Living with dialysis: patients' perceptions and outcomes
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Dialysis techniques have improved tremendously over the last four decades, so much so that dialysis is now routine treatment for persons with end-stage renal disease (ESRD). Nevertheless, dialysis remains a burdensome and intrusive treatment. Therefore, how patients perceive dialysis and its impact on the quality of their remaining life is an important consideration when providing care. Patients’ perceptions can have repercussions on their responses to ESRD and dialysis, and subsequent health outcomes such as health-related quality of life (HRQL) and survival. Leventhal’s Self-Regulating Model (SRM) suggests that two parallel representational pathways, cognitive and emotional, can influence coping strategies and health behaviours which in turn determine patients’ outcomes. Compared with other chronic illnesses, the illness perceptions of dialysis patients have been less well-studied. Using the SRM framework, this thesis explores the role of illness perceptions in determining health outcomes of patients on dialysis participating in the Netherlands Co-operative Study on the Adequacy of Dialysis (NECOSAD).

Although interest in the HRQL of patients undergoing PD has increased in the last decade, nevertheless, it is still under-researched compared with that of patients receiving HD. In Chapter 2, an overview of the complexity involved in the definition of HRQL and the practicalities of HRQL assessment in general are presented together with a summary of research conducted within the last decade on HRQL of PD patients. Currently there are no HRQL assessment protocols developed specifically for use with PD. With PD now being a viable and available modality for a wide patient group, from paediatric patients to adults and elderly with co-morbid conditions, development of PD-specific HRQL assessment should also be sensitive to age-specific needs of patients.

Chapter 3 reports on the symptom burden of patients undergoing dialysis treatment and its association with clinical and behavioural outcomes. Dialysis patients often have a high symptom burden. However clinical understanding of the underlying causes of symptoms is still unclear and the association between symptoms and clinical parameters are often weak. Symptom management research suggests that identifying clusters of related symptoms could provide insight into the underlying determinants associated with multiple symptom experience. In theory, symptoms within a cluster could have a synergistic relationship. Therefore, we assessed the symptom burden of 1,533 haemodialysis (HD) and peritoneal dialysis (PD) patients 3 months after start of dialysis with the Kidney Disease Quality of Life symptom/problem list. Patients were bothered by an average of 2.8 symptoms of ‘moderate bother’ or more. Using principal component analysis, three symptom clusters were identified which explained 49% of the total
variance. All clusters showed strong negative associations with the SF-36 HRQL dimensions and with functional status. In contrast, only the clinical variables serum albumin and haemoglobin were associated with all clusters in HD patients, and Kt/V_{urea} in PD patients. Our results suggest that symptom clustering did not improve the poor association between symptoms and clinical variables found in previous studies. Instead, strong associations of symptom clusters with HRQL suggest that psychological factors could better explain symptom burden. Patients’ perceptions of symptoms should be routinely assessed as part of clinical care to improve self-management strategies.

A single self-rated health (SRH) item was found to be as strong a predictor of mortality in large community-based studies as more detailed health assessments or objective clinical measures. However, there is little research done using large clinical-based samples. In Chapter 4, we examined whether a single self-rated health (SRH) item was associated with mortality in dialysis patients. Our sample of 1,433 dialysis patients was administered a SRH item “How would you say your health is in general” between 1997 and 2004. We also examined if there was an interaction between SRH and age on mortality risks. Patients who perceive their health as ‘poor’, ‘fair’ or ‘good’ had a higher mortality risk than those with ‘excellent/very good’ health ratings, independent of a range of risk factors. Similarly, this SRH-mortality association was found in both the young and old dialysis patients. Given the simplicity and economy of administrating the SRH, patients’ self-assessment of health can be an invaluable complement to clinical measures in risk assessment.

Chapter 5 examined the illness perceptions of dialysis patients’ in relation to HRQL. The illness perceptions of 91 HD and 42 PD patients were assessed with the Illness Perception Questionnaire- Revised. Compared with HD patients, PD patients experienced more personal control and had a better understanding of the illness. Illness perceptions explained from 17% to 51% of the variance in quality of life scores. Patients who perceived having more symptoms, more consequences and lower personal control reported poorer HRQL. Assessment of illness perceptions is useful in understanding the impact of ESRD and of dialysis treatment on HRQL. As such interventions aimed at providing more knowledge about ESRD and dialysis, and provision of skills to coping with the illness and its consequences may improve HRQL in dialysis patients.

In the SRM, social support is postulated as a coping strategy whereby seeking social support behaviours could influence patient outcome such as survival as evidenced in empirical studies in
Summary

patients with cancer or cardiovascular disease. However, this topic has not yet been studied extensively among dialysis patients. In Chapter 6 we described the association between social support and survival for patients on dialysis. Between December 1998 and January 2002, 528 HD and PD patients completed the Social Support List (SSL) at 3 months after the start of dialysis (baseline). The SSL measured two aspects of social support: interaction (frequency of social support) and discrepancy (the perceived difference between the desired and received level of social support). Patients’ mortality risk from baseline until 1 January 2005 was estimated with Cox regression analysis. Social support (interaction) was not associated with survival, neither in the whole sample nor when stratified by therapy modality. Both HD and PD patients who perceived a discrepancy between the level of received and expected level of social companionship, daily emotional support (such as shows of affection), and total support had a higher risk of mortality. However, patients who received or perceived having inadequate emotional support with problems (such as encouragement and advice giving) had no higher mortality risks. This study suggests that different aspects of social support have varying levels of importance dialysis patients. Besides providing medical information regarding lifestyle changes due to dialysis, clinical care providers should also highlight to patients and family/caregivers potential conflicts that could arise when communicating encouragement and support for lifestyle change.