Demographic and clinical data were collected including gender, age, educational level, marital status, dialysis duration (in years), type of treatment (medication, diet and/or exercise for pre-dialysis patients and haemodialysis or peritoneal dialysis for dialysis patients). In addition, for dialysis patients severity of illness was determined by the level of serum albumin. Serum albumin is an important predictor of patient morbidity and mortality in dialysis patients (Lowrie et al., 1990; Plantinga et al., 2007). For pre-dialysis patients, information about comorbid conditions was assessed.

Illness perceptions were assessed with the Brief Illness Perception Questionnaire (Broadbent, Petrie, Main & Weinman, 2006). This scale is an abbreviated version of the Revised Illness Perception Questionnaire (IPQ-R; originally developed as the IPQ by Weinman, Petrie, Moss-Morris and Horne, 1996; in 2002 revised by Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick). The Brief IPQ consists of eight items that are scored on an 11-point scale, ranging from 0 to 10 and an open-ended question about what patients think are the three most important causes of their illness. The latter was not used in this study. Each of the eight items assesses a cognitive illness representation dimension. Higher scores reflect a greater impact on life in general (consequences), a stronger belief in a chronic time course (timeline), higher perceived personal control over the illness (personal control), higher medical control over the illness (treatment control), the experience of more symptoms as a result of the disease (identity), stronger feelings of concern about the illness (concern), a better understanding of the illness (understanding) and a stronger emotional response to the illness (emotional response). The Brief IPQ has proven to be a reliable and valid measure of illness perceptions in a variety of illness populations such as patients with renal disease, asthma patients, diabetes patients and patients with a myocardial infarction (Broadbent et al., 2006).

The Treatment Effects Questionnaire (TEQ, originally developed as the IEQ-Tx by Greenberg and Peterson (2002); adapted by Griva et al., unpublished) was used to assess patients' perceptions about the physical and psychological disruption associated with treatment rather than their illness. The TEQ consists of 20 items and explores issues such as treatment impact, side effects, treatment-associated distress, treatment effectiveness, and treatment dependency. 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 TEQ has been used in two studies with ESRD patients (Griva, Jayasena, Davenport, et al., 2009; Griva, Davenport & Harrison, 2008) and there is empirical support for TEQ's adequate psychometric properties (Greenberg & Peterson, 1997b). The Cronbach's alpha for the scale in this study was .91.

### *Statistical analysis*

In order to answer our first research question, we distinguished between three groups: pre-dialysis patients (n=109), patients up to three years on dialysis (n=69) and patients on dialysis for three years or longer (n=97). The three groups were statistically compared – by means of chi-square tests and analysis of variance tests – with regard to socio-demographic and clinical characteristics, their mean scores on the eight illness perception dimensions, and their total treatment perception score. Statistical differences among the three groups were assessed in the analysis of variance analyses with post-hoc Scheffé tests (in case of equal variances) or Tamhane's T2-tests (in case of unequal variances). Since we had only data of 87 dialysis patients who provided data regarding their illness perceptions and treatment perceptions twice (with a six months interval), we could not study our second research question extensively. In the pre-dialysis group a second assessment was not possible. Therefore, it was decided to explore the change/stability of the illness perceptions and treatment perceptions over the six-month period by means of Spearman's correlations for each of the two dialysis groups separately and for the total group of patients on dialysis. By comparing the correlations found in the two groups differing in duration of the dialysis treatment and by testing if these correlations differed significantly, we were able to get a first impression of the relationship between the stability/change in patients' perceptions on the one hand and the experience with dialysis on the other.

## **5.4 Results**

### *Socio-demographic and treatment characteristics*

Baseline characteristics of the 109 pre-dialysis patients and the two dialysis samples (n=69 and n=97) are outlined in table 5.1. There were no significant differences between the three groups with respect to gender, age, marital status or educational level. In addition, the two dialysis groups did not differ with respect to type of treatment (HD/PD) or mean serum albumin. The latter suggests that both dialysis samples did not vary in the seriousness of their renal disease.

Table 5.1: Socio-demographic and treatment related characteristics of the samples.

	Pre-dialysis patients (n=109)		Patients up to 3 years on dialysis (n=69)		Patients on dialysis for 3 years or longer (n=97)	
	N	%	N	%	N	%
<b>Gender</b>						
- Male	65	65	41	60	65	67
- Female	36	35	27	40	32	33
<b>Age (mean, SD)</b>	64.1 (15.0)		66.5 (11.5)		66.7 (11,9)	
- 18 – 49 years	21	20	6	9	10	10
- 50 – 64 years	24	22	15	22	31	32
- 65 years or older	61	58	48	70	56	58
<b>Marital status</b>						
- Married/ living together	69	64	41	59	64	67
- Not married/ living alone	38	36	28	41	32	33
<b>Educational level</b>						
- Low	46	44	25	39	36	39
- Moderate	43	42	28	44	40	43
- High	14	14	10	16	17	18
<b>Type of treatment</b>						
- Medication	94	93	-	-	-	-
- Diet	87	86	-	-	-	-
- Exercise	10	10	-	-	-	-
- Other	7	7	-	-	-	-
- Haemodialysis	-	-	51	74	67	69
- Peritoneal dialysis	-	-	18	26	30	31
Serum albumin, mean in g/L (SD)	-		36.5 (4.4)		37.2 (4.5)	
**						
<b>Comorbid conditions</b>						
Hypertension	56	65	-	-	-	-
Diabetes	16	19	-	-	-	-
Vascular disease	14	12	-	-	-	-

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

No significant differences were found with respect to gender, age, marital status, type of treatment, time on dialysis, and serum albumin level between the dialysis patients who participated in the study and the non-responders on dialysis treatment. Also responders and non-responders in the pre-dialysis group did not differ significantly with respect to background characteristics.

#### *Differences in illness perceptions and treatment perceptions*

Table 5.2 shows the mean scores and standard deviations of the three patient groups on the illness perceptions and treatment perception measures. Dialysis patients' mean scores on the consequences dimension of the IPQ and the TEQ indicate perceptions of high levels of disruption associated with illness and treatment, whereas mean scores for pre-dialysis patients on these scales indicate perceptions of mild disruptiveness caused by illness and treatment. Patients on dialysis for three years or longer report significantly more physical complaints than patients shorter on dialysis or patients being prepared for dialysis. For patients on dialysis, treatment is more important in managing their disease than treatment is for pre-dialysis patients. Notable are the relatively low scores on personal control in all three groups, indicating that ESRD patients perceive low levels of personal control over their illness. Although not significant, mean scores on the concern-

dimension suggest that pre-dialysis patients are more worried about their disease than patients on dialysis. Scores on the understanding-dimension suggest that patients have a better grip on their disease the longer they are on dialysis. We did some additional analysis in which we split up the group up to three years on dialysis (not in table). We looked at the illness perception scores of patients on dialysis for less than a year (n=22) and patients on dialysis between 1 year and three years (n=47) and compared their scores with the scores of pre-dialysis patients and patients longer on dialysis. The illness perceptions of patients on dialysis for less than a year resemble the illness perceptions of pre-dialysis patients most. Like pre-dialysis patients, they report less physical symptoms and less disruptiveness from treatment than patients longer on dialysis. At the same time, patients just started with dialysis indicate that they are more concerned, that their illness evokes stronger emotions and that they understand less of their illness than patients who are on dialysis for a number of years. Of all groups, patients just started with dialysis treatment report the lowest perceived personal control.

Table 5.2: Mean scores (SD) of illness perceptions (BIPQ) and treatment perceptions (TEQ) of ESRD patients according to stage of treatment.

	<b>Group 1</b>	<b>Group 2</b>	<b>Group 3</b>	
	<b>Pre-dialysis patients (n=109)</b>	<b>Patients up to 3 years on dialysis (n=69)</b>	<b>Patients on dialysis for 3 years or longer (n=97)</b>	
	<b>M(SD)</b>	<b>M(SD)</b>	<b>M(SD)</b>	<b>p</b>
<b>IPQ - Consequences (0 – 10)</b>	6.7 (2.5) <sup>2,3+</sup>	7.6 (2.0) <sup>1</sup>	7.8 (2.0) <sup>1</sup>	***
<b>IPQ -Timeline (0 – 10)</b>	9.3 (1.7)	9.1 (1.7)	9.3 (1.6)	ns
<b>IPQ - Personal control (0 – 10)</b>	4.7(2.9)	4.3 (3.0)	5.3 (3.2)	ns
<b>IPQ - Treatment control (0 – 10)</b>	6.8(2.9) <sup>2,3</sup>	8.1 (2.0) <sup>1</sup>	8.4 (2.1) <sup>1</sup>	***
<b>IPQ - Identity (0 – 10)</b>	5.2 (2.9) <sup>3</sup>	5.7 (2.5)	6.4 (2.4) <sup>1</sup>	***
<b>IPQ - Concern (0 – 10)</b>	6.9 (2.7)	6.1 (3.0)	6.4 (3.0)	ns
<b>IPQ - Understanding (0 – 10)</b>	7.3 (3.1)	7.3 (3.1)	7.9 (2.3)	ns
<b>IPQ - Emotional response (0 – 10)</b>	5.0 (3.1)	4.6 (3.1)	5.2 (3.2)	ns
<b>TEQ - Impact of treatment (0 - 140)</b>	38.8(25.9) <sup>2,3</sup>	58.8 (22.7) <sup>1,3</sup>	66.8 (26.2) <sup>1,3</sup>	***

+ Superscript means: Group 1 differs significantly from Group 2 and 3 with respect to their mean scores on the consequences dimension.

\*\*\* p<.001.

#### *Stability/change in illness and treatment perceptions*

In table 5.3 the Pearson correlations are shown between the illness perceptions and treatment perceptions assessed at T1 and T2 (six months later) for the two dialysis groups separately and for the total group of dialysis patients. Considering the height of the correlations found in the total group of patients on dialysis, some illness perceptions appear to be more stable than others over a six months period. Ideas patients have about the impact of the treatment on daily life are most stable, followed by the emotional response the illness evokes. Ideas about the consequences of the illness in general and the possibilities for personal control change most over a six month period. Ideas about the benefits of treatment are not stable at all. In order to explore whether the stability/change

in patients' perceptions is related to the duration of the dialysis treatment, we compared the correlations of patients who were three years or less on dialysis with the correlations of patients who were longer on dialysis treatment. Given the height of the correlations in both groups, the results suggest that the longer people are on dialysis treatment, the more stable their illness perceptions are, except for perceptions of personal control and consequences. Correlations on timeline ( $p=.0312$ ), concern ( $p=.0541$ ) and emotional response ( $p=.002$ ) differed significantly in magnitude.

Table 5.3: Spearman's correlations between T1 and T2 (six months later) of illness and treatment perceptions of patients on dialysis.

