Citation

Version: Corrected Publisher’s Version
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Downloaded from: https://hdl.handle.net/1887/13526

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

The physician should look upon the patient as a besieged city and try to rescue him with every means that art and science place at his command.

-Alexander of Tralles (c.525-c.605)-
END-STAGE RENAL DISEASE

For patients with end-stage renal disease (ESRD), the need to start renal replacement therapy to prolong life represents the final stage of living with a progressive chronic illness. The annual growth in the number of ESRD patients receiving treatment is approximately 7%. By the end of 2005, there was an estimated 1.9 million ESRD patients worldwide receiving some form of renal replacement therapy. This figure is predicted to increase considerably, mainly contributed by an aging population and the rising incidence of diabetes worldwide.

This trend is similarly reflected in the Netherlands. Between 1990 and 2005, the total number of newly diagnosed ESRD patients rose from 1,005 to 1,584, representing a 58% increase. The greatest increase of newly diagnosed ESRD patients was in the age group ≥65 years, which rose from 362 (36%) in 1990 to 842 (53%) in 2005. Diabetes was the largest identified cause of renal failure in the Netherlands.

RENAL REPLACEMENT THERAPY

Current available treatment options for ESRD include renal transplantation, haemodialysis (HD), and peritoneal dialysis (PD). Due to a shortage of donors and the associated side effects of transplantation, dialysis is the prescribed treatment for the majority of ESRD patients. Of the 1.9 million ESRD patients treated worldwide, approximately 80% receive dialysis, with the remaining 20% receiving transplantation.

Globally, HD is the most prevalent dialysis modality. With HD, waste products accumulated in the blood are removed via an artificial dialyser connected to a fistula fitted in the patients’ forearm. Treatment is usually conducted at an in-hospital dialysis unit, where attendance 3 times a week for up to 4 hours per visit is the norm.

Patients on PD can self-dialyse at home with regular infusions of sterile dialysis solution into the peritoneal cavity, thus offering greater flexibility and privacy for patients.

With its technological improvements over the last four decades, dialysis treatments are now viable even for the elderly and those with comorbid diseases. Nevertheless, mortality rate among dialysis patients in Europe and the US remains high at 10-20% annually, even after
adjustment for age, sex, and primary diagnosis.\textsuperscript{10,14} The Netherlands has a comparable mortality rate of 19\%.\textsuperscript{9}

HEALTH-RELATED QUALITY OF LIFE (HRQL)

Although improving survival of patients on dialysis is paramount, clinicians now also recognise the importance of assessing the quality of this survival. Patients on dialysis are wholly dependent on a machine for their survival. Despite its lifesaving qualities, dialysis treatment is time-consuming, intrusive and can be burdensome for patients.\textsuperscript{15} Therefore, patients’ perceptions of the impact of dialysis on the quality of their remaining life is also an important consideration when providing care.

Compared with the general population, dialysis patients consistently perceive themselves as having a poor health-related quality of life (HRQL), in particular the dimension of physical functioning.\textsuperscript{16,17} Reduced physical functioning can compromise employment opportunities, and participation in social and leisure activities, resulting in poorer HRQL and higher risk of mortality.\textsuperscript{18-22} Poorer HRQL could increase mortality risk through poorer adherence to the strict dietary and medical regimens of dialysis.\textsuperscript{23}

In clinical practice, the focus is to optimise parameters of clinical variables to achieve better HRQL in dialysis patients. Some studies suggest that the management of anaemia with recombinant human erythropoietin\textsuperscript{24,25} and improving nutritional status by increasing the serum albumin levels of dialysis patients\textsuperscript{26} have been associated with improved HRQL. In general, however, observational studies have shown weak or no support of associations between clinical variables with HRQL of dialysis patients.\textsuperscript{27-30} Although this poor association between clinical variables and HRQL is gaining recognition in clinical practice, the understanding of this phenomenon is still far from clear.

