PSYCHOMETRIC TESTING OF THE PATIENT PERCEPTION OF HEMODIALYSIS SCALE

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by

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Abstract

The primary objective of this doctoral research was the psychometric evaluation of the Patient Perception of Hemodialysis Scale (PPHS) and assessment of its ability to identify factors associated with quality outcomes in the hemodialysis (HD) population. The dissertation consists of five chapters including an introductory and summary chapter. The three middle chapters each present a step by step description of how the PPHS and its subscales were developed, refined, and tested.

A convenience sample 236 HD patients was used in the chapters two and three. Stability of the PPHS was examined with 30 patients in chapter three and chapter four included a sample of 85 patients.

Findings support that the PPHS consists of five moderate to strong subscales. These subscales were similar yet distinct in their ability to measure physical health, social supports and adjustment. The PPHS is robust in terms of internal consistency and was stable on retest. Construct validity was supported by factor analysis and convergent/divergent validity with the SF-36 was established.

Assessment of the PPHS's ability to detect change in the patients' physical health, social supports, and adjustment over six months is presented. Sensitivity was examined by assessing the tool's responsiveness to change in illness measures and critical events.

Findings lead to the conclusion that the instrument is mildly responsive to a change in physical health and positive critical events in patients' lives but not to negative critical events.

Based on the examination of the items and subscales in the PPHS and their combined ability to measure a patient's status in terms of their physical health, social supports and adjustment, the instrument establishes itself as valuable clinical monitoring tool. The PPHS is a reliable, valid, user-friendly instrument that may be sensitive to physical changes and positive critical events and may be employed to measure the HD population's adjustment to disease-specific concerns related to their physical health, social supports, psychosocial health, and the occurrence of critical events. Additional examination of the revised PPHS with a different and larger population will allow the opportunity for further psychometric assessment.

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Support comes in many forms. To my family, my mother, sisters and brother whose unconditional love supported me through some difficult times; and to all my encouraging friends and colleagues, to the cheeky girls at the gym and the gang at Ben's who all helped keep me both sane and sanguine; to all I say a most sincere thank you.

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Co-authorship Statement

I, June Creina Twomey, did not contribute to the design or identification of the research proposal. In 1999 I joined the research team and co-ordinated the second part of data collection and data input. I conducted all data analysis and manuscript preparation. Guidance from my supervisors was gratefully accepted and they provided feedback on the manuscript.

CHAPTER 1

Introduction

End-stage renal disease (ESRD) is a phrase used to describe a condition where patients' kidneys begin to fail, or completely fail, and no longer function effectively. Without dialysis or a kidney transplant, a buildup of waste products in the body may cause severe or even fatal complications. The most common form of renal replacement therapy (RRT) to remove toxic wastes is hemodialysis (HD). The number of Canadians requiring RRT has increased dramatically over the years and in 2008, there were approximately 38,000 individuals on RRT, more than triple the number in 1990 (Canadian Institute of Health [CIHI], 2011).

Patients with ESRD usually present with a complexity of co-morbidities. The symtomatology of the disease is specific to the individual, which can create unique implications for a patient's overall quality of life. The complications associated with RRTs add additional stressors to an already difficult situation. The disease and its treatment can impact every aspect of a person's life, including physical, psychological, social, spiritual, and financial health. In order to provide optimal care and promote quality patient outcomes, health care providers must develop a greater understanding of how individuals' perceive illness and treatment experiences, the usefulness of social supports, and how successful they are adjusting to living with a chronic illness and its treatment.

The current study was part of a national study designed to develop a disease specific monitoring tool capable of assessing the total experiences of HD patients with ESRD and conduct a detailed examination of its psychometric properties. The primary purpose of the overall research program was to develop an instrument capable of monitoring changes in how individuals on HD assign meaning to their illness and treatment experiences, rate the quality of their social supports, and adjust to living with ESRD and HD. A secondary purpose was to examine the interrelationships among illness and treatment experiences, social supports, critical events, demographics, medical risk factors, and overall adjustment and how the variables relate to each other. The final purpose, and my specific area of focus, was to examine the psychometric properties of scales developed from the theoretical categories of a substantive theory and to determine each scale's ability to detect changes in patients' status and sensitivity to critical events.

This dissertation is presented in a manuscript format with an introductory chapter and a final chapter acting as bookends to the three manuscripts (chapters two, three, and four). Chapter one provides the reader with an introduction to the study, including the rationale and background information on the program of research. The research objectives and a literature review on the main topics are also provided in the chapter. Chapter two presents the first of a three part paper series. This paper summarizes the basic steps involved in testing and revising subscales of the Patient Perceptions of Hemodialysis Scale (PPHS) which were developed from the data base of a grounded theory study. Chapter three includes a description of an evaluation of the psychometric properties of the

revised subscales of the PPHS as depicted in Chapter two. Chapter four, the third and final paper, summarizes findings derived from evaluating the revised subscales' sensitivity to changes in patients' health status and exposure to critical events. Chapter five presents a summary of the dissertation in relation to the research objectives, as well as a section on limitations and implications of the research.

Background and Rationale

The intent behind this section is to provide the reader with an insightful and succinct overview of the phases of the research project that were initiated and completed prior to the current research project. This content is organized into three sections. The first section presents a brief overview of the qualitative research project and relevant findings. The second section summarizes the methodology. The third section addresses the preliminary psychometric testing findings from the previous testing of the PPHS. The last section describes the program of research for this dissertation.

Qualitative Research

In 1996 the research team (Gregory, Way, Hutchinson, Barrett & Parfrey, 1998) noted the lack of existing disease-specific instruments that reliably and validly measured the process of living with ESRD and HD. The purpose of the original research was to explore patients' experiences with ESRD and HD from the perspective of the symbolic interaction paradigm (Gregory, 1998; Gregory et al., 1998; Gregory & Way, 2008). To accomplish this objective, grounded theory was the method selected to interview 36 HD

patients of various ages and stages in dialysis treatment, and presenting with differing physical health status, concomitant co-morbidities, and social supports. By using the constant comparative method of analysis to identify and confirm substantive codes embedded in the interview transcripts, it was possible to reduce this rich, descriptive data into parsimonious sets of indicators, descriptors and properties used to define the theoretical categories comprising the substantive theory, living with end-stage renal disease and hemodialysis (LESRD-H) (Gregory; Gregory & Way). A more detailed description of the method used for this component is found in Gregory and Way.

The main theoretical categories or constructs defining the patients' experiences as captured by the LESRD-H include: *meaning of illness and treatment experiences*, *social supports*, and *adjustment to a new normal* (see Figure 1). The fourth construct in the substantive theory, *quality outcome*, is the evolving end-point of patients' experiences. The *illness and treatment* construct is defined as the stress of living with the concomitant effects of ESRD, co-morbid conditions and HD treatment, as well as trying to reduce the ambivalence created from knowing what healthy behaviours are required and actually implementing them. The second construct, *social supports*, captures patients' perceptions of the availability and supportiveness of informal (family, friends, dialysis peers) and formal (physicians, nurses, HD technicians, allied health) supports. *Adjustment to a new normal*, the core construct and mediator along the path to quality outcome, captures how patients' view themselves as persons and their adopted role to a life on HD. The emotional and psychosocial struggles permeate this process. The final

construct, *quality outcome*, is defined as the product of the interactions among *illness and treatment experiences*, *social supports* and *adjustment* at any point in time. *Adjustment* is a predictor to *quality outcomes*. As an evolving outcome state it is deemed to have both objective and subjective components and takes on as broader approach than quality of life (QOL). The thread linking all of the theory's constructs is *critical turning points* which refer to the meanings that a positive or negative event, independently or cumulatively, has for each component defining patients' experiences (Gregory & Way, 2008)

The substantive theory's constructs are consistent with comparable ones identified in the literature on ERSD and HD. What is different about the theory is the importance given to the separate and interactive effects of critical events in altering patients' perceptions of *illness and treatment*, *social supports*, and *adjustment* at any defining moment. Equally important is the emphasis placed on separating *adjustment* from *quality outcomes*, which has received extensive attention in the general and ESRD literature, albeit with inconclusive results. Finally, the major premises of the theory include the following: 1) *illness and treatment experiences* and *social supports* exert a direct influence on *adjustment* and *quality outcome*, and an indirect influence on *quality outcome* through adjustment, 2) *adjustment* has a direct impact on *quality outcome*, and 3) *critical events* influence *illness and treatment experiences*, *social supports*, and *adjustment*.

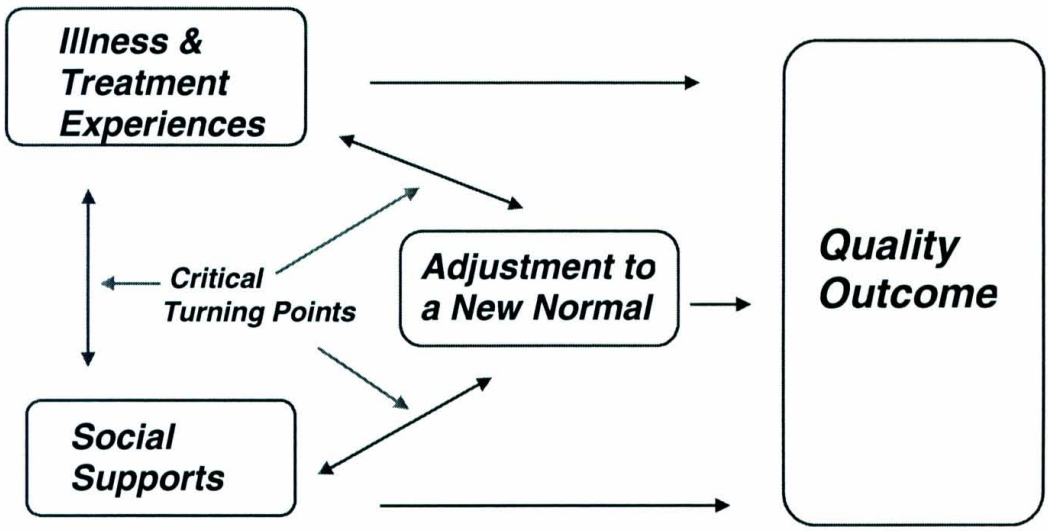

Figure 1.1. Living with End-Stage Renal Disease & Hemodialysis (LESRD-H)

***Note:** The model is based on the proposed Model of Patients' Perception of their Experience with Hemodialysis as presented in "Patients' Perception of their Experience with End-stage Renal Disease and Hemodialysis Treatment" by Gregory (1998), Unpublished master's thesis, Memorial University of Newfoundland, St. John's Canada and Gregory and Way (2008).*

Methodology Research

The objective of this phase of the research was to use the qualitative data base generated in the preliminary phase to develop an instrument capable of capturing patients' experiences with ESRD and HD treatment. The focus of the research team's efforts was on developing a multidimensional instrument to measure the three major constructs that addressed patient experiences (i.e., *illness and treatment*, *social supports* and *adjustmen*t). Using constant comparative analysis the qualitative researchers generated 164 stem items from the grounded theory data base and subjected them to an extensive refinement process to enhance clarity and reduce redundancy. Subsequent content and face validation steps involved consultation with two HD patients, four content experts and one adult literacy expert. These steps resulted in a more manageable number of items (i.e., 42 positively worded and 22 negatively worded). As well, input was sought from experts on the usefulness and appropriateness of different types of rating scales. The final decision was to use a five-point rating scale ranging from 0 (never or not at all) to 4 (almost always or extremely). Details on the process involved in construction of the PPHS have been summarized elsewhere by Gregory and Way (2008).

An important decision at this phase was not to duplicate the efforts of others by attempting to generate items to operationalize quality outcome. The rationale for this decision was that Ferrans and Powers' (1985) had already developed a disease-specific measure of quality of life for use with dialysis patients. This 64-item scale, designed to assess four domains of quality of life (i.e., family, health and functioning,

psychological/spiritual, and social and economic), was conjectured to be an adequate measure of the subjective component of quality outcome for the purposes of testing the major premises of the LESRD-H substantive theory.

Psychometrics

Psychometrics is the theory underlying an evaluation of the quality of an instrument and is based on the results of validity and reliability testing (Polit & Beck, 2008). Validity is the degree to which an instrument accurately measures the construct of choice. Validity will be addressed in terms of face, content and construct validity. Reliability, the ability of a measurement tool to accurately and consistently measure an attribute, is described using Cronbach's alpha and test-retest stability.

The first type of validity, face validity, refers to the appearance of a questionnaire. Items in the questionnaire need to appear as if they're measuring the construct of interest. Content validity is the extent to which an instrument includes all important content of the construct being measured. Construct validity, the third aspect of validity testing, is the extent to which an instrument measures a theoretical construct or trait (Polit & Beck, 2008). The most widely accepted methods to assess a new questionnaire's construct validity are factor analysis and convergent/divergent validity using Pearson's correlation.

Factor Analysis is a statistical method that examines the interrelationships among a set of variables and separates the relationships into factors, or constructs, with common

characteristics (Munroe, 2005). This approach was employed to examine the construct validity and to assist in item reduction. Convergent/divergent validity, also an indicator of construct validity, is assessed by correlating the instrument with another instrument to see whether they converge on similar constructs or diverge on different concepts.

Preliminary Testing of the PPHS

The PPHS was tested in by O'Brien-Connors (2003) with 112 HD patients from Newfoundland. The purpose of her study was twofold: 1) to examine the psychometric characteristics of the scale, 2) to assess the PPHS's ability to document HD patients' illness and treatment experiences, perceptions of support, level of adjustment to the disease and its treatment, and perceptions of quality outcomes , and to provide data for preliminary testing of the LESRD-H theory.

The initial psychometric analysis steps focused on assessing the construct validity, convergent/divergent validity and internal consistency of the PPHS subscales. Exploratory factor analysis and inter-correlation analysis of major subscales suggested that the PPHS had good construct validity. The suggestion was that the major subscales of the PPHS were measuring what they were purported to measure and were, therefore, capable of profiling patients experiences with ESRD and HD. Inter-correlation and regression analyses also supported convergent validity between PPHS subscales and relevant subscales of Ferrans and Powers' (1993) Quality of Life Index (QLI). As well, the internal consistency of the subscales was partially supported by Cronbach's alpha.

Finally, regression analyses provided partial support for the major premises of the LESRD-H (i.e., importance of adjustment as a mediator variable between the effects of illness and treatment experiences and social supports on quality outcomes (O'Brien-Connors; Gregory & Way, 2008).

The PPHS was also tested by Wells (2004). She used a descriptive, correlational design to assess changes in a convenient sample of 60 HD patients' perceptions of their illness and treatment, support system and adjustment to with ESRD and its treatment. Subjects were assessed at one time and again approximately seven months later. Wells used the SF-36 to measure QOL. The secondary goal was to examine the relationship among the PPHS subscales and the PPHS subscales in relation to demographic variables, co-morbidity and critical events.

Reliability and validity of the PPHS and the SF - 36 were also examined for the study population. Cronbach's alpha was used to assess internal consistency. Construct validity was evaluated by examining the intercorrelations among subscales and total scores. At baseline the alphas ranged from .36 to .91 internal consistency and at follow-up they ranged from .26 to .86. Scales with lower Cronbach's alphas also had low alphas in O'Brien-Connors' (2003) study. The major subscales Social Supports, Emotional Well-being, Psychosocial Distress, and the PPHS had alphas over .80 in both studies.

To determine construct validity Wells (2004) studied correlations of the PPHS subscales with total instrument scores, and intercorrelations among major subscales. The major subscales demonstrated moderate to strong correlations with the PPHS score at both times. However, the findings were inconsistent between measurement periods. She concluded that there was moderate to strong support for construct validity and recommended additional longitudinal research with a larger sample.

The research team realized that further studies were needed to make the PPHS a more succinct, reliable and valid, pragmatic, and insightful clinical monitoring tool. As well, a few problem areas were identified. Some of the subscales were not strong in terms of their internal consistency or factor loading, specifically those related to disease knowledge, activities of daily living and self-health management, allied health support, and family supports. A second problem was that the researchers were not content with the way the PPHS lined up with the QLI subscales and it was decided to replace this scale with the Short Form health survey (SF-36) in future investigations. The SF-36 was identified as a well known, reliable, and valid, generic QOL scale that had been tested in the HD population. Finally, adjustments were made to certain items to increase clarity.

Program of Research for Dissertation

The overall goals of the current and final phase of the research project and my part in the project were threefold. The first goal was to examine the multi-trait/multi-item correlation matrix. The second goal was to determine PPHS's ability to meet the Likert

scale assumptions and assess data quality. The next goal was to test the psychometric properties of the revised subscales of the PPHS. The fourth goal was to assess the PPHS's ability to respond to change in the HD population's illness and treatment experiences, social supports, and adjustment at two time periods; to assess the interrelationship among the major subscales; and to determine the impact of demographics, illness characteristics, and biochemical indicators on subscale scores. A final focus was to measure sensitivity of the PPHS subscales to critical events.

Research Program

In 1999 I joined the research team with the expectation that I would be responsible for evaluating the psychometric properties of the PPHS. My initial role was to administer the PPHS to patients in Newfoundland (NL) dialysis units and coordinate data collection outside of the province. In NL two researchers administered the PPHS to patients during dialysis. After data collection was completed the first step was to examine the items. I used a multi-trait/multi-item correlation matrix approach to examine the relationships of between all 64 items in the original PPHS and the relationships of each item with its predicted scale (See Appendix 1.1). Items with coefficients less than .3 were excluded. The team reviewed these items and a decision was made to deleted 18 items leaving 46 items in the PPHS. Using techniques outlined by Ware and Gandek (1998) the items of each major subscale were examined to assess data quality and whether or not they met the Likert scale assumptions. First I examined the mean and standard deviations and the amount of missing data. I also examined the item and scales level characteristics. At this

stage, I was focusing on refining subscale items targeted for inclusion and/or deletion based on their contribution to enhancing or diminishing subscale validity and reliability. An additional 10 items were removed based on their inability to meet Ware and Gandek's (1998) criteria. Once the new subscale structures were determined, the researcher proceeded with further psychometric testing. Construct validity was examined by subjecting the final item-set from step one to Exploratory factor analysis. Following factor analysis, convergent/divergent validity was determined by correlating all the subscales in the PPHS with each other and with the SF-36 subscales. The instrument's reliability was examined by using Cronbach's alpha for internal consistency and test-retest for stability.

The final step in this program of research was to inspect the PPHS's sensitivity to change in illness, treatment, support, or critical events. A sample of patients who provided data during the initial assessment was re-interviewed approximately six months later. Hypotheses for my research examined changes in the PPHS subscale scores between T1 and T2, differences in PPHS subscale scores among subgroups based on demographics, biochemical indicators, the number of co-morbid illnesses, illness severity, and differences in PPHS subscale scores among patients who experienced a change in their health status, biochemical indicators, and/or positive or negative critical events.

Rationale

Each year approximately 5400 individuals in Canada are diagnosed with ESRD and the majority of these patients will start HD as the primary method of RRT (CIHI, 2011). ESRD is a debilitating illness that impacts all aspects of an individual's life. Both the disease and its treatment have a profound impact on the patient's life. Life on HD means permanent attachment to a dialysis machine for approximately four hours, three times a week, unless the individual becomes eligible for renal transplant, undergoes the procedure successfully and no longer requires HD. The long term, time consuming therapy may interfere with the patient's ability to work, travel, and interact with family and friends. As well, the somatic symptoms of ESRD may cause fatigue, anxiety, and depression which may contribute to increased social isolation. In summary, the intrusion of the disease and its treatment may cause a permanent change in the patient's physical, psychological, social, and financial situation. Patients are in a constant state of uncertainty as they struggle to maintain a sense of normalcy. Thus, it is imperative that health care professionals assess not only HD patients' physical well-being but also use a holistic approach during care provision that improves the likelihood of achieving quality patient outcomes.

Research Objectives

This study was designed to address the following research objectives:

1) To reduce scale length by deletion of unnecessary or unhelpful items.
2) To assess construct validity of the PPHS.
3) To test the convergent/divergent validity of the PPHS with the SF-36
4) To calculate internal consistency for the PPHS and its subscales
5) To determine the test-retest reliability of the PPHS (i.e., score variation over a two week period in a group of stable patients).
6) To determine the responsiveness of the PPHS to change by comparing the score change over 6 months among patients who have and have not had a change in clinical status.

Literature Review

This literature review is presented in four sections on the following topics: physical stressors/symptom burden; social support; psychosocial health/health-related quality of life/QOL; and instruments used to measure quality outcomes in the HD population. The first three areas address constructs related to the substantive theory LESRD-H developed from the qualitative study on patients' perceptions of their experiences with ESRD and HD. The final section will present a review of disease and treatment specific instruments developed to assess quality outcomes with HD patients.

The rationale for reviewing literature on the first three topics is to provide the reader with information regarding pertinent research on the main constructs. Examination of these articles supports that measurement and identification of the outcomes can be complex and at times perplexing. The goal of presenting literature on these topics is to disentangle the individual constructs and to set the stage for the three articles included in this dissertation. Section one is related to physical stressors/symptom burden. The second section presents research on social support followed by the third topic adjustment/ health-related quality of life/QOL.

Illness and Treatment

Previous research on the effects of illness and treatment on quality outcomes for the ESRD-HD population has focused on laboratory parameters in terms of biochemical indicators (blood values), dialysis adequacy (Kt/V), and mortality. More recent studies have expanded on that research and investigated stressors related to the illness experience and the impact of symptom burden on QOL.

In 1996, Lok assessed stressors, coping mechanisms and QOL in HD patients. He found that limitation of activity, a decrease in social life, uncertainty, fatigue and muscle cramps were the top five stressors. Psychological and physical stressors were also assessed by Curtin, Bultman, Thomas-Hawkins, Walters, and Schatell (2002). The main stressors in this study were lack of energy, feeling tired, dry mouth, itchy skin and muscle cramps. In both studies the researchers found that subjects rated physical stressors to be more

invasive than psychosocial ones. Jablonski (2007) reported that the HD patients found that their main stressors were again tiredness, difficulty sleeping, cramps, pain and itching. In 2010, Claxton, Blackhall, Weisbord and Holley assessed physical and emotional symptoms in a group of HD patients. These authors found that the main stressors were pain, insomnia, mood disturbances, sexual dysfunction, paresthesia and nausea. Between 1996 and 2010 physical stressors dominated the literature and HD patients' lives.

Jhamb et al. (2011) assessed the impact of fatigue on HD patients. This study differs from some of the previous research in that it assesses the interactive effects of the co-morbid illnesses. Patients with higher levels of fatigue had more co-morbid illnesses, were more likely to have diabetes, had lower albumin levels, poor sleep quality, and had been on dialysis longer. In their study, patients who experienced a significant increase in the SF-36 vitality score had an increase in their mean survival time. Vitality may have acted as a buffer to the illness and treatment anxiety. The majority of concerns cited in these studies relate to physiological stressors and many of the treatment interventions that could be utilized to alleviate symptoms.

Some researchers studied both stressors and coping in the HD population. Mok and Tam (2001) found that physiological stressors (i.e., fluid and food restrictions, itching, fatigue) and the cost of living on HD were the most prevalent concerns. The most frequently used coping mechanism was trying to accept the situation, an effective coping approach for

coming to terms with an illness. The authors noted that the traditional philosophies of the Chinese were used in the management of stressors which is not surprising as the sample was from Hong Kong. In 2006, Logan, Pelletier-Hibbert and Hodgins investigated stressors and coping with patients over 65 years of age. Similar to the findings of Mok and Tam, fluid restrictions and fatigue were constant stressors. These authors also found that patients did not adjust to these HD symptoms over time. Although older patients tended to rely mostly on optimistic coping styles (i.e., using humour, thinking positively) followed by prayer and supportive approaches, the authors noted that study subjects did not find these coping mechanisms very useful for dealing with stress. A final study by Yeh and Chou (2007) sought to examine stress and coping in HD patients. The findings indicated that interference with daily living and physical symptoms were the prevailing stressors. Although problem oriented coping strategies were used most frequently, the authors noted that the style of coping depended on the type of stressor. Between 2001 and 2007 variant approaches to dealing with stressors emerged from findings of research studies.

Other authors have examined the role that physical stressors/symptom burden has on QOL. An early study on stressors was completed in 1998 by Bihl, Ferrans and Powers who assessed stressors and QOL in HD and peritoneal dialysis patients. HD subjects had higher levels of stress with fatigue and boredom being the more frequent concerns than the patients on peritoneal dialysis. The authors also reported that HD patients were less satisfied with their QOL than patients on peritoneal dialysis.

In 2002, Curtin et al. studied physical stressors and QOL for the purpose of developing an instrument to measure both concepts. The top four stressors (i.e., fatigue; lack of energy, dry mouth, and itchy skin) were physical in nature. The SF-36 physical and mental subscales were inversely correlated with an increase in all the physical symptoms. Using multiple linear regression, fatigue, mobility index and itchy skin had a significant association with the SF-36 physical scores whereas fatigue, dry mouth, and lack of appetite had a significant effect on the patients' mental scores. In this study, more frequent symptoms were correlated with lower scores on the SF-36 physical and mental scales.

Kimmel, Emont, Newman, Danko and Moss (2003) assessed QOL and the effects of pain symptoms. These authors found that increased pain was related to lower satisfaction with life and QOL scores. In 2005, Weisbord et al. examined physical and emotional HD symptoms and their effect on QOL. The four main symptoms were dry skin, fatigue, itchy skin, and pain. An increase in the number of symptoms and severity was related to a decrease in health related QOL and supported by higher illness effects scores. The authors suggested that HD patients be monitored regularly in an attempt to improve their overall health. Jhamb et al. (2009 & 2011) examined the role that fatigue had on the SF-36 subscale and QOL as measured by the Choices for Healthy Outcomes in Caring for End-Stage Renal Disease (CHOICE) questionnaire. They found that high levels of fatigue were correlated with low vitality, poor sleep quality, and increased pain. Lower vitality scores at baseline and one year later were both associated with a higher mortality

rate. Davison and Jhangri (2010) investigated the relationship between symptom burden and health related QOL. Pain, fatigue, lack of well-being, and depression were the main symptoms and main predictors of QOL.

The articles referenced in this section of the review on physical stressors include a variety of research designs with varying objectives, instruments and methodologies. As well, the sample size fluctuates from 50 to 2642, with most studies having greater than 150 subjects. The studies took place in Canada, the Unites States, Hong Kong and Taiwan, so there is a mixture of cultures and ethnicities. Some studies were more rigorous than others but the main message supported by these studies is that HD patients are more concerned with physical stressors than psychosocial ones. Furthermore, physical symptoms seem to have a greater impact on overall physical and mental QOL.