	Patients up to 3 years on dialysis (n=42)	Patients on dialysis for 3 years or longer (n=45)	Total group on dialysis (N=87)
	<i>r</i>	<i>r</i>	<i>r</i>
Consequences	.52***	.41**	.44***
Timeline	.49***	.74***	.58***
Personal control	.46***	.38**	.42***
Treatment control	.17	.09	.15***
Identity	.54***	.55***	.54***
Concern	.49***	.71***	.62***
Understanding	.54**	.61***	.56***
Emotional response	.52***	.83***	.73***
Impact of treatment	.76***	.82***	.80***

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

## 5.5 Discussion

The present study examined the nature of illness perceptions and treatment perceptions of patients with ESRD in different phases of their illness. Patients being prepared for dialysis were compared to patients up to three years on dialysis and patients on dialysis for three years or longer. In addition, the stability of the illness perceptions in both dialysis groups was assessed.

The results show that patients in the different phases of ESRD have different beliefs about their illness and treatment. Illness perceptions are considered to be constantly updated as new experience and knowledge are acquired (Leventhal et al., 1984). Changes of treatment are one feature in the course of ESRD, and the results of this study provide some support that illness perceptions appear to be formed at least in part as a function of treatment. Griva et al. (2008) also found evidence for this in their comparison of the illness perceptions of ESRD patients before and after transplantation. Patients being prepared for dialysis and patients shortly after the start of dialysis believed their illness and treatment to be far less disruptive than patients who were already on dialysis for a longer period of time. Patients in pre-dialysis also believed less in the benefits of treatment than patients on dialysis did. Treatment control in the case of ESRD is a difficult concept. For ESRD patients, dialysis is not an option but a vital need. Treatment

control, therefore, has a different meaning for patients with ESRD than for many other patients with chronic diseases. Treatment control for ESRD patients has the connotation of treatment dependency. This may explain the higher scores for patients on dialysis treatment as compared to pre-dialysis patients who use medication or follow a diet, but do not die when they do not. Both pre-dialysis and dialysis patients experience not much personal control over their illness. Patients just started with dialysis feel the lowest personal control over illness. Of course, renal disease is a disease in which a patient is relegated to renal replacement therapy. In that way, it is not surprising that patients have the feeling that they are a passive recipient of medical care. However, personal control goes beyond the control over dialysis treatment. Someone who has personal control over his disease succeeds in fitting the disease and its treatment into his life without as little concessions as possible. Previous studies on illness perceptions and ESRD (Christensen, Moran, Wiebe et al., 2002; Covic, Seica, Gusbeth-Tatomir et al., 2004, Krespi, Bone, Ahmad et al., 2004; Pucheu, Consoli, D'Auzac et al., 2004; Fowler & Baas, 2006; Timmers et al. 2008) or chronic disease in general (for an overview see Hagger & Orbell, 2003) all show that strong beliefs of personal control are related to better outcomes and quality of life. Improving feelings of control seems to be a necessary condition for better outcomes.

Although there were no differences between the two dialysis groups in the level of serum albumin, which is an important predictor of patient morbidity and mortality in dialysis patients, patients in both groups did differ in their beliefs about their illness and treatment. Patients who were in dialysis for three years or longer reported more physical symptoms, more consequences and a much higher disruptiveness from treatment than patients who were in dialysis for a shorter period of time. The results also suggest that the longer people are on dialysis treatment, the more stable their illness perceptions are. Especially beliefs about the disruptiveness of treatment and the consequences for daily life do not change very much after a number of years on dialysis.

Given these results, the present study does offer starting points to developing interventions for ESRD patients to alter maladaptive patients' perceptions on ESRD and dialysis, and in that way to improve quality of life. Beliefs of less control, beliefs in more serious consequences, and the experience of more physical symptoms are the main predictors for maladaptive outcomes (Hagger, & Orbell, 2003). The more negative these cognitions are and the longer they exist, the harder they can be changed. Our results suggest that interventions to change cognitions should focus on patients on pre-dialysis or in the first year of dialysis. Patients on pre-dialysis are less negative about the consequences and the disruptiveness of treatment and they report fewer symptoms than people on dialysis. Probably they also have more energy and time to take part in an intervention than patients on dialysis. What may be more important, patients in pre-dialysis or patients that just started dialysis treatment are more concerned about their disease and have the feeling that they understand less of their ESRD. By giving realistic information and taking away concerns, it may be possible to better prepare pre-dialysis patients for dialysis and to prevent that beliefs about ESRD and dialysis treatment become obstacles for successful adaptation to the disease.

One limitation of this study should be mentioned. We used three different samples to describe the illness perceptions during different phases of ESRD. According to the SRM, illness and treatment perceptions are constantly updated with new experiences. Therefore, it would have been stronger to study illness perceptions longitudinally, to examine the interactions between illness perceptions and treatment perceptions on the one hand and outcomes on the other and how these perceptions change over time and during the course of an illness. Griva et al. (2008) made a first attempt in comparing the illness perceptions of the same ESRD patients before and after transplantation. The number of patients in that study was limited however and larger scale. Longitudinal studies are needed to really understand the developing process of illness and treatment perceptions in ESRD patients.

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## **6 The impact of social support and overprotection on dialysis patients' labour participation, autonomy and self-esteem**

### **6.1 Abstract**

This study investigated whether perceived social support from significant others and overprotection by significant others and doctors is related to employment, perceived autonomy, and self-esteem in end-stage renal disease patients on dialysis.

One hundred sixty-six dialysis patients completed questionnaires at home or in the dialysis centre. Data were analysed using bivariate and multivariate analyses. Perceived overprotection and lack of social support were correlated with low levels of autonomy and self-esteem. Moreover, perceived overprotection by doctors was associated with unemployment. Regression results showed that the overprotection and lack of support variables explained a substantial amount of variance in autonomy (12%) and self-esteem (15%), controlled for socio-demographic and clinical variables.

Results point to the importance of autonomy supportive contexts in improving dialysis patients' sense of autonomy, self-esteem and labour participation. Context focused care is recommended to educate patients and significant others in how to ask for/offer support in an adequate way.

### **6.2 Background and objectives**

In 2003/2004 NIVEL has carried out a literature study (Heijmans & Rijken, 2004) – with a grant of the Dutch Kidney Foundation – in order to gain insight into the state of affairs regarding social participation of patients with end-stage renal disease (ESRD). The study showed that many people with ESRD have problems to maintain their normal daily activities, in particular their paid job. An important finding was that drop out of the labour force already takes place before the start with renal replacement therapy (haemodialysis, peritoneal dialysis, transplantation).

The study has also provided insight into the factors that are important to prevent people from quitting their jobs. Obviously, socio-demographic factors play a role in this, such as patient's age and education, as well as medical factors, such as severity of the health condition and type of treatment. Additionally, external factors play an important role, such as the type of work one performed before or during the illness, or the attitude of the employer and colleagues (at that time). Generally speaking, these factors cannot be changed greatly. Moreover, it was notable that large individual differences exist in the employment status between ESRD patients with a common medical background. This indicates that other factors may play a role too in the maintenance of paid work.

The literature study revealed two psychological factors that may be closely linked to employment in ESRD patients and that are thought to be very interesting, since they might be changeable and therefore offer opportunities to support labour participation of

ESRD patients. First, the way the patient views his/her illness and treatment, and the possibilities he/she believes in for employment and performing other daily activities; second, the way the patient's environment - in particular the partner, family and treating doctor - supports him/her in his/her effort to carry on with daily activities, including work. Within health psychology the first factor is known as illness and treatment perceptions, the latter as social support, including overprotection. These literature findings have led to the start of a project in which the role of these psychological factors in labour participation as well as perceived autonomy of renal patients was investigated more closely. The project consisted of a descriptive and explanatory study (partial study 1) and an intervention study (partial study 2). In this memorandum, results of partial study 1 are reported, that have not been described before in English scientific papers. It concerns the results on dialysis patients' experienced social support and overprotection and its effects on labour participation, autonomy and self-esteem. It can be expected that patients who are being stimulated to carry out daily activities, participate more in the work domain, feel more autonomous and have higher self-esteem than patients who receive little support or who are being overprotected. The following research questions were formulated within the framework of partial study 1:

1. Which beliefs do (pre-)dialysis patients have about their illness and treatment and their abilities to perform a paid job? Are there differences according to socio-demographic and clinical characteristics?
2. Are the illness and treatment perceptions of (pre-)dialysis patients stable over time, or are they changeable?
3. To what extent do dialysis patients experience social support or overprotection by their partner and treating doctor? Are there differences with regard to socio-demographic and clinical characteristics?
4. To what extent are the patient's perceptions and perceived social support/overprotection by his/her partner and treating doctor predictors of labour participation, perceived autonomy and self-esteem?

The findings concerning research questions 1 and 2 and part of research question 4 have already been described in English scientific papers. This memorandum will discuss research question 3 and part of research question 4, resulting in the three research questions below:

1. To what extent do dialysis patients experience social support or overprotection by their significant others and their doctors?
2. Are there differences in experienced social support/overprotection between dialysis patients regarding socio-demographic and clinical characteristics?
3. To what extent is the social support/overprotection dialysis patients experience related to labour participation, perceived autonomy and self-esteem of patients?

## **6.3 Methods**

### ***Respondents***

The data collection for the current study has taken place over the period March-April 2006 by means of a written questionnaire among the 248 dialysis patients who were still being followed within the longitudinal Netherlands Cooperative Study on the Adequacy

of Dialysis phase 2 (NECOSAD-2; Termorshuizen et al., 2003; Timmers et al., 2008). The questionnaire was filled in by 166 patients (response rate 67%).

### ***Definition and operationalisation concepts***

The concepts within this study can be divided into three categories:

- 1) labour participation, perceived autonomy and self-esteem (outcome measures),
- 2) social support/overprotection (by significant others and doctors),
- 3) socio-demographic and clinical characteristics.

#### *Labour participation*

Labour participation was defined in conformity with Statistics Netherlands (CBS), as performance of paid work for at least 12h per week.

#### *Perceived autonomy and self-esteem*

Autonomy is the experienced freedom to make choices that agree with who you are. People are autonomous if they can do what they really want to do within all areas of life. The extent of perceived autonomy was measured using a subscale of the CASP-19 questionnaire (Hyde, Wiggins, Higgs & Blane, 2003). Autonomy is here defined as the individual's right to be free of the unwanted/unwished mediation by others (Patrick, Skinner & Connell, 1993). The autonomy subscale consists of five items. All items were answered using a four-point scale (0=never, 1=sometimes, 2=not so often, 3=often). Based on statistical analysis two measures for autonomy were developed from the original autonomy scale: global autonomy (consisting of two items: 'I can do the things that I want to do', 'I feel that I can please myself what I can do') and health related autonomy (consisting of one item: 'My health stops me from doing the things I want to do' (reverse scored)). High scores on both autonomy measures signify a higher level of perceived autonomy.

Self-esteem refers to the positive and negative evaluations a person makes about him/herself. The extent of self-esteem can fluctuate, partly as a result of success, failure, social interactions and other events in life. Self-esteem was measured with the Current Thoughts Scale (Heatherton & Polivy, 1991). The Current Thoughts Scale measures self-esteem as a 'condition', or in other words, self-esteem at one fixed moment. The Current Thoughts Scale consists of 20 items (e.g. 'I am worried about what other people think of me' (reverse scored)). Each item was answered using a five-point scale (1= not at all, 2=a little bit, 3=somewhat, 4=very much, 5=extremely). High scores indicate a high level of self-esteem. The internal consistency of the scale in the current study was 0.88.

