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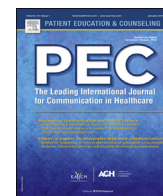
Citation

Note: To cite this publication please use the final published version (if applicable).

Predicting health-related quality of life in dialysis patients: Factors related to negative outcome expectancies and social support

Judith Tommel[a],[*], Andrea W.M. Evers[a], Henk W. van Hamersvelt[b], Rien Jordens[b], Sandra van Dijk[a], Luuk B. Hilbrands[b], Henriët van Middendorp[a], For the E-HELD Study Group

[a] Health, Medical and Neuropsychology Unit, Institute of Psychology, Faculty of Social and Behavioural Sciences, Leiden University, Wassenaarseweg 52, 2333 AK Leiden, the Netherlands
[b] Department of Nephrology, Radboud Institute for Health Sciences, Radboud University Medical Center, Geert Grooteplein Zuid 10, 6525 GA Nijmegen, the Netherlands

ABSTRACT

Objectives: Dialysis patients report a low health-related quality of life (HRQOL) due to high disease burden and far-reaching consequences of dialysis treatment. This study examined several cognitive-behavioral and social factors, with a focus on negative outcome expectancies, that might be relevant for HRQOL in end-stage kidney disease (ESKD) patients treated with dialysis.
Methods: Patients treated with hemodialysis or peritoneal dialysis were recruited from Dutch hospitals and dialysis centers. Patients completed self-report questionnaires at baseline (n = 175) and six months follow-up (n = 130). Multiple regression analyses were performed.
Results: Higher scores on factors related to negative outcome expectancies at baseline, especially helplessness and worrying, and less perceived social support were significantly related to worse HRQOL six months later. When controlling for baseline HRQOL, besides sex and comorbidity, helplessness remained significantly predictive of worse HRQOL six months later, indicating that helplessness is associated with changes in HRQOL over time.
Conclusions: Negative outcome expectancies and social support are relevant markers for HRQOL and/or changes in HRQOL over time.
Practice implications: Negative outcome expectancies could be prevented or diminished by enhanced treatment information, an improved patient-clinician relationship, and interventions that promote adaptive and realistic expectations. Additionally, increasing supportive social relationships could be a relevant treatment focus.

1. Introduction

End-stage kidney disease (ESKD) is the last stage of chronic kidney disease, which has a large impact on patients' lives as it affects patients' physical, psychological, as well as social well-being [1,2]. In patients with ESKD, kidney function has declined to 15 percent of normal functioning. In order to stay alive, patients need a kidney transplant or dialysis treatment to replace kidney function. In the United States, over 700,000 patients receive treatment for ESKD, giving a point prevalence of 2,206 per million population [3]. Most of them are treated with hemodialysis (HD) three times per week. In HD, a machine is used to clean the blood. Peritoneal dialysis (PD) is another type of dialysis treatment which needs to be repeated four to six times a day. In PD, the inside lining of the abdominal cavity (peritoneum) is used as a natural filter [4]. Although the specific consequences differ per dialysis type, dialysis is a highly intrusive and demanding treatment [5].

Many dialysis patients experience disabilities and suffer from various problems, such as fatigue, itch, pain, depression, anxiety, social difficulties, and a decreased sense of independence [6–9]. Not surprisingly, patients' quality of life is remarkably lower than that of the general population [10,11]. Moreover, health-related quality of life (HRQOL) is associated with morbidity and mortality in dialysis patients [11]. Clinical characteristics (e.g., comorbidity,

* Corresponding author.
E-mail addresses: j.tommel@fsw.leidenuniv.nl (J. Tommel), a.evers@fsw.leidenuniv.nl (A.W.M. Evers), Henk.vanHamersvelt@radboudumc.nl (H.W. van Hamersvelt), erienjordens@gmail.com (R. Jordens), SDijk@FSW.leidenuniv.nl (S. van Dijk), Luuk.Hilbrands@radboudumc.nl (L.B. Hilbrands), h.vanmiddendorp@fsw.leidenuniv.nl (H. van Middendorp).

dialysis type, residual kidney function, and hemoglobin level) seem to explain dialysis patients' HRQOL only to a limited extent [10,12,13]. Cognitive-behavioral and social factors, on the other hand, are known to have a considerable impact on HRQOL in patients with a chronic illness [14].

The literature suggests several potential cognitive-behavioral and social predictors of HRQOL in chronic illness. Cognitive-behavioral factors involve general ways patients perceive and think about their illness. For example, having a negative expectancy of treatment outcome is found to have a negative effect on the course and treatment success of a variety of medical conditions [15]. Negative outcome expectancies could be reflected in illness cognitions, such as being able to accept the disease versus experiencing a lack of control in handling the disease, which may lead to feelings of helplessness regarding the disease and its consequences [16,17]. Additionally, patients who tend to worry about future outcomes frequently have both a lower HRQOL [18] and more somatic symptoms [19]. Another potentially important predictor of HRQOL is the patient's confidence in its ability to handle potential stressors, known as self-efficacy [20–23]. In addition to these cognitive-behavioral factors, social aspects have been found to affect HRQOL in patients with various chronic diseases [24]. Social support serves as a buffer to stressors and protects against unfavorable disease outcomes [14] and is associated with better HRQOL and decreased somatic symptoms and worrying [19,22,25–27]. Although the positive consequences of social support have been shown rather consistently, hardly any research in chronic somatic populations has been conducted on the potential consequences of (deficits in) social skills of patients. An example of this is being excessively aware of other people's behavior and feelings, defined as interpersonal sensitivity [28,29].