Social Support

During the last 15 years, research has established that there is a positive relationship between social support and quality outcomes. Social support may act as a moderator or a buffer to the effects of stressors on an individual's physical or psychological well-being. An individual's ability to cope may be affected by the availability of social supports. Social support is a multi-dimensional construct and is based on a variety of variables such as the size of the support system, the persons providing support, intensity and perceived quality.

It is an integral component of coping and may have a crucial part to play in adaptation to chronic illness.

The role of social support is a prevalent topic in research on chronic illness and more specifically ESRD. Studies on the HD population have identified the benefits of having a strong circle of family and formal support (Cohen et al., 2007; Ersoy-Kart & Gulda , 2005; Gregory et al., 1998; Kimmel et al., 1995; Kimmel et al., 1998; Untas et al., 2011). Some of the older research addressed the presence or absence of support and its association with other independent factors prevalent in the patients' lives at one point in time. More recent research examines the relationships between social support and dependent or outcome variables.

Kimmel et al. (1995) found a correlation between social support and depression. Patients with better support systems had lower scores on the depression scale and greater satisfaction with life, their vocation, relationships, and adjustment to their illness. The relationship between social support and more positive patient outcomes was also supported in research by Ersoy-Kart and Gulda (2005). These authors established that subjects with high levels of social support are more self confident and have more effective coping skills for dealing with HD stressors.

A more recent article by Cohen et al. (2007) assessed the impact that social support had on patients with chronic kidney disease. They found that patients with strong support

systems had lower mortality rates, decreased levels of depression, enhanced QOL, and improved compliance with the HD restrictions. Spinale et al. (2008) examined the relationship among spirituality, social support, and survival. They discovered that a positive support system was related to an increase in survival. In 2010, Rambod and Rafii investigated social support in a cohort of Iranian HD patients; results were similar. Patients with more support had increased QOL scores. Plantinga et al. (2010) assessed the relationship between social support in HD and peritoneal dialysis patients. They concluded HD patients perceived less support than the peritoneal group. However, both groups had high levels of support which was related to fewer hospitalizations and greater QOL.

Untas et al. (2011) measured the role that social support and psychosocial variables had on survival and QOL. Psychosocial health was assessed using three questions on each of the following topics: social activities; illness burden; and isolation. QOL was measured using the KDQOL-SF. The authors found that patients with higher levels of support had improved QOL, increased well-being, adjustment and decreased mortality rates. As well, patients were more likely to have improved adherence to the HD regimen when they had more social support.

In terms of formal support from health care professionals, research was found maintaining the positive role that health care professionals can play in improving quality outcomes. In 2002 Patel, Shah, Peterson and Kimmel found that increased satisfaction

with care was correlated with higher perceived quality of life. Kovac, Patel, Peterson and Kimmel (2002) investigated the relationship among satisfaction with care, compliance and perceived social support. They found that higher levels of satisfaction were positively correlated with compliance and increased perception of social support. Untas et al. (2011) examined support from HD staff and the effect it had on the SF-36 subscale scores. Patients with more positive views of staff were more likely to score higher on the physical SF-36 subscale. Neri et al. (2011) also assessed the impact formal supports had on illness intrusiveness and illness burden. They found that patients who perceived higher levels of support from health care professionals had less illness intrusiveness and illness burden. Overall, more positive perceptions of formal support were related to increased QOL scores, improved compliance, better scores on the SF-36 physical scores and decreased illness intrusive.

The effects of social support on quality outcome variables could be related to a variety of factors. Patients with higher levels of support may have fewer problems with transportation to and from the HD unit. They may have a second income in their family, which might ease the financial burden. In terms of compliance with the diet and fluid restrictions, HD patients with strong support systems may have someone to purchase their food, help with meal preparation, or even someone to share a meal with at the end of their day. More formal support systems, such as a positive relationship with health care professionals may also affect compliance and ultimately survival. Patients with strong formal supports might feel more comfortable seeking information related to their

treatment and illness. More specifically, talking with the health care professionals may lead to increased patient satisfaction (Kovac et al. 2002).

Research suggests that social support is an essential part of adjusting to a chronic illness and coping with ESRD, HD, and the restrictions placed on an individual. Family support is imperative in providing emotional and material support for patients living with the disease but patients also need cognitive and moral support from health care professionals. This project will add to the body of knowledge as it investigates the role of formal social support and its effect on quality outcomes.

Psychosocial Health, Health-Related Quality of Life, and Quality of Life

The concepts, psychosocial health, health related QOL (HRQOL), and QOL, have been used interchangeably in the literature on ESRD and the HD population. If one examines the research on the concepts one finds a significant overlap in the instruments used to measure each separate yet related outcome. The difference between HRQOL and QOL is minimal. To try to decrease the confusion surrounding the use and definition of these terms a brief review of the constructs will be presented. Readers are reminded that none of the constructs are a static state but include a process of continual, individual appraisal, and reappraisal.

Psychosocial Health

Psychosocial health is defined as the mental, emotional, social and spiritual well being (D'Amico, Barbarito, Twomey & Harder, 2012). As you will see in the review, the characteristics of psychosocial health have been defined in different ways and measured using a variety of instruments.

In 1996, Kimmel et al. examined psychologic function, QOL and compliance in the HD population. A variety of standardized measures were used to assess psychosocial function. Beck's Depression Inventory (BDI) and its subscale the Cognitive Depression Index (CDI) were used to measure depression. Social support was assessed using the Multidimensional Scale of Perceived Support (MSPSS) and the Dyadic Adjustment Scale (DAS). Adjustment to illness was measured with the Psychologic Adjustment to Illness Scale (PAIS) and three of its six domains relating to adjustment to relationships, adjustment to the patient's vocation and adjustment to their social environment. The last psychosocial area assessed was individuals' perceptions of the impact of ESRD and HD on their behaviour, which was measured using the Illness Effects Questionnaire (IEQ). QOL was measured with the Satisfaction with Life Scale (SWLS). In this study increased perceptions of social support were correlated with improved adjustment with their relationship, more positive scores relating to their satisfaction with life and, less illness intrusiveness.

In 1998, Kimmel et al. investigated psychosocial factors, compliance and survival in HD patients. In this research, they used the BDI, MSPSS, IEQ and the SWLS to determine psychosocial variables. This study supported the earlier research. Patients with more support lived longer, were more satisfied with their life, reported lower depression scores, and stated that they experienced less illness effects.

Psychosocial variables, QOL and the role of religion in HD patients were examined by Patel et al. (2002). Psychosocial variables were again measured using the BDI/CDI, MSPSS and QOL was assessed with the SWLS and the McGill Questionnaire. The team added questions related to satisfaction with care. Three of the questions were adapted from the Kidney Disease QOL scale (KDQOL) and two items used in a previous study by Kovac et al. (2002) were added. Religion was a significant variable in terms of its relationship to the patient's perception of support, and a decrease in the depression and IEQ scores. An increase in the satisfaction with life score was associated with an increase in satisfaction with care and a decrease in the illness effects score. Ultimately, these authors concluded that psychosocial health was influenced by religious beliefs and satisfaction with life.

In 2003 Kimmel et al. examined psychosocial factors, spirituality, occurrence of symptoms and ethnicity. Psychosocial variables were assessed using the SWLS and the McGill questionnaire. Spirituality was measured using the Spiritual Beliefs Scales. The authors also used the SWLS to determine patients' satisfaction with their life.

An increase in symptoms was correlated with a decrease in the McGill scale scores indicating less psychosocial health. Support from health care professionals was correlated with a higher score on the McGill scale and spiritual patients scored higher on both the satisfaction with life and the McGill scale. Psychosocial factors were associated with degree of symptom burden, social support and spirituality.

Psychosocial health, or psychosocial factors, has been measured using a variety of instruments. The lack of consistent measurement tools increases the confusion surrounding accurate representation of the concept and its role in HD patients' lives. We hoped to develop one instrument to measure the multidimensional nature of the patient's experience with HD and avoid using several questionnaires

Health-Related Quality of Life

HRQOL, another indicator of QOL, is defined by Finklestein, Wuerth and Finklestein (2009) as "the extent to which one's usual or expected physical, social, or emotional well-being is affected by a medical condition and/or its treatment." (p.76). Researchers (Unruh & Hess, 2007; Unruh, Weisbord & Kimmel, 2005) reviewed the topic and concur that HRQOL speaks to a component of health as defined in 1998 by the World Health Organization's (WHO). Despite the use of the phrase "QOL" in articles, few authors actually define the term. Most researchers used the SF-36 or the KDQOL to measure HRQOL.

The SF-36 is a generic QOL instrument used in a variety of populations, whereas the KDQOL is a kidney disease specific questionnaire that includes components of the SF-36.

Morsch, Goncales and Barros (2006) investigated HRQOL, biochemical indicators, Kt/V, level of co-morbidity, and mortality among HD patients. They used the SF-36 to assess HRQOL. Findings supported that men had higher energy/fatigue subscale scores than women. Patients on HD for more than one year had higher scores on the general health, role emotional, and energy/fatigue SF-36 subscales than patients on HD for less than one year. They also found that HD patients with higher education had lower perceptions of their general health, which may indicate that they have a more realistic insight into their health status, that they have unrealistic expectations, or it may be an anomaly as higher socioeconomic status/education is usually associated with better health. Morsch et al. also reported a significant correlation among Kt/V and pain levels, albumin and physical functioning, and co-morbidity severity levels and physical functioning. Haematocrit was significantly associated with the SF-36 physical functioning, general health, and role emotional subscale scores. Mortality was not significantly different in terms of any of the variables studied or HRQOL. A limitation of this study is that they only had 47 subjects

Kao et al. (2009) looked at HRQOL and its relationship with economic, social and psychological factors. They used the SF-36, occupation, and income to measure economic status. Psychological factors were quantified using the number of worries, the absence or presence of worries, and the BDI. Results supported that patients with higher economic status had higher scores on the SF-36 role emotional, mental health and social functioning subscales. Higher BDI scores were related to a decrease in all SF-36 domains. As well, an increase in the number of worries was related to a decrease in social functioning and mental health.

Liang et al. (2011) examined HRQOL and degree of heart failure in a group of HD patients. They used the Index of Disease Severity and the Coexistent Disease score to quantify the level of heart failure and the Kidney Disease Quality of Life-Long Form (KDQOL-LF) form to assess HRQOL. This instrument includes the SF-36 and disease specific questions on sleep quality. They found that increasing severity of heart failure was related to decreased KDQOL-LF scores, increased hospitalization and mortality.

The final article to be reviewed was published in 2011 by Thomas. He assessed the relationship among genetics, environment, religion, social support and HRQOL. He asserted that these variables played a role in HD patients HRQOL. Findings supported that an increase in patients' perception of religiosity and social support were related to an increase in HRQOL as measured by the SF-36.

Of the six studies presented in this section, four measure HRQOL with the SF-36, a generic instrument used to measure QOL in a variety of populations. Use of this instrument adds to the confusion over the separation of the topics HRQOL and QOL as the SF-36 is used as a measurement in QOL. Ware, Snow, Kosinski, and Gandek (1993) explicitly state that the SF-36 was developed as a generic health instrument and was never intended to be used for a definite age group, or people with a specific disease. However, the tool became so popular that the SF-36 manual now identifies norms for some disease populations. One study used a different tool, the KDQ, which is reliable, valid, and disease specific measure. The number of patients in each study varies with Morsch et al. (2006) having only forty HD patients. The weakest study in this review was by Thomas (2011) as he does not measure any aspect of physical health. If one purports to assess HRQOL, then a physical or psychological variable that measures health. Any HRQOL study on HD patients should clearly define the term, identify exactly how it will be measured, and ensure that it relates to HD symptoms or treatment.

Quality of Life

Quality of life is defined by the WHO (1998) as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.

It is a broad ranging concept affected in a complex way by the persons' physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment" (p.3).

Many researchers have examined QOL and biochemical indicators and/or co-morbidities in the dialysis population. Cleary and Drennan (2005) measured QOL, Kt/V and compared the HD populations to the general public. Patients with higher Kt/V scored higher on all SF-36 subscales than the group with a lower Kt/V. There was a significant difference in the role emotional and mental health subscales. The HD population scored significantly lower than the general Irish population on all SF-36 subscales with the exception of mental health.

The fact that patients with a chronic disease had lower SF-36 scores than the general population is not surprising as Ware et al. (1993) documented this in their research on normative data for the general population.

Bohlke et al. (2008) researched the connection among biochemical values, demographics, and co-morbidity. They used the SF-36 to measure QOL. Increased age, number of co-morbidities and time on HD were predictors of the physical component summary score. Positive predictors for the mental component score were being on peritoneal dialysis versus HD, being married and employed whereas a negative predictor was hypertension.

Yamana (2009) examined basic demographics variables, laboratory parameters and QOL as measured by the Kidney Disease Quality of Life-Short Form (KDQOL-SF). He found that the burden of kidney disease was significantly lower in patients with low hematocrit. Serum potassium levels had a significant effect on the patients' mental health, social functioning, symptoms, and the effect of kidney disease subscales. Older patients scored higher on the social interaction, social support, and encouragement by dialysis staff subscales. As well, the group on HD for five or more years had significantly better scores on the physical and emotional functioning subscales. Yamana commented that this group were coping better than the group on HD for less than five years because they had more practise coping with the overall experience. Although this conclusion is confounded by survivor bias caused by sicker patients dying more quickly and being over represented in the group on HD for less than five years.

In 2009, Lacson et al. investigated biochemical indicators, the absence/presence of a HD catheter and the effects of these variables on QOL. They set the category specific goal (ideal score) for hemoglobin between 11-12g/dL. Patients with hemoglobin between 10 and 11g/dL scored significantly lower on all the SF-36 subscales than patients in the ideal range. Patients with hemoglobin at less than or equal to 13g/dL scored significantly higher than the ideal goal range and patients with hemoglobin levels greater than 13g/dL scored significantly higher on the vitality subscale than patient in the 11 to 12g/dL. The ideal albumin was set at greater than or equal to 4g/dL. The three groups with less than 4g/dL all scored significantly lower than the ideal albumin group on all SF-36 subscales.

An ideal equilibrated Kt/V was set at equal to or greater than 1.2. Patients who scored less than 1.2 scored lower on all SF-36 subscales. Optimum phosphorus serum levels were set at 3.5-5.5 mg/L. Patients with a lower level had significantly lower scores on all the SF-36 subscales except pain and role emotional. Patients with increased phosphorus levels scored significantly lower on the pain, general health, vitality and mental health subscales. The last variable was the presence of a HD catheter. Patients without a catheter had higher scores on all subscales. The presence of the catheter may have had a positive or negative effect on the outcomes. Patients with a catheter were more likely to get an infection and there's a risk of increased mortality. On the other hand it may indicate that the patient is healthier and prepared to start HD. Without more information no conclusions can be confirmed.

Reflecting on these research articles one can see that the results are at times conflicting. In one article, biochemical indicators and/or Kt/V values seem to play a role in QOL (Lacson et al., 2009) whereas in another study by Yamana only serum potassium had an effect on QOL. Time on Dialysis was a significant variable in assessment of QOL in the study by Bohlke et al. (2008) who found a negative relationship with time on HD and physical component summary score, yet Yamana (2009) found that patients on HD longer than five years had higher scores on the role functional (physical), role functional (emotional), social functional and cognitive function subscales. However, there was no difference in physical functioning subscales score between Bohlke's groups. The mixture of research designs, varying sample sizes and inconsistent findings support the need for

further longitudinal research on the factors affect quality outcome in the HD population. Again, the authors neglect to define what they mean by QOL and they use such a variety of instruments that it is difficult to compare outcomes. One has to question whether the separation between QOL and HRQOL is artificial at best.

Disease-specific QOL Instruments

The final section of this literature review describes a variety of instruments specifically developed to measure QOL in the HD population. The four most popular disease specific instruments used to assess quality outcomes in HD patients are the Kidney Disease Questionnaire (KDQ), the Kidney Disease Quality of Life (KDQOL) instrument, the Health Related Quality of Life (HRQOL) questionnaire and the CHOICE Health Experience Questionnaire (CHEQ).

In 1992 Laupacis, Muirhead, Keown, and Wong developed the KDQ. Data was collected via interviews and reviewed for content relevance by 50 HD patients. The final questionnaire included 26 questions on five dimensions related to: physical symptoms; fatigue; depression; relationships; and frustration. The KDQ is a reliable and valid instrument but fails to capture the essence of adjustment or adaptation to the illness and treatment, social support or quality outcomes.

Hays, Kallich, Mapes, Coons, and Carter (1994) developed the KDQOL. This instrument included the SF-36 and a scale with kidney disease symptom-specific questions. They

constructed the questionnaire using information from three patient focus groups, one HD staff group, and a review of the literature on ESRD patients and quality of life. The patient focus groups included a mixture of people on HD, peritoneal dialysis and some transplant patients. Only seven of the 15 patients who participated in the focus group were on HD. Non-disease-specific questions used in the KDQOL were adopted from a variety of instruments assessing symptoms, work status, cognitive functioning, sleep patterns, patient satisfaction, and sexual functioning that may, or may not, be relevant to the HD population. Limitations of this instrument are that only some of the information collected was from HD patients, so the instrument is not specific to HD treatment or symptoms. Again, no attempt was made to assess social support or adjustment to living with chronic disease or its treatment.

Parfrey et al. (1989) utilized different methods to develop the HRQOL questionnaire: interviews with HD and transplant patients; interobserver reliability and intraobserver reliability. They used a cross-sectional design to test construct validity and a prospective study to determine responsiveness. The instrument included a symptom scale and an affect scale. Symptoms were included in the HRQOL scale if greater that 25% of the HD or transplant patients identified them as a concern, whereas items in the affect scale were chosen by the researchers. The symptom scale was based on patient feedback and more likely relevant to ESRD patients than questions in the affect scale that were chosen by the researchers.

As well, the questionnaire, which was based on a mixed sample of transplant and HD patients, may not be appropriate for this research as our focus is exclusively HD patients and their experiences.

In 2001 Wu et al. designed the Choices for Healthy Outcomes in Caring for End-Stage Renal Disease (CHOICE) study to develop a disease specific instrument titled the CHEQ. The instrument was designed to be used in conjunction with the SF-36 and to differentiate between patients receiving HD and peritoneal dialysis. They used a variety of techniques to identify items including a literature review, five focus groups, a health care professional survey, and an open ended patient survey. Item selection was based on HD and peritoneal dialysis patients' rating of the importance of specific issues. The questionnaire was examined by health care experts and the psychometric properties were examined and confirmed. The final version of CHOICE questionnaire included the eight SF-36 subscales and 14 single items, including questions identified in the importance survey. These questions were adopted from other questionnaires when appropriate. Limitations of this questionnaire are that it isn't specific to the HD population and it doesn't measure social support or adjustment to living with HD treatment.

Researchers attempting to measure quality outcomes in the HD population have also used a variety of non-disease-specific instruments to assess constructs they believe are relevant to the patients. Some examples are stress, fatigue, psychosocial adaptation, depression, and health-related QOL as identified earlier in this literature review. Danquah,

Wasserman, Meinger, and Bergstrom (2010) stated that the approach to measuring the total experience of patients on long-term HD has been fragmented and that the problem with trying to measure such an indistinct construct is that a multitude of research has been completed using different measures with dissimilar findings; this has added confusion to an already complex topic.

This sentiment is reflected in the reviews of quality of life research and instruments by numerous authors (Anderson & Burckhardt, 1999; Danquah et al., 2010; Edgell et al., 1996; Gill & Feinstein, 1994; Prutkin & Feinstein, 2002; Rettig et al., 1997).

Summary

The goal of this project was to bridge the gap in measurement of quality outcomes and develop a feasible method, grounded in the patient's world, to comprehensively assess patients' experiences with ESRD and HD and to monitor change over time. Our objective was to develop a clinical monitoring tool to assess factors that may have effect on patient's experience with HD and to determine their ability to predict to quality outcomes. The PPHS differs from the instruments cited above. The PPHS and the KDQ are the only disease specific instruments based on what HD patients considered to be important. The PPHS also measures formal social support which is not assessed in the questionnaires cited in this section.

All of the questionnaires highlighted purport to measure QOL; our instrument predicts to quality outcomes a broader perspective. As indicated in the LESRD-HD, model the focus of the PPHS is broad and the concepts are interrelated and overlapping. The aim of this research is to develop a valid, reliable, responsive rating tool that will distinguish patients in regard to their status at different points in their illness and treatment.

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Appendix 1.1

PPHS _____ Patient ID# _____

Patient Perceptions of Hemodialysis Scale

The following scale contains a list of items that reference events/situations that you may have experienced since the onset of kidney failure and staring hemodialysis. You are being asked to rate each item on a 5 point rating scale located in the columns to the right. In the first instance you are asked to indicate **'how often you feel this way'** (never, rarely, sometimes, often, or almost always). Finally, you are asked to indicate **'how satisfied, how confident or how concerned are you'** (not at all, a little bit, moderately, quite a bit, extremely).

RATING SCALES

How Often

Never	Rarely	Sometimes	Often	Almost Always
0	1	2	3	4

How Satisfied/How Concerned/How Confident

Not at all	A little bit	Moderately	Quite a bit	Extremely
0	1	2	3	4

Circle the response that best applies to you.

1.	How confident are you that you understand the illness events that cause the loss of your kidney function?	0 1 2 3 4
2.	How concerned are you that your health will get worse regardless of what you or doctors do?	0 1 2 3 4
3.	How often do you experience breathing difficulties?	0 1 2 3 4
4.	How often do you feel tired and low in energy?	0 1 2 3 4
5.	How often are you bothered by walking short distances (e.g., tired feelings, breathing problems, etc.)?	0 1 2 3 4
6.	How confident are you that you understand why you need diet or fluid restrictions?	0 1 2 3 4
7.	How satisfied are you with the information that you have about the benefits/side effects of dialysis?	0 1 2 3 4

PPHS Patient ID#

8.	How often do you think about what could happen if you did not follow recommended diet and fluid restrictions?	0	1	2	3	4
9.	How often do you experience muscle cramps during or after dialysis?	0	1	2	3	4
10.	How often do you experience a drop in blood pressure during or after dialysis?	0	1	2	3	4
11.	How often do you experience itching due to your kidney disease?	0	1	2	3	4
12.	How often do you feel exhausted after dialysis?	0	1	2	3	4
13.	How often do you feel comfortable after dialysis (e.g., generally good feeling, less breathing problems, less swelling, etc.)?	0	1	2	3	4
14.	How often do you feel that dialysis has improved the quality of your life?	0	1	2	3	4
15.	How confident are you about knowing what is required to have a kidney transplant (e.g., waiting period, reasons for not being placed on or coming of the wait-list, etc.)?	0	1	2	3	4
16.	How often do you follow recommended diet and fluid restrictions?	0	1	2	3	4
17.	How often do you pay attention to what nurses/techs do during dialysis (e.g., needling , saline for cramps, checking blood pressure, turning off heparin, etc.)?	0	1	2	3	4
18.	How often do you watch for problems that could occur during dialysis such as bleeding/clotting of access site, cramps, or changing blood pressure?	0	1	2	3	4
19.	How often do you inform the nurse/tech about problems that occur during dialysis (e.g., positioning of needle, feeling unwell, problems with access site, etc.)?	0	1	2	3	4

20.	How often does your family try to help you accept your illness and dialysis treatment requirements?	0	1	2	3	4
21.	How concerned are you about becoming too dependent upon your family?	0	1	2	3	4
22.	How often do family members remind you about diet, fluid, or activity restrictions?	0	1	2	3	4
23.	How concerned are you about the impact of your illness and treatment on family members? (e.g., decreased social activities, dietary restrictions, time commitments with dialysis, etc.)	0	1	2	3	4
24.	How often do you do things to lessen the impact of your illness and treatment on family members?	0	1	2	3	4
25.	How often do you feel that your family is coping well with your illness and dialysis treatment requirements?	0	1	2	3	4
26.	How often do you experience delays in getting on dialysis or receiving scheduled treatment (e.g., turning off heparin etc.)?	0	1	2	3	4
27.	How concerned are you that nurses/techs may be too busy to pay attention to what is happening to you during dialysis?	0	1	2	3	4
28.	How satisfied are you with the overall quality of nursing/tech care in the dialysis unit?	0	1	2	3	4
29.	How confident are you that nurses/techs have the knowledge and abilities to know what to do if you become ill on dialysis?	0	1	2	3	4
30.	How satisfied are you with nurses/techs willingness to listen to what you have to say about your illness and treatment?	0	1	2	3	4
31.	How satisfied are you with the amount of time that nurses/techs take to help you understand your illness and treatment?	0	1	2	3	4

32.	How often do you fell that nurses/techs try to promote a relaxed, family-like atmosphere on the dialysis unit?	0	1	2	3	4
33.	How satisfied are you with the comfort measures provided by nurses/techs during dialysis (e.g., providing a blanket, pillow, refreshments, etc.)?	0	1	2	3	4
34.	How confident are you that dialysis doctors have the necessary knowledge and abilities to monitor or deal with your overall physical needs?	0	1	2	3	4
35.	How satisfied are you with how quickly doctors respond to your needs when you are on dialysis?	0	1	2	3	4
36.	How satisfied are you with the quality of overall medical care in the dialysis unit?	0	1	2	3	4
37.	How satisfied are you with doctors willingness to listen to what you have to say about your illness and treatment requirements?	0	1	2	3	4
38.	How satisfied are you with the amount of time that doctors take to help you understand your illness and treatment requirements?	0	1	2	3	4
39.	How satisfied are you with the support provided by dialysis social workers to help you deal with illness or treatment–related problems?	0	1	2	3	4
40.	How satisfied are you with information provide by the dietician about your diet?	0	1	2	3	4
41.	How often do you feel so frustrated with things that you would like to get off the machine and go home?	0	1	2	3	4
42.	How concerned are you for your personal safety while on dialysis (i.e., worried about what would happen to you)?	0	1	2	3	4

PPHS Patient ID#

43.	How concerned are you about voicing your needs to nurses/techs or doctors due to the physical closeness of others during dialysis?	0	1	2	3	4
44.	How often are you upset by seeing others become suddenly ill (i.e., worried that it would happen to you)?	0	1	2	3	4
45.	How often do you dwell on your own health problems following the death of another patient?	0	1	2	3	4
46.	How often do you feel depressed (i.e., feeling down, fed-up, frustrated) about your illness and long-term treatment requirements?	0	1	2	3	4
47.	How satisfied are you with your ability to do household or other work activities?	0	1	2	3	4
48.	How often do you experience fears or worries about unexpected illness/dialysis events (e.g., sudden drop in blood pressure, clotting of access site, breathing problems due to too much fluid?	0	1	2	3	4
49.	How often do you feel that depending on others makes you feel useless (e.g., self-esteem, self-worth)?	0	1	2	3	4
50.	How often do you feel distressed by the severity of your illness and the long-treatment requirements (e.g., troubled, worried, upset, etc)?	0	1	2	3	4
51.	How often do you feel stronger as a person because of your illness (i.e., discovery of inner strength, spiritual comfort, courage)?	0	1	2	3	4
52.	How often do you try to maintain a positive attitude towards dialysis?	0	1	2	3	4
53.	How often do you feel good about the 'special closeness' among patients during dialysis?	0	1	2	3	4
54.	How confident are you that you will come to terms with your illness (e.g., accepting)?	0	1	2	3	4

55.	How often do you accept dialysis as something you have to do (i.e., scheduled appointment, part of weekly norm)?	0	1	2	3	4
56.	How often do you relax during dialysis?	0	1	2	3	4
57.	How often do you participate in recreational activities (e.g., travel, volunteer work, hobbies, etc.)?	0	1	2	3	4
58.	How satisfied are you with how well you have adjusted to the effects of dialysis (e.g., pain, restrictions, problems with access site, delays, machine functioning, drop in blood pressure)?	0	1	2	3	4
59.	How confident are you that you can manage financial costs resulting from dialysis?	0	1	2	3	4
60.	How satisfied are you with the amount of quality time spend with family and friends?	0	1	2	3	4
61.	How confident are you that you are coping well with dialysis restrictions?	0	1	2	3	4
62.	How often do you feel that you have some control over the ups and downs of dialysis and the effects on your health and well-being (e.g., assuming responsibility for recommended treatment, monitoring dialysis run)?	0	1	2	3	4
63.	How often do you try to weigh the benefits/negatives of different treatment options before making a decision (e.g., home vs. hemodialysis, transplant, counseling, time of the day, or days on dialysis, etc.)?	0	1	2	3	4
64.	How satisfied are you with the amount of self-care responsibilities that you are able to assume on a given day?	0	1	2	3	4

Chapter 2

Item Refinement and Instrument Development: The Patient's Perception of Hemodialysis Scale

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Abstract

Objectives: The objectives were 1) to examine item correlations, data quality, scales and assumptions underlying Likert scoring of the Patient's Perception of Life on Hemodialysis Scale (PPHS) and 2) to refine the PPHS and assess its internal consistency.