#### *Social support and overprotection*

The concept social support refers to the support offered by people in the close environment, such as family, friends, etc. People can feel the need for support, in daily situations as well as when having problems. Within a relationship social support can be provided as interactions.

Social support was measured with the Social Support List-Interactions and Discrepancies (Van Sonderen, 1993). 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, neighbours, colleagues, etc. The Social Support List-Discrepancies measures the experienced discrepancy between desired amount of social support and received amount of social support from the close environment.

The interaction and discrepancy scale each consists of six sub-scales: these six sub-scales measure six different types of support, i.e. daily emotional support, emotional support with problems, appreciation support, instrumental support, social companionship (seek each other's company) and informative support. Within this study we have chosen to explore only the subscales daily emotional support, emotional support with problems and support by social companionship.

The interaction subscales daily emotional support, emotional support with problems and support by social companionship consist of respectively, four items (e.g. 'Does it ever happen that you are hugged/caressed?'), eight items (e.g. 'Does it ever happen that you are cheered up?'), and five items (e.g. 'Does it ever happen that someone pays you a social visit?'). The items were all answered on a four-point scale (1=seldom or never, 2=once in a while, 3=regularly, 4=very often). The higher people score on the different subscales, the more support people experience.

The discrepancy subscales daily emotional support, emotional support with problems and support by social companionship consist of respectively, four items (e.g. 'You are given hugs/caresses'), eight items (e.g. 'You are cheered up'), and five items (e.g. 'You are paid a social visit'). 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 were also answered on a four-point scale (1=I miss it, I would like more, 2=I do not really miss it, but it would be pleasant if it happened a bit more often, 3=exactly right this way; I would not want it more or less often, 4=happens too often; it would be pleasant if it happened less often). The scores on the discrepancy scales were recoded, in such a way that a high score indicates a great experienced lack of support. The internal consistency of the interaction and discrepancy scales varied in this study from 0.81 to 0.95.

The concept overprotection refers to the extent to which a person receives too much protection from his/her environment. Overprotection occurs when a person has the idea that he/she is overwhelmed, induced to be dependent, shielded from stress, and in general not treated as an adult (Thompson & Sobolew-Shubin, 1993). Overprotection by significant others was measured using the Overprotection Scale for Adults (OPSA; Thompson & Sobolew-Shubin, 1993). 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 were answered on a four-point scale (1=strongly disagree, 2=disagree, 3=agree, 4=strongly agree). A high score on this scale is an indicative of a high level of perceived overprotection. The internal consistency of the scale in this study was 0.85.

Overprotection by doctors (GP and medical specialist (nephrologist/internist) was measured using a self-developed scale, based on the OPSA. The scale consists of four subscales. Two subscales with each three items measuring the perceived overprotection by the GP or the medical specialist in his treatment ('Sometimes I am treated like a little

child by my GP/medical specialist', 'My GP/medical specialist fully trusts that I have the right attitude towards my illness' (reverse scored), 'I am treated like a responsible adult by my GP/medical specialist' (reverse scored)). And two subscales with each two items measuring the perceived overprotection by the GP or medical specialist regarding undertaking activities ('Undertaking social activities (going out, sport, holidays, etc.) is stimulated by my GP/medical specialist'(reverse scored), 'I am stimulated to do the things I like to do by my GP/medical specialist'(reverse scored)).

All items were answered on a five-point scale (1=I fully disagree, 2=I disagree, 3=I don't know, 4=I agree, 5=I fully agree). A high score indicates a high level of perceived overprotection. The internal consistency of the subscales of perceived overprotection in treatment by the GP, medical specialist were respectively, 0.56 and 0.69. The internal consistency of the subscales perceived overprotection by the GP, medical specialist, regarding undertaking activities were respectively, 0.91 and 0.90.

*Socio-demographic characteristics* included gender, age, educational level, and marital status. 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 characteristics* included treatment modality, time on dialysis treatment (in years), and severity of the health condition. Treatment modality refers to type of dialysis treatment. Patients can be treated with peritoneal dialysis (PD) or haemodialysis (HD) in order to purify patients' blood. Peritoneal dialysis is a method bringing an irrigating solution into the abdominal cavity in order to purify the blood. Haemodialysis is done using a coil kidney which filters the blood. The group of respondents was divided into PD and HD patients, depending on the type of treatment patients received at the time of the survey.

Severity of the health condition was determined by the level of serum albumin. Serum albumin is an important predictor of patient morbidity and mortality in dialysis patients (Blake, Flowerdew, Blake, & Oreopoulos, 1993; Churchill et al., 1992; Lowrie & Lew, 1990; Plantinga et al., 2007). High values of serum albumin are an indication of better health status. Normal values are around 40-50 g/L.

### ***Statistical analysis***

Univariate analyses have been carried out in order to examine the extent to which dialysis patients perceive social support and overprotection (research question 1). Associations between background characteristics and experienced social support/overprotection (research question 2) have been examined with analysis of variance (ANOVA) and Pearson's correlation coefficients. Associations between experienced social support and overprotection on the one hand, and perceived autonomy, self-esteem and labour participation on the other hand (research question 3), have been studied using Pearson's correlation coefficients and Student's t-tests. Additionally, hierarchical multiple linear regression analyses have been conducted to investigate the effects of experienced social support and overprotection on perceived autonomy and self-esteem, controlling for socio-

demographic as well as clinical characteristics. In the regression analysis three different models were tested: model 1 the predictive value of socio-demographic characteristics, model 2 the predictive value of clinical characteristics, controlled for socio-demographic characteristics, and model 3 the predictive value of experienced social support and overprotection, controlled for socio-demographic as well as clinical characteristics.

## 6.4 Results

### 6.4.1 *Dialysis patients' experienced social support and overprotection*

This section expounds on the findings regarding the research question below.

- To what extent do dialysis patients experience social support or overprotection by their significant others and their doctors?

Table 6.1 gives the mean scores of the total group on experienced social support. No norm data are available on the social support scales. By comparing the mean sum scores on the social support interaction scales of the total group with the answer scale (1=seldom or never, 2=once in a while, 3=regularly, 4=very often) we can in general conclude that patients once in a while experience support. However, when we consider the mean scores on the discrepancy subscales (lack of support), we see that the patient group as a whole does not experience extensive lack of support.

Table 6.1: Alpha's, mean scores and standard deviations of experienced (lack of) social support (total group).

	Number of items	$\alpha$	Range scale scores	M (SD)	Range scores respondents	N
<i>Social Support Interactions</i>						
Total support	17	.94	17-68	40.40 (9.51)	17-65	157
Daily emotional support	4	.82	4-16	9.98 (2.61)	4-15	158
Emotional support with problems	8	.92	8-32	18.69 (5.12)	8-32	155
Social companionship	5	.81	5-20	11.65 (3.05)	5-20	156
<i>Social Support Discrepancies (lack)</i>						
Total support	17	.95	17-51	24.84 (8.25)	17-51	157
Daily emotional support	4	.86	4-12	5.85 (2.32)	4-12	157
Emotional support with problems	8	.93	8-24	11.49 (4.02)	8-24	156
Social companionship	5	.85	5-15	7.50 (2.75)	5-15	158

Table 6.2 gives the mean scores of the total group on perceived overprotection by significant others and by doctors (GP as well as medical specialist). Again, there are no norm data available for these scales. By comparing the mean sum scores of the total group on perceived overprotection by significant others with the answer scale (1=strongly disagree, 2=disagree, 3=agree, 4=strongly agree) we can conclude that, in general, patients perceive a low level of overprotection by significant others.



This pattern is also visible in the mean scores on perceived overprotection by doctors (treatment and stimulation); the group as a whole experiences a low level of overprotection in the way they are treated by the GP and the medical specialist. The mean scores on perceived overprotection regarding undertaking activities are somewhat higher for GP as well as medical specialist. These results indicate that, generally speaking, patients do not have the idea that their doctor treats them in a patronizing or protecting way.

Table 6.2: Alpha's, mean scores and standard deviations of perceived overprotection (total group).

	Number of items	$\alpha$	Range scale scores	M (SD)	Range scores respondents	N
<i>Overprotection by significant others</i>	18	.85	18-72	34.34 (7.44)	18-60	158
<i>Overprotection by doctors</i>						
Treatment by GP	3	.56	1-5	2.00 (.72)	1-4.33	153
Treatment by medical specialist	3	.69	1-5	1.76 (.72)	1-5	155
Stimulation by GP	2	.91	1-5	3.49 (1.08)	1-5	152
Stimulation by medical specialist	2	.90	1-5	3.00 (1.23)	1-5	152

Table 6.3 shows the intercorrelations of the various types of perceived social support and overprotection. The social support interaction subscales are positively interrelated, and the social support discrepancy subscales are also positively interrelated. This means that the more social support people experience in the one area, the more social support is experienced in the other area. And that an experienced lack of social support in the one area is associated with an experienced lack of social support in the other area. In addition, it is shown that the social support interaction subscales are negatively correlated with the social support discrepancy subscales; thus, a higher level of experienced social support is associated with a lower level of experienced lack of social support.

Furthermore, the results show that when people experience ample daily emotional support and social companionship, they feel less overprotected by significant others. The various ways of social support also show associations with perceived overprotection by doctors; in particular daily emotional support is related to low levels of perceived overprotection in the treatment and stimulation by doctors.

It is notable that as people experience higher levels of lack of support, they experience more overprotection by their significant others. This pattern of associations is also visible concerning perceived overprotection by doctors.

A high level of perceived overprotection by significant others appears to be related to a high level of perceived overprotection by doctors in their treatment. The results further show that when people feel overprotected in the way their GP treats them, these people also experience overprotection in the way they are treated by their medical specialist. This also applies to the aspect of stimulation; the more overprotection they experience by the GP, the more overprotection they experience by the medical specialist.

Table 6.3: Pearson's correlation coefficients of the various kinds of experienced social support and overprotection (total group N= 146-158)

	1	2	3	4	5	6	7	8	9	10
<i>Social Support Interactions</i>										
1. Daily emotional support	-									
2. Emotional support with problems	.68***	-								
3. Social companionship	.62***	.66***	-							
<i>Social Support Discrepancies (lack)</i>										
4. Daily emotional support	-.63***	-.44***	-.43***	-						
5. Emotional support with problems	-.56***	-.57***	-.48***	.78***	-					
6. Social companionship	-.49***	-.39***	-.67***	.68***	.72***	-				
<i>Overprotection</i>										
7. Overprotection by significant others	-.28***	.05	-.22**	.38***	.26**	.41***	-			
8. Treatment by GP	-.23**	-.13	-.15	.31***	.19*	.28***	.35***	-		
9. Treatment by medical specialist	-.18*	-.07	-.13	.30**	.17*	.25**	.39***	.58***	-	
10. Stimulation by GP	-.24**	-.17*	-.16	.16	.14	.17*	.04	.19*	-.03	-
11. Stimulation by medical specialist	-.15	-.23**	-.23**	.18*	.20*	.22**	.06	.10	.17*	.62***

\* &lt;.05.