The importance of these cognitive-behavioral and social factors has been demonstrated before; however, there remains a clear need for a thorough examination of multiple cognitive-behavioral and social factors in dialysis patients. Especially with regard to negative outcome expectancies, little work has been done to asses if and how outcome expectancies relate to treatment outcome in dialysis patients.

The objective of the current study is to determine which cognitive-behavioral and social factors are relevant for HRQOL and HRQOL changes in dialysis patients, after taking into account demographic and clinical characteristics. It is expected that factors related to negative outcome expectancies (higher levels of helplessness and worrying and lower levels of self-efficacy) will be associated with lower HRQOL. In addition, we expect lower levels of illness acceptance and social support and higher levels of interpersonal sensitivity to be associated with lower HRQOL. By examining a broad range of factors, this study may provide concrete indications for screening and interventions for improving HRQOL in dialysis patients.

2. Methods

2.1. Participants and procedure

During the data collection period (2013–2015), hemodialysis and peritoneal dialysis patients from multiple Dutch hospitals (Radboud University Medical Center, VieCuri medical center, Jeroen Bosch Hospital, Ravenstein Dialysis Centre, Bernhoven Hospital, Canisius Wilhelmina Hospital) were screened for participation. Exclusion criteria were: not being fluent in the Dutch language, life expectancy <6 months, psychiatric problems, recent major life events, and cognitive problems. After signing informed consent, patients completed questionnaires at baseline and at six months follow-up.

The Ethics Committee of the Radboud University Medical Center decided that the study did not fall within the scope of the Medical Research Involving Human Subjects Act, because of the observational nature of the study in which no action or behavior was imposed on the participants. Based on the validity of the scientific research questions, the methodology, the safety and privacy of the participants, they had no objections against the conduct of the study. In all participating centers, the executive board approved the study. The research was conducted in accordance with the Helsinki Declaration.

2.2. Measures

2.2.1. Demographic and clinical characteristics

Demographic and clinical characteristics were assessed with a general checklist and extracted from medical files. The Charlson Comorbidity Index was determined by a trained nurse specialist (RJ), with higher scores indicating a higher level of comorbidity.

2.2.2. Physical and mental HRQOL

The RAND Short Form-36 Health Status Inventory (RAND SF-36) [30] was used to measure HRQOL at baseline and 6 months follow-up. The RAND SF-36 contains 36 items that can be summarized into two composite scores: physical health and mental health, with higher scores indicating better HRQOL. The Hays norm-based scoring algorithm was applied, transforming raw scores into T-scores ($M = 50 \pm 10$ in the general population) [30]. In this sample, the internal consistencies were good (physical health composite: $\alpha = 0.91$ and 0.93; mental health composite: $\alpha = 0.86$ and 0.90 at baseline and follow-up, respectively).

2.2.3. Cognitive-behavioral factors

2.2.3.1. Negative outcome expectancies.
The subscale Helplessness of the Illness Cognition Questionnaire (ICQ) [16] was used to assess helplessness. This subscale contains 6 items, with higher scores indicating a higher level of helplessness (Cronbach's $\alpha = 0.87$). The Penn State Worry Questionnaire (PSWQ) [31] was used to measure worrying. The PSWQ contains 16 items. Higher scores indicate a stronger tendency to worry (Cronbach's $\alpha = 0.91$). The Generalized Self-Efficacy Scale (GSES) [32] was used to assess self-efficacy. The GSES consists of 10 items, with higher scores indicating a greater generalized sense of self-efficacy (Cronbach's $\alpha = 0.86$).

2.2.3.2. Acceptance.
The subscale Acceptance of the Illness Cognition Questionnaire (ICQ) [16] was used to assess illness acceptance. This subscale consists of 6 items, with higher scores indicating a higher level of acceptance (Cronbach's $\alpha = 0.91$).

2.2.4. Social factors

2.2.4.1. Social support.
The Perceived Support subscale of the Inventory of Social Reliance (ISR) [33] was used to measure perceived support. This subscale contains 5 items, with higher scores indicating a higher level of perceived support (Cronbach's $\alpha = 0.89$).

2.2.4.2. Interpersonal sensitivity.
The Interpersonal Awareness subscale of the Interpersonal Sensitivity Measure (IPSM) [34] was used to assess sensitivity to personal interactions. This subscale contains 7 items, with higher scores indicating a stronger sense of interpersonal sensitivity in social contexts (Cronbach's $\alpha = 0.80$).

2.3. Statistical analyses

First, the descriptives of the demographic, clinical, HRQOL, cognitive-behavioral, and social variables were calculated.

Second, zero-order correlations between the demographic and clinical variables on the one hand and HRQOL on the other hand were calculated in order to examine which demographic and clinical variables should be controlled for in further analyses. Associations with categorical variables were examined with t-tests and ANOVAs.