Methods: Using a cross-sectional design, data collection was completed in three HD units in Newfoundland and one in Ontario, Canada. A convenient sample (N = 236) was obtained for this study. Data were analyzed using Statistical Package for Social Sciences (SPSS). Item inclusion was based on findings from a multi-trait/multi-item correlation matrix evaluating each item's relationship with its purported scale. Then, the remaining items were assessed for data quality and examined using Ware and Gandek's (1998). Likert scale assumptions. Item level data analysis included assessment of indices of central tendency, missing values and other basic descriptives. Using a corrected Pearson's correlation coefficient subscale-level characteristics such as item internal consistency, equality of the item to scale correlations, and item discriminat validity were examined. Subscales were also correlated to assess convergent/divergent validity. Items considered for elimination were outside of the desired range in any of the above criteria and examined by content experts for theoretical fit.

Results: The sample consisted of 236 patients from Newfoundland and Ontario. Item responses included the full range of characteristics identified in the Likert scale which ranged from 0 to 4. Item correlations greater than .3 were kept in the scale. There was a

limited amount of missing data, and the means, standard deviations, and frequency distributions of responses approximated normalcy about the mean score for each item. The ceiling and floor statistics suggested that subjects experienced the entire scope of the trait of interest. Items in each scale were correlated with their own scale and other PPHS scales to assess for divergent and convergent validity. The number of scales was reduced to seven and another 28 items were removed from the original 64 item PPHS. The Cronbach's alpha for the new scales was between .70 and .89.

Conclusion: The PPHS subscales were examined, and the number of items in each was reduced based on the theoretical underpinning of the item, item correlations, and the inclusion criteria as outlined in the Likert assumptions. The scales are distinct yet similar in terms of their ability to measure the main subscales: Physical Health, Social Supports, and Psychosocial Health, all predictors of quality outcomes. Indicators of Cronbach's alpha for the scales are high, supporting the internal consistency/reliability of the instrument. As a result of this approach to item refinement, the overall PPHS scale is stronger in terms of its validity and reliability and can be considered an appropriate indicator of the patients' perceptions of life on HD.

Introduction

During the last decade, the number of patients with end-stage renal disease (ESRD) has tripled, and each year approximately 5,400 Canadians are newly diagnosed (Canadian Institute of Health Information [CIHI], 2011). ESRD is a debilitating illness with many patients equally challenged by the presence of co-morbidities. A diagnosis of ESRD, its symptoms, and treatment may impact every aspect of life: physical, psychological, social, spiritual, and financial. In the last decade, health care professionals have acknowledged their responsibility in addressing clients' psychosocial status as well as their physiological needs. In an attempt to improve assessment of psychosocial adjustment in the hemodialysis (HD) population, the Patient's Perception of Life on Hemodialysis Scale (PPHS) was developed (Gregory, Way, Hutchinson, Barrett, & Parfrey, 1998). The purpose of this paper is to describe the steps taken in development and refinement of the PPHS and its subscales.

The term *adjustment to a new normal,* which may be defined in a number of ways, is most commonly included as an element of psychosocial health or quality outcomes. While reviewing the literature on quality of life (QOL), it becomes evident that the term is defined using a variety of concepts that overlap to some degree, making it challenging to differentiate among the various ways that QOL may be measured by researchers. Some terms commonly identified as components of QOL are *stress, coping, psychosocial adaptation, depression, health-related QOL,* and *illness intrusiveness.*

Since the early 1980s, researchers have looked at stressors and styles of coping (Baldree, Murphy, & Powers, 1982) as a means of quantifying QOL. Today, despite numerous studies measuring these concepts, it remains unclear which types of stressor, psychosocial or physical, has the greater impact on the lives of patients affected by ESRD or which type of coping mechanism is most effective in buffering the impact of variable stressor types (Gregory et al., 1998; Yeh & Chou, 2007). A second approach has been to look at depression or anxiety as indicators of adjustment or QOL (Cukor et al., 2007; Cukor, Coplan, Brown, et al., 2008; Cukor, Coplan, Brown, Peterson, & Kimmel, 2008; Johnson & Dwyer, 2008; Zimmerman, Poli de Figueirdo, & Fonseca, 2001). Living with ESRD and the physical and psychological outcomes have also been measured by assessing psychosocial adaptation (Burns, 2004; Cukor, Cohen, Peterson, & Kimmel, 2007; Kimmel, Emont, Newman, Danko, & Moss, 2003; Lew & Patel, 2007). Quality of life and health-related QOL are also cited as measures of quality outcomes in the HD population (Hsieh, Lee, Huang, & Chang, 2007; Kimmel & Patel, 2006; Kutner, 2004; Lew & Patel, 2007).

Devins (1994), a pioneer in the assessment of psychosocial adjustment to chronic diseases, examined the role of "illness intrusiveness," a construct developed from his research on QOL. Illness intrusiveness, the degree to which an illness or its treatment interferes with one's lifestyle, was identified as a mediator between emotional distress, psychosocial well-being, and quality outcomes. This author conjectured that interactive

relationships that existed among the different stressors (i.e., treatment and disease factors; psychological and social factors; and illness intrusiveness) had major implications for individuals with ESRD. Devin's hypothesized relationship among the variables is one of the most comprehensive approaches to assessment of living with a chronic illness. Many of these constructs are similar to those identified in the current research. Devins et al. (1990) proposed that illness intrusiveness was an important mediator in how patients adjusted to illness and treatment experiences, coped with stressors, adjusted to the psychological and social effects of illness and treatment, and, ultimately, were able to enjoy a reasonable QOL. An instrument measuring 13 life domains was developed and used with the HD population. Although reported to be reliable and valid, it originated from previous research and may not be a well-founded source for identifying major concerns of the HD population.

The studies highlighted above illustrate the variety of terms utilized to define and assess QOL in the ESRD/HD population. The approach to measuring the total experience of patients on HD has been fragmented, and it is difficult to get an overall picture of patients' adjustment to living with the disease and its treatment, and, ultimately, quality outcomes. After two decades of review and examination, measurement of these constructs remains splintered. One of the main problems with trying to measure such an indistinct construct is that a multitude of research has been completed using different measures with dissimilar findings that have added confusion to an already elusive topic. This attitude is also reflected in the reviews of QOL research with the HD population and

the instruments used by numerous authors from 1994 to the present (Anderson & Burckhardt, 1999; Danquah, Wasserman, Meinger & Bergstrom, 2010; Edgell et al., 1996; Gill & Feinstein, 1994; Kimmel & Patel, 2006; Prutkin & Feinstein, 2002; Rettig et al., 1997). For the purpose of this study we believe that the construct *quality outcome* has a broader scope that QOL, but includes all subjective aspects of QOL. Our goal was not to measure QOL but to identify how patients interpret the meaning of their illness, treatment, support system, emotional well-being and psychosocial distress and to examine the ability of the PPHS to capture these constructs in an attempt to predict to quality outcomes.

The disjointed approach to measurement of patients' experiences and QOL, the lack of existing instruments that reliably and validly measure the process of living with ESRD and HD, and patient adjustment to these challenges were the impetus for a qualitative study that was the basis for the PPHS (Gregory, 1998; Gregory et al., 1998). The most effective method to accurately measure the patient's total experience is to start with a scale that originates from the patient's words, experience, and perspective. Using a grounded theory approach, Gregory and colleagues examined the overall psychosocial and physiological experience of patients with ESRD treated with in-center HD. Three theoretical constructs emerged from the research: *meanings of illness and treatment*, *social supports* and *adjustment to a new normal*. The *meaning of illness and treatment* construct integrated concepts related to dealing with the stress of living with ESRD, its symptoms, the multitude of co-morbid conditions, the frustration of ambivalence, and the

conflict between knowing what to do to stay healthy and actually leading a healthy life according to the renal failure and hemodialysis restrictions. The second construct, *social supports*, included formal supports such as physicians, nurses, HD technicians, and informal supports such as family and friends. *Adjustment to a new normal* integrated content related to emotional well-being and psychosocial distress resulting from the burden of decision making associated with adapting to living with disease and the hemodialysis environment. The last construct, *quality outcome,* is a result of the ever changing subjective and objective experience of living with and adapting to life on HD (Gregory & Way, 2008). These constructs are consistent with those identified in the literature on chronic illness, ESRD, and HD; yet, the interactions among the variables present a unique holistic perspective on the resulting impact on quality outcomes.

The main theoretical constructs identified in the substantive theory were the foundation for the construction of the PPHS and its main subscales. Items from the theory were operationalized and the instrument was examined by content experts, HD patients, and an expert in adult literacy and modified to increase item clarity and decrease redundancy. Findings supported the use of a 5-point Likert scale. All items were rated from 0 to 4, with 0 indicating that individuals have no incidence of the symptom or no satisfaction/concern/confidence with the item and 4 indicating that they almost always experience the symptom or that they are extremely satisfied/concerned/confident about the item/statement. Two subscales were worded negatively. Following this initial review, the number of items in the PPHS was reduced from 120 to 64.

In 2003, O'Brien-Connors tested the instrument with a HD population of 112 HD patients in Newfoundland. Preliminary analysis supported the reliability and validity of the PPHS however, the researchers were not content with the length of the scale or the way items were lining up from the factor analysis. The instrument was modified slightly, and the three main scales were further divided into a total of ten subscales. Wells (2004) also used the PPHS in a descriptive correlational design with 60 subjects. Following these studies it was evident that certain subscales could not reliably and validly assess important aspects of certain constructs. Five of the nine subscales were not strong in terms of their internal consistency and/or the correlations among items of the predicted subscales.

In this stage of the research project we are further refining and testing the scales and subscales suggested by the range of findings resulting from the work by O'Brien-Connors's and Wells' (2004) research and the multi-trait/multi-item correlation matrix. In this study we are using a larger population of HD patients. The objectives of this research are to: examine item correlations, data quality, scales and assumptions underlying Likert scoring of the PPHS and refine the PPHS and assess its internal consistency. The multi-trait/multi-item correlation matrix was used to examine item correlations. Sixty-four were correlated with each other. Items were analyzed for strength of correlation with each other. A set cut off of between 0.30 and 0.40 was used for examination. A summary table was constructed of the items correlating the strongest at the set level. This process was used to identify/determine items to be retained for

assessed Likert assumptions. The approach taken to assess Likert scale assumptions, the scales and data quality were guided by the steps outlined by Ware and Gandek (1998). Each major subscale of the PPHS was subjected to the same process in terms of development and refinement. Additional purposes of this paper are to describe the steps taken in the development and refinement of the PPHS, and more specifically the steps taken to decide which items should remain in the total scale and subscales.

Methods

Data Collection and Sample

Using a cross-sectional design, data collection was completed in the HD unit in three sites in Newfoundland and one HD unit in Ontario, Canada. The accessible population was restricted to patients meeting the inclusion criteria: (a) on in-center HD for at least 12 weeks, (b) mentally competent, (c) not experiencing an acute illness episode, (d) over the age of 19, and (e) able to understand and speak English. A convenient sample (N = 236) was obtained for testing the psychometric properties of the PPHS.

Initial contact with the potential participants was made by a HD unit nurse to decrease any pressure the patients may have felt about their decision to become involved in the research study. If the client agreed, a follow-up interview was arranged, and the research assistant explained the purpose of the research, obtained written consent, and collected the data. The HD unit was the chosen setting as the participants were on dialysis and the

time consumed by the interview would not interfere with their free time. The study received ethical approval from the research ethics boards at each site.

Each interview took approximately 60 to 90 minutes. The majority of subjects could read so they completed the scale with the researcher by their side. Items were only read aloud if the subject had visual problems. The data extraction form was administered first, then the PPHS and then the SF-36.

Data Analysis

Data were analyzed using Statistical Package for Social Sciences (SPSS). To make interpretation easier, the initial subscale ratings were transformed from the summated Likert score to yield a score ranging from 0 to 100. Criteria for item inclusion in the subscales were dependent on item correlations and conditions outlined by Ware and Gandek (1998). Item from the correlation matrix were kept in the scales if their correlation was above .3.

Ware and Gandek's conditions were based on item-level and scale-level characteristics. Assessment of item-level characteristics was related to inspection of indices of central tendency and other basic descriptives. Subscale-level characteristics were examined in terms of the item internal consistency, equality of the item to scale correlations, and item discriminat validity. Item descriptives, means, standard deviations, ranges, floor and ceiling statistics were examined, and items with a large amount of missing data were

scrutinized. Scale items were correlated with each other and the correlations among the subscales in the PPHS were studied to assess their relationship and convergent/divergent validity. Items considered for elimination were outside of the desired range in any of the above criteria and examined by content experts for theoretical fit. If an item was felt to be important to evaluating the patients' experience of life on HD it was kept in the subscale despite the statistical indicator.

Results

Demographics

The sample consisted of 156 patients from Newfoundland (66%) and 80 patients from Ontario (34%) for a total sample of 236. The youngest patient was 21 years old, and the oldest was 91 years old with a mean age of 59 years. There were more males (54%) than females (46%) and the majority of patients (81%) lived with another adult or a family member.

Item-Level Characteristics

Recommended first steps in examining the psychometric properties of scales is to assess item correlations, data quality and item level assumptions. First we used a multi-trait/multi-item correlation approach to examine all the 64 items in the original PPHS. At the end of the analysis approximately 28 items were removed from the PPHS. It was disappointing to lose scales related to disease knowledge, activities of daily living, self health management, allied health support or family support but the correlations were less

than 0.3 suggesting very weak relationships among the items. The items removed had low correlations with their own hypothesized scales and with all other items. This left us with narrower operational definitions of *illness and treatment* (i.e., physical health), *social supports* (i.e., formal) and *adjustment* (psychosocial distress and emotional well-being). The five subscales are: Emotional well-being (EWD), Psychosocial Distress (PSD), Nurse Support, Physician Support and Physical Health (PH).

Subsequently we applied the outlined by Ware and Gandek (1998). The majority of items had limited to no missing data and the spread of scores across the steps of the rating scales are useful indicators of data quality. The descriptive statistics for items comprising the PPHS are presented in Tables 2.1a, 2.1b, and 2.1c. The minimal amount of missing data suggests that the items were relevant, clear, and easy to understand and that the subjects did not have a problem completing scales. Fox-Wasylyshyn and El-Masri (2005) state that it's not so much the amount of missing data that is important, but rather that it is missing at random and not related to a few specific items. Next, the item scores were examined (data not shown). The item scores approximated normalcy with some skewed more to the lower or higher ends of the subscale. This is to be expected when measuring traits such as feelings of dependence on family members, as the subjects had differing levels and types of support.

Variances in an item such as difficulty walking can be expected as the patients ages ranged from 21 to 91 and there was an array of co-morbidities that may or may not have affected the individual's ability to ambulate.

The means and standard deviations of each item were assessed. Ware and Gandek (1998) suggested that the means of all items included in summative scales be roughly equal and that the standard deviation be no more than one. For four of the five subscales in the PPHS this was true. There was a difference of greater than one point among the items included in the fifth subscale, PH. The specific items related to difficulty breathing, feeling tired and low on energy, and feeling exhausted after dialysis. The first item, breathing difficulties, had a mean of 3.1 which suggests that the patients, in general, did not have a hard time breathing, which may reflect adequate fluid removal by dialysis. The two items with the lowest mean scores (1.6 and 1.6) suggest that the patients were feeling tired or exhausted quite often. Considering that fatigue is a common side effect of kidney disease and HD (Caplin, Kumar, & Davenport, 2011), it's not surprising that our subjects often considered these physical symptoms to be a concern; the more positive news is that they rarely experienced dyspnea. As well, when measuring constructs with varying states it's not surprising to find subjects at opposite ends of the scale as the purpose is to measure people with differing amounts of that characteristic.

Table 2.1a: *Item Descriptives*

Item	Mean	SD	Missing data	
			Number	%
Emotional Well-Being (EWB)	2.99	0.7	3	1.3
PPHS 14 - HD improved quality of life	2.86	1.3	2	0.8
PPHS 52 - Maintain a positive attitude to HD	3.46	0.9	1	0.4
PPHS 54 - Come to terms with illness	3.02	1.2	0	0
PPHS 56 - Relax while on HD	3.20	0.9	0	0
PPHS 58 - Adjusted to effects of HD	3.01	0.9	0	0
PPHS 60 - Spend quality time with family	2.87	1.0	0	0
PPHS 61 - Coping with HD restrictions	2.99	0.9	0	0
PPHS 62 - Control over ups and downs	2.57	1.2	0	0
Psychosocial Distress (PSD)	2.50	0.9	3	1.3
PPHS 2 - Concern that health will get worse	2.39	1.33	0	0
PPHS 21- Becoming dependent on family	2.17	1.56	0	0
PPHS 23 - Impact of ESRD and HD on family	1.79	1.40	0	0
PPHS 42 - Personal safety on HD	2.92	1.35	1	0.4
PPHS 43 - Lack of privacy in HD	3.13	1.27	0	0
PPHS 44 - Upset by others becoming ill	2.65	1.31	0	0
PPHS 45 - Dwell on health problems	2.85	1.25	2	0.8
PPHS 46 - Feel depressed	2.36	1.27	0	0

Table 2.1b: *Item Descriptives*

Item	Mean	SD	Missing data	
			Number	%
PPHS 48 - Worry about illness/HD events	2.60	1.28	0	0
PPHS 49 - Feel useless	2.39	1.34	0	0
PPHS 50 - Distressed by illness and HD	2.32	1.3	0	0
Nurse Support	3.35	0.6	0	0
PPHS 28 - Overall quality of care	3.56	0.6	0	0
PPHS 29 - Knowledgeable	3.59	0.6	0	0
PPHS 30 - Willing to listen	3.41	0.7	0	0
PPHS 31 - Help you understand illness and HD	3.26	0.8	0	0
PPHS 32 - Promote family atmosphere	3.38	0.9	0	0
PPHS 33 - Comfort measures	3.56	0.7	0	0

Table 2.1c: *Item Descriptives*

Item	Mean	SD	Missing data	
			Number	%
Physician Support	3.26	0.7	7	3
PPHS 34- Knowledgeable	3.34	0.8	0	0
PPHS 35 - Quick to respond	3.21	0.8	6	0
PPHS 36 - Overall quality of care	3.38	0.7	0	0
PPHS 37 - Willing to listen	3.29	0.9	0	0
PPHS 38 - Help you understand Illness and HD	3.09	1.0	1	0.4
Physical Health	2.22	0.8	2	0.8
PPHS 3- Breathing difficulties	3.06	1.1	0	0
PPHS 4 - Feel tired and low on energy	1.61	1.1	0	0
PPHS 5 - Difficulty walking	2.20	1.5	1	0.4
PPHS 11 - Itching	2.35	1.4	1	0.4
PPHS 12 - Exhausted after HD	1.64	1.4	0	0
PPHS 13 - Comfortable after HD	2.42	1.2	0	0

Scale-Level Characteristics

The PPHS was also assessed for scale-level assumptions (i.e., item internal consistency, equality of item-scale correlations and item discriminant validity). The first step was examining the correlation between each item and other items in a subscale and the relationship between that item and the subscale itself (see Tables 2.2a, 2.2b, 2.2c, and 2.2d). A corrected Pearson's statistic is presented as the indicator for each item with the subscales to which it belongs. Using a corrected Pearson's coefficient statistic controls for overestimation of the relationship between an item and its corresponding subscale by calculating the coefficient without that particular item in the subscale (Ware & Gandek, 1998).

Item internal consistency was generated by calculating the subscale's reliability statistic. Corrected Pearson's indicators are identified in Table 2.2 with a superscript letter *a*. Ware and Gandek (1998) state that each item should be correlated at .40 or above with its target subscale to meet this criterion. Two of the Pearson's coefficients in the PH subscale were $r = .36$. Both items, itchiness and feeling comfortable after HD, are common concerns for patients on HD. These items were left in the subscale because they are symptoms that our subjects had experienced, sometimes too often. The importance of these items is supported by their mean scores in Table 2.1.

Equality of item-scale correlations examines the relationship of all items with their purported subscale. The desired range for correlations is between .40 and .70 (Ware &

Gandek, 1998). If the item scale correlation is below .40, it may not be relevant, while if the statistic is above .70, it may be redundant. All of the subscales, with the exception of the Physician Support subscale, met this criterion. Three coefficients were above .70 in this subscale. These items relate to the physicians' quick response to the clients' needs, their willingness to listen, and their desire to help the patient understand their illness and treatment requirements. After assessing the theoretical fit of each item and taking into account that each item is measuring a different component of the doctor-patient relationship, it was felt that these items should remain in the subscale. Similar items scored high (i.e., .54 to .70) as well on the Nurse Support subscale. These items were retained because they are believed to be an integral part of the formal support relationship between a health care professional and the HD client.

Item discriminant validity assesses the strength of relationship between items included in a scale with items not included in that subscale. Scale items should have a higher correlation coefficient with their own subscale than with other subscales, and the difference between an item's coefficient with its subscale and that item's coefficient with all other subscales should be greater than 0.1. In Table 2.2 the subscales generally meet this criterion. The exceptions are the EWB subscale and the PH subscale.

The item of concern in the EWB subscale relates to the coefficient corresponding to "spending quality time with family and friends" ($r = .45$), which overlaps with the Physician Support ($r = .39$) and Nurse Support ($r = .34$) subscales. A possible rationale

for the close coefficients may be that patients come to view the physician and the nurse as their friends. Each patient spends approximately 10 hours each week on HD or in the HD unit. The high mean scores for both subscales indicate that individuals are happy with the care they receive from the health care professionals. This item was kept in the subscale because it is theoretically important to overall well-being, and examination of the other statistics supported its inclusion. As well, when assessing the internal consistency of the overall subscale that item was integral and increased the Cronbach's alpha.

The second item of concern is "experiencing itchiness." The correlation of the item with the PH subscale is $r = .36$, yet the correlation for the PSD subscale with that item ($r = .32$), is very close and the difference between them is certainly less than 0.1. A possible explanation for the closely similar statistics is that the PSD measures an aspect of the burden of the disease and distress, while itchiness can cause both.

All subscale items, with the exception of those noted above, were correlated at an appropriate level. The numerical difference was 1 to 1.6 points between the coefficients. This meets the researchers' and Ware and Gandek's (1998) conditions for item discriminatory strength and inclusion.