\*\* &lt;.01.

\*\*\* &lt;.001.

#### 6.4.2 *Associations between experienced social support, overprotection and background characteristics*

This section expounds on the findings regarding the research question below.

- Are there differences in experienced social support/overprotection between dialysis patients regarding socio-demographic and clinical characteristics?

We have examined whether there are differences in experienced social support and overprotection regarding the socio-demographic characteristics gender, age, educational level, marital status, and the clinical characteristics type of treatment (PD/HD), time on dialysis (in years), and serum albumin level (indicator of severity of the health condition).

##### *Socio-demographic characteristics*

###### *Social support*

Married dialysis patients and those who are living with a partner differ from patients who live without a partner in experienced social support: Married patients and those who are living with a partner generally experience more daily emotional support, emotional support with problems and total support (table 6.4). No differences were found in experienced social support according to gender, age and level of education.

Table 6.4: Significant differences in mean experienced social support scores according to marital status (total group).

	Married/ living with partner		Living alone	
	N	M (SD)	N	M (SD)
Daily emotional support <sup>***</sup>	101	10.49 (2.42)	50	8.73 (2.56)
Emotional support with problems <sup>**</sup>	100	19.55 (4.93)	48	17.10 (5.32)
Total support <sup>*</sup>	101	41.89 (9.21)	49	37.43 (9.90)

\* p<.05.

\*\* p<.01.

\*\*\* p<.001.

A similar pattern is visible when we look at experienced lack of support. Married patients and those who are living with a partner generally experience less lack of daily emotional support, emotional support when they are having problems and total support (table 6.5). Again, no differences were found in experienced social support according to gender, age and level of education.

Table 6.5: Significant differences in mean experienced lack of social support scores according to marital status (total group).

	<b>Married/ living with partner</b>		<b>Living alone</b>	
	N	M (SD)	N	M (SD)
Lack of daily emotional support*	103	5.57 (2.22)	47	6.52 (2.50)
Lack of emotional support with problems*	103	10.99 (3.57)	47	12.74 (4.84)
Lack of total support	103	23.83 (7.37)	47	27.25 (9.91)

\*p<.05

\*\* p<.01

\*\*\* p<.001

### *Overprotection*

The results do not show significant differences in perceived overprotection by significant others according to socio-demographic characteristics. A significant difference between low-educated and high-educated patients does exist, however, in the perceived overprotection by the GP in his treatment. People with a low education experience more overprotection in this area than people with a high educational level (table 6.6).

Also, a significant difference is visible in perceived overprotection by doctors regarding undertaking activities according to marital status. People who live without a partner turn out to experience more overprotection in this area compared to married people/people living together with a partner (table 6.7).

Table 6.6: Significant differences in mean perceived overprotection scores according to educational level (total group).

	<b>High-educated</b>		<b>Low-educated</b>	
	N	M (SD)	N	M (SD)
Treatment by GP*	27	1.70 (.59)	53	2.13 (.76)

\* p<.05.

\*\* p<.01.

\*\*\* p<.001.

Table 6.7: Significant differences in mean perceived overprotection scores according to marital status (total group).

	<b>Married/ living with partner</b>		<b>Living alone</b>	
	N	M (SD)	N	M (SD)
Stimulation by GP*	97	3.36 (1.06)	48	3.82 (1.09)
Stimulation by medical specialist*	97	2.84 (1.19)	48	3.36 (1.26)

\* p<.05.

\*\* p<.01.

\*\*\* p<.001.

### ***Clinical characteristics***

#### *Social support*

In addition, we have examined whether the severity of the health condition is associated with the extent to which social support is experienced. To study this, we have looked at the correlation between the serum albumin value and experienced support. A significant positive relationship is only visible between experienced daily emotional support and serum albumin value (Pearson's correlation coefficient=.21,  $p<.05$ ); more experienced daily emotional support is associated with a higher serum albumin value, i.e. a more favourable health condition.

We also have investigated whether the duration of the dialysis treatment is associated with the extent to which social support is experienced. The results show a significant positive relationship between experienced lack of social companionship and time on dialysis (table 6.8). Patients who have been dialysing for two to five years appear to experience less lack of social companionship than patients who have been dialysing for five to ten years. PD and HD patients do not differ regarding experienced social support.

Table 6.8: Significant differences in mean experienced lack of social support scores according to time on dialysis (total group).

	Time on dialysis 2-5 years		Time on dialysis 5-10 years	
	N	M (SD)	N	M (SD)
Lack of social companionship*	71	6.93 (2.49)	37	8.43 (3.06)

\*  $p<.05$ .

\*\*  $p<.01$ .

\*\*\*  $p<.001$ .

#### *Overprotection*

It turns out that there are no significant differences in perceived overprotection by significant others according to time on dialysis, type of treatment and health condition. The results do show differences with respect to perceived overprotection by doctors. PD and HD patients differ in the extent to which they feel overprotected by doctors regarding undertaking activities. HD patients turn out to perceive more overprotection by doctors in this area than PD patients (table 6.9). No associations were found between perceived overprotection by doctors on the one hand and time on dialysis and health condition on the other hand.

Table 6.9: Significant differences in mean perceived overprotection scores according to type of treatment (total group).

	PD patients		HD patients	
	N	M (SD)	N	M (SD)
Stimulation by GP*	46	3.21 (1.12)	106	3.61 (1.05)
Stimulation by medical specialist**	46	2.49 (1.20)	106	3.22 (1.18)

\* p<.05.

\*\* p<.01.

\*\*\* p<.001.

### 6.4.3 Associations with autonomy, self-esteem and labour participation

This section expounds on the findings regarding the research question below.

- To what extent is the social support/overprotection dialysis patients experience related to perceived autonomy, self-esteem and labour participation of patients?

By calculating Pearson's correlation coefficients, the associations between experienced social support and overprotection on the one hand, and perceived global autonomy, health related autonomy and self-esteem on the other hand, were investigated. Relationships with labour participation were studied using Student's t-tests.

#### *Associations social support and overprotection with autonomy and self-esteem*

The Pearson's correlation coefficients in table 6.10 show that experienced lack of daily emotional support, social companionship and total support are related to either low levels of health related autonomy or global autonomy. A high level of experienced support by daily emotional support and social companionship is associated with a high level of self-esteem. Moreover, experienced lack of support in all areas appears to be associated with a low self-esteem.

Table 6.10: Pearson's correlation coefficients between experienced social support on the one hand and perceived autonomy and self-esteem on the other hand (total group: N=151-155).

	Health related autonomy	Global autonomy	Self-esteem
<i>Social Support Interactions</i>			
Total support	.02	.03	.14
Daily emotional support	.01	.10	.24**
Emotional support with problems	-.07	-.05	-.01
Social companionship	.16	.06	.22**
<i>Social Support Discrepancies (lack)</i>			
Total support	-.17*	-.13	-.39***
Daily emotional support	-.14	-.16*	-.39***
Emotional support with problems	-.09	-.06	-.28***
Social companionship	-.24**	-.13	-.43***

\* p<.05.

\*\* p<.01.

\*\*\* p<.001.

Table 6.11 shows the Pearson's correlation coefficients between perceived overprotection (by significant others and doctors) on the one hand and perceived health related autonomy, global autonomy and self-esteem on the other hand. It is notable that a high level of perceived overprotection by significant others, as well as by the medical specialist is associated with a low level of perceived global autonomy and self-esteem.

Table 6.11: Pearson's correlation coefficients between perceived overprotection on the one hand en perceived autonomy, self-esteem on the other hand (total group: N=147-155).

	Health related autonomy	Global autonomy	Self-esteem
<i>Overprotection by significant others</i>	-0.09	-.25**	-.44***
<i>Overprotection by doctors</i>			
Treatment by GP	-.03	-.13	-.13
Treatment by medical specialist	-.04	-.28**	-.27**
Stimulation by GP	-.07	-.05	.01
Stimulation by medical specialist	-.02	-.19*	-.09

\* p<.05.

\*\* p<.01.

\*\*\* p<.001.

#### *Associations social support and overprotection with labour participation*

The results of the Student's t-tests do not show relationships between experienced social support on the one hand and labour participation (unemployed vs. employed for at least 12h per week) on the other hand. A slight trend is visible, however, regarding the extent of experienced lack of emotional support with problems between people who are working and those who are not working. People who are not working appear to experience more lack of emotional support with problems than those who are working (table 6.12).

The associations of perceived overprotection with labour participation have also been examined and the results clearly show trends between perceived overprotection by doctors and whether a person is working or not. People who are not working turn out to perceive, on average, more overprotection by the medical specialist regarding undertaking activities, than those who are working. The same association is more clearly visible regarding the perceived overprotection by the GP related to undertaking activities (table 6.13).

Table 6.12: Differences in mean experienced social support scores between unemployed and employed patients (group 18-64 years: N=62).

	Unemployed		Employed		p
	N	M (SD)	N	M (SD)	
<i>Social Support Interactions</i>					
Total support	37	41.95 (10.39)	15	40.82 (7.75)	.672
Daily emotional support	38	10.06 (3.27)	15	10.13 (2.26)	.928
Emotional support with problems	37	19.57 (5.62)	15	18.67 (4.08)	.525
Social companionship	37	12.19 (3.09)	15	12.00 (3.42)	.847
<i>Social Support Discrepancies (lack)</i>					
Total support	39	27.38 (10.11)	15	25.47 (8.26)	.516
Daily emotional support	39	6.56 (2.83)	15	6.47 (3.00)	.912
Emotional support with problems	39	12.92 (5.01)	15	11.20 (3.28)	.224
Social companionship	40	8.00 (3.03)	15	7.80 (2.93)	.827

Table 6.13: Differences in mean perceived overprotection scores between unemployed and employed patients (group 18-64 years: N=62).

	Unemployed		Employed		p
	N	M (SD)	N	M (SD)	
<i>Overprotection by significant others</i>	37	34.90 (9.77)	15	34.53 (6.48)	.895
<i>Overprotection by doctors</i>					
Treatment by GP	38	1.96 (.75)	15	2.18 (.58)	.309
Treatment by medical specialist	39	1.71(.75)	15	1.89 (.53)	.399
Stimulation by GP	38	3.64 (1.20)	15	3.03 (.90)	.051
Stimulation by medical specialist	38	3.18 (1.36)	15	2.57 (1.05)	.121

#### *Predicting perceived autonomy and self-esteem*

By means of regression analysis we have investigated the extent to which overprotection by significant others and the medical specialist and the experienced lack of social support are predictors of perceived autonomy (health related and global autonomy) as well as self-esteem. The effects of socio-demographic and clinical characteristics on the outcomes have been controlled for. We have decided to only include the variables concerning perceived overprotection by significant others and the medical specialist and lack of social support in these analyses, since these groups of variables are clearly associated with the three outcome variables.