Third, zero-order correlations between possible predictor variables (i.e., cognitive-behavioral and social variables) and HRQOL were calculated in order to examine the potential individual contribution of these variables. These analyses were repeated while controlling for baseline HRQOL to examine the association of the individual variables with changes in HRQOL over time.

Fourth, to examine the relative contribution of the predictor variables, hierarchical regression analyses were performed while entering the variables showing significant zero-order correlations with HRQOL. Demographic and clinical variables were entered in the first block, followed by the cognitive-behavioral predictors in the second block, and the social predictors in the third block. To examine which predictors were associated with changes in HRQOL over time, analyses were repeated while entering baseline HRQOL in the second block preceding the cognitive-behavioral (3rd block) and social (4th block) predictors. Correlation and regression coefficients above 0.10, 0.30, and 0.50 were interpreted as small, medium, and large, respectively [35]. Due to incidental missing values, sample size varies per analysis. The lowest sample size was 83.

SPSS 23.0 (IBM, Armonk, NY, USA) was used to perform all statistical analyses.

3. Results

3.1. Participant characteristics

In total, 365 patients were screened for participation of which 95 were excluded based on our exclusion criteria. Of the remaining 270 patients, 175 patients completed the baseline questionnaires (response rate 65 %) and 130 patients completed the follow-up questionnaires. Patients who either were excluded or otherwise decided not to participate did not differ in sex, age, or dialysis type compared to participating patients. Also, no differences in any study variables were found between patients who completed both measurements and patients who completed only the baseline measurement.

Baseline demographic and clinical characteristics of the 130 participants who completed both measurements are shown in Table 1. Participants' mean age was 69 ± 14 years (range, 28–90), 57 % were male, and 61 % had a secondary-level education. Most patients were treated with center hemodialysis (79 %), followed by home hemodialysis (11 %) and peritoneal dialysis (10 %). Mean dialysis duration was 58 ± 56 months (range, 5–287), mean albumin level was 33.6 ± 3.9 g/L (range, 20.0-–42.0), and the mean Charlson Comorbidity Index was 5.5 ±1.6 (range, 2.0–9.0). Most reported comorbidities involved cardiovascular diseases, pulmonary diseases, and diabetes type II.

3.2. HRQOL and cognitive-behavioral and social factors

Means and standard deviations of HRQOL and cognitive-behavioral and social factors can be found in Table 1. Patients' mean physical and mental HRQOL did not significantly differ between baseline and follow-up (physical HRQOL: 36.6 ± 10.3 and 35.6 ± 11.1; p=0.44; mental HRQOL: 45.3 ± 10.0 and 44.5 ± 11.3; p=0.33).

Table 1
Patient characteristics of patients who completed both baseline (T1) and six months follow-up (T2) measurements.

Characteristic	
Demographic	
Age, years	68.9 ± 13.8
Male sex	74 (56.9 %)
Education level	
Primary	25 (19.2 %)
Secondary	79 (60.8 %)
Tertiary	18 (13.8 %)
Unknown	8 (6.2 %)
Marital status	
With partner	73 (56.2 %)
No partner	51 (39.2 %)
Unknown	6 (4.6 %)
Employment status	
Employed	
Paid	10 (7.7 %)
Unpaid/volunteer	4 (3.1 %)
Unemployed	
Retired	69 (53.1 %)
Other (e.g., domestic work, unemployment insurance)	31 (23.8 %)
Unknown	16 (12.3 %)
Clinical	
Type of dialysis	
Centre hemodialysis (day/night)	103 (79.2 %)
Home hemodialysis	14 (10.8 %)
Peritoneal dialysis	13 (10.0 %)
Dialysis duration, months	58 ± 56
Albumin, g/L	33.6 ± 3.9
Charlson score	5.5 ± 1.6
Comorbidity	
Yes	96 (73.8 %)
No	26 (20.0 %)
Unknown	8 (6.2 %)
HRQOL	
Physical health composite score (RAND SF-36; *T*-scores)	36.3 ± 10.3
Mental health composite score (RAND SF-36; *T*-scores)	45.3 ± 10.0
Cognitive-behavioral factors	
Helplessness (ICQ)	13.8 ± 4.6
Acceptance (ICQ)	18.3 ± 4.8
Worrying (PSWQ)	39.2 ± 9.9
Self-efficacy (GSES)	31.2 ± 5.0
Social factors	
Perceived support (ISR)	15.9 ± 3.7
Interpersonal awareness (IPSM)	12.3 ± 3.5

Notes: n = 130.
Categorical data expressed as count (percentage); continuous data as mean ± standard deviation.
HRQOL = health-related quality of life; RAND SF-36 = RAND Short Form-36 Health Status Inventory; ICQ = Illness Cognition Questionnaire; PSWQ = Penn State Worry Questionnaire; GSES = Generalized Self-Efficacy Scale; ISR = Inventory of Social Reliance; IPSM = Interpersonal Sensitivity Measure.

3.3. Associations of demographic and clinical characteristics with HRQOL at six months follow-up

In comparison to women, men scored higher on physical HRQOL (32.0 ± 11.2 versus 38.4 ± 10.3; p=0.003). Age, education level, marital status, and employment status were not found to be associated with HRQOL.

Higher Charlson comorbidity scores were associated with lower physical (r=−0.25; p = 0.02) and mental HRQOL (r=−0.20; p = 0.04). Dialysis type and albumin level were not related to HRQOL.

