Living with dialysis: patients' perceptions and outcomes
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In the sick room, ten cents' worth of human understanding equals ten dollars' worth of medical science

-Martin H. Fischer (1879-1962)-
Renal medicine, like medicine in general, has traditionally focused on clinical parameters as outcome assessment. It is heartening to note that current renal medicine, like mainstream medicine, is increasingly focused on patient-reported outcomes for assessment of treatment efficacy. In his seminal paper, Sullivan states that complete and meaningful health assessments are now seen to include patient perspectives such as perceived health, health-related quality of life (HRQL), values, and health status utilities.

It is of note that the three major concepts highlighted by Sullivan, that is, perceived health, HRQL, and subjective evidence, are the core concepts in three chapters of this thesis. This greater focus on patient’s perspectives is certainly of relevance to many patients with end-stage renal disease (ESRD) whose survival is totally dependent on dialysis treatments. Dialysis is a time consuming and burdensome treatment. Patients’ perceptions of their HRQL following their diagnosis and treatment are important considerations in the clinical care of ESRD patients undergoing dialysis. The aim of this thesis was to examine the association of illness perceptions on outcomes of patients treated with haemodialysis (HD) or peritoneal dialysis (PD) within the theoretical frameworks of Leventhal’s Self-Regulation Model (SRM) and the biopsychosocial model.

THEORETICAL MODELS

BIOPSYPHYSICAL MODEL

Traditional medicine, until recently, was characterised by the biomedical model of care provision. The biopsychosocial model, described by Engel, aims to bring into the centre of focus the dimension missing in the biomedical model, that is the patient and his/her attributes as a person, a human being. The model encourages the physician to incorporate the psychological and social aspects of the patient into the assessment process to optimise patient care.

SELF-REGULATION MODEL (SRM)

The SRM consists of two parallel representational pathways; cognitive (causes, illness, identity, timeline, consequences, and controllability) and emotional, which together can influence subsequent coping strategies and health behaviours which in turn determine patients’ outcomes.
The SRM is well-researched with substantial support of its validity and value established from empirical studies.\textsuperscript{4,5} Although still relatively scarce, recent intervention studies suggest that changing illness cognitions can lead to improvements in outcome.\textsuperscript{6-9} In this thesis, the SRM serves as an elegant guiding principle for the four empirical papers that precede this General Discussion. These studies will be reviewed in the context of this model.

**THE NECOSAD PROJECT**

The Netherlands Co-operative Study on the Adequacy of Dialysis project first began in 1993 as a pilot study and with its success, a more extensive study (NECOSAD-2) was started in 1997. The data used in the empirical papers of this thesis were from the NECOSAD-2, a large prospective study involving up to 38 Dutch dialysis centres and inclusion of nearly 2,000 incident dialysis patients. From its inception, outcome measurements such as patient-reported HRQL has featured prominently in the NECOSAD project.\textsuperscript{10-21} The studies included in this thesis continue this tradition.

**THEORETICAL CONTEXT OF EMPIRICAL STUDIES IN THIS THESIS**

**SYMPTOMS**

In Chapter 3, the symptom burden of patients undergoing dialysis treatment and its association with clinical and behavioural outcomes were investigated. Symptoms are the subjective experiences of people with medical problems, and symptoms shape illness representations.\textsuperscript{22,23} Symptoms are not necessarily associated with objective indicators or medically-oriented phenomena of illness. Symptom perception theory outlines that psychosocial factors such as previous experiences with the particular illness or with physical problems in general, learning history (modelling response from parents or significant others), social influences (cultural images of illness or culturally shaped responses, for example, to pain), and psychological phenomena (competition of cues) are more robust determinants of symptom perception.
In our study, symptom clusters were found to be only weakly related to ‘objective’ medical variables but had strong associations with HRQL dimensions. While our finding is in line with symptom perception theory\(^2\) and contributes further to the literature on the relation between symptoms and outcome, these results can be quite difficult to understand in clinical practice.

**Self-rated health**

We examined self-rated or self-perceived health in a large number of incident dialysis patients in Chapter 4. This concept fits within the biopsychosocial model in that self-perceived health impacts on physiological processes and ultimately, even on mortality\(^2\) – or as Kaplan stated: “The point at which there is no observable behaviour” (pg. 1212).\(^2\) Leventhal’s SRM does not explicitly include a concept such as self-perceived health. Theoretically and empirically, more work has been done on the SRM than on self-perceived health of clinical populations. This is probably one explanation for the somewhat puzzling mechanisms between self-perceived health and mortality.

**Illness perceptions**

Chapter 5 is a direct test of the SRM where we examined the illness perceptions of dialysis patients’ in relation to HRQL. The study provides a comparative outline to other chronic physical disorders samples, including studies of dialysis patients from other research groups. Even more importantly, it reports on the substantial contribution of illness perceptions in explaining HRQL in this group of patients. Our study fits within the SRM by contributing to the empirical studies on the relationship between illness perceptions and HRQL.\(^4\)

**Social support**

In the SRM, social support is postulated as a coping strategy whereby seeking social support behaviours could influence patient outcome. In our study (Chapter 6), we found that dialysis patients who perceived having inadequate social support had poorer survival. Although survival or mortality as an outcome is not explicitly stated in the SRM, it could be a topic/subject for future investigation. Furthermore, the chapter also illustrates the value of the biopsychosocial model, in demonstrating how, even after controlling for a host of demographical and clinical confounding variables, social support predicted survival in dialysis patients. Again this is consistent with the literature on social support in persons with chronic physical illnesses.\(^2\)
HRQL AND PERITONEAL DIALYSIS

The HRQL of patients undergoing peritoneal dialysis (PD) is less researched compared with haemodialysis (HD). In Chapter 2, 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. Although interest in the HRQL of PD patients has increased in the last decade, nevertheless, it is still under-researched compared with HD. 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.