The results of the regression analysis with perceived health related autonomy being the outcome variable are outlined in table 6.14. All three models hardly explain variance and the models turn out not to be significant. In the third model, in which the social support and overprotection variables have been added, the variable 'lack of social companionship' is a significant predictor. This indicates that a high level of experienced lack of social companionship is associated with a low level of health related autonomy.

Table 6.15 shows the results of the regression analysis with perceived global autonomy being the outcome variable. The first two models show that a high educational level is a significant predictor of perceived global autonomy. Both models, however, turn out to



explain hardly any variance. In the third model, in which the social support and overprotection variables have been added, perceived overprotection in the treatment by the medical specialist and experienced lack of emotional support with problems turn out to be significant predictors as well; as patients experience low levels of overprotection in the treatment by the medical specialist and high levels of lack of emotional support with problems, patients have a higher level of global autonomy. This last model explains 12% of the variance and is an improvement compared to the second model.

Finally, table 6.16 shows the results of the regression analysis with state self-esteem being the outcome variable. The socio-demographic characteristics explain only 1% of the variance (Model 1). The model in which the clinical characteristics have been added (Model 2) explains 2% more. When the experienced social support and overprotection variables are added to the model (Model 3) the explained variance increases by 15%. It turns out that the third model is an improvement compared to the second model. In this model, the serum albumin value is a significant predictor of state self-esteem. This means that a high level of serum albumin, i.e. a more favourable health condition, is associated with a high level of self-esteem. Furthermore, the results show that an experienced lack of daily emotional support and social companionship are associated with a low level of self-esteem, while an experienced lack of emotional support with problems is associated with a high level of self-esteem.

Table 6.14: Hierarchical multiple linear regression models to predict perceived health related autonomy (total group).

	<b>Model 1</b> (step 1) (N=103) Beta	<b>Model 2</b> (step 1+2) (N=103) Beta	<b>Model 3</b> (step 1+2+3) (N=103) Beta
<b>Step 1: Socio-demographic characteristics</b>			
Gender (ref: male)	-.09	-.10	-.07
Age in years	.09	.12	.02
Marital status (ref: married/living with partner)	.01	.04	.05
Educational level (ref: low)			
Moderate	.02	.02	.03
High	-.04	-.05	-.11
<b>Step 2: Clinical characteristics</b>			
Serum albumin		.08	.09
Type of treatment (ref: HD treatment)		.05	.02
Time on dialysis in years		.01	.03
<b>Step 3: Experienced social support and overprotection</b>			
<i>Overprotection</i>			
Significant others			.07
Treatment by medical specialist			-.03
Stimulation by medical specialist			.09
<i>Social support</i>			
Lack of daily emotional support			-.26
Lack of emotional support with problems			.32
Lack of social companionship			-.37*
R square (adjusted)	-.03	-.06	.01
F change model	.403	.243	2.054

\* p < .05.

\*\* p < .01.

\*\*\* p < .001.

Table 6.15: Hierarchical multiple linear regression models to predict perceived global autonomy (total group).

	<b>Model 1</b> (step 1) (N=103) Beta	<b>Model 2</b> (step 1+2) (N=103) Beta	<b>Model 3</b> (step 1+ 2+3) (N=103) Beta
<b>Step 1: Socio-demographic characteristics</b>			
Gender (ref: male)	-.08	-.08	-.01
Age in years	-.02	.03	.02
Marital status (ref: married/living with partner)	.02	.05	.06
Educational level (ref: low)			
Moderate	.17	.16	.11
High	.24*	.24*	.22*
<b>Step 2: Clinical characteristics</b>			
Serum albumin		-.04	-.04
Type of treatment (ref: HD treatment)		.15	.12
Time on dialysis in years		-.03	.02
<b>Step 3: Experienced social support and overprotection</b>			
<i>Overprotection</i>			
Significant others			-.06
Treatment by medical specialist			-.20*
Stimulation by medical specialist			-.20
<i>Social support</i>			
Lack of daily emotional support			-.22
Lack of emotional support with problems			.38*
Lack of social companionship			-.08
R square (adjusted)	.01	.00	.12*
F change model	1.225	.694	3.171**

\* p < .05.

\*\* p < .01.

\*\*\*p < .001.

Table 6.16: Hierarchical multiple linear regression models to predict state self-esteem (total group).

	<b>Model 1</b> (step 1) (N=103) Beta	<b>Model 2</b> (step 1+2) (N=103) Beta	<b>Model 3</b> (step 1+ 2+3) (N=103) Beta
<b>Step 1: Socio-demographic characteristics</b>			
Gender (ref: male)	-.18	-.19	-.13
Age in years	.03	.09	-.06
Marital status (ref: married/living with partner)	-.11	-.07	-.05
Educational level (ref: low)			
Moderate	.08	.09	.09
High	.09	.07	-.02
<b>Step 2: Clinical characteristics</b>			
Serum albumin		.19	.19*
Type of treatment (ref: HD treatment)		.05	.02
Time on dialysis in years		-.10	-.05
<b>Step 3: Experienced social support and overprotection</b>			
<i>Overprotection</i>			
Significant others			-.14
Treatment by medical specialist			.01
Stimulation by medical specialist			.09
<i>Social support</i>			
Lack of daily emotional support			-.32*
Lack of emotional support with problems			.32*
Lack of social companionship			-.33*
R square (adjusted)	.01	.03	.18**
F change model	1.297	1.481	3.773**

\* p < .05.

\*\* p < .01.

\*\*\* p < .001.

## 6.5 Conclusions

The results show that dialysis patients, on average, experience once in a while support from their close environment. At the same time, they do not feel deprived, as the low scores in the discrepancy variables show. The results show that patients who have been dialysing for more than five years have a greater unfulfilled need for company than patients who have been dialysing for two to five years. This association is plausible, because dialysis treatment heavily impacts upon the patient's physical condition. Therefore it can be expected that the longer one is on dialysis, the more limited the opportunities are to take part in social life, such as go shopping together, go to the cinema, or go out for a day.

On average, patients do not have the feeling that they are being overprotected by their significant others (like family, friends) or their doctors. It is notable that people who live without a partner and people who are treated with haemodialysis treatment turn out to experience more overprotection by their doctors (GP and medical specialist) with regard to undertaking activities, compared to, respectively, married people/people who are living with a partner and peritoneal dialysis patients.

The associations between the various kinds of social support show that people who experience little support or a lack of support have a stronger feeling to be overprotected. This is not in concordance with the definition of overprotection as receiving too much support. These findings indicate that a feeling of overprotection follows from receiving support that is not seen as supportive, but that is perhaps more controlling. People who feel that they are protected too much by their significant others also feel that they are protected too much by their doctors in the way they are treated by them. Additionally, we have seen that when patients feel overprotected by their GP, they also experience overprotection by their medical specialist. This is a striking result and it could be explained in two ways. This group of people presumably tends to regard support from whoever as being too much, patronizing, controlling etc. In this case, the association is explained by the perceptions of these patients. However, the relationship could also be explained by the fact that doctors and the patient's close environment, such as the partner, mutually influence one another. When, during a check-up visit, a doctor is for example very patronizing in presence of the patient and the partner, this behaviour can be copied by the partner and this can have an impact on the way the partner treats the patient.

When we look at the associations with perceived autonomy and self-esteem, we can see that there exist relationships between experienced social support and overprotection on the one hand, and perceived autonomy and self-esteem on the other hand. In general, we can conclude that low levels of experienced lack of social support and low levels of perceived overprotection, are associated with high levels of autonomy. People who feel that they receive high levels of social support, and who experience low levels of lack of support, have a higher self-esteem. In addition, a low level of perceived overprotection is related to higher self-esteem as well. Thus, people who feel that they receive sufficient support and who are supported in a positive way have a stronger feeling that they can do the things in life they wish to do and have stronger feelings of self-worth. There are trends visible with respect to employment (for at least 12h per week). People who are working turn out to experience less lack of emotional support with problems, and feel less overprotected by doctors regarding undertaking activities compared with people who are not working.

The associations between experienced support and overprotection on the one hand and perceived autonomy and self-esteem on the other hand are also demonstrated, to a certain degree, by the results of the regression analyses, which are corrected for socio-demographic and clinical characteristics. The results show that experienced lack of social support and overprotection explain the major part of the variance in self-esteem as well as perceived global autonomy. Perceived lack of social companionship is associated with a stronger feeling not being able to do what one wants to do, because of their health (low levels of health related autonomy). This association might be caused by the idea that social contacts, such as having visitors, a day trip with a friend, going to a party, are hardly possible any more because of the health condition. A high educational level is a significant predictor of a high level of perceived global autonomy. Additionally, the results show that people who feel less overprotected in the treatment by their medical specialist experience more global autonomy. A striking finding is that experiencing a lack of emotional support with problems is a predictor of high global autonomy.

A high serum albumin value, i.e. a more favourable health condition, is a predictor of high self-esteem. Less perceived lack of daily emotional support and social companionship turns out to be related to high self-esteem as well. A high level of experienced lack of emotional support with problems, on the other hand, is related to high self-esteem. It is possible that people with more self-esteem radiate a larger degree of self-esteem, with the result that their need for emotional support in case of problems is not noticed properly by their close environment. This kind of support should be triggered by a visible need for help with problems. The association between experienced lack of emotional support with problems and a high level of global autonomy could be explained in the same way; people who feel autonomous are perhaps not expected to need any help and, therefore, their need is not recognised.

The results of this study show that in particular experienced lack of support by the close environment or protective, controlling kinds of support from both significant others and doctors are associated with a low level of perceived autonomy and self-esteem and unemployment in dialysis patients. These findings suggest that it is important to take into account patients' need for support and to stimulate autonomy supportive behaviours in both patients and their social context. Patients' partners are probably the most important actors within the patients' social context, since they are directly involved with the patients' illness and treatment. They are affected by the patients' restrictions, and play a role in patients' adjustment to the illness and treatment. Therefore, they often feel responsible for their partners' well-being, and this may result in negative social support interactions, i.e. controlling, overprotective behaviour, which undermines patients' feelings of autonomy. For example one might take over tasks because one is worried about the amount of physical activities his/her partner undertakes. Care that focuses on the social context of the patient, partners in particular, is therefore recommendable; enabling patients to learn how to recruit the support they feel is needed from both significant others and doctors in an effective and positive way, and enabling partners to learn how to develop autonomy supportive behaviours to support patients with keeping up their daily activities, including work. Furthermore, it seems important to raise awareness among doctors about their role in this matter.

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## **7 Development of and first experiences with a behavioural self-regulation intervention for ESRD patients and their partners<sup>7</sup>**

### **7.1 Abstract**

Patients with end-stage renal disease (ESRD) experience difficulties participating in several domains, in particular paid work. The aim of this study was twofold: 1) to develop a psychological group intervention aimed at maintaining or widening ESRD patients' daily activities, including paid work, and increasing patients' feelings of autonomy, and 2) to evaluate the intervention on feasibility and first experiences.