Resultantly, for the subsequent analyses, we adjusted for sex and the Charlson Comorbidity Index.

3.4. Associations of cognitive-behavioral and social factors with HRQOL

Partial correlations of physical and mental HRQOL at six months follow-up with HRQOL and cognitive-behavioral and social factors at baseline, while controlling for sex and the Charlson Comorbidity

Table 2

Correlation coefficients of HRQOL at six months (T2) with HRQOL and cognitive-behavioral and social factors at baseline (T1) when controlled for sex and the Charlson Comorbidity Index.

Variable	Physical HRQOL (T2)		Mental HRQOL (T2)	
	Not controlled for baseline[a]	Controlled for baseline[b]	Not controlled for baseline[c]	Controlled for baseline[d]
HRQOL				
Physical HRQOL (T1)	0.81***	–	–	–
Mental HRQOL (T1)	–	–	0.70***	–
Cognitive-behavioral factors				
Helplessness	−0.61***	−0.29**	−0.48***	−0.08
Acceptance	0.36***	0.16	0.45***	0.13
Worrying	−0.31**	−0.24*	−0.53***	−0.28**
Self-efficacy	0.20	−0.01	0.33**	0.08
Social factors				
Perceived support	0.17	0.08	0.29**	0.18
Interpersonal awareness	−0.20	−0.02	−0.38***	−0.21*

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

Comparison in patients who completed both measurements; [a]n = 90; [b]n = 89; [c]n = 97; [d]n = 94.

T1 = baseline; T2 = six months follow-up; HRQOL = health-related quality of life.

Index, are shown in Table 2. More helplessness was strongly related to worse physical HRQOL six months later. Lower levels of acceptance and higher levels of worrying were moderately related to worse physical HRQOL. After controlling for baseline physical HRQOL, small correlations with helplessness and worrying remained significant.

More worrying was strongly related to worse mental HRQOL six months later. Lower levels of acceptance and self-efficacy and higher levels of helplessness and interpersonal awareness were moderately related to a lower mental HRQOL. A lower level of perceived support was slightly related to worse mental HRQOL. After controlling for baseline mental HRQOL, small correlations of worrying and interpersonal awareness with mental HRQOL at six months remained significant.

3.5. Regression analyses

Table 3 presents the results of multiple regression analyses with physical and mental HRQOL at six months follow-up as outcome measure and demographic, clinical, and cognitive-behavioral and social factors as predictive factors. All analyses included only those variables that correlated significantly with either physical or mental HRQOL at follow-up.

3.5.1. Physical HRQOL

Demographic and clinical variables explained 17.0 % of the variance in physical HRQOL at six months ($p<0.001$), with female sex being related to lower physical HRQOL. Adding the cognitive-behavioral factors in block 2 resulted in a total of 41.3 % of the explained variance of the model ($p< 0.001$), with higher levels of helplessness at baseline being related to lower physical HRQOL six months later. The other cognitive-behavioral factors were not found to be significant (p-values ≥ 0.64). The social factors added in block 3 did not significantly add to the model ($p=0.38$).

To examine whether the predictor variables accounted for a change in physical HRQOL, we repeated the multiple regression analyses while controlling for baseline physical HRQOL. Sex and Charlson score were independently not significantly related to physical HRQOL, but together explained a significant 15.7 % of the variance ($p=0.001$). In block 2, adding baseline physical HRQOL

Table 3

Physical and mental HRQOL at six months follow-up (T2) as predicted by cognitive-behavioral and social factors.

	Physical HRQOL β		Mental HRQOL β	
	Not controlled for baseline[a]	Controlled for baseline[b]	Not controlled for baseline[c]	Controlled for baseline[d]
Demographic and clinical factors				
Sex	0.24**	0.04	0.08	−0.07
Charlson score	−0.10	−0.05	−0.05	−0.07
Baseline HRQOL				
Physical HRQOL	–	0.65***	–	–
Mental HRQOL	–	–	–	0.52***
Cognitive-behavioural factors				
Helplessness	−0.45***	−0.23*	−0.29**	−0.20*
Acceptance	0.05	−0.002	−0.05	−0.03
Worrying	−0.05	0.01	−0.28**	−0.16
Self-efficacy	0.004	−0.05	0.07	−0.004
Social factors				
Perceived support	0.12	0.02	0.23*	0.15
Interpersonal awareness	−0.05	−0.01	−0.06	−0.03
Total R^2	0.43	0.67	0.42	0.57

HRQOL = health-related quality of life; β = standardized coefficients.

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

[a] n = 88, R^2 = 0.17 for block 1, ΔR^2 = .24 for block 2, ΔR^2 = 0.01 for block 3.

[b] n = 83, R^2 = 0.16 for block 1, ΔR^2 = .48 for block 2, ΔR^2 = .03 for block 3, $\Delta R^2<$.001 for block 4.

[c] n = 94, R^2 = .07 for block 1, ΔR^2 = .30 for block 2, ΔR^2 = 0.05 for block 3.