Table 2.2a:

Item to Subscale Correlations

Item	Pearson Item to Subscale Correlation				
Emotional Well-being (EWB)	EWB	PSD	Nurse	Physician	PH
PPHS 14 - HD improved quality of life	.40[a]	.09	.21	.23	.14
PPHS 52 - Maintain a positive attitude to HD	.52[a]	.26	.26	.20	.16
PPHS 54 - Come to terms with illness	.57[a]	.39	.25	.36	.23
PPHS 56 - Relax while on HD	.42[a]	.25	.24	.31	.20
PPHS 58 - Adjusted to effects of HD	.61[a]	.22	.25	.33	.30
PPHS 60 - Spend quality time with family	.45[a]	.23	.34	.39	.26
PPHS 61 - Coping with HD restrictions	.68[a]	.28	.33	.43	.36
PPHS 62 - Control over ups and downs	.52[a]	.13	.16	.30	.26

Note: PSD: EWB = Emotional Well-Being; Psychosocial Distress; Nurse = Nurse Support; Physician = Physician Support, PH = Physical health,

Table 2.2b:

Item to Subscale Correlations

Item	Pearson Item to Subscale Correlation				
Psychosocial Distress (PSD)	EWB	PSD	Nurse	Physician	PH
PPHS 2- Health will get worse	.19	.48[a]	.14	.21	.27
PPHS 21- Dependent on family	.12	.50[a]	.20	.02	.25
PPHS 23- Impact of ill on family	.13	.48[a]	.15	-.01	.27
PPHS 42- Personal safety on HD	.10	.52[a]	.21	.13	.17
PPHS 43- Lack of privacy in HD	.17	.49[a]	.20	.17	.13
PPHS 44- Upset by others ill	.08	.52[a]	.03	.09	.22
PPHS 45- Dwell on health problems	.18	.52[a]	.16	.09	.18
PPHS 46- Feel depressed	.43	.59[a]	.21	.27	.38
PPHS 48- Worry re illness/HD	.24	.62[a]	.21	.20	.27
PPHS 49- Feel useless	.42	.55[a]	.28	.18	.42
PPHS 50- Distressed by illness	.43	.69[a]	32	.24	.44

Note: PSD: EWB = Emotional Well-Being; Psychosocial Distress; Nurse = Nurse Support; Physician = Physician Support, PH = Physical health,

Table 2.2c:

Item to Subscale Correlation

Item	Pearson Item to Subscale Correlation				
Nurse	EWB	PSD	Nurse	Physician	PH
PPHS 28- Overall quality of care	.30	.19	.60[a]	.30	.13
PPHS 29- Knowledgeable	.24	.18	.53[a]	.34	-.02
PPHS 30- Willing to listen	.43	.19	.70[a]	.49	.20
Nurse 31- Help understand ill	.38	.17	.66[a]	.51	.20
PPHS 32- Promote family environ	.28	.17	.61[a]	.40	.15
PPHS 33- Comfort measures	.25	.15	.60[a]	.33	.16
Physician	EWB	PSD	Nurse	Physician	PH
PPHS 34- Knowledgeable	.37	.11	.31	.68[a]	.13
PPHS 35- Quick to respond	.38	.08	.37	.73[a]	.09
PPHS 36- Overall quality of care	.45	.20	.48	.67[a]	.06
PPHS 37- Willing to listen	.42	.17	.41	.80[a]	.08
PPHS 38- Help understand illness and HD	.40	.18	43	.78[a]	.14

Note: PSD: EWB = Emotional Well-Being; Psychosocial Distress; Nurse = Nurse Support; Physician = Physician Support, PH = Physical health,

Table 2.2d:

Item to Subscale Correlation

Item	Pearson Item to Subscale Correlation				
Physical Health (PH)	EWB	PSD	Nurse	Physician	PH
PPHS 3- Breathing difficulties	.15	.20	.11	.14	.43[a]
PPHS 4-Tired & low on energy	.30	.34	.16	.15	.50[a]
PPHS 5- Difficulty walking	.17	.17	.01	.01	.42[a]
PPHS 11- Itching	.17	.32	.18	.03	.36[a]
PPHS 12- Exhausted after HD	.33	.36	.23	.10	.50[a]
PPHS 13 - Comfortable after HD	.25	.22	.05	.08	.36[a]

Note: PSD: EWB = Emotional Well-Being; Psychosocial Distress; Nurse = Nurse Support; Physician = Physician Support, PH = Physical health,

Scale-Level Descriptive Statistics

Each of the five subscales included in the PPHS were constructed to allow for summative scores reflecting the constructs of interest. Cumulative scores were calculated for each subscale and then the scores were transformed to make comparisons easier. Overall descriptive statistics for the transformed scores are presented in Table 2.3. A higher mean score represents a more positive outcome in all the subscales. Even for the subscales that are reverse coded, such as PSD and PH, a high score equals a lower level of distress and/or less physical stressors.

At the first step, the subscale means and standard deviations were examined. Ware and Gandek (1998) stated that the means should be approximately equal amongst the scales. The most notable variation is in the formal support subscales. Both subscales measuring the perceived supportive of health care professionals have much higher mean scores than the other subscales. This suggests that the HD population was very happy with the quality of care received and doctors' and nurses' knowledge, as well as their willingness to listen. The next highest mean relates to the hemodialysis environment and distress; a score of 68.85 indicates that the HD patients were experiencing moderate to low levels of stress. The low stress levels may be related to the fact that our population considered themselves healthy, perceived a low level of stress, or had effective coping mechanisms. This is also supported in the mean scores for individual items comprising the two support subscales listed in Table 2.1.

At the second step, an examination was undertaken of the difference between observed scores and possible score values. The score spread or range for each subscale indicate that study participants used response categories from both ends of the Likert scale. The floor and ceiling percentages also reflect the range of responses. The support subscales are definitely skewed to the higher end of the Likert scale.

Table 2.3

Descriptive Statistics for Subscales' Transformed Scores

			Observed/Possible Values				
Subscale	Mean	SD	Lowest	Highest	Range	Floor %	Ceiling %
Emotional Well-being	59.96	13.60	7.5/0	80/100	72.50	0.4	5.2
Psychosocial Distress	62.58	21.24	9/0	100/100	90.91	0.4	1.7
Nurse Support	86.45	13.65	37.5/0	100/100	62.50	0.4	28.4
Physician Support	81.42	17.66	5/0	100/100	95.00	0.4	24.0
Physical Health	55.56	20.44	8.33/0	100/100	91.67	0.4	0.9

The final step in development and refinement of the PPHS involved an examination of the scales' correlations to each other, and their internal consistency. The internal consistency of each of the subscales is shown in parentheses in Table 2.4. Some subscales are significantly correlated with each other with correlation coefficients ranging

between .40 and .70 sustaining convergent validity with subscales measuring similar constructs. The support subscales and the PH subscale and the PSD subscale have weak to no correlations, suggesting that these areas have little to no relationship with each other, suggesting divergent validity. However, each topic is integral in the assessment of patients' experience of living with ESRD and HD. Cronbach's alpha's for the subscales were all acceptable with the lowest being the PH subscale at .69.

Table 2.4

Internal Consistency [a] *and Inter-Subscales Correlations*

Subscale	EWB	PSD	Nurse Support	Physician Support	Physical Health
Emotional Well-being (EWB)	(.80)				
Psychosocial Distress (PSD)	.35**	(.85)			
Nurse Support	.40**	.30**	(.83)		
Physician Support	.49**	.22**	.50**	(.89)	
Physical Health	.36**	.43**	.19*	.13	(.69)

Note. [a] Cronbach's alpha coefficient is bracketed in the diagonal.

** $p < .001$ * $p < .01$

Ultimately 28 items were removed from the PPHS. The most surprising loss was the family support subscales as there's a fairly substantial body of research evidence on chronic illness that reinforces the relationship between family support and better outcomes (Bury 1982; Cohen et al., 2007; Ersoy-Kart & Gulda , 2005; Gregory et al., 1998; Kimmel et al., 1995; Kimmel et al., 1996; Kimmel et al., 1998; Untas et al., 2011). Other scales that were removed were related to self-health management, disease knowledge, activities of daily living and allied health.

Discussion

One of the main purposes of the larger research project was to develop an instrument that captured the experience of living with ESRD and HD. The qualitative study gave the research team the theoretical basis for the items included in the PPHS. In 2003, the scale was tested and the preliminary psychometric analysis completed. The resulting psychometric assessment data were promising but the team wanted a shorter instrument that would be useful for clinical monitoring. This stage of the research was the first step in assessment of the PPHS with a larger HD population. Using a multi-trait/multi-item correlation matrix and the guidelines established by Ware and Gandek (1998), items were examined from the ground up. Starting with the most basic correlations, descriptives, each item was scrutinized and assessed before a decision was made to keep in it in the subscale or to discard. The following discussion provides the reader with information related to our sample demographics and then the item and scale assumptions.

The population was not a representative sample of the HD patients; however, the HD group's demographics are consistent with characteristics of the Canadian HD population. The two groups are similar in terms of their age, gender, and living situation (CIHI, 2011). Findings are not generalizable to the national HD population but may be interpreted with caution.

Item and scale examination of the PPHS resulted in a more reliable and valid instrument. Items that were retained in the PPHS are based on their correlation with other items in the subscale and/or either the criteria outlined by Ware and Gandek (1998) and/or a particular item's theoretical fit with its respective subscale. First, the interitem correlations were examined and 18 items were removed. Then the items themselves were assessed, and then each subscale and its item were studied. Descriptives for each item were examined. The distribution for each item score displayed approximate symmetry and despite slight skewness to the upper or lower end of the subscales, it appears responses from both ends of the Likert scale were used by the patients. This assumption was supported in the subscale assessment through examination of the range, upper and lower observed scores, and the floor and ceiling statistics. If an item was heavily weighted at the top or the bottom of the subscale, it may have indicated that the trait was always present or nonexistent in this population and ultimately not worth measuring. The means and standard scores also give the researcher an idea of the amount of each construct that the sample was experiencing, this again was supported in the subscale raw and transformed scores. A lower mean subscale score indicates a low to moderate level

of the characteristic being measured whereas a higher mean represents a more positive outcome. As well, the limited amount of missing or out-of-range data for the items in each subscale and the estimated symmetrical distribution implies that the questions were clear and not biased in a positive or negative direction. Overall, item examination was positive and certain items were considered for removal.

Scale-level assessment included examination of the item internal consistency, equality of item-scale correlations, and item discriminat validity. Item internal consistency was strong for all subscales as the correlations between a subscale and its item were above .40. Statistics supporting the equality of items ranged between .40 and .70 in most cases. As mentioned, the Support subscales had a higher coefficient, but the items were left in the subscale as they measure different components of support provided by health care professionals. The correlations between each item and the total subscales presented support the convergent validity of the items with their subscale. Munro (2005) stated that the desired correlation coefficients fall between .40 and .70; a score under .40 is not sufficiently correlated, and a score over .70 may be an indication that the questions are too similar and possibly redundant.

Item discriminatory power was sustained by the difference in correlations between items within a subscale versus correlations with items in another subscale. The main area of concern was the PSD subscale. Many of the items in this subscale included examples of the trait being measured and some of the examples were related to illness events and

some were related to HD events. These items will be further scrutinized in future research and the items and examples may be altered slightly to decrease confusion between burden of illness events and HD environment concerns. Otherwise, it was confirmed that the items and subscales were able to discriminate between different levels of the characteristic being measured.

The scale-level descriptives emphasized the level of satisfaction with health care providers. This is a very important result, and it bodes well for the instrument in terms of identifying areas of concern with the quality of care. During this examination of the subscales, data quality was also maintained, as the observed score, range, and floor and ceiling indicators implied that the data are normally distributed and responses from both ends of the Likert scales were used.

The next step in the item refinement and instrument development was the examination of convergent/divergent validity of the subscales. Pearson's correlation coefficient was used to determine the validity. The subscales were moderately correlated which was the desired finding as they ranged between .40 and .70. This supports that the PPHS subscales are measuring distinct yet similar concepts.

The last component of this evaluation was the internal consistency of the newly designed subscales. Internal consistency scores for the seven subscales ranged from .70 to .89. Munro (2005) stated that the closer the alpha is to 1.00, the greater the reliability/internal

consistency. Based on her interpretation, the Cronbach's alpha for each of the subscales are more than adequate and suggest that the items are consistently measuring theoretical constructs.

These findings support the conclusions from O'Brien-Connors's (2003) study, and the end result of this process of item refinement is a tighter, more valid and reliable PPHS. There was no movement of items between the subscales, and the theoretical underpinning of each subscale was as originally defined in the preliminary analysis. The exception is the psychosocial distress subscale that may be divided into two subscales. What has changed is that 28 items were removed from the PPHS reducing it to 36 items in total. Items relating to activities of daily living, disease knowledge, self-health management, allied health and family support were removed after examination of their correlation in the multi-trait/multi-item matrix. Despite the criteria outlined by Ware and Gandek (1998), some items that did not achieve high scores in the item analysis but were deemed theoretically sound remain in the PPHS. These items may be altered or reworded in future research.

Limitations of the present research were the setting and the sample. A drawback of using the HD unit as the site for administration of the PPHS was that at times other patients or staff were close by and the subjects may not have felt comfortable answering all questions honestly, especially those about fellow patients or the health care workers. Steps were taken to ensure that patients felt comfortable answering the questions, as a

member of the research team not directly involved in the clients' care administered the instrument. As well, the non-probability sample was from four HD sites with the majority representing one province, Newfoundland. The next step in examination of the PPHS is to assess the psychometric properties and its ability to measure and monitor changes in the HD patients' condition over time.

Conclusion

The PPHS subscales were examined, and the number of items in each subscale was reduced based on statistical indicators and the theoretical underpinning of the item. The subscales are distinct yet similar in terms of their ability to measure aspects of the larger construct, experiences in living with ESRD and HD. Cronbach's alphas for the subscales are high, which strongly supports the internal consistency/reliability of the measurements. As a result of this approach to item refinement, the overall final scale is stronger in terms of its validity and reliability and can be considered a valid indicator of the patient's adjustment to ESRD and life on HD. Further psychometric assessment of the PPHS will be presented in a subsequent paper.

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Chapter 3

Psychometric Properties of the Patient's Perception of Life on Hemodialysis Scale

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Abstract

Objective: The objective was to assess reliability and validity of the Patient's Perception of Hemodialysis Scale (PPHS).

Methods: Using a cross-sectional design, data collection was completed in three HD units in Newfoundland and one in Ontario, Canada. A convenience sample (N = 236) was obtained for testing the psychometric properties of the revised PPHS and N =30 was used to examine stability. Data was collected using the PPHS, a personal data extraction form, co-morbidity index, the SF-36, and biochemical indicators. Data were analysed using Statistical Package for the Social Sciences (SPSS). Construct validity of the PPHS subscales was assessed using the Pearson correlation coefficient and factor analysis. Reliability was determined by calculating Cronbach's alpha of internal consistency. Stability was examined using the intraclass correlation coefficient. The significance level was set at $p < .05$ for all statistical calculations.

Results: Face and content validity of the PPHS were established in previous research. Construct validity was examined using factor analysis with a principal components approach and varimax rotation. Five factors emerged: Emotional Well-being; Psychosocial Distress; Nurse Support; Physician Support; and Physical Health. The total factor structure explained 51% of the variance. After examination of the factor loadings, it was decided that no further item reduction was necessary. Convergent/divergent

validity of the subscales was assessed using Pearson's correlation. Convergent validity was ascertained by correlating the PPHS scales with the SF-36 scales. The Physical Health subscale was correlated with all SF-36 scales, supporting the role that health plays in both physical well-being and mental health. The Physical Health subscale was more highly correlated with the SF-36 subscale Physical Functioning, and the Physical Component Summary score. Emotional Well-being and Psychosocial Distress subscales were significantly related to the Mental Component score of the SF-36, again supporting convergent construct validity. The Social Supports subscales, Physician Support and Nurse Support, demonstrated low correlations or no correlation with any of the SF-36 scales or subscales, sustaining divergent validity as the SF-36 only measures social activities and not social support. Reliability was established using test-retest stability and by computing Cronbach's alpha. The test-retest analysis supported that the instrument was stable over time with an intraclass correlation coefficient ranging between .72 and .94. Cronbach's alpha for each subscale was calculated with a range of .69 to .90, suggesting moderate to strong internal consistency.

Conclusion: Findings from this examination of the psychometric properties support the PPHS's validity and reliability. The PPHS presents as a valuable instrument for measuring disease specific concerns with the HD population, assessing how people experience life on HD, and identifying the ways in which people interpret the meaning of their physical, social, and psychosocial health, and, ultimately, their adaptation to life on HD.

Introduction

Each year approximately 5,400 individuals are diagnosed with end-stage renal disease (ESRD), and the majority (59%) will use hemodialysis (HD) as the primary method of renal replacement therapy (Canadian Institute of Health Information [CIHI], 2011). Both the disease and the treatment may have a profound impact on the patient's quality of life (QOL). With over 38,000 Canadians receiving HD it is imperative that health care professionals assess not only the patients' physical well-being but also their psychosocial health, and approach their overall care in a holistic manner that improves the likelihood of quality outcomes (CIHI).

The term *quality outcomes,* as used in this article, is a end result of the ever changing subjective and objective experience of living with and adapting to life on HD (Gregory & Way, 2008). It has similarities to other domains, like psychosocial adaptation and quality of life; both topics have been extensively studied in patients with ESRD. Prior research has approached the measurement of patient experiences or perceptions of life on HD in a piecemeal fashion, focusing on topics such as quality of care, social supports, health-related quality of life, and quality of life without trying to integrate all the components.

Some of the more popular disease-specific instruments used to assess quality outcomes in HD patients are the Kidney Disease Questionnaire (KDQ), and the Kidney Disease Quality of Life (KDQOL) and Health Related Quality of Life (HRQOL) scales. Laupacis, Muirhead, Keown, and Wong (1992) constructed the KDQ from interview data. The items were reviewed for content relevance by 50 HD patients. The final

version included five dimensions related to physical symptoms, fatigue, depression, relationships, and frustration. The KDQ is both reliable and valid but fails to capture the essence of adjustment or adaptation to the illness and treatment, any aspect of support or ultimately quality outcomes.

The KDQOL developed by Hays, Kallich, Mapes, Coons, and Carter (1994) is based on information derived from three HD patient focus groups and one HD staff group, and a review of the literature on ESRD patients and quality of life. It is comprised of a generic QOL scale, the SF-36, a reliable and valid instrument that has been used to measure QOL with the HD population, as well as a scale with kidney disease symptom-specific items. Limitations of the KDQOL are that only some of the information collected for development of the questionnaire was collected from HD patients, so the instrument is not specific to HD treatment or symptoms. As well, no attempt was made to assess social support or adjustment to living with chronic disease or its treatment.

Parfrey, Vavasour, Bullock, Henry, Harnett and Gault (1989) utilized four different methods to develop the HRQOL scale: interviews with HD and transplant patients; interobserver reliability and intraobserver reliability; cross-sectional research to test construct validity; and a prospective study to determine responsiveness. The HRQOL includes a symptom scale and an affect scale. Although symptoms item inclusion was based on patient input (more than 25% of the HD or transplant patients identified them as a concern), affect scale items were chosen by the researchers which could limit their relevancy. The concepts included in the patient based symptom scale are more likely relevant to ESRD patients than questions in the affect scale that were chosen by the

researchers. Relevancy of the HRQOL may vary as the questionnaire was based on a mixed sample of transplant and HD patients and our focus is exclusively HD patients and their experience.

Researchers attempting to measure quality outcomes in the HD population have also used a variety of non-disease-specific instruments to assess constructs believed to be relevant for patients. Some examples of targeted constructs include stress, coping, psychosocial adaptation, depression, health-related QOL and illness intrusiveness. Danquah, Wasserman, Meinger and Bergstrom (2010) stated that the approach to measuring the total experience of patients on long-term HD has been fragmented and that the problem with trying to measure such an indistinct construct is that a multitude of research has been completed using different measures with dissimilar findings; this has added confusion to an already elusive topic. This sentiment is reflected in the reviews of quality of life research and instruments by numerous authors (Anderson & Burckhardt, 1999; Edgell et al., 1996; Gill & Feinstein, 1994; Danquah et al., 2010; Prutkin & Feinstein, 2002; Rettig et al., 1997). Our goal was to bridge the gap in measurement of quality outcomes and develop a feasible method, grounded in the patient's world, to comprehensively assess patients' experiences with ESRD and HD and to monitor changes over time.

The purpose of the research was to develop reliable and valid scales to measure and follow change in how people experience life on HD. In doing so, we hoped to identify (a) ways in which people assign meaning to their illness and treatment, (b) rate the social

supports (formal and informal support systems), and (c) view adjustment to ESRD and life on HD. Weaknesses in these three areas may be amenable to interventions capable of facilitating the emergence of a positively viewed new self with resulting enhancement of quality outcomes. Our purpose is unique in that it takes a broad focus and does not narrowly limit itself to "quality-of care," or "quality-of-life," while overlapping these concepts in some ways. To achieve our goals the scales developed must be valid, reliable, and capable of differentiating people with regard to their status at a point in time as well as being responsive to change through natural evolution or as a result of planned intervention. Examination of the instrument's ability to detect change over time will be addressed in future papers.

This research project is part of a larger national study that has been completed in a series of stages. The first stage of the project began with a qualitative study in 1992. Using a grounded theory approach, the research team investigated the patient's perception of life on HD (Gregory, 1998; Gregory, Way, Hutchinson, Barrett, & Parfrey, 1998). Three theoretical constructs emerged from the substantive theory: *meanings of illness and treatment*, *social supports* and *adjustment to a new normal*. The *meaning of illness and treatment* construct integrates concepts related to dealing with the stress of living with ESRD, its symptoms, the multitude of co-morbid conditions, and the frustration of ambivalence, the conflict between knowing what to do to stay healthy and actually leading a healthy life according to their level of renal failure and hemodialysis restrictions. The second construct, *social supports,* includes formal supports such as

physicians, nurses and HD technicians, as well as informal supports. *Adjustment to a new normal* incorporates content related to emotional well-being and psychosocial distress resulting from the burden of decision making associated with adapting to living with disease and the hemodialysis environment (Gregory & Way, 2008). A theory linking aspects of these three key constructs depicts the relationship amongst the variables. Meanings of illness and treatment and *social supports* exert a direct impact on *adjustment* and *quality outcome*, as well as an indirect impact on quality outcome through *adjustment*. *Adjustment to a new normal* is also conjectured to exert a direct impact on *quality outcome*. *Quality outcome* includes a subjective and objective component. The subjective aspect relates to satisfaction with life and the objective element is morbidity or mortality. The theory is unique in its approach to defining the relationship among the main constructs and reflective of concepts identified in the literature on ESRD and quality outcomes. Additional discussion of the qualitative research methods can be found in Gregory and Way.

Based on the findings from the qualitative research and constructs outlined in the substantive theory, a draft instrument titled Patient Perceptions of Hemodialysis Scale (PPHS) was constructed. After review by experts and HD patients, the number of items was reduced from 120 to 64. In 1999, the PPHS was used to assess a sample (N =112) of HD patients from Newfoundland (O'Brien-Connors, 2003) and again in 2004 by Wells. Preliminary psychometric analysis supported that the PPHS was feasible, internally consistent, had construct validity.

The team's original plan was to develop a more succinct clinical monitoring tool by further item reduction.

In 2010, using a multi-trait/multi-item correlation matrix and the techniques outlined by Ware and Gandek (1998) the scale was further refined and each of the 64 items was examined. The number of questions was reduced from 64 to 36. Five subscales were removed; they were Allied Health, Family Support, Disease Knowledge, Self Help Management and Activities of Daily Living. Basically we lost many all aspects of treatment experiences and the ability to measure the patient's ambivalence toward treatment regimens. It was disappointing that the family subscale was not strong in terms of correlations among the items or its internal consistency. Our inability to measure the construct may be due to the variant needs of HD patients and their definition of family and family support. In the formal support subscales, titled Physician Support and Nurse Support, patients identified that the health care providers are like family. This approach to scale refinement resulted in five subscales – the Physical Health (PH) subscale measures the meaning of *illness and treatment construct*; the Physician Support and Nurse Support subscales assess the *social supports* construct; and, the Emotional Well-being and Psychosocial Distress subscales measure the *adjustment no a new normal* construct. The results of these analyses are detailed in chapter two. The objective of this component of the research is to examine the psychometric properties, more specifically the validity and reliability of the PPHS with a larger population from four different HD sites in Canada.

Methods

Data Collection and Sample

Using a cross-sectional design, data collection was completed in the HD unit in three sites in Newfoundland and one HD unit in Ontario, Canada. The accessible population was restricted to patients meeting the inclusion criteria: (a) on in-center HD for at least 12 weeks, (b) mentally competent, (c) not experiencing an acute illness episode, (d) over the age of 19, and (e) able to understand and speak English. A convenient sample (N = 236) was obtained for testing the psychometric properties of the PPHS. Using a subsample of the same cohort, test –retest reliability of the instrument was examined approximately two weeks after participants had completed the initial PPHS (n = 30). These patients were chosen based on the stability of their clinical circumstances.

Instruments

Data were collected utilizing the PPHS, a personal data extraction form that captured information such as age, gender, date started dialysis, cause of ESRD, major co-morbidities, and hospitalizations in the past year. Data related to co-morbid illnesses was collected and biochemical indicators (laboratory values) were recorded. Quality of Life was measured using the SF-36. The SF-36 is a QOL questionnaire that includes 36 questions, eight subscales, two major scales. It was originally developed as a generic health instrument but it has been tested in a variety of chronic illnesses (Ware, Kosinski, & Gandek, 1993).

The PPHS is an instrument developed to assess HD patients' perception of illness and treatment experiences, social support systems and adjustment to a new normal. These constructs were operationalized in the PPHS. The revised PPHS which is being tested includes 36 items, 17 were negatively worded and 19 items were positively worded items. Negative items were reverse scored and a higher score was indicative of a more positive experience or rating of each subscale (See Appendix 3.1).

Procedure

The research study was approved by the research ethics boards at each of the sites. Written consent was obtained before the interview. Initial contact with the potential participants was made by a HD unit nurse to decrease any pressure the patients may have felt about their decision to become involved in the research study. If the client agreed, a follow-up interview was arranged, and the research assistant explained the purpose of the research, obtained written consent, and collected the data. The HD unit was the chosen setting as the participants were on dialysis and the time consumed by the interview would not interfere with their free time. The study received ethical approval from the research ethics boards at each site.

Data Analysis

The data were analysed using Statistical Package for the Social Sciences (SPSS). The focus of this paper is construct validity and reliability. Construct validity of the PPHS subscales was assessed using the Pearson correlation coefficient and factor analysis. Reliability of the PPHS was determined by calculating Cronbach's alpha of internal consistency. Stability was examined using the intraclass correlation coefficient. The significance level was set at $p < .05$ for all statistical calculations.

Results

Demographics

There were 236 study participants. Over half (55%) were male, 99% were English-speaking, and 73% were over the age of 50, with a mean age of 60 years and a range of 21 to 91 years. Seventy-three percent lived with an adult/spouse and 66% of the subjects lived in Newfoundland.

Illness and Treatment Related Variables

Tables 3.1a and 3.1b summarize the illness and treatment related variables. Diabetes (23%) was the leading cause of ESRD, followed by glomerulonephritis/autoimmune disease (17%) and renal vascular disease (17%). The average time since initiation of HD was 25 months and the majority (77%) of subjects had been on dialysis for less than 3 years. Most participants (66%) had one or more co-morbid illnesses.

The most frequent co-morbid illnesses included diabetes (33%), ischemic heart disease (22%), congestive heart failure (21%), and cancer (14%).

Table 3.1a

Illness and Treatment Related Characteristics (N = 236)*

Characteristic	n	%
Cause of ESRD		
Diabetes	54	22.9
Glomerulonephritis/autoimmune	41	17.4
Renal vascular disease	41	17.4
Polycystic kidney disease	20	8.5
Congenital/hereditary renal disease	10	4.2
Other (unknown, acute renal failure, cancer)	70	29.7
Time on hemodialysis		
< 1 year	102	43.8
1-3 years	79	33.9
> 3 years	52	22.3

* *Note*: Sample size may vary depending on missing data.

Table 3.1b

Illness and Treatment Related Characteristics (N = 236)*

Characteristic	n	%
Co-morbid illness		
CHF on exertion[a]	39	16.7
CHF at rest[b]	11	4.7
New angina > 6 months	48	21.5
Unstable angina < 6 months	13	5.8
Arrhythmia	14	7.3
Peripheral vascular disease < 6 months	10	5.2
Diabetes	77	32.6
Cancer	32	13.6
Lung disease	14	6.0
Stroke	19	8.1

* *Note*: Sample size may vary depending on missing data.

[a] Heart failure symptoms on strenuous or prolonged activity or prior to heart failure.