The content of the intervention is based on the results of an empirical study and three theoretical models: self-regulation theory, social learning theory and self-determination theory. The intervention was evaluated by means of a pilot study in cooperation with three Dutch dialysis centres. Seven patients took part in the pilot study, of which five together with their partner.

The process of development and the components of the intervention are described. Implementation of the intervention in a clinical setting was successful. The results of the pilot study show that the intervention is feasible and acceptable to both participants and course leaders. Patients' self-observed results are encouraging. Furthermore, the study reveals areas of attention regarding the processes in the development and implementation of psychological interventions in general.

The results suggest that an approach in which cognitive, behavioural, and context aspects are integrated is promising, and lend support to evaluate both short term and long run effects of the intervention after refinement.

### **7.2 Introduction**

End-stage renal disease (ESRD) is a functional definition for the point at which a patient with chronic or acute renal failure cannot longer survive on existing kidney function. The patient with ESRD must then undergo dialysis or have a kidney transplant in order to survive. At the end of 2005, about 1,9 million people were receiving renal replacement therapy worldwide; about three quarters being treated by dialysis and one quarter by kidney transplant (Grassman, Gioberge, Moeller, & Brown, 2006). In 2006, 12,038 people in the Netherlands received renal replacement therapy (737 people per million Dutch residents) of whom 5,437 people received dialysis treatment and 6,601 received a kidney transplant (Oppe, Treur, Barendregt, & de Charro, 2007). ESRD patients on dialysis experience multiple symptoms, with pain, fatigue, pruritus and constipation in the majority of the patients (Murtagh, Addington-Hall, & Higginson, 2007). Several studies have demonstrated that ESRD patients on dialysis experience impaired physical, mental, and social functioning compared to general population samples (e.g. Khan et al., 1995; Merkus et al., 1997;1999; Mittal et al., 2001).

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<sup>7</sup> Zal ter publicatie worden aangeboden aan het tijdschrift *British Journal of Health Psychology* (Jansen et al.).

The combination of chronic dialysis with having or keeping a job seems especially difficult. Unemployment is common in dialyzed ESRD patients, with most studies reporting 24% to 40% of dialysis patients aged 18 to 64 years still working (Braun Curtin, Oberly, Sacksteder, & Friedman, 1996; Jansen, Rijken, Heijmans, & Boeschoten, in press; Theorell, Konarski-Svensson, Ahlmen, & Perski, 1991; Van Manen et al., 2001). In a Dutch study 35% of the ESRD patients of working age were still employed at the start of dialysis compared to 61% in the general population (Van Manen et al., 2001). During dialysis this percentage decreased further to 31% after six months of treatment. An important finding from the studies on ESRD patients is that many patients already quit their jobs before starting dialysis during the so-called pre-dialysis phase, which refers to the period in which patients are being prepared for renal replacement therapy. In the Netherlands, patients enter this phase when their renal function decreased to 20%.

A literature study by Heijmans and Rijken (2004) revealed a number of factors that contribute to unemployment in ESRD patients: socio-demographic factors such as age, gender, educational level; disease related factors such as severity of the disease, treatment modality, primary renal disease, comorbidity and pre-morbid physical and social functioning; external factors such as the type of work one performed before or during the illness and the attitude of the employer and colleagues (at that time). Findings are not consistent however, and there are still large individual differences in employment status between ESRD patients with a common socio-demographic or medical background. This indicates that other factors may play a role too.

The literature study revealed two psychological factors that may be closely linked to employment in ESRD patients, but that have not been studied systematically: 1) the patient's cognitive representation of the illness and its treatment and the possibilities he believes in for employment; 2) the way people in his immediate surroundings (spouse, children, doctor) support him in his effort to carry on with daily activities, including work. Within health psychology the first factor is known as illness and treatment perceptions, the latter as social support, including overprotection. These psychological factors are interesting as they might be changeable. Evidence for this comes from a study by Petrie and colleagues (Petrie, Cameron, Ellis, Buick, & Weinman, 2002) in which they showed that an in-hospital intervention designed to change patients' illness perceptions can result in improved functional outcome and an earlier return to work after myocardial infarction. Chronic pains studies provide evidence that altering patients' cognitions may be an important component of the effects of multidisciplinary pain programs. Reductions in pain catastrophizing have consistently been associated with improvements in pain severity, pain interference and depression (Moss-Morris, Humphrey, Johnson, & Petrie, 2007).

### **Empirical study**

The findings of the literature made us decide to start a study in which we investigated how ESRD patients' cognitive representations of their illness and treatment and the type of support they experience are associated with labour participation (employment for at least 12h per week), feelings of autonomy and self-esteem. Between March-December 2006 questionnaires were sent to 248 patients receiving dialysis treatment and 185

patients being prepared for dialysis (pre-dialysis patients); 166 dialysis (67%) and 109 pre-dialysis (59%) patients returned their questionnaires.

The results will be presented in detail elsewhere, but in general, we found that illness and treatment perceptions contributed significantly to the explained variance in perceived autonomy and self-esteem, after controlling for socio-demographic and clinical characteristics. Beliefs of personal control, less impact of the illness and its treatment and less concern were significant predictors of perceived autonomy and self-esteem in dialysis patients (Jansen et al., in press). In pre-dialysis patients, perceived autonomy and self-esteem were predicted by less perceived treatment disruption (Jansen et al., submitted). Furthermore, consistent bivariate relationships were observed in both patient groups with respect to employment status and perceptions about the illness and treatment, though these relationships did not reach statistical significance due to the low number of patients still employed. Furthermore, the results showed that social support, including overprotection by significant others and doctors, significantly contributed 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., in preparation).

### **7.3 Development intervention**

In view of these results, it seems beneficial to focus on these factors when contributing to the promotion of ESRD patients' labour participation and well-being. Nevertheless, evidence based interventions intervening on these factors in relation to labour participation and well-being are lacking. We decided to develop and pilot test a psychological intervention targeting these factors in order to maintain or widen ESRD patients' daily activities, including the performance of paid work, and increase patients' feelings of autonomy. By offering support in an early stage, drop out of the labour force and/or other daily activities might be prevented.

#### *Theoretical background*

The content of the intervention is based on the results of the empirical study and three theoretical models: self-regulation theory by Leventhal and colleagues (Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steele, 1984), social learning theory by Bandura (1977) 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 (CSM; Leventhal et al., 1980; Leventhal et al., 1984). According to this model people make sense of a threat to their health, such as symptoms or an illness, by developing their own cognitive representation of that threat. This representation varies along five dimensions: 1) the identity or label for the threat (e.g. flu, asthma, diabetes or renal disease) and its symptoms (e.g. cough, headache, or dizziness); 2) the time-line, i.e. the time it takes for the disease to develop as well as the duration of and recovery from the disease; 3) the cause (e.g. exposure to a draft, stress, bad food, or alcohol abuse); 4) the consequences, both real and imagined (e.g. hospitalisation, absence

from work, sexual dysfunction, sudden death, etc.); and 5) cure or control, i.e. the perception of the degree to which a disease can be influenced or cured (Maes & Karoly, 2005). These representations determine how patients respond on a behavioural and emotional level to their illness. Previous research has shown that positive illness perceptions are associated with better outcomes (Hagger & Orbell, 2003; Petrie, Jago, & Devcich, 2007; Petrie & Weinman, 1997). Petrie and colleagues (Petrie, Weinman, Sharpe, & Buckley, 1996; Petrie et al., 2002) were one of the first who translated the principles of self-regulation theory into an in-hospital intervention to change illness perceptions after myocardial infarction (MI). Results of a RCT study showed that the intervention produced positive changes in patients' views of their MI, and resulted in earlier return to work and lower reported rates of angina symptoms, relative to a control group. Besides illness representations, patients' ideas about treatment also play a role in the way patients cope with their illness (Horne, 1997; Horne, 2003; Horne et al., 2004). A recent pilot study demonstrated that a simple intervention to change haemodialysis patients' perceptions of phosphate-binding medication, improved treatment beliefs and knowledge immediately after the intervention, in comparison to a control group (Karamanidou, Weinman, & Horne, 2008).

According to Leventhal and colleagues (Leventhal, Leventhal, & Nguyen, 1985), illness perceptions of patients' family members should be taken into account as well when investigating patients' illness representations. Heijmans, De Ridder and Bensing (1999) found that dissimilarity of illness perceptions of chronic ill patients and their spouses have a strong impact on patients' adaptive outcomes, such as physical functioning, social functioning, psychological adjustment and vitality. These results demonstrate the importance of the role of significant others and their beliefs for patient's coping and adaptation with chronic illness.

### *Social learning theory*

According to Bandura's social learning theory (Bandura, 1977; 1997) human beings learn by watching other people behave, reading about what other people do, and generally observing the world (observational learning). Use of peer modelling, that is using other patients as role models, and peer support are approaches grounded in this theory. Central concepts within this theory are self-efficacy and outcome expectations. Self-efficacy is a person's belief in his own ability to perform a particular behaviour successfully regardless of circumstances or contexts. Outcome expectations are beliefs about the effectiveness of the behaviour, for example the advantages and disadvantages of an action. These cognitive processes play an important role in the acquisition and retention of new behaviour. If people think that a certain behaviour will lead to a certain outcome, they will adopt that behaviour, but only if they consider themselves able to do so. Improving patients' self-efficacy beliefs is a key element of the Chronic Disease Self-Management Program (CDSMP; Lorig et al., 2001). The overall goal of the CDSMP is to enable participants to build self-confidence to assume a major role maintaining their health and managing their chronic health conditions. Program sessions are highly participative, where mutual support and success builds the participants' confidence in their ability to manage their health and maintain active and fulfilling lives. Results from a RCT study showed that the intervention group experienced, both at six months and two years after the start of the program, an increase in self-efficacy, well-being, health

behaviours, and physical health status in comparison to the control group (Lorig et al., 1999; Lorig et al., 2001). However, results are not consistent. A study by Elzen and colleagues (Elzen, Slaets, Snijders & Steverink, 2007) did not yield any evidence for the effectiveness of the CDSMP on self-efficacy, self-management behaviour or health status of chronically ill older people in the Netherlands.