[d] n = 86, R^2 = 0.05 for block 1, ΔR^2 = .46 for block 2, ΔR^2 = 0.04 for block 3, ΔR^2 = 0.02 for block 4.

resulted in a total explained variance of 63.8 % (p<0.001), with lower physical HRQOL at baseline strongly predicting lower physical HRQOL at six months follow-up. In block 3, adding the cognitive-behavioral factors explained a total of 67.1 % of the variance (p=0.12), with higher levels of helplessness predicting a larger decrease in physical HRQOL six months later. The other cognitive-behavioral factors were not found to be significant (p-values ≥ 0.50). The social factors added in block 4 did not significantly add to the model (p=.97).

3.5.2. Mental HRQOL

Sex and Charlson score were independently not significantly related to mental HRQOL, but together explained a significant 7.3 % of the variance (p=0.03). Adding the cognitive-behavioral factors resulted in a total explained variance of 37.3 % (p<0.001), with higher levels of helplessness and worrying being related to lower mental HRQOL six months later. The other cognitive-behavioral factors were not found to be significant (p-values ≥ 0.46). In block 3, adding the social factors resulted in a total of 42.3 % explained variance (p=0.03), with lower levels of perceived support being related to lower mental HRQOL. Interpersonal awareness was not found to be significant (p=0.51).

Including baseline mental HRQOL, the demographic and clinical variables explained a non-significant 5.4 % of the variance (p=0.10). In block 2, adding baseline mental HRQOL explained 51.0 % of the total variance (p<0.001), with lower mental HRQOL being predictive of lower mental HRQOL at follow-up. Cognitive-behavioral factors entered in block 3 resulted in a total explained variance of 54.9 % (p=0.16), with higher levels of helplessness being predictive of a larger decrease in mental HRQOL six months later. The other cognitive-behavioral factors were not found to be significant (p-values ≥ 0.12). Adding the social factors in block 4 did not significantly add to the model (p=0.17).

4. Discussion

4.1. Discussion

Patients' lives consist of more than just the disease they have. If we truly want to improve patients' quality of life, we should not only focus on patients' physical functioning but also on their psychological and social well-being. This study found that patients' feelings and thoughts regarding their disease are significantly associated with HRQOL and, as a result, may be of essential importance in improving HRQOL. Adopting realistic and adaptive feelings and thoughts in addition to establishing a strong social support system is recommended for patients to achieve a life as normal and as comfortable as possible, despite the unalterable consequences of their disease.

Mean HRQOL scores were similar to those found in two Dutch cohort studies focusing on dialysis patients [11] and were one to two standard deviations lower compared to the general population [36]. These low HRQOL scores were relatively stable over the course of the study: baseline HRQOL was found to be the strongest predictor of HRQOL six months later. Patients' low HRQOL will largely be the direct result of the high disease burden and intrusive dialysis treatment, and will, therefore, be hard to change directly. However, identification of factors that influence HRQOL could help improving HRQOL in a more indirect way.

We observed a clear relation between HRQOL and the negative outcome expectancy-related constructs of helplessness and worrying, both reflecting a negative outlook on the future. These findings are in line with accumulating evidence underscoring the relevance of outcome expectancies for quality of life and treatment outcome in patients with a variety of somatic diseases. Moreover, the way patients perceive and think about their illness influences

physical and mental outcome [16,37]. Expecting positive treatment outcomes leads, for instance, to substantial improvements in quality of life and relief of pain [15,38,39]. With regard to dialysis patients, personal beliefs concerning the effectiveness of treatment are even suggested to be predictive of survival [40,41]. However, little work has been carried out to study the role of negative outcome expectancies in dialysis patients, making this study one of the first. In our study, feelings of helplessness clearly emerged as the strongest and most consistent predictor of both physical and mental HRQOL, also being the only factor predicting a worsening of HRQOL over time. To some degree, worrying also uniquely added to patients' mental HRQOL, which was in line with previous studies linking worrying to increased emotional distress in patients with chronic disease [42] and to increased somatic symptoms [19] and worse HRQOL in ESkD [18]. Other studied cognitive-behavioral factors, such as acceptance and self-efficacy showed a significant association with HRQOL at six months follow-up but did not predict a change of HRQOL over time.

Social factors showed to have additional value in predicting future HRQOL in dialysis patients on top of the cognitive-behavioral factors. More perceived support and less interpersonal sensitivity were significantly related to a better mental HRQOL after six months, although both did not independently predict a change in HRQOL over time. The associations between social factors and mental HRQOL are in line with previous research showing that being excessively aware of the way one is perceived is linked to anxiety and depression [28,29] and with the theory and previous findings that social support could protect against psychological distress in patients with chronic disease [14,43].

A specific strength of this study is the multivariate analysis with the inclusion of a broad range of possible predictive cognitive-behavioral and social factors while taking into account the effects of demographic and clinical characteristics. In addition, assessing HRQOL at baseline and six months follow-up provided the opportunity to detect possible changes over time.

A limitation of our study is the relatively small sample size in light of the amount of predictors we examined and the 25 % drop-out across the six month assessment period. Nonetheless, adequate care was taken to maintain sufficient power for the regression analyses by including only those variables that showed a significant correlation with HRQOL. Reasons for drop-out were not acquired but were probably related to death, the high disease burden, and patients receiving a kidney transplant during the course of the study. Another limitation was the design of our study, which prevented us from assessing causal relations. However, the prospective design did enable us to address changes in HRQOL over time.