IMPLICATIONS FOR CLINICAL CARE

The studies in this thesis clearly indicate that psychosocial factors indeed influence outcomes such as HRQL and survival in incident dialysis patients. Patients on dialysis are often burdened with a myriad of uraemic symptoms. Clinicians who rely on clinical interventions for symptom reduction and to improve the HRQL of dialysis patients need to realise that these interventions do not necessarily correlate meaningfully with patients’ subjective assessments of their symptom burden. Therefore, assessment of patients’ cognitions and perceptions should also be incorporated into symptom management interventions. Previous research on behavioural medicine approaches such as biofeedback, guided-imagery, and self management skills provide empirical support of their effectiveness.27,28

Addressing patients’ illness perceptions by their attending physicians and nurses is another important clinical implication of our study. As illustrated in previous intervention studies, eliciting inappropriate, self-defeating illness representations and changing them into more constructive and productive illness perceptions may be associated with improvements in outcomes of patients.6-9 Similar interventions could also work with dialysis patients. For example, in a small controlled intervention pilot study, Karamanidou, et al successfully showed that a psycho-educational programme was successful in changing HD patients understanding and perception of the problem associated with high phosphate levels and the necessity for phosphate-binding medication.29 While the intervention improved understanding and knowledge of the treatment, the authors reported that it did not increase the patients’ perceived need for or adherence to treatment. In another small experimental study, HD patients assigned to an intervention
reshaping patients’ self-representation of coping skills on disease adjustment were better adjusted, and had less depression and physical symptoms compared to two other treatment conditions of problem disclosure and control.\textsuperscript{30} Although small in size and limited to HD patients, these studies indicate the feasibility of interventions to address maladaptive illness perceptions of dialysis patients.

In our study the predictive power of a single self-rated health item in relation to mortality was very strong (Figure 1 in Chapter 4), even when controlling for a wide range of demographic and clinical confounders. With its predictive ability and simplicity of administration, self-rated health assessment should be a useful and cost-effective complement to the more ‘objective’ assessments in the clinical care of dialysis patients.

High levels of social support may translate into adequate illness representations (both cognitive and emotional) and better coping behaviour, and therefore, better outcome such as survival. Although we found that patients who perceive having inadequate social support have poorer outcome, the type of social support provided to patients is also important. Therefore clinical implications for ESRD patients starting dialysis could include recommendation for participation in patient groups or associations, involving expert-patients in dialysis units and pre-dialysis units which may impact on social support. Psycho-educational programmes involving patients and family may translate into better survival as patients and family learn to adapt to the lifestyle changes brought on by dialysis and the stress such changes place on the relationship.

**FUTURE DIRECTIONS**

In this thesis, the extensive data collected on behalf of the NECOSAD study allowed for the examination of a set of behavioural and psychological characteristics of dialysis patients, and its associations between these characteristics with major outcomes, such as HRQL and survival. The sheer size of the NECOSAD study, its prospective design and its extensive set of variables assessed in the context of the study still provides important research opportunities.\textsuperscript{31} Also of interest would be patients’ perceptions of their treatment as this could influence adherence and thus outcome.

In this thesis, behavioural and psychosocial characteristics were assessed with instruments of solid psychometric quality (for example, the SF-36 for generic HRQL, the IPQ-R for illness
perceptions, SSL for social support, and the KDQOL for disease-specific HRQL). Given the state-of-the-art in behavioural medicine research in 2008, it is evident that future research in dialysis patients would benefit from using dialysis-specific questionnaires in addition to those used in our current study. A second major strong component of the work that is described in this thesis pertains to the solid theoretical context which was used to put the empirical studies into modern theoretical frameworks used in behavioural medicine research and clinical care. Again, future theoretical developments will probably pertain to developing dialysis-specific theories and models, which would also allow illness-specific behavioural medicine interventions.

In this final section of the thesis, speculation about future research is presented. In the SRM, SRH can be linked to the ‘personal control’ dimension in the Illness Perception Questionnaire – Revised. Future research could target associations between self-perceived health and personal control (and coherence, as another potential proxy suggests itself), where patients are being taught skills which would increase their self-efficacy and self-management skills, and thereby their self-perceived health. Intervention studies involving larger numbers of patients from different dialysis modalities and well-grounded in a theoretical framework such as the SRM, could be implemented to address patients’ perceptions to ESRD and its treatments. It is emphasised that not only dialysis patients (and their partners) could be object of behavioural medicine interventions but also health-care providers and society at large. Patient education, patient support groups, societal pressure on the current kidney donation policy, and government policy regarding kidney donation may all contribute to improving the HRQL of ESRD patients surviving with dialysis.

REFERENCES

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