[b] Heart failure on ordinary activity or at rest or recurrent admissions to hospital in heart failure.

Psychometric Findings

Psychometric assessment of an instrument is based on the results of validity and reliability testing. As face and content validity have been established in previous research (O'Brien-Connors, 2003) construct and convergent/divergent validity are addressed in this paper. Reliability is described using Cronbach's alpha and the intraclass correlation coefficient for stability.

During O'Brien-Connors's (2003) and Wells' (2004) study the PPHS included 64 items. In 2010, after further item examination of the multi-trait/multi-item correlation matrix and based on the guidelines outlined by Ware and Gandek (1998), the number of items was reduced to 36. Item cut off for the multi-trait/multi-item correlation matrix was 0.3. The correlations between all items were examined and internal consistency alpha was generated for each subscale. The Ware and Gandek criteria guided our inspection the data quality and the Likert assumptions. All these approaches were used to finalize the number of items per subscale and the number of subscales

Construct validity was examined using factor analysis and Pearson's correlation coefficient. Factor analysis, a statistical method that examines the interrelationships among a set of variables and separates the relationships into factors with common characteristics was employed to examine the construct validity and to assist in item reduction. This is the first major assessment of the revised 36 item PPHS Exploratory analysis is the appropriate approach to examining factor structures (Thompson, 2004).

The data set was appropriate for this analysis as indicated by the strong Kaiser-Meyer-Oklin statistic (.86) which signified a high measure of sampling adequacy. As well, Bartlett's test of sphericity score, 3390.75 ($p = < .0001$), demonstrated that the correlation matrix was suitable for the use of factor analysis.

In total 36 items were entered into the statistical program. Original running of the factor analysis, using principal components analysis and varimax rotation, resulted in six factors with two items in factor six which were cross loading with the items in the subscale titled Psychosocial Distress (PSD). The data was reanalysed forcing a five factor solution and the two variant items from factor six loaded with the PSD subscale. The following factors emerged: Emotional Well-being (EWB); PSD; Nurse: Physician; and PH. The total factor structure explained 51% of the variance in the items. After assessment of the factor loadings, it was decided that no further item reduction was necessary. These five factors supported the five subscales indentified in the examination of the Likert assumptions in the first stage of the data analysis. See Table 3.2 for a list of the subscales and the item factor loadings.

Factors one and two represent EWB and PSD. Factors three and four, characterize Nurse and Physician subscales and factor five is the PH subscale. The factor structure generated from this analysis was similar to the constructs originally identified in the study by Gregory (1998) and Gregory et al. (1998). Regretfully we were unable to operationalize some key constructs we lost five subscales.

In terms of the factor loading, with the exception of one item in the PH subscale all other item loadings are above greater than or equal to 0.34. The suggested cut-off for inclusion of an item varies among researchers. Parshall (2002) and Schilling et al. (2009) suggest a factor loading above .20 whereas Kline (1993) and (Thompson, 2004) recommend factor loadings above .6. The item with a score below 0.34 is related to feeling more comfortable after HD and is a significant concern for HD patients. Two items from the Physician subscale have high factor loadings, approximately 0.80. The high coefficient suggests that these items may be measuring similar perceptions (Kline). However, the items are measuring two different characteristics of support. One speaks to the speed of physicians' response to patients' needs during HD while the other item communicates the degree of satisfaction with physicians' willingness to listen to patients. All items, despite their factor loading value, are considered integral to measuring the patient's physical experience and their satisfaction with physician support and are left in their respective subscales. Thirty six items remain in the PPHS (See Appendix 3.1).

Table 3.2

PPHS Factor Loading

Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
	Psychosocial Distress	Emotional Well-being	Nurse Support	Physician Support	Physical Health
1	.572	.520	.744	.755	.650
2	.504	.698	.605	.790	.740
3	.458	.667	.695	.604	.699
4	.715	.530	.663	.795	.479
5	.668	.695	.730	.798	.508
6	.660	.426	.701		.344
7	.666	.703			
8	.526	.607			
9	.676				
10	.420				
11	.615				

Note. EWB = Emotional Well-Being; PSD: Psychosocial Distress; Nurse = Support Nurse; Physician = Support Physician ; Physical = Physical Health

The first step was to examine the PPHS subscales relationship to each other. Results from the correlation analysis are used to determine the convergent/divergent validity of the subscales in relation to each other (data not shown). The Pearson correlation coefficients, supported that both the PH subscale (r = .49) and the Support subscales (r =

.42) are related to the larger construct Adjustment to a New Normal which includes the EWB and the PSD subscales. Adjustment to a New Normal showed a weak relationship (r = .17) with the PH and Support subscales. PH and Support are divergent constructs, as one subscale measures physical symptoms and the other formal supports. The three major subscales are significantly correlated (r range .64-.93) to the PPHS scale as a whole, which sustains that they have convergent validity with the overall PPHS.

Convergent/divergent construct validity with the SF-36 is supported (see Tables 3.3a and 3.3b). Coefficients indicate that the subscales are measuring similar constructs yet are not so highly correlated that they are measuring the exact same construct. Divergent validity requires a meaningful separation of content. Both of the Adjustment to a New Normal subscales, PSD and EWB, have a robust relationship with the SF-36 Mental Health subscale (MH) and the Mental Component Summary (MCS) score. The MH and MCS are predictably highly correlated with the PSD and EWB subscales as all the scales deal with emotional, social, and mental health concerns. EWB subscale is also correlated with General Health (GH) and Vitality (V). Vitality is a component of the MCS score and looks at feeling peppy, tired or worn out, all characteristics that could be related to mental well-being. The GH scale asks questions about whether the individual thinks they are as healthy as other people and if they feel they will get sicker. These questions, or thinking about their response, may make patients feel sad and may overlap with their mental well-being. Ware, Kosinski and Keller (1994) concur with this finding as they identified that part of the GH scale measures a component of mental health.

Table 3.3a

Correlations between PPHS subscales and Physical Health SF-36 subscales

Variable	RP	BP	GH	PF	V	PCS
PSD	.33**	.22*	.38**	.30**	.35**	.27**
EWB	.26**	.20**	.44**	.25**	.57**	.27**
Nurse	.06	.23*	.21*	.22*	.18*	.19*
Physician	.01	.13	.32**	.13	.15	.17
PH	.40**	.46**	.45**	.61**	.67**	.59**

Note: PSD: Psychosocial Distress; EWB = Emotional Well-Being; Nurse = Nurse Support; Physician = Physician Support, PH = Physical health, RP = Role Physical; BP= Bodily Pain; GH= General Health; PF= Physical Functioning; V = Vitality; PCS = Physical Component Summary

*p <.05

** p < .01

Table 3.3b

Correlations between PPHS subscales and Mental Health SF-36 subscales

Variable	SF	RE	MH	GH	V	MCS
PSD	.35**	.37**	.51**	.38**	.35**	.51**
EWB	.37**	.30**	.47**	.44**	.57**	.49**
Nurse	.22*	.12	.27**	.21*	.18*	.29**
Physician	.25**	.06	.17	.32**	.15	.19*
PH	.45**	.38**	.47**	.45**	.67**	.53**

Note: PSD: Psychosocial Distress; EWB = Emotional Well-Being; Nurse = Nurse Support; Physician = Physician Support, PH = Physical health; SF= Social Functioning; RE = Role Emotional; MH = Mental Health; GH= General Health; V = Vitality; MCS = Mental Component Summary

*p <.05

** p < .01

Neither of the Support subscales have a meaningful relationship with either the MCS nor the Physical Component Summary (PCS) scores of the SF-36 or its subscales. The Social Functions (SF) subscale is related to social activities and does not assess any component of social support. PH subscale score demonstrates a stronger relationship with the PCS score than the MCS score which makes theoretical sense as both relate to physical experiences. An interesting result is that the PH subscale is significantly correlated with all the SF-36 subscales and the larger mental health summary and physical component summary scales. These findings support the overall effect that physical health may have on every aspect of an individual's quality of life.

Reliability testing includes examination of the subscales' internal consistency and stability. The internal consistency of each subscale was examined using Cronbach's alpha. The Cronbach's alpha for four of the five subscales was close to one, indicating that the items were consistently measuring a single construct (see Table 3.4). The weakest subscale was PH which still evidences a moderate to strong internal consistency with an alpha of .69.

Table 3.4

Cronbach's Alpha Coefficients of PPHS (N = 236)

Variable	Cronbach's Alpha
- Psychosocial Distress	*.85*
- Emotional Well-Being	*.80*
Social Supports	*.88*
- Nurse Support	*.83*
- Physician Support	*.90*
Physical Health	*.69*
PPHS Scale	*.89*

Stability, another component of reliability assessment, refers to the consistency with which a monitoring tool assesses a construct over time. During the initial assessment, patients completed the PPHS, and approximately two weeks later a subsample was retested (n = 30). A span of approximately two weeks was chosen for two reasons. First so that patients would not remember their answers from T1 and second, we didn't want the time span to be so long that their physical or psychosocial health may change. Nunnally and Bernstein (1993) state that approximately two weeks is an adequate length of time between testing for stability. Before the retest, the patient's physician and the HD nurse were questioned about any changes in the patient's physical or psychological

conditions. As well, the patients themselves were asked whether they had experienced a setback in their illness, treatment, support system, or any aspect of their lives that they felt might affect their overall well-being. If anyone verbalized a concern, the interview was either rescheduled or, depending on the reason for a change, the patient was excluded from the retest process.

Stability was examined using the intraclass correlation coefficient (ICC). The ICC measures the correlation between two sets of data but also considers the change in mean scores so that the coefficient is not over inflated. The ICC coefficients ranged between .72 and .94 (see Table 3.5), indicating a significant relationship between measurements over time and support the stability/consistency of the instrument upon retest.

Table 3.5

Intraclass Coefficients for Subscale Test-Retest Scores

Subscale	Intraclass Correlation
PSD	.92*
EWB	.88*
Nurse	.88*
Physician	.92*
Physical Health	.72*
PPHS	.94*

Note. EWB = Emotional Well-Being; PSD: Psychosocial Distress; Nurse = Nurse; Physician = Physician

* $p < .001$

Discussion

The HD group's demographics in the study are comparable with characteristics of the Canadian HD population. The two groups are similar in terms of their age, gender, and living situation but our sample had a lower percentage of patients with diabetes (CIHI, 2011). While the similarity between the groups does not guarantee the results are generalizable, it does suggest that they can be applied with caution to other HD patients.

The purpose of designing a scale is to develop a reliable and valid instrument to measure the construct of interest. The PPHS has face and content validity as demonstrated in earlier studies by O'Brien-Connors (2003) and Wells (2004). Both may need to be re-established in future research. In this study, the findings sustain the validity and reliability found in the early phases of the project. Construct validity was examined using Pearson's correlation and factor analysis. The inter-scale correlations support the convergent and divergent validity of the scale to measure the separate yet linked concepts. The high correlation between the PPHS and the Adjustment to a New Normal scale is not surprising as the subscale comprises the majority of the instrument's items and it is the mediator for quality outcomes as presented in the substantive theory (Gregory, 1998; Gregory et al., 1998).

Results from the factor analysis support the PPHS items and subscale structures. Factor loadings confirmed that items belonged in each subscale, as most loadings for the social supports subscale and the adjustment subscales were equal to or over 0.35. One item

disease specific than the KDQ, the KDQOL, and the HRQOL questionnaires. In the future health care professionals may be able to use the instrument as a means of monitoring patient health, and assessing patients' responses to alternate treatments and interventions. The PPHS could also be used as a method to monitor patients' progress or decline in the hope that early intervention may be able to alleviate problems with their illness, treatment, changes in their formal support systems, and overall adjustment to life on HD. The PPHS is a disease-specific instrument that captures many of the domains identified in the literature as characteristics of quality of life and may be used with confidence to assess quality outcomes in the HD population.

Limitations of the research project are the use of a non-probability convenience sample; thus, findings may not be generalized to the HD population. However, as mentioned, the demographic profile is similar to the report from CIHI (2011) on the characteristics of the HD population in Canada. Another limitation is that the interviews took place in the HD unit. Despite efforts to provide privacy, and ensure that the research assistant was not involved with patient care, there were always other patients and health care professionals nearby, which may have limited the patient's desire to discuss certain topics.

Conclusion

Health care professionals must recognize the psychosocial impact of renal disease and develop mechanisms for psychosocial assessment, intervention, and evaluation to provide complete care to each individual. The evaluative properties of the PPHS have been supported in this research and the instrument is both valid and reliable. The PPHS is user friendly, stable on retest, and shows construct validity by factor analysis in light of the proposed substantive theory and convergent/divergent construct validity with the SF-36. In future, the scale may be used for assessing/identifying needs, designing and evaluating interventions, thus making it a useful instrument for measuring how people experience life on HD and for identifying the ways in which people adjust to changes in their physical health, their support systems, how they redefine their sense of self-worth and eventually their satisfaction with life.

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Appendix 3.1

PPHS _____ Patient ID# _____

Patient Perceptions of Hemodialysis Scale

The following scale contains a list of items that reference events/situations that you may have experienced since the onset of kidney failure and starting hemodialysis. You are being asked to rate each item of a 5 point rating scale located in the columns to the right. In the first instance you are asked to indicate **'how often you feel this way'** (never, rarely, sometimes, often, or almost always). Finally, you are asked to indicate **'how satisfied, how confident or how concerned are you'** (not at all, a little bit, moderately, quite a bit, extremely).

RATING SCALES

How Often

Never	Rarely	Sometimes	Often	Almost Always
0	1	2	3	4

How Satisfied/How Concerned/How Confident

Not at all	A little bit	Moderately	Quite a bit	Extremely
0	1	2	3	4

Circle the response that best applies to you

1.	How often do you experience breathing difficulties?	0	1	2	3	4
2.	How often do you feel tired and low on energy?	0	1	2	3	4
3.	How often are you bothered by walking short distance? (e.g. Tired feelings, breathing problems, etc.)?	0	1	2	3	4
4.	How often do you experience itching due to your kidney disease?	0	1	2	3	4
5.	How often do you feel exhausted after dialysis?	0	1	2	3	4
6.	How often do you feel comfortable after dialysis (e.g. general good feeling, less breathing problems, less swelling, etc)?	0	1	2	3	4
7.	How satisfied are you with overall quality of nursing/tech care in the dialysis unit?	0	1	2	3	4

8. How confident are you that nurses/techs have the knowledge and abilities to know what to do if you become ill on dialysis?	0	1	2	3	4
9. How satisfied are you with nurses/techs willingness to listen to what you have to say about your illness and treatment?	0	1	2	3	4
10. How satisfied are you with the amount of time that nurses/techs take to help you understand your illness and treatment?	0	1	2	3	4
11. How often o you feel that nurses/techs try to promote a relaxed, family-like atmosphere on eh dialysis unit?	0	1	2	3	4
12. How satisfied are you with the comfort measures provided by nurses/techs during dialysis (e.g. Providing a blanket, pillow, refreshments, etc.)?	0	1	2	3	4
13. How confident are you the dialysis doctors have the necessary knowledge and abilities to monitor or deal with your overall physical needs?	0	1	2	3	4
14. How satisfied are you with how quickly doctors respond to your needs when you are on dialysis?	0	1	2	3	4
15. How satisfied are you with the quality of overall medical care in the dialysis unit?	0	1	2	3	4
16. How satisfied are you with doctors willingness to listen to what you have to say about your illness and treatment requirements	0	1	2	3	4
17. How satisfied are you with the amount of time that doctors take to help you understand your illness and treatment requirements	0	1	2	3	4
18. How concerned are you that your health will get worse regardless of what you or doctors do?	0	1	2	3	4
19. How concerned are you about becoming too dependent upon your family?	0	1	2	3	4

20. How concerned are you about eh impact of your illness and treatment on family members (e.g. Decreased social activities, dietary restrictions, time commitments with dialysis, etc.)?	0	1	2	3	4
21. How concerned are you for your personal safety while on dialysis (i.e., worried about what would happen to you)?	0	1	2	3	4
22. How concerned are you about voicing your needs to nurses/techs or doctor s due to the physical closeness of others during dialysis?	0	1	2	3	4
23. How often are you upset by seeing others become suddenly ill (i.e., worried that it would happen to you)?	0	1	2	3	4
24. How often do you dwell on your own health problems following the death of another patient?	0	1	2	3	4
25. How often do you feel depressed (i.e., feeling down, fed-up, frustrated) about your illness and long-term treatment requirements?	0	1	2	3	4
26. How often do you experience fears or worries about unexpected illness/dialysis events (e.g., sudden drop in blood pressure, clotting of access sites, breathing problems due to too much fluid?	0	1	2	3	4
27. How often do you feel that depending on others makes you feel useless (i.e., self-esteem, self-worth)?	0	1	2	3	4
28. How often do you feel distressed by the severity of your illness and the long-term treatment requirements (e.g., troubled, worried, upset, etc.)?	0	1	2	3	4
29. How often do you feel that dialysis has improved the quality of your life?	0	1	2	3	4
30. How often do you try to maintain a positive attitude towards dialysis?	0	1	2	3	4
31. How confident are you that you will come to terms with your illness (i.e., accepting)?	0	1	2	3	4
32. How often do you relax during dialysis?	0	1	2	3	4

33. How satisfied are you with how well you have adjusted to the effects of dialysis (e.g., pain, restrictions, problems with access site, delays, machine functioning, drop in blood pressure)?	0	1	2	3	4
34. How satisfied re you with the amount of quality time spend with family and friends?	0	1	2	3	4
35. How confident are you that you are coping with dialysis restrictions?	0	1	2	3	4
36. How often do you feel that you have some control over the ups and downs of dialysis and the effects on your health and well being (e.g., assuming responsibility for recommended treatment, monitoring dialysis run)?	0	1	2	3	4

Chapter 4

The Patient's Perception of Hemodialysis Scale: Sensitivity to Change

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Abstract

Objectives: The first objective was to assess hemodialysis (HD) patients' physical health, social supports, and psychosocial health at two time periods as well as the interrelationship among patients' experiences, demographics, illness characteristics, and biochemical indicators. The second objective was to determine sensitivity of the Patient's Perception of Hemodialysis Scale (PPHS) to change in health status and critical events.

Methods: Using a longitudinal design, the PPHS's ability to measure change and sensitivity was examined. HD patients (n = 85) were assessed at two time periods approximately six months apart. Data analysis included measures of central tendency and tests of difference to assess the effects of demographic variables on PPHS subscales. To evaluate the sensitivity of the PPHS, means and standard deviations were examined.

Results: There were no significant changes in any of the five PPHS subscales scores between measurement times. Scores were also examined in terms of demographic variables. There were no significant differences in the PPHS subscale scores when the patients were divided into subgroups based on gender, cause of ESRD, living arrangements, hospitalization, hemoglobin, urea clearance or phosphate levels. The number of co-morbid illnesses, illness severity, albumin, and urea reduction between the two time periods changed significantly. The PPHS subscale scores were examined in relation to changes in health status and the presences of critical events. The Psychosocial Distress subscale varied significantly in relation to time on HD, reason for admission to

hospital, and number of admissions. The Physical Health scores were significantly different for subgroups of patients divided by illness severity, number of co-morbid illnesses, age, albumin, reason for admission to hospital, and for patients with congestive heart failure on exertion, new angina, and unstable angina. The Nurse Support scores varied significantly by length of time on dialysis, age and presence of new angina. HD patients living in Newfoundland had significantly lower Physician Support subscale scores than their counterparts living in Ontario. As well, Physician Support scores tended to be significantly lower for HD patients with lower serum albumin levels. The presence or absence of critical events and the PPHS's sensitivity to each occurrence was also examined. PPHS subscale mean scores changed in the predicted direction 63% of the time. The presence of positive events appeared to have had more of an effect on the PPHS scores. Scores changed in the predicted direction 83% of the time with positive occurrences, while scores decreased with negative events only 44% of the time. Results suggest that the PPHS may be sensitive to specific critical events and to a change in the patients' health status.

Conclusion: Findings from this examination of the PPHS's ability to assess HD patients' physical health, social supports, and adjustment and the interrelationship among the patients' experiences, demographics variables, physical well-being, and critical events lead to the conclusion that the instrument may be responsive to a change in physical health and positive critical events in patients' lives. In terms of sensitivity to negative critical events, the results were unsubstantiated. Additional examination with a different

and larger population will allow the opportunity for further psychometric assessment. The PPHS is reliable, valid, and sensitive to physical changes and positive critical events. This instrument offers health care professionals a viable method for assessing important factors capable of predicting quality outcomes.

Introduction

The revised Patient's Perception of Hemodialysis Scale (PPHS) is a valid and reliable instrument for measuring kidney disease-specific experiences of life on hemodialysis (HD). The tool was developed specifically to capture factors influencing quality outcomes. Streiner and Norman (2008) state that before researchers set out to develop an instrument, they must first be certain that a comparable one does not exist which measures the same variables. After an extensive review of the literature, various instruments were identified that measure different aspects of living with end-stage renal disease (ESRD) and HD.

A number of researchers have investigated the role that physical and psychological stressors play in the lives of patients on HD (Baldree, Murphy, & Powers, 1982; Curtin, Bultman, Thomas-Hawkins, Walters, & Schatell, 2002; Gregory, Way, Hutchinson, Barrett, & Parfrey, 1998; Parfrey et al., 1989; Welch & Austin, 1999; Yeh & Chou, 2007). Some research supports that physical stressors have a greater impact on the lives of HD patients (Curtin et al., 2002; Kutner, Zhang, & McClellen, 2000; Walters, Hays, Spritzer, Fridman, & Carter, 2002), while other research suggests that patients are more concerned with their mental health. Depression and anxiety, two psychological symptoms, have been the focus of several research studies that conclude that mental stressors are more intrusive than physical stressors (Cukor et al., 2008a; Cukor, Coplan, Brown, Peterson, & Kimmel, 2008b; Johnson & Dwyer, 2008; Kimmel et al., 1995; Kimmel et al., 1996; Kovac, Patel, Peterson, & Kimmel, 2002; Patel, Shah, Peterson, &

Kimmel, 2002; Son, Choi, Park, Bae, & Lee, 2009; Walters et al., 2002; Zimmerman, Poli de Figueirdo, & Fonseca, 2001). After at least 30 years of research, it appears as if the types of stressor and their impact on the lives of HD patients remain uncertain, and the discussion continues. The inconsistency in the research findings may be impacted by variable scales and populations

The role of a social support system is prevalent in research on chronic illness and ESRD. Bury (1982) states that chronic illness interferes with familial and social roles because the people is incapable of maintaining normal activities. Studies on the HD population provide evidence for the conjecture that having a strong circle of family, friends, and formal support improves the likelihood of experiencing positive outcomes (Cohen et al., 2007; Ersoy-Kart & Gulda, 2005; Plantinga et al.,2010; Rambod & Rafii 2010; Spinale et al., 2008: Untas et al., 2011).

Research on the adaptation, adjustment, psychosocial health, and living with a chronic disease and HD also illuminate the struggle that patients encounter. Living with ESRD and the physical and psychological outcomes have been measured by examining these concepts (Burns, 2004; Cukor, Cohen, Peterson, & Kimmel, 2007; Kimmel, Emont, Newmann, Danko, & Moss, 2003; Lew & Patel, 2007). Similar constructs, "quality of life" and "health related quality of life," have also been measured as indicators of quality outcomes in the HD (Kimmel & Patel, 2006; Kutner, 2004; Hsieh, Lee, Huang & Chang, 2007; Lew & Patel, 2007; Wu et al., 2001).

The variety of concepts used to identify concerns with this population and the amount of information can be overwhelming. In the reviews of quality of life research, numerous authors agree that the problem with trying to measure such an indistinct construct is that a multitude of research has been completed using different measures with dissimilar findings; this has added confusion to an already elusive topic (Danquah, Wasserman, Meininger, & Bergstrom, 2010; Kimmel & Patel, 2006; Prutkin & Feinstein, 2002; Rettig et al., 1997).

Prior research has approached the measurement of patient experiences or perceptions of life on HD in a fragmented fashion, focusing on topics such as stressors, anxiety, depression, quality of care, social supports, adaptation, and quality of life without trying to integrate all the separate components. Despite the logic of the approach to instrument development researchers continue to fall short in their goal to holistically measure adjustment to living with ERSD and HD and its impact on patients' adjustment and overall quality outcomes. Our research team decided that the best method to assess the patient's experience was to conduct a qualitative research study and build an instrument on the resulting data base. The intention was that the rating tool developed in this multilevel national study, the PPHS, would be different from most measurement instruments in that it would be grounded in the patient's experience and would not be from the point of view of physicians, nurses, or previous research. Although the qualitative research was completed in 1999, the constructs maintain their relevance today and, in fact, are derived from more recent information than many of the generic and

ESRD-specific instruments presently available to researchers. The scales are novel in that they measure a variety of concepts including the physical, social, and psychosocial aspects of the patient's experience. As well, the PPHS is designed to be used as a clinical monitoring tool to assess the HD patient's progress over time, so the testing process is shorter and more user-friendly than it would be if using a variety of other instruments.

This is the final paper in a three-part series describing the development of the PPHS. In paper one, item correlations, data quality, subscales, and assumptions underlying Likert scoring of the PPHS were examined. In paper two, I described the psychometric assessment and evaluation of the instrument designed to assess and monitor changes in HD patients. In this paper, I report on the HD population's physical health, social supports, and psychosocial health at two time periods and the interrelationship among aspects of the patient's experience, demographics, illness characteristics, and biochemical indicators. The second purpose of this paper is to present results that address the sensitivity of the PPHS.

Background

The project began with a qualitative study in 1992. Using a grounded theory approach, the research team investigated the patient's perception of life on HD (Gregory, 1998; Gregory et al., 1998). Results from this study were used to develop a substantive theory on the experience of people living with ESRD and HD. Three major theoretical constructs emerged from the theory: *illness and treatment experiences*, *social supports*, and *adjustment to a new normal*.

Illness and treatment experiences integrate concepts related to dealing with the stress of living with ESRD, its symptoms, the multitude of co-morbid conditions, the frustration of ambivalence, and the conflict between knowing what to do to stay healthy and actually leading a healthy life according to ESRD and HD restrictions. The second construct, *social supports*, focuses on the perceived usefulness of informal/family supports and formal supports such as physicians, nurses, and HD technicians. *Adjustment to a new normal* incorporates content related to emotional well-being and psychosocial distress resulting from the burden of decision making associated with adapting to living with disease and the HD environment (Gregory & Way, 2008). The substantive theory linking these three constructs describes the interrelationship among the variables and how they all relate to *quality outcomes*. A change in one area may result in a change in any of the other main constructs and, ultimately, quality outcomes.