4.2. Conclusion

In this study, we assessed multiple possible predictors for HRQOL, including cognitive-behavioral factors, incorporating potentially relevant negative outcome expectancies, and social factors. Although the importance of these factors has been demonstrated before, only few studies have addressed the role of this broad range of factors for dialysis patients.

In conclusion, we found that factors related to negative outcome expectancies, especially helplessness and worrying, and less perceived support were related to worse HRQOL six months later. Additionally, helplessness was independently associated with changes in HRQOL over time, on top of demographic and clinical characteristics.

4.3. Practice implications

Although an experimental design is needed to confirm causality, our results provide some practical suggestions to

improve HRQOL in dialysis patients. First, health care professionals should be educated on the role of negative outcome expectancies and supportive social interactions in treatment outcome and HRQOL [44].

Second, health care professionals can implement several strategies to prevent or reduce negative outcome expectancies. Patient expectations can, for example, be managed by providing enhanced treatment information [45,46]. In addition to information on patients' treatment and its consequences, this could include psychoeducation on the effect of negative outcome expectancies [44,47]. Additionally, an improved patient-clinician relationship and an empathic communication style that promotes mutual understanding, trust, and reassurance is found to be effective in preventing negative outcome expectancies [45,48]. By means of these processes, positive expectations are promoted and health outcomes are found to improve [45,48–50]. Lastly, existing negative outcome expectancies could be addressed by changing any unrealistic, maladaptive expectations into more adaptive and realistic expectations. This starts with regular screenings to recognize patients with a vulnerability for negative outcome expectancies, followed by specific interventions to support these patients. Expectation-focused psychological interventions (EFPIs), for example, have shown to be effective for both regular treatment of chronic disease (e.g., coronary heart disease, cancer, and chronic pain) and optimization of specific medical interventions such as a scheduled surgery [15]. Cognitive-behavioral therapy (CBT) is another effective approach in addressing patient expectations and improving HRQOL in chronic disease patients [14], including dialysis patients [51,52].

Third, as social support also was related to future HRQOL on top of demographic and clinical characteristics, it could be relevant if health care professionals could pay attention to a patient's support system. In case a lack of social support is noted, patients could be attended to the presence of group- and individual-based CBT as well as social support groups, which have been found to be effective in strengthening the social support system and improving social skills in dialysis patients [53,54].

Author contributions

A.E., H.v.H., R.J., and H.v.M. designed the study; R.J., H.v.H., L.H., and H.v.M. collected the data, J.T. and H.v.M. analyzed the data; J.T., A.E., H.v.H., R.J., S.v.D., L.H., and H.v.M. drafted and revised the paper; all authors approved the final version of the manuscript.

Funding

Informed consent and patient details

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Declaration of Competing Interest

None.

Acknowledgements

References

[1] K. Abdel-Kader, M.L. Unruh, S.D. Weisbord, Symptom burden, depression, and quality of life in chronic and end-stage kidney disease, Clin. J. Am. Soc. Nephrol. 4 (2009) 1057–1064.

[2] M.P. Merkus, K.J. Jager, F.W. Dekker, R.J. De Haan, E.W. Boeschoten, R.T. Krediet, Quality of life over time in dialysis: the Netherlands Cooperative Study on the Adequacy of Dialysis. NECOSAD Study Group, Kidney Int. 56 (1999) 720–728.

[3] United States Renal Data System, USRDS Annual Data Report: Epidemiology of Kidney Disease in the United States, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, 2018.

[4] Dutch Kidney Foundation, Facts and Numbers., (2020) . https://www.nierstichting.nl/leven-met-een-nierziekte/feiten-en-cijfers/.

[5] L. Mellon, D. Regan, R. Curtis, Factors influencing adherence among Irish haemodialysis patients, Patient Educ. Couns. 92 (2013) 88–93.

[6] F.E. Murtagh, J. Addington-Hall, I.J. Higginson, The prevalence of symptoms in end-stage renal disease: a systematic review, Adv. Chronic Kidney Dis. 14 (2007) 82–99.

[7] D. Cukor, S.D. Cohen, R.A. Peterson, P.L. Kimmel, Psychosocial aspects of chronic disease: ESRD as a paradigmatic illness, J. Am. Soc. Nephrol. 18 (2007) 3042–3055.

[8] B. Caplin, S. Kumar, A. Davenport, Patients' perspective of haemodialysis-associated symptoms, Nephrol. Dial. Transplant. 26 (2011) 2656–2663.

[9] T. Abma, C. Nierse, J. van de Griendt, K. Schipper, E. van Zadelhoff, Learning about Body and Life. An Agenda for Social Scientific Research by Kidney Disease Patients, NSN, Bussum, 2007.

[10] L. Timmers, M. Thong, F.W. Dekker, E.W. Boeschoten, M. Heijmans, M. Rijken, J. Weinman, A. Kaptein, Illness perceptions in dialysis patients and their association with quality of life, Psychol. Health 23 (2008) 679–690.

[11] A.H. Mazairac, G.A. de Wit, E.L. Penne, N.C. van der Weerd, B. de Jong, M.P. Grooteman, M.A. van den Dorpel, E. Buskens, F.W. Dekker, M.J. Nube, P.M. ter Wee, E.W. Boeschoten, M.L. Bots, P.J. Blankestijn, Changes in quality of life over time–Dutch haemodialysis patients and general population compared, Nephrol. Dial. Transplant. 26 (2011) 1984–1989.