THEORETICAL MODELS

BIOPSYCHOSOCIAL MODEL
Renal medicine, as medicine in general, tends to be dominated by the biomedical model. In reaction to what he considered the inadequacy of the biomedical to include the patient and
his/her attributes as a person as the central focus of study, Engel proposed as an alternative, the biopsychosocial model. In this model, social and psychological factors are explicitly incorporated into research and clinical care for patients with physical disorders. Interactions run both ways from cell to society and from society to cell, with the person/patient in the central position (Figure 1). In this thesis, the empirical studies clearly belong in the domain of the biopsychosocial model as outlined by Engel.

EXPLANATORY MODELS

While patients’ stories of their illness complaints and symptoms have time and again fascinated clinicians, this fascination is often coupled with some perplexity as clinicians note discrepancies between these ‘idiosyncratic’ stories of patients on the one hand and ‘scientific, objective’ medical or behavioural explanations on the other. For instance, a clinician might be at a loss to explain a patient’s complaints of uraemic symptoms such as itch, muscles cramps and fatigue even though clinical indicators suggest that this patient is receiving optimal dialysis. At the same time, social scientists regard these discrepancies between the subjective and objective narrations of disease a rich source of research opportunities. By exploring patients’ (and healthy persons’) explanations of their illnesses and complaints, social scientists aim at understanding the motivations underlying patients’ subsequent behaviour. Illness representations (or illness perceptions) and explanatory models are two major concepts explored in this research. As illness perceptions form the conceptual framework of this thesis, it will be discussed in depth further in this chapter. Briefly, an explanatory model refers to the notions that patients and those in their social environment have about a specific illness episode. According to Kleinman, “…these informal descriptions of [the illness] have enormous clinical significance [and] to ignore them may be fatal. Explanatory models are responses to urgent life circumstances. Thus, they are justifications for practical action more than statements of a theoretical and rigorous nature” (1988, p. 121)

Persons diagnosed with ESRD become patients with a serious life-threatening illness, and these persons/patients make sense of ESRD and its impact by telling stories of the illness to themselves and to relevant persons around them. These stories or explanatory models are not vague, ‘unscientific’ or to be dismissed. Instead, stories of illness are representations of the identity, causes, course, consequences and timeline of a given symptom or illness congruent to a patient. In turn, these representations or illness perceptions determine the actions of a patient regarding that symptom or illness. Only having made sense of the illness, can a patient start adapting to the illness, its treatment and its consequences.
SELF-REGULATION MODEL

Beginning in 1956 with Bard & Dyk, interviews with patients regarding their stories or narratives on the causes of their illness have been published. In 2006 Broadbent et al. published the Brief Illness Perception Questionnaire (B-IPQ) comprising of eight questions assessing various dimensions in the stories of how patients make sense of their illness. In these 50 years, scientists from the biomedical and behavioural domains have developed models and various instruments to assess the stories of patients. One of the most influential models, the Common Sense Model of self-regulation, also known as the Self-Regulation Model (SRM) was developed by Leventhal.

The SRM outlines the process in which physical sensations and illnesses are stimuli for persons/patients in constructing a model which encompasses a cognitive and an emotional representation of those stimuli and their meaning (Figure 2). The cognitive representation pathway is distinguished by five dimensions: causes (pertains to beliefs of causes responsible for illness); identity (beliefs regarding the labels and symptoms associated with the disease); timeline (relates to beliefs on the duration of the illness); consequences (beliefs pertaining to the impact of illness on quality of life and functioning); and controllability (pertains to the beliefs of self-empowerment and the efficacy of treatment). Emotional representation determines emotional outcomes. The emotional representation encompasses concepts such as anxiety, depression, and coherence. This latter component of the model is only recently receiving attention in research literature. Together these two pathways can influence subsequent coping strategies and health behaviors which in turn determine patients’ outcomes.