### *Self-determination theory*

Self-determination theory, a motivation theory, emphasises the importance of autonomy for individual's well-being (SDT; Deci & Ryan, 1985). One is autonomous to the degree that one experiences choice, willingness, and personal endorsement of one's actions. It is important to note that autonomy is different from independence (Deci & Ryan, 2000; Ryan, 1995). 'Behaving autonomously does not, however, mean behaving independently. Rather, it means behaving of one's own volition and will, in accord with one's inner self. One need not be independent to be volitional.' (Williams & Deci, 1998). A person can at the same time be dependent on for example knowledge, guidance and support from others. According to SDT, successful accomplishment of desired behaviours, for example increasing daily activities, occurs when patients themselves view this behaviour as important, and not because the behaviour is pressured or coerced by for example one's spouse or health care provider. Whether people will be autonomous in regulating a behaviour can be predicted from individual characteristics as well as characteristics of relevant social contexts. Contexts which are autonomy-supportive, facilitate more autonomous regulatory processes, and thus promote effective behaviour change. 'The behaviours that are integral to autonomy support concern providing choices about how to behave, the information necessary to make wise choices, meaningful rationales for suggested behaviours, acknowledgment of feelings about behavioural options, and encouragement to choose and to persist (Deci, Eghrari, Patrick & Leone, 1994; Ryan, 1982). In contrast, being controlling means pressuring others to behave in particular ways while taking little account of their perspectives.' (Williams & Deci, 1998). Autonomy support by health care providers and important others has resulted in improved health behaviours (Williams, Grow, Freedman, Ryan, & Deci, 1996; Williams et al., 2006; Williams, Rodin, Ryan, Grolnick, & Deci, 1998), and positive relationships have been found between autonomy support and both psychological experience and well-being in various contexts (Baard, Deci & Ryan, 2004; Deci, La Guardia, Moller, Scheiner, & Ryan, 2006; Kasser & Ryan, 1999). Patients' family members are probably the most important actors within the patients' social context, since they are directly involved with the patients' illness and treatment. Members of the family are affected by the patients' restrictions, and play a role in patients' adjustment to the illness and treatment. Family members, in particular spouses, therefore often feel responsible for their partners' well being, and this may result in negative social support interactions, i.e. controlling, overprotective behaviour, which undermines patients' feelings of autonomy. For example, one might take over tasks because one is worried about the amount of physical activities his/her partner undertakes and insists his/her partner takes more rest. Clark and Dunbar (2003a) translated the principles of SDT into a family partnership intervention developed for heart failure patients and their family members, in which family members learned how to develop autonomy supportive behaviours to support patients with the required lifestyle changes, and patients learned how to recruit the support they felt was

needed in an effective and positive way. The results of an experimental pilot study demonstrated that patients who received the family partnership intervention showed greater self-management in dietary sodium behaviours than patients who received a minimal intervention (Dunbar et al., 2005).

The self-regulation theory, social learning theory and the self-determination theory all focus on different aspects, and the combination of the three theories might be promising.

#### *Outline intervention*

The intervention was a group course for ESRD patients aged 18 to 64 years, who were being prepared for dialysis or who recently started with dialysis ( $\leq 12$  months). The course group consisted of at least five ESRD patients and their partners if they wished to attend. The course comprised six sessions every two weeks of 2,5 hours each, and one return session after three months. Course material for participants included a handbook which contained assignments, practical and theoretical information.

The course focused on changing misperceptions and negative illness and treatment perceptions, increasing self-efficacy beliefs, and stimulating social support. The course was delivered by a health psychologist using a detailed teaching manual. The first course session was given in cooperation with a nephrologist (renal specialist) and in half of the sessions a labour expert was present.

#### *Content sessions*

For the first three sessions of our intervention we followed the method developed by Petrie et al. (1996; 2002). In the first session ('Dialysis, what does this mean to me and my work?' part 1), information is given about the illness and treatment by a nephrologist, with special attention for ESRD symptoms. Next, illness and treatment perceptions are explored on the basis of participants' responses on items of the brief Illness Perception Questionnaire (Brief IPQ; Broadbent, Petrie, Main, & Weinman, 2006) and the Treatment Effects Questionnaire (TEQ; originally developed as the IEQ-Tx by Greenberg & Peterson (2002); adapted by Griva, Jayasena, Davenport, Harrison, & Newman (2009)). Subsequently, perceptions are discussed in order to recognise different beliefs and different ways of coping.

In the second session ('Dialysis, what does this mean to me and my work?' part 2), participants' beliefs about the importance and attainability of work and private life related activities are explored and discussed, on the basis of their responses to a short questionnaire based on the SHOCQ (De Ridder & Kuijer, 2007). During this session a labour expert is present to explain about work and ESRD. Topics such as continuation of work, reintegration, retraining, work adjustments, and legislation are addressed.

Questions, personal experiences and wishes regarding these topics are discussed, and solutions are provided for possible problems. Perceived possibilities are encouraged if attainable, and discouraged if not feasible. In both session one and two, special attention is given to ideas about the consequences of the disease and treatment, particularly beliefs that activities need to be reduced because of the dialysis treatment, and work cannot be combined with dialysis treatment. Negative beliefs and misperceptions are challenged and invalidated by highlighting positive beliefs, giving practical examples, and addressing

personal stories of ESRD patients which are described throughout the course book; broadening participants' views on available possibilities.

The third session (*'Thinking and doing'*), builds on the patients' and partners' perceived consequences, and special attention is given to personal control beliefs. Furthermore, information is provided on the relationship between events (getting a disease, starting with a treatment), beliefs, feelings and behaviour, and on the importance of turning maladaptive thoughts into constructive thoughts. In preparation of this session, all patients have to think of two personal goals (one related to work and one related to their private lives), which they themselves want to realise during the course, and evaluate these goals extensively on personal importance and attainability. Patients' goals are discussed within the group and adjusted if necessary. Whether goals need to be adjusted or not is based upon patients' personal importance and attainability scores. Examples of goals are starting and maintaining a walking program, starting volunteer work (collecting for charity) etc. Subsequently, patients divide their main goals into sub-goals and learn how to develop an action plan in order to reach their sub-goals. Thus people work towards their main goals in small steps. In the plan one has to indicate what one is going to do, and how much, how often, and when one is going to carry out the action. Furthermore, one has to think about the attainability of the action and the required social support. From this third session on, patients have to develop and carry out an action plan every two weeks, with assistance of their partners. In these three sessions, observational learning techniques are used, such as didactic teaching, written material, practice stories from peers, and group discussion.

Perceived self-efficacy influences the choice of behaviour and settings, and it also influences how much effort will be spent on a given behaviour and how long this effort will be maintained. So, changing inadequate perceptions is a first step towards behaviour change, but self-efficacy and autonomy support are necessary to actually perform the intended behaviour. In session 4 to 6 the focus is on self-efficacy. For the development of a framework for sessions 4 to 6, the CDMP (Lorig et al., 2001) served as an example. In these sessions self-efficacy beliefs in relation to work and activities in general are explored and enhanced using techniques such as self-monitoring, guided mastery of skills through two weekly action plans and feedback of progress, modelling of self-management behaviours and problem solving strategies, to for example overcome barriers and handle conflicting goals.

In session four (*'Fatigued, but active'*), special attention is given to the relationship between (in)activity and fatigue. Participants' experiences with fatigue, limited energy and coping strategies are discussed together with practice examples. In preparation to the session patients keep a daily fatigue diary for two weeks, in order to gain more insight into existing fatigue complaints and discover patterns regarding fatigue complaints. Experiences with the diaries are discussed and information is given on how to manage time and energy in an adequate way by structuring and setting priorities with regard to daily activities.

In session five (*'Being active, is teamwork'*), attention is particularly paid to the role of the social network. Patients who participate without a partner are invited to bring along a family member or friend. Supportive and unsupportive behaviours of spouses (family members/friends) are discussed together with the ways patients ask for support, on the base of participants' responses to short questionnaires which were based upon the BSSS

(Schwarzer & Shulz, 2000), FCCQ (Clark & Dunbar, 2003b), Overprotection scale (Buunk, Berkhuysen, Sanderman, Nieuwland, & Ranchor, 1996), and their experiences with social support when carrying out action plans. Partners (family members/friends) learn ways to give support and to prevent overprotection, and patients learn how to ask for support from spouses (family members/friends) as well as health care providers in an adequate way. The intervention by Clark and Dunbar was used as an example for the development of this session.

In session six (*'Work and dialysis'*), the focus is on developing an action plan with respect to a work related goal, for the next three months. Advice is given on which steps to take within domains such as work, reintegration, and how to prepare and have a conversation with relevant parties, such as employers, colleagues and company doctors. In preparation of this session, all patients have to think of a personal work goal, and have to check whether these goals are attainable and important for them. During the session patients' goals are discussed and adjusted if necessary. Subsequently, patients develop an action plan together with their partners, under guidance of the labour expert and health psychologist, and explain and discuss their plans within the group.

During the return session the implementation of the work related action plans will be evaluated. Furthermore, participants tell about what the course has given them, and attention will be paid to how one can maintain or widen reached goals.

## 7.4 Pilot intervention

In the months April-August 2008 the intervention was evaluated on feasibility and first experiences by means of a pilot study. During this period a course was given to patients and their partners from three Dutch dialysis centres, by a health psychologist in cooperation with a nephrologist and labour expert. Patients were recruited by social workers working in the dialysis centres. All meetings were held in one of the three participating centres. Feasibility and first experiences were investigated by means of evaluation forms and interviews. Four topics and related questions were identified by which the feasibility and first experiences were evaluated:

### 1) Implementation intervention

Were we able to implement the intervention in a clinical setting? Were there any side effects, like increased work loads for health care providers?

### 2) Recruitment and retention

Were we able to reach the target group? What was the participation rate? What can be said about drop outs?

### 3) Acceptability

*Course participants' views:* Was the course acceptable to participants; what did participants think about working in groups, the delivery of the course, the provided information and applied techniques?

*Course leaders' views:* Was the course acceptable to course leaders; what did course leaders think about working in groups, the feasibility and delivery of the course, the provided information and applied techniques?

### 4) Perceived outcomes

What were the course outcomes perceived by the participating patients?



### **Implementation intervention**

The involved social workers within the three dialysis centres were positive about the organisation of the course. Two social workers stated that the recruitment of the patients resulted in a minimal burden. The other two social workers indicated that it was a substantial burden, but regarded it as manageable. The social workers furthermore indicated that they did not experience an increase in requests for information and support of participating patients, neither did the other health care providers (nephrologists and dialysis nurses). According to the social workers, the number and nature of their contacts with the participating patients remained the same during the period in which the course was held.

### **Recruitment and retention**

Participants were recruited from three dialysis centres situated in the central part of the Netherlands, during February 2008. The inclusion criteria were: patient has got a decreased renal function and renal replacement therapy is inevitable (ESRD), is being prepared for dialysis treatment or is receiving dialysis for a maximum period of 12 months. The exclusion criteria were: patient is younger than 18 years or older than 64 years, speaks the Dutch language insufficiently, has got a life expectancy of less than 6 months, is not able to perform any work (in the future) because of a very poor health status, has got insufficient intellectual/cognitive capacities to participate in the course and study, is momentarily undergoing psychological, psychotherapeutic or psychiatric treatment. Twenty-eight eligible patients were selected by the involved social workers and received information on the course and the study. Among the 28 approached patients were 19 males and 9 females between the ages of 20 and 62 years ( $M=45.5$  yrs,  $SD=12.1$  yrs). Social workers contacted patients to inform whether patients were planning to participate; ten patients signed on. Reasons for non response were mostly related to the inability to fit the course into one's daily schedule. Three patients dropped out without attending any meetings because of health related reasons, resulting in seven patients who actually participated. All participating patients lived together with a partner, and five of them took part with their partner. Among the participating patients were four males and three females, 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.