[12] M.P. Merkus, K.J. Jager, F.W. Dekker, R.J. de Haan, E.W. Boeschoten, R.T. Krediet, Physical symptoms and quality of life in patients on chronic dialysis: results of the Netherlands Cooperative Study on Adequacy of Dialysis (NECOSAD), Nephrol. Dial. Transplant. 14 (1999) 1163–1170.

[13] B. Mozes, E. Shabtai, D. Zucker, Differences in quality of life among patients receiving dialysis replacement therapy at seven medical centers, J. Clin. Epidemiol. 50 (1997) 1035–1043.

[14] H. van Middendorp, A.W. Evers, The role of psychological factors in inflammatory rheumatic diseases: from burden to tailored treatment, Best Pract. Res. Clin. Rheumatol. 30 (2016) 932–945.

[15] T. Kube, J.A. Glombiewski, W. Rief, Using different expectation mechanisms to optimize treatment of patients with medical conditions: a systematic review, Psychosom. Med. 80 (2018) 535–543.

[16] A.W. Evers, F.W. Kraaimaat, W. van Lankveld, P.J. Jongen, J.W. Jacobs, J.W. Bijlsma, Beyond unfavorable thinking: the illness cognition questionnaire for chronic diseases, J. Consult. Clin. Psychol. 69 (2001) 1026.

[17] H. Leventhal, Symptom reporting: a focus on process, illness behavior: a multidisciplinary model, in: S. McHugh, T.M. Vallis (Eds.), Illness Behavior: A Multidisciplinary Model, Plenum Press, New York, 1986, pp. 219–237.

[18] T.W. Kao, M.S. Lai, T.J. Tsai, C.F. Jan, W.C. Chie, W.Y. Chen, Economic, social, and psychological factors associated with health-related quality of life of chronic hemodialysis patients in northern Taiwan: a multicenter study, Artif. Organs 33 (2009) 61–68.

[19] C.M. Perales-Montilla, S. Duschek, G.A. Reyes-Del Paso, The influence of emotional factors on the report of somatic symptoms in patients on chronic haemodialysis: the importance of anxiety, Nefrologia 33 (2013) 816–825.

[20] A. Bandura, Self-efficacy: toward a unifying theory of behavioral change, Psychol. Rev. 84 (1977) 191.

[21] J.-Y. Kim, B. Kim, K.-S. Park, J.-Y. Choi, J.-J. Seo, S.-H. Park, C.-D. Kim, Y.-L. Kim, Health-related quality of life with KDQOL-36 and its association with self-efficacy and treatment satisfaction in Korean dialysis patients, Qual. Life Res. 22 (2013) 753–758.

[22] C.M. Perales-Montilla, A. Garcia-Leon, G.A. Reyes-del Paso, Psychosocial predictors of the quality of life of chronic renal failure patients undergoing haemodialysis, Nefrologia 32 (2012) 622–630.

[23] S.-L. Tsay, M. Healstead, Self-care self-efficacy, depression, and quality of life among patients receiving hemodialysis in Taiwan, Int. J. Nurs. Stud. 39 (2002) 245–251.

[24] J.G. Walker, H.J. Jackson, G.O. Littlejohn, Models of adjustment to chronic illness: using the example of rheumatoid arthritis, Clin. Psychol. Rev. 24 (2004) 461–488.

[25] S.S. Patel, V.S. Shah, R.A. Peterson, P.L. Kimmel, Psychosocial variables, quality of life, and religious beliefs in ESRD patients treated with hemodialysis, Am. J. Kidney Dis. 40 (2002) 1013–1022.

[26] H. Li, Y.-f. Jiang, C.-C. Lin, Factors associated with self-management by people undergoing hemodialysis: a descriptive study, Int. J. Nurs. Stud. 51 (2014) 208–216.

[27] R. Chan, R. Brooks, J. Erlich, M. Gallagher, P. Snelling, J. Chow, M. Suranyi, Studying psychosocial adaptation to end-stage renal disease: the proximal–distal model of health-related outcomes as a base model, J. Psychosom. Res. 70 (2011) 455–464.

[28] J.C. Butler, M.S. Doherty, R.M. Potter, Social antecedents and consequences of interpersonal rejection sensitivity, Pers. Individ. Dif. 43 (2007) 1376–1385.

[29] K. Wilhelm, P. Boyce, S. Brownhill, The relationship between interpersonal sensitivity, anxiety disorders and major depression, J. Affect. Disord. 79 (2004) 33–41.

[30] R.D. Hays, C.D. Sherbourne, R.M. Mazel, The rand 36-item health survey 1.0, Health Econ. 2 (1993) 217–227.

[31] T.J. Meyer, M.L. Miller, R.L. Metzger, T.D. Borkovec, Development and validation of the Penn State Worry Questionnaire, Behav. Res. Ther. 28 (1990) 487–495.

[32] R. Schwarzer, M. Jerusalem, Generalized self-efficacy scale, in: J. Weinman, S. Wright, M. Johnston (Eds.), Measures in Health Psychology: A User's Portfolio. Causal and Control Beliefs, NFER-NELSON, Windsor, England, 1995, pp. 35–37.