The term *quality outcome* is defined as an end result of the ever-changing subjective and objective experience of living with and adapting to life on HD. The subjective aspect relates to satisfaction with life and living with HD, whereas the objective elements are morbidity and mortality. The concept is not new and is often used interchangeably with other domains such as psychosocial adaptation and quality of life, two constructs extensively studied in research on patients with ESRD. This theory is reflective of concepts identified in the literature on ESRD as influencing quality outcomes; however, it is distinct in its approach to defining the interrelationship among the main constructs.

The purpose of this research project was to develop a feasible method to measure and follow change in how people experience life on HD. In doing so, we hoped to identify (a) ways in which people interpret the meaning of their illness and/or treatment, (b) strengths and weaknesses in their support systems, and (c) overall adjustment to life on HD. These areas may be amenable to interventions capable of facilitating adaptation to life on HD and enhance the emergence of a positive self-concept with resulting improvement in quality outcomes.

Our purpose is unique in that it takes a broad focus and does not narrowly limit itself to "quality-of-life" but focuses in addition on how *meaning of the illness and treatments,* strengths and weaknesses in *support* systems, and adjustment to life on HD overlap. To achieve our goals, the scales developed had to be capable of differentiating people with regard to their status at a point in time as well as being responsive to change through

natural evolution or planned intervention. In papers one and two, the PPHS was refined and reduced in size from 64 to 36 items. Many items were removed from the original - illness and treatment subscale. All items measuring treatment-related characteristics such as Self-health Management, Disease Knowledge and Activities of Daily Living were taken out, and the new subscale, Physical Health (PH), only measures physical stressors. The original social support subscale measured family, allied health and formal supports. Items relating to the family and allied health subscales had poor psychometric properties and were removed from the PPHS. The new subscale, Supports, focuses on assessing formal supports, specifically health care practitioners.

The last section of the instrument, adjustment to a new normal, was quantified in a subscale titled Psychosocial Health it consists of two subscales labelled Emotional Well-being (EWB) and Psychosocial Distress (PSD).

This third paper addresses measurement and sensitivity of the revised PPHS subscales. The three hypotheses being tested are:

1) There will be a difference in PPHS scores between T1 and T2.

2) There will be a difference in the PPHS subscale scores amongst subgroups based on patients' demographics, biochemical indicators, the number of co-morbid illnesses, and illness severity at T2.

3) There will be a difference between PPHS subscale scores among patients who experience a change in their health status, biochemical indicators, and/or positive or negative critical events at the second measurement time.

Methods

Research Design

Using a longitudinal design, the PPHS's ability to assess physical stressors, social supports, and adjustment was examined. As well, the scale's sensitivity was assessed in relation to a change in status or the occurrence of critical events. The research included a two-phase procedure. Data were collected at time one (T1), and approximately six months later at time two (T2), patients were re-interviewed.

Sample

The target population was all patients with ESRD who were on in-center HD in Newfoundland and Ontario. The accessible population was restricted to patients meeting the following inclusion criteria: (a) on in-center HD for at least12 weeks; (b) mentally competent, (c) not experiencing an acute illness episode, (d) over the age of 19, and (e) able to understand and speak English. A convenient sample (N = 236) was obtained at T1, and healthy patients who were willing to be re-interviewed (n = 85) were assessed at T2. The projected T2 sample was 120. Some patients refused to be tested again, others were sick, and some patients had died in between measurement times. No record was maintained regarding nonparticipation at T1 or T2.

The focus of the analysis is the paired sample of patients re-interviewed at T2 for whom all measurements were available.

Instruments

Data presented in this paper were collected utilizing the following instruments: the PPHS, a personal data extraction form, a co-morbidity scale, and a critical events checklist. Instruments were administered while patients were receiving HD.

In previous research and the present study, the PPHS has been found to be reliable and valid (Gregory & Way, 2008; O'Brien-Connors, 2003; Wells, 2004). The PPHS was used to identify events/ concerns, related to Physical Health, Social Support, or Psychosocial health. The PPHS items were rated on a 5-point Likert scale and included the five subscales: EWB, PSD, Nurse Support (Nurse), Physician Support (Physician) and Physical Health (PH) (see Appendix 4.1).

The personal data extraction form was developed by the team of researchers for use in the larger study. It included questions pertaining to patient demographics and illness and treatment information such as age, gender, dialysis start date, cause of ESRD, major co-morbidities, and hospitalizations in the previous six months. Biochemical indicators such as urea reduction ratio, hemoglobin, albumin, and phosphate level were also recorded. A score for each biochemical indicator was determined by taking the average value for all biochemical indicator measurements over the previous three months. In the absence of

any specific rule and after a discussion with clinicians, it was decided that the serum average over three months would be a more accurate gauge of biochemical levels than one month's recording. Information from the personal data extraction form was used to calculate the illness severity index score using a scale developed by Barrett et al. (1997). The score is based on a variety of factors that allow the researcher to calculate an illness severity score ranging between 1 and 22, with a score of 0 to 4 suggesting low risk of mortality, a score of 5 to 9 suggesting moderate risk, and a score of greater than 9 suggesting high risk of mortality within the next 6 months. The personal data extraction form was completed at T1 and T2 (see Appendix 4.2).

The critical events checklist was only administered at T2 since the intent was to assess positive or negative changes during the six months between T1 and T2. Gregory (1998) defined critical turning points/events as significant moments that separately or cumulatively affect the individual depending on his or her situation. The research team developed the critical events checklist and divided it into four sections reflecting constructs in the substantive theory (*illness and treatment experiences*, *social supports*, and *adjustment to a new normal*). Each section has 10 to 16 items relating to the following areas: illness experiences, treatment experiences, social support, and adjustment to changes in the sense of self. Patients were required to give a yes/no response to indicate the presence or absence of each of the 48 critical events. Examples of an illness event are a change or loss of renal function, as indicated by no or minimal urine output or increased time on dialysis, and having a predictable illness course.

Treatment event items related to a well-functioning dialysis access site and the absence of travel worries. Support items asked about the presence or absence of confidence in physicians and nurses. The last section of the checklist documented events related to self events, such as feelings of hopelessness, uncertainty, and a positive or negative attitude (see Appendix 4.3).

Procedure

This study was approved by the research ethics boards at each site. Initial contact with the potential participants was made by the HD unit nurse to decrease any pressure the patients may have felt about their decision to become involved in the research study. If the client agreed, an interview was arranged, and the assistant explained the purpose of the research and obtained written consent for participation at T1 and T2. Each interview took approximately 60 to 90 minutes depending on the client and dialysis events. The majority of subjects could read so they completed the scale with the researcher by their side. Items were only read aloud if the subject had visual problems. The data extraction form was administered first, and then the PPHS followed by the critical events checklist at T2.

Data Analysis

The data were entered into the Statistics Package for Social Sciences (SPSS).
Indices of central tendency were calculated and alpha was set at $p < .05$ for all statistical calculations.

A weighted mean was calculated for each PPHS subscale by summing the score for items in the subscale and dividing the total by the number of items.

Paired *t* tests and Pearson's correlation coefficients were used to examine the relationship or difference between the PPHS subscale scores at T1 and T2. These statistics were also used to examine changes in the biochemical indicators, the number of co-morbid illnesses, and the illness severity index between measurement periods.

Independent *t* tests or their non-parametric equivalents were calculated to compare the PPHS scores for subgroups defined by various demographic and other factors at T2. Continuous variables were divided into approximately equal subgroups for the analysis. Groups were categorized around the mean score for the following variables: age, amount of time on HD, and the number of co-morbid illnesses.

The critical events checklist included nominal level data which recorded the presence or absence of occurrences. To examine the PPHS's sensitivity, the mean and standard deviation of relevant PPHS scores at T1 and T2 were calculated separately for those reporting a critical event versus not reporting a critical event. If the patient said yes to a positive event, the PPHS score at T2 should be higher than at T1. When the patient experienced a negative occurrence during the previous six months, the PPHS subscale mean score should be lower at T2. If the subscale score remained the same or if a score could be rounded to make the scores equivalent, they were considered equal. Each mean

score that either stayed the same or moved in the predicted direction was counted as one positive change. Only the critical events associated with a specific subscale were included in the final tally. For example, PH scores were inspected in relation to illness critical events, the Nurse or Physician subscale scores were examined subsequent to a positive or negative support occurrence, and the EWB and PSD subscales were examined after personal critical events.

Results

This section presents an overview of study findings with respect to demographic and illness/treatment-related variables. Descriptive findings are presented for key PPHS study variables followed by an examination of the PPHS's sensitivity to a change in the patients' status and critical events.

Table 4.1 summarizes demographic characteristics of study participants (n = 85). All participants spoke English, and the mean age was 59 years with a range from 22 to 84 years. Ninety percent lived with a significant other and the majority (71%) resided in Newfoundland. The characteristics of patients that participated at both T1 and T2 (the repeat subjects) are reflective of the total sample at T1 in terms of the key demographic variables; the only exception was living arrangement. Significantly fewer of the repeat subjects lived alone.

Table 4.1

Description of the Sample T2 (n = 85)

Characteristic	Number	Percent
Gender		
Male	47	55.3
Female	38	44.7
Living Arrangements		
Alone	8	9.4
Spouse	53	62.4
Parents/children	6	7.1
Another adult	17	20.0
Institution	1	1.2
Hemodialysis site		
Newfoundland	60	70.6
Hamilton	25	29.4
Age in years		
< 30	4	4.7
31 - 49	22	25.9
50 - 69	29	34.1
> 70	30	35.3

Tables 4.2a, 4.2b and 4.2c include a breakdown of the illness and treatment-related characteristics of the participants. The three main causes of ESRD were glomerulonephritis/autoimmune disease, diabetes, and renal vascular disease. A majority of the patients had been on dialysis for approximately two years. Thirty-six percent of the subjects had no co-morbid illness, and 41% had one or two co-morbid illnesses with cardiovascular/peripheral vascular disease and diabetes being the most prevalent. Fifty-five percent of the patients had an illness severity index less than 4 with only 4% scoring higher than 9.2. Thirty subjects were hospitalized between T1 and T2, with 14 being admitted more than once.

Table 4.2a

Illness and Treatment Related Characteristics (N = 85)*

Characteristic	Number	Percent
Cause of ESRD		
Diabetes	17	20.0
Glomerulonephritis/autoimmune	17	20.0
Renal vascular disease	14	16.5
Polycystic kidney disease	7	8.2
Congenital/hereditary renal disease	2	2.4
Other (unknown, acute renal failure, cancer)	28	32.9
Time on hemodialysis		
< 1 year	40	47.1
1-3 years	26	30.6
> 3 years	19	22.4

* *Note*: Sample size may vary depending on missing data.

Table 4.2b

*Illness/Treatment-Related Characteristics T2 (n =85 *)*

Characteristic	Number	Percent
Number of co-morbid illnesses		
0	30	35.3
1-2	35	41.2
>2	19	22.4
Co-morbid illness		
CHF on exertion[a]	25	29.4
CHF at rest[b]	8	9.4
New angina > 6 months	30	35.3
Unstable angina < 6 months	6	7.1
Arrhythmia	6	7.1
Peripheral vascular disease	10	11.8
Diabetes	22	9.3
Cancer	12	14.1
Lung disease	8	9.4
Stroke	7	8.24

* *Note*: Sample may vary depending on missing data.

[a] Heart failure symptoms on strenuous or prolonged activity or prior to heart failure.

[b] Heart failure on ordinary activity or at rest or recurrent admissions to hospital in heart failure.

Table 4.2c

*Illness/Treatment-Related Characteristics T2 (n =85 *)*

Characteristic	Number	Percent
Illness severity[1]		
< 4	46	54.8
4.1-9	35	41.7
>9.1	3	3.6
Number of hospitalizations past 6 months		
1	16	18.8
2	10	11.8
≥3	4	4.8

* *Note*: Sample may vary depending on missing data.

[1] Illness severity index is based on prediction of early death in ERSD patients on HD as defined by Barrett et al. (1997).

Measures of central tendency and *t* values are used to describe and compare demographic variables and the PPHS scores between T1 and T2 (see Table 4.3). At T2, patients had significantly more co-morbid illnesses than at T1. The increased morbidity is mirrored in the illness severity index that is also significantly different between measurement times. Albumin, an indicator of illness severity, and urea reduction, a marker for dialysis clearance, were both significantly higher at T2.

There was no significant change in the five PPHS subscales scores between measurement times. The scores range from 0 to 4 with higher scores being indicative of a more positive response. A score of 2.5 or above in each of the five subscales would suggest that a patient was *sometimes to often* satisfied or had few concerns with that specific area.

Table 4.3

Co-morbidity, Biochemical Indicators and PPHS Scores at T1 andT2 (n = 85)

Variable	T1	T2	
	Mean (SD)	Mean (SD)	*t*
Co-morbidity			
Number of co-morbid illnesses	1.2 (1.3)	1.5 (1.5)	-3.5***
Illness severity score	4.0 (2.4)	4.6 (2.9)	-4.1***
Biochemical parameters			
Hemoglobin (g/L)	113.7 (15.2)	116.0 (14.3)	-1.8
Albumin (g/L)	36.9 (5.7)	37.3 (4.5)	-2.7***
Urea reduction rate (%)	69.2 (6.2)	71.1 (4.9)	-3.6***
Phosphorous (mmol/L)	1.9 (0.55)	1.8 (0.52)	1.3
PPHS Subscales			
Physical Health	2.22 (.82)	2.19 (.68)	-.99
Social Supports	3.36 (.54)	3.34 (.52)	.14
Nurse	3.35 (.55)	3.40 (.55)	-1.2
Physician	3.25 (.71)	3.25 (.68)	-.52
Psychosocial Health	2.71 (.65)	2.75 (.67)	-.14
Emotional Well-being	2.99 (.68)	2.98 (.67)	-.06
Psychosocial Distress	2.50 (.87)	2.57 (.87)	-.02
PPHS	2.82 (.52)	2.81 (.48)	-.27

Note: $^{**}p < .05$, $^{***}p < .001$

In Tables 4.4a, 4.4b and 4.4c, the PPHS subscales scores at T2 are being compared across subgroups. The subgroups are based on demographic characteristics, number of co-morbid illnesses, illness severity score, and biochemical indicators. Older patients (above 59) scored significantly lower on the PH subscale than younger patients. There was a significant difference between groups when the number of co-morbidities was examined. Patients with a higher number of illnesses scored significantly lower on the PH subscale. Three specific co-morbid illnesses also affected the PH subscale scores. Patients with congestive heart failure on exertion, new angina, and unstable angina had significantly lower PH scores.

Length of time since initiation of HD played a key role in patients' ratings of their psychosocial distress and the evaluation of nurses' support (see Table 4.4a). Patients' mean time on HD (1.8 years) was taken into consideration when dividing the sample into two approximately equal groups for further analysis. Forty nine patients had been on HD for less than the mean and 34 had been on longer than 1.81 years. Patients' perception of their PSD was affected by time. Significantly lower distress levels were reported by patients who had been on dialysis less than 1.8 years. Time on HD also had a significant role in the patients' rating of nurses. Patients on HD for fewer than 1.8 years gave nurses a higher score than their counterparts on HD for longer periods of time. However, the mean ratings were over 3, indicating that both subgroups were *quite to extremely* satisfied with nurses' support (data not shown).

Further examination of the effects of albumin levels indicated that when the sample was divided into two groups, based on the mean albumin level, a significant difference was noted in the PH subscale. Patients with higher albumin levels, that is, over 37.1, had significantly better PH scores. As well, patients' with higher albumin levels were more positive in their rating of the nurses' and physicians' support at T2. There were no differences in PPHS subscale scores between subgroups defined by differences in hemoglobin, phosphate, and urea reduction rate (see Table 4.4c).

There was no significant difference in the PPHS subscale scores between those who were hospitalized and those who were not. However, there was a significant difference in the PH subscale for patients who had been admitted for illness versus a surgical procedure: patients admitted for surgery scored one point higher on the PH subscale. As well, patients who were admitted to hospital two or more times experienced significantly more stress as indicated by the PSD score (see Table 4.4c).

Table 4.4a

Demographics, Co-morbidity, Illness severity, Biochemical Indicators and Hospitalization on PPHS Subscales at T2: Tests of Difference

Independent t test for demographics

Variable	PH	Nurse	Physician	PSD	EWB
Age (< 59 years and > 59.1)	2.5**	0.17	0.70	1.28	-.25
Gender	-0.89	0.46	-0.06	-0.86	-1.48
Province	0.56	-.35	-3.8***	-0.25	-1.71
Living arrangements	-0.06	-0.41	0.13	0.49	-0.94
Time on HD (< 1.8 years and ≥ 1.81)	1.88	2.2**	0.29	2.9**	0.98
Number of co-morbid illnesses (0 to1 and 2 to7)	2.8**	0.98	-0.06	0.49	0.10

*Note: **p < .05, ***p < .001*

PH = Physical health, Nurse = Support: Nurse, Physician = Support: Physician, PSD = Psychosocial Distress and EWB = Emotional Well-being

Table 4.4b

Demographics, Co-morbidity, Illness severity, Biochemical Indicators and Hospitalization on PPHS Subscales at T2: Tests of Difference

Independent t test for demographics

Variable	PH	Nurse	Physician	PSD	EWB
CHF on exertion[a]	3.5***	1.17	-1.88	-0.37	0.45
CHF at rest[b]	1.97	-0.83	-1.42	-0.19	0.88
New angina > 6 months	2.8**	2.7**	0.52	0.71	0.77
Unstable angina < 6 months	2.2**	1.11	0.05	0.59	0.55
Arrhythmia	1.7	0.21	0.32	0.16	-0.30
PVD/gangrene	0.22	0.66	1.35	1.03	-0.16
Diabetes	0.47	0.21	0.20	0.13	-0.38
Cancer	-0.36	0.98	0.74	-0.91	-0.68
Lung problems	189 MWU[c]	0.62	202 MWU	-0.47	-0.29
Stroke	0.79	-0.10	257 MWU	-1.55	-0.81

*Note: **p < .05, ***p < .001*

[a] *Heart failure symptoms on strenuous or prolonged activity or prior to heart failure.*

[b] *Heart failure on ordinary activity or at rest or recurrent admissions to hospital in heart failure.*

[c] *MWU = Mann-Whitney U*

PH = Physical health, Nurse = Support: Nurse, Physician = Support: Physician, PSD = Psychosocial Distress and EWB = Emotional Well-being

Table 4.4c

Demographics, Co-morbidity, Illness severity, Biochemical Indicators and Hospitalization on PPHS Subscales at T2: Tests of Difference

Independent t test for demographics

Variable	PH	Nurse	Physician	PSD	EWB
Albumin (< 37.6 and ≥ 37.7)	-2.5**	-2.7**	-2.7**	-1.86	-1.94
Hemoglobin (< 116.4 and ≥116.5)	0.36	0.11	-0.17	0.50	-0.88
Percent urea reduction (< 71 and ≥ 71.1	1.49	1.47	1.17	-1.18	-0.91
Phosphate (< 1.9 and ≥ 1.91)	0.57	-0.46	0.07	0.67	0.70
Hospitalization	0.74	-0.18	1.0	0.95	-0.62
Admissions (1 vs ≥ 2)	-1.4	0.55	-0.17	3.1**	0.82
Illness versus surgery	3.0**	0.86	-0.97	0.55	0.54

*Note: **p < .05, ***p < .001*

PH = Physical health, Nurse = Support: Nurse, Physician = Support: Physician, PSD = Psychosocial Distress and EWB = Emotional Well-being

Critical Events

Critical events, or turning points, include positive and negative incidents that relate to the four major constructs in the substantive theory on living with ESRD. Subjects completed the critical events checklist and informed the researcher of the presence or absence of positive and/or negative illness, treatment, support, and self events, for the previous six months (see Table 4.5).

At T2, patients reported having experienced more negative illness events than positive illness events. Illness events such as unpredictable illness (n = 28) and a decline in health and well-being (n = 19) were the most common negative events. Despite these negative events, 51 patients stated that they had a predictable illness course, and 34 stated that their health status and well-being had improved.

In the section related to treatment, patients reported more positive than negative events. That is, 50 patients reported that they had a well-functioning dialysis access site and 49 stated that they felt good during HD. Treatment events such as feeling unwell during HD (n = 28) and problems with HD access site (n = 25) were the most frequently reported negative experiences.

In the support section, more patients reported having had negative (n = 63) than positive (n = 42) events, with the loss of fellow patients being the most commonly reported negative occurrence (n = 34). Fifty-seven patients reported positive support in that they

acknowledged the trust they had in nurses and physicians and the support they received from fellow HD patients (n = 58) and family (n = 57).

The last section of the checklist concerned personal events. Sixty-one patients reported one or more positive events while 42 reported one or more negative events. Frequently reported positive events were the ability to continue to live independently (n = 48), having a positive attitude (n = 53), and feeling hopeful (n = 49). The more commonly identified negative self events were uncertainty (n = 29) and dissatisfaction with social activities (n = 24) (see Tables 4.6a and 4.6b and Supplementary Tables 4.7a to 4.7f).

Table 4.5

Critical Events T2 (n = 85)

Variable	Number	Percent
Positive Illness events - Present	24	28.2
Positive Illness events - Absent	61	71.8
Negative Illness events - Present	46	54.1
Negative Illness events - Absent	39	45.9
Positive Treatment events - Present	67	78.8
Positive Treatment events - Absent	18	21.2
Negative Treatment events - Present	55	64.7
Negative Treatment events - Absent	30	35.3
Positive Support events - Present	42	49.4
Positive Support events - Absent	43	50.6
Negative Support events - Present	63	74.1
Negative Support events - Absent	22	25.9
Positive Self events - Present	61	71.8
Positive Self events - Absent	24	28.2
Negative Self events - Present	42	49.3
Negative Self events - Absent	43	50.6

Examination of the specific critical events and the effect these occurrences had on the PPHS subscales included an assessment of mean scores at T1 and T2. The subscale scores at T2 were assessed to determine if the score had increased after a positive event or decreased after a negative critical event in relation to the individual's score at T1 (see Supplementary Table A). It was hypothesized that answering yes to a positive event would be associated with a higher score in the PPHS subscales at T2 and yes to a negative event would be associated with a lower score in the PPHS subscales at T2. In the absence of critical events, the PPHS might not be expected to change, and, as such, responding no to critical events was not included in the analysis. Higher scores on each PPHS subscale are more desirable as an elevated score indicates a higher degree of satisfaction or less concern with that variable.

In total, 240 mean PPHS subscale scores were examined. Sixty-three percent of the change scores for the entire checklist were in the predicated direction with 37% moving in the opposite direction. Affirmative responses to positive events resulted in increased PPHS subscale scores 83% (100 out of 120 events) of the time. Negative events were associated with decreased mean scores on PPHS subscales 44% (53 out of 120 events) of the time.

Specific assessment of the individual events and the most likely affected subscales were examined. The PH subscale and negative illness events resulted in scores moving in the predicted direction one out of five times as shown in the column labelled Physical Health.

Conversely, positive illness events were associated with an increased PH score five out of five times. Mean scores changing in the correct direction are bolded (see Table 4.6a and 4.6b). For a complete list of all scores for the remaining four PPHS subscales see Supplementary Tables 4.7a to 4.7f.

Treatment concerns were most closely related to the PH subscale. The PH subscale mean scores changed in the desired direction 1 out of 5 times for a negative treatment event, while positive treatment events produced a correct change in the PH subscale scores for 3 out of a possible 5 times (see Supplementary Tables 4.7a to 4.7f).

The Support subscales, Nurse and Physician, were examined in relation to support critical events. Negative support events resulted in a change in the Nurse subscale 1 out of 6 times, while the Physician subscale only changed in the desired direction twice. The Nurse subscale mean score changed in the predicted direction after a positive event 5 out of 6 times and the Physician subscale changed in the predicted direction 4 out of 6 times (see Supplementary Tables 4.7a to 4.7f).

The eight self events were hypothesized to affect the two Psychosocial Health subscales, EWB and PSD. Negative self events produced a change in the correct direction for the EWB 3 out of 8 times and the PSD mean scores changed in the predicted direction 4 out of 8 times. A positive event caused a change in the EWB subscale mean scores 8 times and the PSD subscale 4 times (see Supplementary Tables 4.7a to 4.7f).

Table 4.6a

Means and Standard Deviations for the PHHS Subscale and Yes responses to Illness Related Critical Events at T2

Critical Event (- or +)[a]	**n**[b]	**EWB Mean (SD)**		**PSD Mean (SD)**		**Nurse Mean (SD)**		**Physician Mean (SD)**		**Physical Health Mean (SD)**	
Negative events		**T1**	**T2**	**T1**	**T2**	**T1**	**T2**	**T1**	**T2**	**T1**	**T2**
1.1 Loss of renal function (-)	16	**2.9 (.72)**	**2.8 (.69)**	**2.6 (.91)**	**2.6 (.66)**	**3.6 (.38)**	**3.5 (.48)**	**3.1 (.87)**	**3.1 (.89)**	2.1 (.89)	2.3 (.58)
1.2 Loss of alternate Rx (-)	1	3 (0)	3 (0)	**1.5 (0)**	**1.2 (0)**	3.5 (0)	3.8 (0)	1.6 (0)	2.8 (0))	1.8 (0)	2.2 (0)
1.3 Unpredictable illness (-)	28	**2.9 (.72)**	**2.8 (.82)**	**2.4 (.94)**	**2.3 (.86)**	**3.3 (.68)**	**3.3 (.68)**	**3.1 (.87)**	**3.1 (.78)**	2.1 (.77)	2.2 (.71)
1.4 Decline in health (-)	19	**2.9 (.9)**	**2.9 (.85)**	**2.4 (.92)**	**2.4 (.85)**	**3.2 (.64)**	**3.2 (.62)**	**3.2 (.87)**	**3.2 (.91)**	**1.9 (.64)**	**2 (.77)**
1.5 Reduced motivation (-)	6	2.8 (.82)	2.9 (.74)	**2.4 (.86)**	**2.4 (.82)**	3.3 (.69)	3.5 (.63)	**2.7 (1.2)**	**2.4 (1.2)**	1.8 (.61)	2.1 (.56)

Note[a]. - = negative event,
Note[b]. n = Sample who responded to critical event

Table 4.6b

Means and Standard Deviations for the PHHS Subscale and Yes responses to Illness Related Critical Events at T2

Critical Event (- or +)[a]	**n**[b]	**EWB Mean (SD)**		**PSD Mean (SD)**		**Nurse Mean (SD)**		**Physician Mean (SD)**		**Physical Health Mean (SD)**	
Positive events											
2.1 Improved renal function (+)	4	2.8 (.21)	2.7 (.8)	2.6 (1.1)	2.4 (1.1)	**3.2 (.89)**	**3.5 (.44)**	**3.1 (.74)**	**3.4 (.34)**	**2.2 (.83)**	**2.4 (1.2)**
2.2 Alternate treatment (+)	13	**2.8 (.86)**	**3 (.73)**	**2.2 (.71)**	**2.4 (.84)**	**3.1 (.9)**	**3.3 (.87)**	**2.8 (1.1)**	**3 (.82)**	**2.2 (.75)**	**2.6 (.77)**
2.3 Predictable illness (+)	51	**3 (.64)**	**3 (.55)**	**2.6 (.78)**	**2.7 (.83)**	**3.3 (.58)**	**3.4 (.55)**	**3.3 (.73)**	**3.3 (.62)**	**2.2 (.73)**	**2.3 (.68)**
2.4 Improved health (+)	34	**3.1 (.69)**	**3.2 (.56)**	2.8 (.81)	2.7 (.96)	**3.3 (.62)**	**3.5 (.54)**	**3.3 (.75)**	**3.4 (.61)**	**2.2 (.62)**	**2.2 (.65)**
2.5 Increased motivation (+)	10	**3.1 (.56)**	**3.4 (.44)**	2.7 (1)	2.6 (1.4)	**3.1 (.98)**	**3.5 (.89)**	**3.1 (.89)**	**3.3 (.8)**	**2.2 (.56)**	**2.3 (.8)**

Note[a]. + = positive event

Note[b]. n = Sample who responded to critical event

Discussion

Data collection for this research study was completed in 2000; however, the sample characteristics of the population at T1 (N = 236) are fairly consistent with demographics of the Canadian HD population in terms of their age, gender, and form of renal replacement therapy (CIHR, 2011). The use of a convenience sample limits the generalizability of the findings to the national HD population, and the results should be interpreted with caution. The only significant difference among the demographic variables between the original sample (N=236) at T1 and the repeat sample subset (n=85) at T2 was the HD patients' living arrangements. Fewer of the repeat sample subjects lived alone. This suggests that the repeat participants may have had more informal support as they were more likely to be living with a spouse, another adult, a parent, or a child. Based on examination of patients who lived alone versus those that lived with another person, there were no significant differences in any of the PPHS subscales. However, with such a small sample and unequal group sizes, there was not sufficient power for inferential analyses.