Leventhal’s model has been tested in a range of populations, including individuals at risk for venous thrombosis, and chronic physical illnesses including myocardial infarction, venous thrombosis, chronic obstructive pulmonary disease, breast cancer, chronic fatigue syndrome, psoriasis, multiple sclerosis, rheumatoid arthritis, and Huntington’s disease. Results from these studies indicate that positive beliefs in controllability and curability of the illness are positively associated with well-being.
**Figure 1.** The biopsychosocial model hierarchy of natural systems (adapted from Engel, pg 537)\(^{31}\)
Exploring patients’ perceptions of a chronic illness such as ESRD and its treatments is especially relevant. Undeniably, how patients make sense of their illness can have repercussions on their responses to the disease and its treatments, and their subsequent health outcomes. Compared with other chronic illnesses, the illness perceptions of dialysis patients have been less well-studied. The few studies limited to relatively small samples of HD patients suggest that patients who perceive that they have more control over and fewer consequences as a result of their disease had better health outcomes. A patient’s negative perceptions of illness have been associated with an increased risk of depression, poorer adjustment to the disease and treatment, and poorer HRQL. Perceiving ESRD as a negative intrusion into lifestyle is more likely to be associated with poorer treatment compliance and higher symptom burden.

![Figure 2. Leventhal’s Self-Regulation Model (adapted from Hagger & Orbell, 2003)](image-url)
OBJECTIVE OF THIS THESIS

While clinical associations with health outcomes in dialysis patients are at best weak, psychosocial factors have shown to be stronger determinants of HRQL and survival. However, the role of illness perceptions in determining health outcomes in dialysis patients is still not well understood. With Leventhal’s SRM providing an elegant theoretical framework, this thesis aims to investigate the perceptions that dialysis patients have on ESRD and its treatment, and its effect on their HRQL and survival.

STUDY SAMPLE

Participants in the Netherlands Cooperative Study on the Adequacy of Dialysis (NECOSAD-2) provided the data used in all the studies in this thesis. NECOSAD-2 is a prospective observational study involving up to 38 dialysis centres throughout The Netherlands. From 1997 to 2007, over 2,000 ESRD patients with no previous history of renal replacement therapy were recruited. Data on demographics, clinical parameters, and psychosocial variables were collected from start of dialysis, and at three and six months after start of dialysis, and every six months thereafter. Patients were followed-up until kidney transplantation or death.

THESIS OUTLINE

This thesis begins with a review chapter which focuses on the determinants of HRQL (Chapter 2). This chapter was limited to PD patients as HRQL of PD patients is under-researched compared to those on HD.

To explore the role of psychological factors, specifically patients’ perceptions on health outcomes, we studied several components of Leventhal’s SRM. First, we examined the association between symptoms and clinical variables, and quality of life dimensions (Chapter 3). Dialysis patients have high symptom burden although the underlying pathophysiology is not well understood. Differential symptom clusters in dialysis patients were identified and the associations between these clusters and clinical variables and HRQL dimensions were studied.
Second, another concept in the theoretical model that guided our work is the research tradition on the subject of general perceptions of health. We therefore investigated the robustness of a self-rated health item in predicting mortality, after correcting for a range of demographics and clinical variables (Chapter 4). In addition, the interaction of age on self-rated health and mortality was examined.

From general perceptions, we next investigated the impact of specific cognitive representations of illness on patients’ outcome (Chapter 5). This cross-sectional study examined aspects of patients’ illness perceptions as proposed by Leventhal’s SRM, and their associations with HRQL. Differences in illness perceptions between HD and PD patients were examined.

Leventhal’s model suggests that coping strategies can affect outcome. We explored the association between social support and survival of patients over a 3-year follow-up (Chapter 6). Two aspects of social support were examined: 1) the perceived amount of social support received, and 2) the perception of discrepancy between desired and received levels of social support. Differences between HD and PD patients on their social support needs were identified.

Lastly, we provide a general discussion on the major results found in our studies (Chapter 7). Clinical implications and future research conclude this thesis.

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