[33] V. Dam-Baggen, F. Kraaimaat, The Inventory for Social Support (ISB): a self-report inventory for the measurement of social support, Gedragstherapie 25 (1992) 27–46.

[34] P. Boyce, G. Parker, Development of a scale to measure interpersonal sensitivity, Aust. N. Z. J. Psychiatry 23 (1989) 341–351.

[35] J. Cohen, Statistical Power Analysis for the Behavioral Sciences, 2 ed., Lawrence Erlbaum, New Jersey, 1988.

[36] J.C. Korevaar, M.A. Jansen, M.P. Merkus, F.W. Dekker, E.W. Boeschoten, R.T. Krediet, Quality of life in predialysis end-stage renal disease patients at the initiation of dialysis therapy. The NECOSAD Study Group, Perit. Dial. Int. 20 (2000) 69–75.

[37] M. Maas, E. Taal, S. van der Linden, A. Boonen, A review of instruments to assess illness representations in patients with rheumatic diseases, Ann. Rheum. Dis. 68 (2009) 305–309.

[38] D.D. Price, D.G. Finniss, F. Benedetti, A comprehensive review of the placebo effect: recent advances and current thought, Annu. Rev. Psychol. 59 (2008) 565–590.

[39] K.J. Peerdeman, A.I. van Laarhoven, M.L. Peters, A.W. Evers, An integrative review of the influence of expectancies on pain, Front. Psychol. 7 (2016) 1270.

[40] S. van Dijk, M. Scharloo, A.A. Kaptein, M.S.Y. Thong, E.W. Boeschoten, D.C. Grootendorst, R.T. Krediet, F.W. Dekker, f.t. N.S. Group, Patients' representations of their end-stage renal disease: relation with mortality, Nephrol. Dial. Transplant. 24 (2009) 3183–3185.

[41] J. Chilcot, The importance of illness perception in end-stage renal disease: associations with psychosocial and clinical outcomes, Seminars in Dialysis, Wiley Online Library, 2012, pp. 59–64.

[42] L. Trick, E. Watkins, S. Windeatt, C. Dickens, The association of perseverative negative thinking with depression, anxiety and emotional distress in people with long term conditions: a systematic review, J. Psychosom. Res. 91 (2016) 89–101.

[43] J.A. Sturgeon, P.H. Finan, A.J. Zautra, Affective disturbance in rheumatoid arthritis: psychological and disease-related pathways, Nat. Rev. Rheumatol. 12 (2016) 532–542.

[44] A.W. Evers, L. Colloca, C. Blease, M. Annoni, L.Y. Atlas, F. Benedetti, U. Bingel, C. Büchel, C. Carvalho, B. Colagiuri, Implications of placebo and nocebo effects for clinical practice: expert consensus, Psychother. Psychosom. 87 (2018) 204–210.

[45] M. Manaï, H. van Middendorp, D.S. Veldhuijzen, T.W. Huizinga, A.W. Evers, How to prevent, minimize, or extinguish nocebo effects in pain: a narrative review on mechanisms, predictors, and interventions, Pain Rep. 4 (2019).

[46] S.R. Heisig, M.C. Shedden-Mora, P. von Blanckenburg, F. Schuricht, W. Rief, U.S. Albert, Y. Nestoriuc, Informing women with breast cancer about endocrine therapy: effects on knowledge and adherence, PsychoOncology 24 (2015) 130–137.

[47] D. Varelmann, C. Pancaro, E.C. Cappiello, W.R. Camann, Nocebo-induced hyperalgesia during local anesthetic injection, Anesth. Analg. 110 (2010) 868–870.

[48] R.L. Street Jr, G. Makoul, N.K. Arora, R.M. Epstein, How does communication heal? Pathways linking clinician–patient communication to health outcomes, Patient Educ. Couns. 74 (2009) 295–301.

[49] T.F. Hack, L.F. Degner, P.A. Parker, The communication goals and needs of cancer patients: a review, PsychoOncology 14 (2005) 831–845.

[50] J.M. Kelley, G. Kraft-Todd, L. Schapira, J. Kossowsky, H. Riess, The influence of the patient-clinician relationship on healthcare outcomes: a systematic review and meta-analysis of randomized controlled trials, PLoS One 9 (2014) e94207.

[51] D. Cukor, M. Pencille, D. Rosenthal, P.L. Kimmel, Psychosocial issues in dialysis patients Chapter 70, in: A.R. Nissenson, R.N. Fine (Eds.), Handbook of Dialysis Therapy, 5th edition, Elsevier, 2017, pp. 844–854.

[52] C.Z. Ng, S.C. Tang, M. Chan, B.X. Tran, C.S. Ho, W.W. Tam, R.C. Ho, A systematic review and meta-analysis of randomized controlled trials of cognitive behavioral therapy for hemodialysis patients with depression, J. Psychosom. Res. 126 (2019) 109834.

[53] B.E. Hogan, W. Linden, B. Najarian, Social support interventions: do they work? Clin. Psychol. Rev. 22 (2002) 381–440.

[54] S.D. Cohen, Social Support Interventions Will Improve the Quality of Life of ESRD Patients, Seminars in Dialysis, Wiley Online Library, 2013, pp. 262–265.