The PPHS subscales did not change significantly between measurement periods. These findings support rejection of the first hypothesis. In our population time between measurement periods may have been too short for a significant change to occur in the patients' health, support or adjustment.

When the PPHS subscales were examined in relation to groups of subjects, it was not surprising that older patients were significantly sicker and had lower PH subscale mean scores. Research on age suggests that older patients are more likely to have decreased physical health, higher incidence of congestive heart failure, and poorer quality of life (Canaud et al., 2011; Germin-Petrović et al., 2011; Liang et al., 2011).

Time on HD had an impact on the Nurse Support and PSD subscales. Patients who had been on HD less than 1.8 years gave significantly higher ratings to the perceived supportiveness of nurses. However, both groups' ratings were above 3 which imply that all of the HD patients participating in the study were *quite* to *extremely* satisfied with the nurses. The PSD score was also significantly different for the two groups. Patients on HD for less than 1.8 years had a significantly better PSD score which is suggestive of less stress early in the HD period. Bohlke et al. (2008) found a negative relationship between time on HD and physical component summary score of the SF-36. Yamana (2009) found the opposite to be the case with patients on HD for five years or longer having better coping skills and finding dealing with stressors less challenging than patients on HD for five or less years. While psychosocial distress and coping with stressors are not one and the same, there are many articles linking the two constructs.

In terms of illness and treatment characteristics, there were some significant differences between T1 and T2. By T2, there had been a decline in health or an increase in illness, which was reflected by the expected changes in PH subscale scores. Patients with more

co-morbid illness, congestive heart failure on exertion, new angina, and/or unstable angina scored significantly lower on the subscale. These findings provide support for the fact that the PH subscale is sensitive to a change in physical status. Although other PPHS subscale scores also decreased, with the exception of the Physician subscale score, in response to increasing co-morbidity, these changes failed to achieve statistical significance. While this supports mild sensitivity, it does suggest that the EWB and PSD were slightly affected by the decreased PH score. The research hypothesis, that a change in co-morbidity between the first and second testing would be reflected in an appropriate increase or decrease in the PH subscale score at T2 was supported. The hypothesis that a change in co-morbidity would affect the other PPHS subscales was rejected. It appears as if the PH subscale is sensitive to an alteration in physical health.

Changes in the illness severity index show that patients were, on average, sicker at T2. Significantly, fewer subjects had a score on the index below 4, and approximately 3% more of the subjects had a score between 4.1 and 9. Most of the patients were in the medium illness severity level as their scores were between 4 and 9 on a scale from 1 to 22. (A score of 1 is associated with a low risk of early death, and a rating of 22 is associated with a high risk.). Individuals who had higher illness severity scores at T2 also showed a significant decrease in their PH subscale score. Again, the hypothesis that a decrease in physical status, as indicated by the higher illness severity score, would result in a decrease in the PH subscale score was accepted.

The significant effect of the higher illness severity index, the increased morbidity, and the subsequent lower ratings of PH suggest there is sensitivity to actual changes in one's physical status.

There was a significant difference between T1 and T2 in two of the four biochemical indicators: albumin and urea reduction rate (PRU). Albumin levels for both T1 and T2 were within the normal range. However, patients with high albumin levels rated their physical health and the perceived supportiveness of physicians and nurses significantly higher than those with lower albumin levels. Research supports the conclusion that lower levels of albumin are associated with increasing illness severity, decreasing physical functioning, and declining overall health (Kimmel et al., 1998; Kovac et al., 2002; Kring & Crane, 2009; Kutner, et al., 2000; Wells, 2002). The urea reduction level, one measure of dialysis adequacy, is correlated with other measures such as the dialysis urea concentrations. The proportions cited in Table 3 did not meet minimal targets of 65% clearance at each time point. The change in the PRU levels was minimal and may not have had any impact on the patients. As well, despite the statistically significant difference, there was a very small change in the mean PRU scores. This may or may not be clinically significant for the HD patients and may not be a good test of sensitivity.

At T2, 35% of the HD patients had been hospitalized at least once during the previous six months; 16 were admitted for surgery, 11 for illness, and three for more than one reason. Admission to a hospital implies that these subjects were sicker at T2 than they were at

T1. Admission to hospital did not affect the PPHS subscales scores, and the research hypothesis that there would be a difference was not supported. However, when the patients are divided into groups based on the reason for their admission, illness versus surgery, the patients hospitalized for illness had significantly lower PH scores. Without knowing the type of surgery or whether the surgery was planned or was performed because of an emergency, conclusions based on this information are suspect.

The increased illness severity, urea clearance levels, and number of co-morbid illnesses at T2 all contribute to the patient feeling unwell. These changes may have influenced admission to hospital. There was a significant difference in the PH subscales (but none of the other PPHS subscales) as a result of the change in the physical status. Looking at the substantive theory, the PH subscale is the most likely to be affected by illness and is an indication of the subscale's sensitivity. Changes in the PH, PSD, Nurse, and Physician subscales, as a result of changes in the patients' age, albumin, time on dialysis, type, and the number and severity of co-morbid illnesses support the substantive theory, sensitivity of the PPHS, and the second hypothesis. Again, most other research that found biochemical indicators affect the outcomes variables took place over a longer period of time. Six months may not have been a sufficient period of time to expect a change in blood values or their effect on physical health.

Critical Events

The purpose of the critical events checklist was to record the presence or absence of events related to illness, treatment, support, and the sense of self. All responses are either positive or negative, so there is no means to evaluate the intensity of items listed in the scale. Loss of family and good rapport with fellow patients and loss of alternate treatment modality are worth equal value in a summative score, yet each may have a completely different effect on the patient's overall well-being. As well, there is no way to determine when the event occurred. An event may have taken place just after administration of the PPHS at T1 and the patient may have had six months to adapt to the change. So, even though the event occurred, the patient may no longer have been feeling better or worse. Hypothesizing that there would be a significant change in any of the PPHS subscales scores as the result of a critical event makes the assumption that each event is contextualized in the manner that the researchers expected. An example is the loss of a fellow patient: individuals experience grief in different ways and the level of grief depends on the level of attachment. Whether or not the fellow patient was a friend or someone they knew might make a difference in their response. Most long-term HD patients know of another patient who has died, yet they may not have been friends. On the other hand, loss of a fellow HD patient, who is not a friend, may cause the person to re-evaluate their own sense of mortality. Assessing sensitivity of the PPHS based solely on changes related to the presence or absence of a critical event should be interpreted with caution, and a lack of sensitivity may be a result of the items included in the critical events checklist and timing of the event versus lack of responsiveness of the PPHS.

All PPHS subscale scores were evaluated based on the mean and standard deviation of the patients' subscale scores at T2 and whether they increased or decreased in comparison with T1 and the occurrence of a critical event. Secondly, the scores for positive versus negative events were assessed in relation to their ability to effect PPHS subscale scores in the predicted manner.

Specific assessment of the critical events was accomplished by looking at the events and the subscales most likely to change as a result of the presence or absence of that classification of event. There was no predicted change in the PH score associated with the negative illness events. Few people reported negative illness events, with an unpredictable illness having the largest response, yet none of the scales moved in the predicted direction. One explanation may be that patients may be used to the erratic highs and lows of living with a chronic disease and its treatment. As Yamana (2009) stated, patients become accustomed to dealing with the symptoms and complications of HD.

Alternatively, positive illness events resulted in an increased PH score for all items included in the category, suggesting that positive critical events had more impact on the patients' physical health.

Treatment negative events did not seem to have an effect on the PH scale. Of note is that two negative events had fewer than seven responses. Again, patients may have become

used to coping with these critical events. However, four times out of five, positive treatment events produced an increase in the PH mean subscale scores. The PH subscales appear to be responsive to specific treatment events.

It was expected that changes in the patients' perception of support would result in a change in one of the two Support subscales. Of the six negative critical events, only two were directly related to formal supports, and these occurrences had a very low response rate, less than four affirmatives, which suggest that the patients did not have many negative support critical events. When patients had lost a family member or a friend, the nurse and physician subscales scores decreased indicating the patients' perceived less support from their health care providers. Overall, negative support events resulted in a desired change in the Nurse subscale five times out of six times and in the Physician subscale twice. Patients were less likely to rate the support of their physician as positive when they had experienced a negative event. This response was tricky to interpret, either there was less support or during a difficult time the patients perceived less support. Both the Nurse and Physician subscales scores changed in the predicted direction as a result of the occurrence of positive support events. The Nurse and the Physician subscales increased their mean scores five out of six times with positive events. Patients were likely to be more appreciative of the health care professional's support when they felt better.

This section had one of the highest response rates in the critical events checklist, and patients consistently rated their support very favourably. The Nurse and Physician subscales are sensitive to specific critical events relating to the support of the nurse and the physician.

Self events were hypothesized to affect the two PSD subscales, EWB and PSD. Negative self events produced a change in the predicted direction for two PSD scores and two EWB scores out of eight possible events, whereas self positive occurrences caused a change in the PSD subscale mean score three times and the EWB subscales six times. With the exception of the statement regarding finances, all critical events produced a change in one of the two core constructs, PSD and EWB, related to adapting to life on HD. Results from this examination again support that the PSD and EWB subscales are sensitive and proficient in monitoring a change patients' status.

In all sections of the critical events checklist assessment, positive events were more likely to result in a change in the predicted direction. This suggests that positive events were more likely to have an impact on patients. It is possible that patients are more likely to suppress a negative memory than a positive one. However, each category of events is based on one of four constructs from the original substantive theory, and specific items may be more indicative of an actual critical event and more specific than assessing the category of positive or negative responses. The hypotheses related to the occurrence of a critical event and subsequent changes in relevant PPHS subscale scores were partially

supported. What was strengthened was that the subscales are sensitive to critical events, and more research is required to assess these assumptions.

Limitations

The use of a convenience sample with mainly Caucasian English-speaking patients certainly creates a selection bias. However, this is the first examination of this instrument in the eastern part of Canada where the majority of the population are Caucasian English-speaking people. Our sample is similar to the HD population as described by CIHI (2011) with the exceptions that there are fewer ESRD patients on HD than in 1999 and there has been growth in the proportion of elderly patients and patients with diabetes with attendant increase in co-morbidity. This change in the population's method of renal replacement therapy doesn't negate the importance of having an instrument to measure outcomes in the HD population. In 2008, 17,765 patients were receiving HD as their type of renal replacement therapy. Another difference between our sample and the Canadian HD population is in the number of cases of ESRD caused by diabetes. In 2011, CIHI reported that diabetes was the primary cause of ESRD in 48% of prevalent cases; in our study only 23% were on HD a result of diabetes. This may be a more a reflection of society, dietary choices, obesity, and the number of young people diagnosed with diabetes. This variation does not affect the applicability of the PPHS to measure HD dialysis patients' experiences. The subjects in this study were slightly older than the national population with no patients under 19 years of age and fewer patients over 75. Another limitation is that the HD environment may have been too close for subjects to

feel comfortable about giving the physicians or nurses a low rating. The research assistant assured the subjects that all responses were confidential and staff would not know about their specific response.

In terms of the instruments used to examine sensitivity, there were a few limitations with the critical events checklist. First, the use of the term *event* may be misleading as some items related to a state of being versus a change/event. For example, living independently was listed as a positive critical event, yet if the individual had been living without assistance for many years it was not a change, or an event, as much as a continuation of the norm. So, saying yes to this item may not have had any effect on the PPHS subscales score and may not be a valid test of the PPHS's sensitivity to change. Second, the nominal level rating scales did not measure intensity, so there was no way to identify the impact of any event. Third, not all questions in each section of the checklist were relevant to a PPHS subscales as were had excluded items relating to treatment and family. There was no examination of reliability or validity. Finally, there was no means to capture when the event took place, so patients may have had time to adjust to the change, which would not be captured by the PPHS subscales. These limitations infer that the critical events checklist may not be the measure to use when assessing sensitivity. In future longitudinal work, one could advocate for fine tuning the instrument and more frequent assessment by PPHS to try to capture dynamic change.

Conclusion

The PPHS is a reliable and valid measurement instrument for monitoring HD patients' physical, social, and psychological health. Examination of the PPHS's response to changes in the patient's physical health status and positive critical events implies that the tool is sensitive to some events. The PPHS requires further examination using the new 36-item instrument with a different and larger population to allow the opportunity for further psychometric assessment. Using a larger population and having three versus two measurement times may allow for more significant changes in the patients' health and well-being and allow for further instrument testing.

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Appendix 4.1

PPHS _____ Patient ID# _____

Patient Perceptions of Hemodialysis Scale

The following scale contains a list of items that reference events/situations that you may have experienced since the onset of kidney failure and starting hemodialysis. You are being asked to rate each item of a 5 point rating scale located in the columns to the right. In the first instance you are asked to indicate **'how often you feel this way'** (never, rarely, sometimes, often, or almost always). Finally, you are asked to indicate **'how satisfied, how confident or how concerned are you'** (not at all, a little bit, moderately, quite a bit, extremely).

RATING SCALES

How Often

Never	Rarely	Sometimes	Often	Almost Always
0	1	2	3	4

How Satisfied/How Concerned/How Confident

Not at all	A little bit	Moderately	Quite a bit	Extremely
0	1	2	3	4

Circle the response that best applies to you.

1.	How often do you experience breathing difficulties?	0	1	2	3	4
2.	How often do you feel tired and low on energy?	0	1	2	3	4
3.	How often are you bothered by walking short distance? (e.g. Tired feelings, breathing problems, etc.)?	0	1	2	3	4
4.	How often do you experience itching due to your kidney disease?	0	1	2	3	4
5.	How often do you feel exhausted after dialysis?	0	1	2	3	4
6.	How often do you feel comfortable after dialysis (e.g. general good feeling, less breathing problems, less swelling, etc)?	0	1	2	3	4
7.	How satisfied are you with overall quality of nursing/tech care in the dialysis unit?	0	1	2	3	4

8. How confident are you that nurses/techs have the knowledge and abilities to know what to do if you become ill on dialysis?	0	1	2	3	4
9. How satisfied are you with nurses/techs willingness to listen to what you have to say about your illness and treatment?	0	1	2	3	4
10. How satisfied are you with the amount of time that nurses/techs take to help you understand your illness and treatment?	0	1	2	3	4
11. How often o you feel that nurses/techs try to promote a relaxed, family-like atmosphere on eh dialysis unit?	0	1	2	3	4
12. How satisfied are you with the comfort measures provided by nurses/techs during dialysis (e.g. Providing a blanket, pillow, refreshments, etc.)?	0	1	2	3	4
13. How confident are you the dialysis doctors have the necessary knowledge and abilities to monitor or deal with your overall physical needs?	0	1	2	3	4
14. How satisfied are you with how quickly doctors respond to your needs when you are on dialysis?	0	1	2	3	4
15. How satisfied are you with the quality of overall medical care in the dialysis unit?	0	1	2	3	4
16. How satisfied are you with doctors willingness to listen to what you have to say about your illness and treatment requirements	0	1	2	3	4
17. How satisfied are you with the amount of time that doctors take to help you understand your illness and treatment requirements	0	1	2	3	4
18. How concerned are you that your health will get worse regardless of what you or doctors do?	0	1	2	3	4
19. How concerned are you about becoming too dependent upon your family?	0	1	2	3	4

PPHS Patient ID#

20. How concerned are you about eh impact of your illness and treatment on family members (e.g. Decreased social activities, dietary restrictions, time commitments with dialysis, etc.)?	0	1	2	3	4
21. How concerned are you for your personal safety while on dialysis (i.e., worried about what would happen to you)?	0	1	2	3	4
22. How concerned are you about voicing your needs to nurses/techs or doctor s due to the physical closeness of others during dialysis?	0	1	2	3	4
23. How often are you upset by seeing others become suddenly ill (i.e., worried that it would happen to you)?	0	1	2	3	4
24. How often do you dwell on your own health problems following the death of another patient?	0	1	2	3	4
25. How often do you feel depressed (i.e., feeling down, fed-up, frustrated) about your illness and long-term treatment requirements?	0	1	2	3	4
26. How often do you experience fears or worries about unexpected illness/dialysis events (e.g., sudden drop in blood pressure, clotting of access sites, breathing problems due to too much fluid?	0	1	2	3	4
27. How often do you feel that depending on others makes you feel useless (i.e., self-esteem, self-worth)?	0	1	2	3	4
28. How often do you feel distressed by the severity of your illness and the long-term treatment requirements (e.g., troubled, worried, upset, etc.)?	0	1	2	3	4
29. How often do you feel that dialysis has improved the quality of your life?	0	1	2	3	4
30. How often do you try to maintain a positive attitude towards dialysis?	0	1	2	3	4
31. How confident are you that you will come to terms with your illness (i.e., accepting)?	0	1	2	3	4
32. How often do you relax during dialysis?	0	1	2	3	4

33. How satisfied are you with how well you have adjusted to the effects of dialysis (e.g., pain, restrictions, problems with access site, delays, machine functioning, drop in blood pressure)?	0	1	2	3	4
34. How satisfied re you with the amount of quality time spend with family and friends?	0	1	2	3	4
35. How confident are you that you are coping with dialysis restrictions?	0	1	2	3	4
36. How often do you feel that you have some control over the ups and downs of dialysis and the effects on your health and well being (e.g., assuming responsibility for recommended treatment, monitoring dialysis run)?	0	1	2	3	4

APPENDIX 4.2

Patient Initials: _____ **Study ID#:** _____

Date of baseline interview: _____ (d/m/yr) **Start Date of Dialysis:** _____ (d/m/yr)

Site: St. John's _____ HSC_____ SAGGH _____ Grand Falls _____
Corner Brook _____ Montreal _____ Hamilton _____ Calgary _____

Preferred Language: _____ **Age** (years): _____ **Date of Birth:** _____ (d/m/yr.)

Sex:_____

Cause of End-stage Renal Disease:
Diabetes _____
Glomerulonephritis/Autoimmune Diseases _____
Renal Vascular Disease _____
Polycystic Kidney Disease _____
Congenital/Hereditary Renal Disease _____
Other _____

Current Living Arrangements:
Living Alone _____
Living with Spouse _____
Living with Parents _____
Living with Another Adult _____

Average of the last three months:
Albumin Level: _____
Hgb: _____
Percent reduction in urea: _____
Phosphate: _____

Co-morbid Diseases:	Yes	No
Heart Failure symptoms on strenuous or prolonged activity, or prior heart failure		
Heart failure on ordinary activity, at rest, or recurrent admissions in heart failure		
New onset or stable angina or myocardial infarct > 6 mo previously		
Unstable angina or myocardial infarct < 6 months previously		
Treated arrhthymia present		
Gangrene, inoperable or surgery for peripheral vascular disease < 6 months previously		
Diabetes		
Current malignancy		
Major lung problems		
Stroke with disability		

APPENDIX 4.3

CRITICAL EVENTS CHECKLIST

I am interested in any significant experiences that you may have had within the past six months. I have a list of events/situations that were identified by a group of patients receiving hemodialysis. I would like for you to take some time to reflect upon these events/situations and indicate whether or not you have experienced any of them since our last interview with you.

		Yes	No
I	**Illness Related - Negative**		
1.	**Loss of renal function** (e.g., no/minimal urine output, increased time on dialysis).	_____	_____
2.	**Loss of alternate treatment modality** (e.g., transplant not an option, failure of home dialysis).	_____	_____
3.	**Unpredictable illness course** (i.e., variable level of physical functioning)	_____	_____
4.	**Declining health status and well-being** (e.g., negative effects of comorbid illness and/or acute illness episodes - walking/breathing difficulties, reduced energy, insomnia, itching, leg cramps, social restrictions).	_____	_____
5.	**Reduced desire/motivation to following recommended lifestyle changes** (i.e., diet modifications, fluid/exercise/work restrictions).	_____	_____
II	**Illness Related - Positive**		
1.	**Improved renal function** (e.g., increased urine output, reduced dialysis time).	_____	_____
2.	**Availability of Desired alternate treatment modality** (e.g., transplant, home dialysis).	_____	_____
3.	**Predictable illness course** (i.e., stable physical functioning)	_____	_____
4.	**Improved health status and well-being** (e.g., positive effects from dialysis, no/minimal effects of comorbid illness, absence of acute illness episodes, increased stamina, etc.).	_____	_____
5.	**Increased desire/motivation to following recommended lifestyle changes** (i.e., diet modifications, fluid/exercise/work restrictions).	_____	_____

		Yes	No
V	**Quality of Supports - Negative**		
1.	**Loss of fellow patients**	_____	_____
2.	**Loss of family**	_____	_____
3.	**Loss of friends and/or support network**	_____	_____
4.	**Reduced trust and confidence in nurses**	_____	_____
5.	**Reduced trust and confidence in physicians**	_____	_____
6.	**Dissatisfaction with dialysis environment** (e. g., lack of privacy, cluttered space, presence of acutely ill or dying patients, etc.)	_____	_____
VI	**Quality of Supports - Positive**		
1.	**Good rapport with fellow patients**	_____	_____
2.	**Strong family supports**	_____	_____
3.	**Positive social environment** (i.e., friendships, colleagues, leisure activities)	_____	_____
4.	**Trust and confidence in nurses**	_____	_____
5.	**Trust and confidence in physicians**	_____	_____
6.	**Satisfied with dialysis environment** (e. g., level of privacy, space, etc.)	_____	_____

		Yes	No
VII	**Loss of "Old Self" - Negative**		
1.	**Reduced self-worth/self-esteem**	_____	_____
2.	**Feeling of loss control of life events/environment**	_____	_____
3.	**Loss of independence**	_____	_____
4.	**Dissatisfied with level of social activities**	_____	_____
5.	**Potential/actual threats to financial security**	_____	_____
6.	**Negative attitude towards illness/treatment**	_____	_____
7.	**Uncertainty and stress associated with health and quality of life**	_____	_____
8.	**Feelings of hopelessness**	_____	_____
VIII	**Adapting to New Normal - Positive**		
1.	**Increased self-worth/self-esteem**	_____	_____
2.	**Feeling in control of life events/environment**	_____	_____
3.	**Independent living**	_____	_____
4.	**Satisfied with level of participation in social activities**	_____	_____
5.	**No/minimal impact on financial security**	_____	_____
6.	**Positive attitude towards illness/treatment**	_____	_____
7.	**Satisfied with health and quality of life**	_____	_____
8.	**Feeling hopeful**	_____	_____

Chapter 5

Summary, Limitations and Implications

This chapter presents a brief summary of the dissertation, my objectives, limitations, and implications from the psychometric assessment of the PPHS. The first section of this chapter provides the reader with a summary of the findings of the research in relation to the objectives. Section two speaks to the limitations in the research while the third section addresses implications for the PPHS and future practice and research. The final section presents conclusions from the research.

Summary

The primary goal of this doctoral research was the psychometric evaluation of the Patient Perception of Hemodialysis Scale (PPHS) and assessment of its ability to identify factors associated with quality outcomes in the Hemodialysis/End Stage Renal Disease (ESRD) population.

The dissertation consists of three components, each presenting a step by step description of how the PPHS and its subscales were developed and tested. Each component is presented independently. Chapter two utilizes multi-trait/multi-item correlation matrix and the techniques of Ware and Gandek (1998) to assist with item refinement and scale development. Chapter three examines the psychometric properties of the new scales. Chapter four presents examination of the PPHS's ability to assess hemodialysis (HD)

patient's physical health, social supports, and psychosocial health and the interrelationship among the patients' experience, demographics, medical risk factors, biochemical indicators, and the PPHS's sensitivity to detect the impact of critical events.

A convenience sample of in-center hemodialysis (HD) patients was used in the study. Chapters two and three included a sample of 236 patients, 156 from NL (66%) and 80 from Hamilton (34%). Using the same cohort, stability of the instrument was examined approximately 2 weeks after the patients had completed the initial PPHS (N = 30). In chapter four 85 patients completed the scale on two occasions. The second measure being completed six months after the first to determine the PPHS's ability to identify any change in the patients' responses in relation to their health status and the instruments' responsiveness to critical events.

The first objective of this research was to reduce scale length by deletion of unnecessary or unhelpful items. This objective was met in chapter two. Using a multi-trait/multi-item correlation matrix items in the PPHS were assessed and approximately 18 items were removed. Items with correlations lower than 0.3 were excluded. Many of these items didn't correlate with their own subscale or any other items in the PPHS. The remaining items were examined using Ware and Gandek's (1998) guidelines for assessing data quality and Likert assumptions. After this appraisal a further 10 items were excluded. The multi-trait/multi-item correlation matrix and Ware and Gandek's criteria supported that the PPHS consists of five moderate to strong subscales including 36 items.