### **Acceptability**

#### *Course participants' views*

The majority of the participants was satisfied about the length, number, and frequency of the meetings, though there was more variability with regard to the experiences with the course time. All participants stated that they liked to work in a group; the mixture of experiences and information of both pre-dialysis and dialysis patients was highly valued. Participants considered all the attended meetings as useful or considerably useful on a three point scale (useful - considerably useful - not useful). The meetings in which the action plan was introduced (meeting 3), the topic fatigue was addressed (meeting 4), and the focus was on developing an action plan for a long term work related goal (meeting 6) were most often indicated as useful. According to a majority of the participants the various aspects of living with ESRD got sufficient attention within the course. However,

it is notable that the need for information differed between the participants; some patients reported that they were interested in more information on certain addressed topics, like dialysis and labour legislation, while others reported that they were less interested in these topics. Furthermore, two participating partners wanted more attention for the partner role, in particular for topics such as how partners cope with the disease. Developing and carrying out action plans were important elements within the course, the experiences with these plans are outlined in table 7.1. The great majority considered the action plans as useful and the number of plans as good. Five out of ten participants regarded the difficulty grade of the action plans as good; however, an equal part found the development of these plans difficult. Notwithstanding that, the practicability of the action plans was mostly considered as good. Furthermore, participants stated that all the assignments within the course were useful. When asking patients which exercises helped them the most, the answers mostly referred to the fatigue diary and the development of the action plans. One of the participating partners indicated that the assignments in which one was stimulated to think about ways to help your partner to cope with the illness were very helpful.

Table 7.1: Participants' experiences with action plans (N=9-11)

	<i>Too much</i>	<i>Good</i>	<i>Too little</i>
<b>Number of plans</b>	<b>1</b>	<b>9</b>	<b>-</b>
	<i>Difficult</i>	<i>Good</i>	<i>Easy</i>
<b>Difficulty</b>	<b>5</b>	<b>5</b>	<b>-</b>
	<i>Useful</i>	<i>Rather useful</i>	<i>Not useful</i>
<b>Usefulness</b>	<b>7</b>	<b>2</b>	<b>-</b>
	<i>Poor</i>	<i>Reasonable</i>	<i>Good</i>
<b>Practicability</b>	<b>-</b>	<b>4</b>	<b>6</b>

According to the majority of the participants, the course leaders addressed individual needs, situations and questions adequately. In addition, participants indicated that the course leaders were much involved with the group as a whole. The greater part of the participants was satisfied about the clarity of the provided feedback and information (table 7.2).

Table 7.2: Participants' experiences with course leaders (N=11)

	<i>Not at all</i>	<i>Somewhat</i>	<i>Quite a lot</i>	<i>Very much</i>
<b>Were your personal situation and needs considered?</b>	-	<b>1</b>	<b>7</b>	<b>3</b>
<b>Was there attention for your questions and needs?</b>	-	<b>1</b>	<b>4</b>	<b>6</b>
<b>Was the provided feedback clear?</b>	-	<b>1</b>	<b>6</b>	<b>4</b>
<b>Was the provided information clear?</b>	-	<b>1</b>	<b>7</b>	<b>3</b>
<b>Was there involvement towards the group?</b>	-	-	<b>6</b>	<b>5</b>

### *Course leaders' views*

According to the course leaders, participants regarded it as pleasant to work in groups; there was a lot of open discussion, cooperation, motivation, and mutual interest. All course leaders are advocates of larger course groups, so that opportunities for cooperation and discussion will increase. In case of larger groups it is proposed to work with two main course leaders, in order to monitor the group process and the process with respect to content. The course leaders had good experiences with the course feasibility and delivery. According to the course leaders, the course content corresponded with the participants' personal needs and situations. In order to optimize this link, it was advised to reduce general information and promote participants' personal contribution. Furthermore, it was advised to create more opportunities for partners to exchange experiences. Participants sometimes had difficulty doing the exercises. It is therefore recommended to work mainly in (sub)groups on the various exercises, and to spend more time on the pre and post discussion of the exercises, in particular the action plans. The course leaders stated that the group composition was good. Though, they stress that it is important to maximize the strains to include patients shortly after diagnosis. In this phase of the illness, patients often do not have insight into the consequences of the illness and treatment for their daily life, and as a result they are not able to anticipate on necessary adjustments in order to prevent problems in for example the work domain. Therefore this group of patients can probably benefit the most from the assistance offered in the course. By making participants timely aware of problems which can occur, and assisting them with making a plan in order to anticipate on these problems, it is prevented that patients end up in hopeless situations and that issues have to be fixed later on.

### **Perceived outcomes**

#### *Self-observed results*

Most patients indicated that they were able to work on their goals during the course (table 7.3). In addition, several patients observed changes in their personal situations as a result of the course. One patient stated: 'I have found a job, do more at home and I have become more active in general.'. Another patient reported: 'I have become calmer when doing activities, because I take more time for it.'. Several patients indicated that by mainly the action plans and fatigue diary they were better able to divide their time and energy during the day. The answers furthermore showed that some patients learned to involve their social environment in their illness and treatment: 'I am more conscious of the consequences of my illness and get more support from family and friends.', '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 expect that they will put the things they have learned into practice in the future (table 7.3).

Table 7.3: Patients' experienced results (N=7)

	<i>Not at all</i>	<i>Somewhat</i>	<i>Quite a lot</i>	<i>Very much</i>
<b>Were you able to work on your goals during the course?</b>	-	3	3	1
<b>To what extent do you think you will put the things you have learned into practice in the future?</b>	1	2	3	1

Participants, both patients and partners, valued the course with an average grade of 7,6 on a scale from 1 to 10, and all participants recommended the course to other patients and their partners. Accompanying statements were:

- The course gives insight into how “healthy” you still are, and what and how much you still can do.’
- ‘You learn a lot, not only from the information offered by the course leaders, but also from each other.’
- ‘Wonderful way to learn what you should do to stay on the job. 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.’
- ‘By following the course one is better prepared for possible future complications.’

## 7.5 Discussion

The first aim of this study was to develop a psychological intervention to assist ESRD patients and their partners with integrating the renal disease and treatment in their daily activities, primarily work, and increasing patients’ autonomy. The focus of the intervention can be divided into three broad aspects: 1) stimulate positive (realistic) beliefs about the disease, treatment and possibilities to stay active in both patients and partners and change maladaptive beliefs, 2) increase patients’ self-efficacy, and 3) stimulate autonomy supportive behaviour in both patients and partners. The second aim of this study was to test the intervention on feasibility and to evaluate the first experiences with the course of the participants, course leaders and involved health care providers.

We were successful in developing a psychological intervention in which various aspects that are important for patients’ self-regulatory processes are addressed, namely cognitive, behavioural, and contexts aspects. Furthermore, the implementation of the intervention in a clinical setting was successful. The dialysis centres who participated were strongly supportive of the intervention, since all the three centres endorse the necessity of this type of assistance. The cooperation with the three dialysis centres worked very well; together the centres approached enough potential participants. An area of attention however is the participation rate, which was below the expected rate regarding intervention studies. The reasons for refusal provide information for subsequent intervention recruitment, and show that it is especially important that the course can be fitted into patients’ daily affairs. Thus, with respect to future courses it is wise to consider where and when the meetings are held and how the patient can get there. When we compare the approached patients with the patients who actually participated then we can see that no young patients (<30 yrs) took part in the course, while some of them were approached. Thus, more efforts are needed to reach this group of patients. It is advisable to emphasize that besides work, attention is given to aspects like education and training. None of the seven participating patients withdrew from the course, which indicates that all patients regarded the course as useful.

The participants and course leaders were on the whole positive about the course format. Participants were less satisfied about the moment on which the course was held. Preference for course times seems very personal since patients differ regarding dialysis and working schedules. These findings highlight the importance of flexibility in scheduling future courses.

Group discussion, practice stories and didactic teaching were important elements within the course and strategies to broaden participants' views on available possibilities and consequently to promote positive beliefs in participants. 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. Participants had positive attitudes towards the group element, and indicated that they valued the opportunity to exchange knowledge and experiences and learned from it. The course leaders also indicated that there was a lot of open discussion, cooperation and mutual interest, and think it is important to increase the opportunities for cooperation and discussion in order to improve the group process and in turn the learning process. This should be done by increasing the number of participants within the group to a minimum number of eight patients. However, when working with larger groups it is essential to have two course leaders so that the process with respect to the content and group will be warranted. Regarding the group composition course leaders stress that more efforts have to be undertaken to include patients shortly after diagnosis, in order to assist them during the early phase of the illness and to work preventative. Moreover, research suggests that interventions to change cognitions should focus on patients in an early stage of the illness process (Heijmans et al., submitted; Petrie et al., 2002). The fact that various disciplines and consequently knowledge come together in an early phase of the illness process, can be seen as a great advantage of the course. The addressed topics within the course appeared to be relevant to all the participants. One area of attention though is the adjustment of the given information to the individual information preferences. The differences in these preferences are probably partly caused by the differences in participants' illness and/or treatment stages. It is therefore advised to reduce the amount of general information and spend more time on exploring and discussing individual information needs. This can be done throughout the course or by organising separate question times. Furthermore, it was suggested to create more possibilities for partners to exchange experiences with respect to how they deal with their partners' disease. One can think of occasionally letting partners work in separate groups, so that partners can talk about their experiences more freely. Clark and Dunbar (2003a) stress the importance of taking into account the family members' experiences and own needs for support.

The participants' attitudes towards the exercises were good, especially the fatigue diary and action plans were regarded as useful. These exercises aimed at providing a framework for ways to structure desired activities and make activities better attainable, lowering the threshold for performing these activities and consequently promoting patients' self-efficacy beliefs. Patients indicated that by means of these exercises they were better able to divide their time and energy during the day. Furthermore, one patient stated that creating plans to reach goals gave peace of mind. However, some participants encountered difficulties with the exercises. To tackle this problem, it is recommended to work in small groups on these exercises, to pay more attention to the discussion of exercises and to give more examples so that participants are better able to relate to it.

In addition, patients' self-observed results from the course were encouraging. The involved health care providers reported no unfavourable consequences because of their cooperation with the course. Moreover, it could be expected that health care providers, especially social workers, in the long run experience favourable consequences from the intervention, since it can be expected that an intervention of this kind prevents problems or anticipates on problems which social workers normally encounter in their regular care.

Further research is needed to evaluate the actual effectiveness of the course both short term and in the long run, i.e. whether the course leads to less drop out of the labour force and increased feelings of autonomy. Findings from this pilot study are encouraging and suggest that the approach in which cognitive, behavioural, and context aspects are integrated is promising. Maintenance of paid work and reintegration into employment are complex processes, and a positive attitude, social support as well as self-efficacy beliefs are needed to pass through these processes. Many reintegration programs use action plans, i.e. plans by which goals are reached in small steps, but for these plans to be effective it is of great importance that patients themselves support these goals (autonomous rather than controlled).

The results lend support to further study this intervention after refinement based on the given recommendations. Moreover, 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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