Objectives two and three both addressed assessing the PPHS's construct validity. Validity was established by using factor analysis and testing convergent/divergent validity of the PPHS with the SF-36. Factor analysis maintained that the PPHS included five factors/subscales. Evaluation of convergent/divergent validity with physical and mental subscales of the SF-36 upheld previous findings from O'Brien- Connors (2003) and Wells (2004). The subscales were similar yet distinct in their ability to measure the overall factors affecting adjusting to life on HD.

My third objective was to calculate internal consistency for the PPHS and its subscales Again these findings maintained the results found in previous research by O'Brien-Connors (2003) and Wells (2004). Cronbach's alpha for the subscales were high which supports the internal consistency of the PPHS.

Test-retest stability of the PPHS and its subscales was tested using the intraclass correlation coefficient. The PPHS was administered two weeks apart. The high correlation supported that the instrument is stable over time.

My last objective was to determine the responsiveness of the PPHS to change by comparing the score change over 6 months among patients who have and have not had a change in clinical status. I inspected the PPHS's sensitivity to a change in illness measures, support, EWB and PSD post critical events. Findings from this examination

lead to the conclusion that the instrument is mildly responsive to a change in physical health and positive critical events in patients' lives. In terms of sensitivity to negative critical events, the results were unsubstantiated. As discussed at length in the limitations section of this chapter the critical events checklist was not a robust instrument and had some major weaknesses.

Based on the examination of the items and subscales in the PPHS and their combined ability to measure a patient's status in terms of their psychosocial health the instrument is limited in its ability to measure all the constructs identified in the LESRD-HD theory and is only mildly sensitive to critical events. We do know that the PPHS is a reliable, valid, user-friendly instrument which may be employed to measure the HD population's adjustment to disease specific concerns related to their physical health, social supports, psychosocial health.. Additional examination with a different and larger population will allow the opportunity for further psychometric assessment.

Limitations

Limitations of the present research centre on the setting, the sample, the critical events checklist, and the time between measurements. Patients are fairly close to one another in the HD unit, so patients may have felt uncomfortable rating nurses or physician in that environment. The research assistant, who was not involved in the clients' care, attempted to provide as much privacy as possible or had the subject point to the rating score versus say the number out loud.

Our sample included mostly Caucasian, English-speaking, patients from Newfoundland. The convenient sample created a selection bias and some of the patients characteristics varied from CIHI's (2011) data. Another difference is that fewer patients ESRD was caused by diabetes CIHI 48 versus our sample, 23%. The number of cases of diabetes has increased since this research was completed. This change may be a reflection of the selection bias, differences in dietary choices, the prevalence of obesity, and the number of young people diagnosed with diabetes. The last issue related to differences in our sample versus the Canadian population with HD was that the subjects in this study were slightly older than the national population with no patients under 19 years of age. These differences between our study population and the Canadian HD population overall don't negate the importance of having an instrument to measure disease and treatment-specific outcomes in the HD population.

Many of the subscales in the 64 item PPHS were removed in chapter two. However, prior work by O'Brien- Connors (2003) found that the family subscale had an alpha coefficient of .53. An alpha of .53 is weak in terms of internal consistency but family support has been linked with more positive outcomes in patients with chronic illness (Bury 1982; Cohen et al., 2007; Ersoy-Kart & Gulda , 2005; Kimmel et al., 1995; Kimmel et al., 1996; Kimmel et al., 1998; Untas et al., 2011. Once the sample was expanded to include the Ontario cases the family scale ceased to line up and was eliminated in the chapter two. I am unsure why this changes but one explanation is that

in St. John's NL only two researchers administered the PPHS and other instruments, and despite training for the research assistants in Ontario, the instruments may have been administered in a different manner.

There were several limitations related to the critical events checklist and its appropriateness as an indicator of the sensitivity of the PPHS. First, the use of the term *event* may have been misleading, as some items on the checklist related to a state of being versus a change or event. For example, living independently was listed as a positive critical event; yet, if the individual had been living without assistance for many years, it was not a change or an event as much as a continuation of the norm. So, saying yes to this item may not have had any effect on the PPHS subscale scores and may not be a valid test of the PPHS's sensitivity to change. Second, the critical event self-rating scales merely asked the subjects whether the event had occurred or not and did not measure the intensity of any events or change, so there was no way to quantify the impact any event had on an individual from an external viewpoint, against which the sensitivity of the PPHS could be truly assessed. Third, not all questions in each section of the checklist were relevant to a specific PPHS subscale. There were no items to measure family support in the PPHS, yet family support was included as a positive and a negative event in the support section of the critical events checklist. One might expect that aspects of the PPHS would be more sensitive to critical events occurring in one domain versus another, but not being able to line up the events with the appropriate subscales in some cases made it difficult to assess whether this was true. And, finally, the exact timing of

the event relative to the subsequent completion of the PPHS was not recorded. As a result it might have been that some patients had already adjusted to the change, which might not have been reflected in the PPHS subscale scores. These limitations infer that the critical events checklist as used may not be a valid or reliable measure to use when assessing sensitivity of the PPHS. In future longitudinal work, one could design a more valid and reliable indicator for assessing critical events and plan for more frequent assessment with the PPHS to try to capture dynamic change.

The PPHS was based on a substantive theory developed from a qualitative research project. After psychometric evaluation of the instrument and removal of the weaker subscales we were unable to measure all aspects of the theoretical constructs. As mentioned we lost five subscales after the multi-trait/multi item examination. We may need to revisit the qualitative data or maybe the patients to determine their response to these missing subscales and their level of importance.

The final limitations may have been the length of time between measurements and that we only assessed the population twice. Patients are monitored very closely during HD, and, despite the change in patients' illness severity and blood values, six months may not have been long enough to allow for any significant changes.

More frequent measurements over a longer period of time may provide a more thorough test of the ability of the PPHS to be responsive to change.

Implications

The findings have implications for clinical practice and research. The PPHS is a valid, reliable, and feasible instrument. It can be used in practice as a clinical monitoring tool to determine HD patients' status and assess patients' physical, social, and psychosocial heath. We realize that further research is required before the PPHS can be used as a standalone monitoring tool and additional work needs to be completed testing its sensitivity. The research team will also need to revisit the family subscale and other subscales that were removed in chapter two.

Prior to using the PPHS as an outcome measure for a clinical trial further research needs to focus on the PPHS's sensitivity. In order to test sensitivity the team needs to find a better way to capture change when it occurs with the HD population. The critical events checklist will need to be refined. Then researchers could design a study to examine what staff learned from the responses to the questionnaire that they did not already know about the patient and what they would do differently as a result. Once the PPHS and the critical events checklist have been modified, we then need to do studies to establish the incremental clinical utility of actually using the tool to monitor the population.

The last implication is that additional research should be conducted outside NL. In NL the subscales were fairly robust, yet when we added the Ontario population we lost five subscales. This will be added to our future research program on the PPHS.

Conclusions

The revised 36 item PPHS is a reliable and valid measurement instrument for measuring HD patients' physical, social, and psychological health. In chapter two, the PPHS subscales were examined, refined and reduced based on conditions of the correlation matrix and Ware and Gandek's (1998) guidelines.

In term of validity, face and content validity of the PPHS were established in previous research. Construct validity of the instrument was further validates in this research supporting that the PPHS consists of five strong subscales: Emotional Well-being; Psychosocial Distress; Nurse; Physician; and Physical Health. Convergent/divergent validity was also ascertained by correlating the PPHS scales with the SF-36 scales. After examination of the data it was felt that no further item reduction was necessary.

Reliability was established using test-retest stability and by computing Cronbach's alpha. The test-retest analysis supported that the instrument was stable over time with an intraclass correlation coefficient ranging between .72 and .94 for the different components of the PPHS and the scale as a whole.

Cronbach's alpha for each scale was calculated with a range of .69 to .90, suggesting moderate to strong internal consistency.

The ability of the revised PPHS and its new subscales to assess patient's physical health, social supports, and psychosocial health at two time periods and the interrelationship among the patients' experience, demographics, medical risk factors and biochemical indicators was supported for specific subscales and events.

Examination of the PPHS's response to critical events implies that the tool is mildly sensitive to certain occurrences but not others. Examination of the measures of central tendency supports that, in the majority of cases, the instrument's subscale scores moved in the predicted direction. Results suggest that the PPHS may be sensitive to specific critical events and to a change in the patients' health status. This requires additional research.

Health care professionals must recognize the impact of HD renal disease and develop mechanisms for psychosocial assessment, intervention, and evaluation to provide complete care to each individual. The evaluative properties of the PPHS have been supported in this research and the instrument is both valid and reliable. The PPHS is user friendly, stable on retest, and shows construct validity by factor analysis in light of the proposed substantive theory and convergent/divergent validity with the SF-36. Additional work is required on the critical events checklist and further research is recommended with the new refined 36-item instrument with a larger, different population outside of NL.

Using a larger population and having more frequent measurement over a longer period of time may allow for more significant changes in the patients' health and well-being and allow for further instrument testing.

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Supplementary Table 4.7a:

Means and Standard Deviations for the PPHS Subscales and Yes responses to Critical Events at T1and T2

Critical Event (- or +)[a]	**SS**[b]	**EWB Mean (SD)**		**PSD Mean (SD)**		**Physical Mean (SD)**	
		T1	**T2**	**T1**	**T2**	**T1**	**T2**
1.1 Loss of renal function (-)	16	**2.9 (.72)**	**2.8 (.69)**	**2.6 (.91)**	**2.6 (.66)**	2.1 (.89)	2.3 (.58)
1.2 Loss of alternate Rx (-)	1	3 (0)	3 (0)	**1.5 (0)**	**1.2 (0)**	1.8 (0)	2.2 (0)
1.3 Unpredictable illness (-)	28	**2.9 (.72)**	**2.8 (.82)**	**2.4 (.94)**	**2.3 (.86)**	2.1 (.77)	2.2 (.71)
1.4 Decline in health (-)	19	**2.9 (.9)**	**2.9 (.85)**	**2.4 (.92)**	**2.4 (.85)**	1.9 (.64)	2 (.77)
1.5 Reduced motivation (-)	6	2.8 (.82)	2.9 (.74)	**2.4 (.86)**	**2.4 (.82)**	1.8 (.61)	2.1 (.56)
2.1 Improved renal function (+)	4	2.8 (.21)	2.7 (.8)	2.6 (1.1)	2.4 (1.1)	**2.2 (.83)**	**2.4 (1.2)**
2.2 Alternate treatment (+)	13	**2.8 (.86)**	**3 (.73)**	**2.2 (.71)**	**2.4 (.84)**	**2.2 (.75)**	**2.6 (.77)**
2.3 Predictable illness (+)	51	**3 (.64)**	**3 (.55)**	**2.6 (.78)**	**2.7 (.83)**	**2.2 (.73)**	**2.3 (.68)**
2.4 Improved health (+)	34	**3.1 (.69)**	**3.211 (.56)**	2.8 (.81)	2.7 (.96)	**2.2 (.62)**	**2.2 (.65)**
2.5 Increased motivation (+)	10	**3.1 (.56)**	**3.4 (.44)**	2.7 (1)	2.6 (1.4)	**2.2 (.56)**	**2.3 (.8)**
3.1 Problem with HD access (-)	25	3.1 (.68)	3 (.71)	2.5 (.87)	2.6 (.88)	2.1 (.62)	2.3 (.74)
3.2 Travel worries (-)	12	**2.8 (.63)**	**2.6 (.92)**	**2.2 (.89)**	**2.2 (1.1)**	1.9 (.93)	2.3 (.82)
3.3 Increase time on HD (-)	22	**2.9 (.9)**	**2.8 (.91)**	**2.4 (1.0)**	**2.4 (1.0)**	1.8 (.7)	2.2 (.65)
3.4 Unwell in HD (-)	28	**2.9 (.5)**	**2.8 (.67)**	2.4 (.87)	2.5 (1)	**2 (.78)**	**2 (.54)**
3.5 Decline in physical health (-)	13	**2.8 (.88)**	**2.7 (.81)**	2.2 (1)	2.3 (.75)	1.6 (.7)	1.7 (.59)
4.1 No problem with HD access (+)	50	**2.9 (.65)**	**2.9 (.63)**	**2.5 (.86)**	**2.5 (.85)**	**2.1 (.79)**	**2.1 (.62)**
4.2 No travel concerns (+)	44	**3 (.69)**	**3. (.58)**	**2.7 (.84)**	**2.8 (.8)**	2.1 (.69)	2.2 (.66)
4.3 Usual time on HD (+)	22	**3.1 (.54)**	**3.1 (.5)**	2.7 (.87)	2.6 (1)	2.2 (.65)	2.1 (.73)
4.4 Feel good in HD (+)	49	**3 (.7)**	**3 (.63)**	**2.5 (.91)**	**2.6 (.92)**	**2.3 (.68)**	**2.3 (.61)**
4.5 Improved physical health (+)	28	**3 (.7)**	**3.2 (.6)**	**2.6 (.71)**	**2.6 (.87)**	**2.3 (.66)**	**2.3 (.62)**

Supplementary Table 4.7b:
Means and Standard Deviations for the PPHS Subscales and Yes responses to Critical Events at T1and T2

Critical Event (- or +)[a]	**SS**[b]	**Nurse Mean (SD)**		**Physician Mean (SD)**	
		T1	**T1**	**T1**	**T2**
1.1 Loss of renal function (-)	16	**3.1 (.87)**	**3.1 (.87)**	**3.1 (.87)**	**3.1 (.89)**
1.2 Loss of alternate Rx (-)	1	1.6 (0)	1.6 (0)	1.6 (0)	2.8 (0))
1.3 Unpredictable illness (-)	28	**3.1 (.87)**	**3.1 (.87)**	**3.1 (.87)**	**3.1 (.78)**
1.4 Decline in health (-)	19	**3.2 (.87)**	**3.2 (.87)**	**3.2 (.87)**	**3.2 (.91)**
1.5 Reduced motivation (-)	6	**2.7 (1.2)**	**2.7 (1.2)**	**2.7 (1.2)**	**2.4 (1.2)**
2.1 Improved renal function (+)	4	**3.1 (.74)**	**3.1 (.74)**	**3.1 (.74)**	**3.4 (.34)**
2.2 Alternate treatment (+)	13	**2.8 (1.1)**	**2.8 (1.1)**	**2.8 (1.1)**	**3 (.82)**
2.3 Predictable illness (+)	51	**3.3 (.73)**	**3.3 (.73)**	**3.3 (.73)**	**3.3 (.62)**
2.4 Improved health (+)	34	**3.3 (.75)**	**3.3 (.75)**	**3.3 (.75)**	**3.4 (.61)**
2.5 Increased motivation (+)	10	**3.1 (.89)**	**3.1 (.89)**	**3.1 (.89)**	**3.3 (.8)**
3.1 Problem with HD access (-)	25	**3.1 (.98)**	**3.1 (.98)**	**3.1 (.98)**	**3.1 (.82)**
3.2 Travel worries (-)	12	2.7 (.79)	2.7 (.79)	2.7 (.79)	3.1 (.51)
3.3 Increase time on HD (-)	22	**2.9 (.9)**	**2.9 (.9)**	**2.9 (.9)**	**2.9 (.8)**
3.4 Unwell in HD (-)	28	**3.1 (.7)**	**3.1 (.7)**	**3.1 (.7)**	**3.1 (.74)**
3.5 Decline in physical health (-)	13	**3 (.72)**	**3 (.72)**	**3 (.72)**	**3 (.77)**
4.1 No problem with HD access (+)	50	3.1 (.72)	3.1 (.72)	3.1 (.72)	3.2 (.59)
4.2 No travel concerns (+)	44	3.3 (.76)	3.3 (.76)	3.3 (.76)	3.2 (.74)
4.3 Usual time on HD (+)	22	**3.3 (.67)**	**3.3 (.67)**	**3.3 (.67)**	**3.3 (.61)**
4.4 Feel good in HD (+)	49	3.3 (.73)	3.3 (.73)	3.3 (.73)	3.2 (.77)
4.5 Improved physical health (+)	28	**3.2 (.84)**	**3.2 (.84)**	**3.2 (.84)**	**3.2 (.52)**

Supplementary Table 4.7c
Means and Standard Deviations for the PPHS Subscales and Yes responses to Critical Events at T1and T2

Critical Event (- or +)[a]	**SS**[b]	**EWB Mean (SD)**		**PSD Mean (SD)**		**Physical Mean (SD)**	
		T1	**T2**	**T1**	**T2**	**T1**	**T2**
5.1 Loss of HD patients (-)	34	2.8 (.73)	2.9 (.71)	2.4 (.80)	2.5 (.87)	2.2 (.73)	2.3 (.65)
5.2 Loss of family (-)	7	2.8 (.47)	3.0 (.48)	**2.5 (.73)**	**2.5 (.9)**	2.1 (.67)	2.5 (.83)
5.3 Loss of friends (-)	11	**2.7 (1.0)**	**2.5 (.81)**	2.4 (.77)	2.6 (.59)	**2 (.67)**	**2 (.71)**
5.4 Reduce trust in nurses (-)	2	3.1 (.44)	3.3 (1.0)	**1.8 (.45)**	**1.6 (.84)**	1.3 (.69)	2.3 (.82)
5.5 Reduce trust in physicians (-)	4	2.1 (.59)	3.2 (.77)	**1.9 (.83)**	**1.9 (1.3)**	1.1 (.42)	1.9 (.62)
5.6 Unhappy with HD environment(-)	14	2.7 (.79)	2.8 (.75)	2.3 (.87)	2.4 (1)	2.1 (.71)	2.2 (.85)
6.1 Rapport with HD patients (+)	58	**2.9 (.68)**	**2.9 (.65)**	**2.5 (.88)**	**2.5 (.92)**	**2.1 (.77)**	**2.3 (.62)**
6.2 Support from Family (+)	57	**2.9 (.68)**	**2.9 (.68)**	**2.5 (.89)**	**2.5 (.91)**	**2.1 (.8)**	**2.2 (.63)**
6.3 Positive social environment (+)	59	**2.9 (.68)**	**2.9 (.67)**	2.6 (.87)	2.5 (.91)	**2.2 (.76)**	**2.2 (.64)**
6.4 Trust nurses (+)	57	**2.9 (.66)**	**2.9 (.66)**	**2.6 (.87)**	**2.6 (.93)**	**2.2 (.77)**	**2.2 (.64)**
6.5 Trust physicians (+)	57	3 (.66)	2.9 (.65)	**2.6 (.86)**	**2.6 (.9)**	**2.2 (.74)**	**2.2 (.65)**
6.6 Satisfied with HD environment (+)	48	**3 (.59)**	**3 (.62)**	**2.6 (.84)**	**2.6 (.89)**	**2.2 (.77)**	**2.2 (.63)**

Note[a]. - = negative event, + = positive event
Note[b]. SS = Sample who responded to critical event

Supplementary Table 4.7d
Means and Standard Deviations for the PPHS Subscales and Yes responses to Critical Events at T1and T2

Critical Event (- or +)[a]	**SS**[b]	**Nurse Mean (SD)**		**Physician Mean (SD)**	
		T1	**T2**	**T1**	**T2**
5.1 Loss of HD patients (-)	34	**3.3 (.65)**	**3.3 (.63)**	**2.9 (.88)**	**2.9 (.78)**
5.2 Loss of family (-)	7	2.8 (.47)	3.0 (.48)	2.1 (.67)	2.5 (.83)
5.3 Loss of friends (-)	11	**2.7 (1.0)**	**2.5 (.81)**	**2 (.67)**	**2 (.71)**
5.4 Reduce trust in nurses (-)	2	3.1 (.44)	3.3 (1.0)	1.3 (.69)	2.3 (.82)
5.5 Reduce trust in physicians (-)	4	2.1 (.59)	3.2 (.77)	1.1 (.42)	1.9 (.62)
5.6 Unhappy with HD environment(-)	14	2.7 (.79)	2.8 (.75)	2.1 (.71)	2.2 (.85)
6.1 Rapport with HD patients (+)	58	**2.9 (.68)**	**2.9 (.65)**	**2.1 (.77)**	**2.3 (.62)**
6.2 Support from Family (+)	57	**2.9 (.68)**	**2.9 (.68)**	**2.1 (.8)**	**2.2 (.63)**
6.3 Positive social environment (+)	59	**2.9 (.68)**	**2.9 (.67)**	**2.2 (.76)**	**2.2 (.64)**
6.4 Trust nurses (+)	57	**2.9 (.66)**	**2.9 (.66)**	**2.2 (.77)**	**2.2 (.64)**
6.5 Trust physicians (+)	57	3 (.66)	2.9 (.65)	**2.2 (.74)**	**2.2 (.65)**
6.6 Satisfied with HD environment (+)	48	**3 (.59)**	**3 (.62)**	**2.2 (.77)**	**2.2 (.63)**

Note[a]. - = negative event, + = positive event

Note[b]. SS = Sample who responded to critical event

Supplementary Table 4.7e
Means and Standard Deviations for the PPHS Subscales and Yes responses to Critical Events at T1and T2

Critical Event (- or +)[a]	**SS[b]**	**EWB Mean (SD)**		**PSD Mean (SD)**		**Physical Mean (SD)**	
		T1	**T2**	**T1**	**T2**	**T1**	**T2**
7.1 Reduce self worth (-)	4	2.7 (.61)	2.8 (.89)	1.8 (.93)	2 (.46)	**2.3 (.88)**	**2 (.76)**
7.2 Loss of control (-)	17	2.7 (.82)	2.8 (.75)	**2.2 (.78)**	**2.2 (.74)**	2.1 (.78)	2.2 (.58)
7.3 Loss of independence (-)	10	2.6 (.94)	2.6 (.83)	2.2 (.84)	2.5 (.98)	1.8 (.69)	2 (.75)
7.4 Unhappy with social life (-)	24	**2.6 (.77)**	**2.6 (.77)**	**2.2 (.82)**	**2.2 (.9)**	2 (.86)	2.1 (.63)
7.5 Financial insecurity (-)	7	3 (.45)	2.9 (.63)	2.4 (.67)	2.5 (.94)	2 (.91)	2.7 (.66)
7.6 Negative attitude (-)	12	**2.3 (.77)**	**2.2 (.7)**	**1.9 (.79)**	**1.7 (.64)**	1.5 (.82)	1.8 (.53)
7.7 Uncertainty (-)	29	2.7 (.75)	2.8 (.79)	2.1 (.81)	2.1 (.84)	1.9 (.86)	2.2 (.71)
7.8 Hopelessness (-)	16	2.3 (.76)	2.4 (.75)	1.9 (.84)	2 (.77)	1.7 (.87)	2.0 (.68)
8.1 Improved self worth (+)	26	**3.2 (.46)**	**3.2 (.45)**	2.8 (.77)	2.7 (.92)	**2.3 (.58)**	**2.4 (.57)**
8.2 Control (+)	38	**3.1 (.65)**	**3.1 (.65)**	**2.8 (.71)**	**2.8 (.8)**	**2.2 (.71)**	**2.3 (.65)**
8.3 Independence (+)	48	**2.97 (.62)**	**2.96 (.63)**	2.7 (.85)	2.6 (.87)	**2.2 (.75)**	**2.3 (.6)**
8.4 Happy with social life (+)	41	**3.1 (.57)**	**3.1 (.56)**	**2.8 (.78)**	**2.8 (.82)**	**2.2 (.68)**	**2.2 (.66)**
8.5 Financial security (+)	35	**3 (.69)**	**3 (.64)**	2.5 (.97)	2.4 (.99)	**2 (.69)**	**2.1 (.63)**
8.6 Positive attitude (+)	53	**3 (.67)**	**3 (.63)**	2.6 (.85)	2.6 (.92)	**2.2 (.74)**	**2.3 (.65)**
8.7 Satisfied with QoL (+)	34	**3.2 (.52)**	**3.2 (.45)**	**2.8 (.77)**	**2.8 (.81)**	**2.3 (.71)**	**2.4 (.66)**
8.8 Hopeful (+)	49	**3.0 (.58)**	**3.0 (.63)**	2.7 (.84)	2.6 (.89)	**2.26 (.74)**	**2.32 (.63)**

Note[a]. - = negative event, + = positive event
Note[b]. SS = Sample who responded to critical event

Supplementary Table 4.7f
Means and Standard Deviations for the PPHS Subscales and Yes responses to Critical Events at T1and T2

Critical Event (- or +)[a]	**SS[b]**	**Nurse Mean (SD)**		**Physician Mean (SD)**	
		T1	**T1**	**T1**	**T2**
7.1 Reduce self worth (-)	4	2.9 (1.1)	2.9 (1.1)	2.9 (1.1)	3 (.5)
7.2 Loss of control (-)	17	2.8 (1.1)	2.8 (1.1)	2.8 (1.1)	2.9 (.62)
7.3 Loss of independence (-)	10	2.7 (1.2)	2.7 (1.2)	2.7 (1.2)	3.1 (.92)
7.4 Unhappy with social life (-)	24	2.9 (1.0)	2.9 (1.0)	2.9 (1.0)	3.1 (.68)
7.5 Financial insecurity (-)	7	2.4 (1.4)	2.4 (1.4)	2.4 (1.4)	3.1 (.59)
7.6 Negative attitude (-)	12	2.8 (.84)	2.8 (.84)	2.8 (.84)	3 (.81)
7.7 Uncertainty (-)	29	**3 (.85)**	**3 (.85)**	**3 (.85)**	**3 (.82)**
7.8 Hopelessness (-)	16	2.5 (1.1)	2.5 (1.1)	2.5 (1.1)	2.9 (1)
8.1 Improved self worth (+)	26	3.2 (.73)	3.2 (.73)	3.2 (.73)	3.1 (.53)
8.2 Control (+)	38	**3.3 (.69)**	**3.3 (.69)**	**3.3 (.69)**	**3.3 (.56)**
8.3 Independence (+)	48	**3.2 (.73)**	**3.2 (.73)**	**3.2 (.73)**	**3.2 (.55)**
8.4 Happy with social life (+)	41	3.2 (.74)	3.2 (.74)	3.2 (.74)	3.1 (.71)
8.5 Financial security (+)	35	**3.1 (.6)**	**3.1 (.6)**	**3.1 (.6)**	**3.1 (.67)**
8.6 Positive attitude (+)	53	**3.1 (.7)**	**3.1 (.7)**	**3.1 (.7)**	**3.1 (.63)**
8.7 Satisfied with QoL (+)	34	3.3 (.77)	3.3 (.77)	3.3 (.77)	3.2 (.53)
8.8 Hopeful (+)	49	**3.2 (.74)**	**3.2 (.74)**	**3.2 (.74)**	**3.2 (.57)**

Note[a]. - = negative event, + = positive event
Note[b]. SS = Sample who responded to critical event