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Illness Perceptions of Hemodialysis Patients with Type 2 Diabetes Mellitus and their Association with Empowerment

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**ILLNESS PERCEPTIONS OF
HEMODIALYSIS (HD) PATIENTS WITH TYPE 2 DIABETES MELLITUS (DM)
AND THEIR ASSOCIATION WITH EMPOWERMENT**

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Date 3/6/12



Date 3/6/12



Date 3/6/12

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Dr. Cahill – Caring, Intuitive, Dedicated
Dr. DeBari – Intense, Brilliant, Loyal

Devotion

To my Gramps, I feel you know "I did it!" Keep sending me ladybugs...

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ABSTRACT

Illness Perceptions of Hemodialysis (HD) Patients with Type 2 Diabetes Mellitus (DM) and their Association with Empowerment

Pula, J.L.; St. Joseph's Regional Medical Center & Seton Hall University

INTRODUCTION: According to the U.S. Renal Data System, DM was the primary cause of ESRD for 54% of all new patients in 2007. Hemodialysis patients with Type 2 DM are faced with many treatment challenges, which may lead to a *negative* perception of illness and a *decrease* in empowerment. The Common Sense Model (CSM) based on Leventhal's Self-Regulation Model provides a theoretical framework for the concept of illness perceptions in relation to coping behaviours and measurable outcomes such as well-being, quality of life (QoL), and self-management. The purposes of this study were: 1) to examine if there is an association between illness perceptions and perceptions of empowerment in HD patients with Type 2 DM; and 2) to investigate what differences in illness perceptions and perceptions of empowerment exist between HD patients with Type 2 DM and non-dialysis patients with Type 2 DM.

METHODS: This was a prospective, cohort-nested, case-control study. A total of 101 participants {51 HD patients with Type 2 DM (Group 1; case) and 50 non-dialysis patients with Type 2 DM (Group 2; control)} signed an IRB approved written informed consent and authorization form prior to screening. Participants were asked to offer responses regarding their illness perceptions, empowerment, and sociodemographic information, which took approximately 45 minutes, one-time during their regularly scheduled HD treatment or family medicine clinic visit.

The measures included the Diabetes Empowerment Scale – Short Form (DES-SF), Brief Illness Perception Questionnaire (Brief-IPQ), and General Information Form (GIF). Calculations were performed using GraphPad Prism (Version 5.0) and SPSS (Version 18.0) on a personal computer platform for data analysis. Differences between sociodemographic characteristics, Brief-IPQ scores and DES-SF scores between the two groups were compared by use of non-parametric tests. In addition, multivariate analyses were used to adjust for potential confounders amongst the baseline characteristics.

RESULTS: Univariate analyses indicated differences between 3 characteristics of the Brief-IPQ. First, the non-dialysis group perceived illness affects their lives more severely (*consequences*; $P = 0.005$). Secondly, the dialysis group perceived illness will more likely last forever (*timeline*; $P = 0.040$). However, via multivariate analyses, the PI discovered male dialysis patients, 56 years of age or older, are particularly affected. Lastly, the non-dialysis groups perception of emotion affecting their lives is greater (*emotional representation*; $P = 0.0002$), which turned out to be insensitive to any of the 3 potential confounders (*age, gender, and years of schooling, respectively*).

CONCLUSIONS: Findings from this study may positively impact educational threads by bringing attention to the need for nephrology healthcare providers to identify HD patients' (with Type 2 DM) illness perceptions and their association with perceptions of empowerment. By modifying illness perceptions impairments, empowerment can, therefore, be indirectly addressed. Educational interventions for this patient population may then be designed (based on the

CSM and Empowerment Theory), specifically for identification and coping strategies, ultimately increasing QoL.

Keywords: end stage renal disease, dialysis, diabetes, hemodialysis, illness perceptions, empowerment, self-regulation model, common sense model, quality of life

Chapter 1

INTRODUCTION

Background of the Problem

Diabetes mellitus (DM) is a chronic illness caused by an error in carbohydrate metabolism that affects over 16 million individuals in the U.S. The chronic nature of DM presents considerable physiological and psychological concerns. This dissertation study explored illness perceptions in hemodialysis (HD) patients' with Type 2 DM and whether there is an association with perceptions of empowerment.

Dialysis patients with Type 2 DM are faced with demanding treatments and need to have empowerment when taking care of their health and treatments (Rantanen, et. al., 2008).

Patients with Type 2 DM must monitor their blood sugars regularly and adhere to meal planning and scheduled appointments. They may experience loss of sensation; therefore, need to observe foot care practices. Psychological stressors include loss of self-concept and self-esteem.

According to the U.S. Renal Data System, as of December 31, 2007, nearly 111,000 people living in the U.S. have end stage renal disease (ESRD), the final stage of kidney disease. Of those ESRD patients, 44% (48,871) also have DM (either Type 1 or Type 2) (USRDS, 2009).

In 2007, the calculated rate of new ESRD cases was 354 per million patient population. Diabetes mellitus was the primary cause of ESRD for 54 percent of all new patients in 2007 (USRDS, 2009). The overall adjusted rate of ESRD due to DM was 155 million per population in 2007; 36 percent higher than a decade before.

Dialysis patients may be faced with serious stressors related to the illness and its treatment, arising from the chronic nature of kidney disease and the intrusiveness of the medical treatment (Parmer, 2002; Ruggenenti, Schieppati, & Remuzzi, 2001). For this dissertation study's purposes we will focus on those patients being treated via HD.

Challenges of HD treatment include adherence to fluid restriction as well as additional food restrictions. Patients are often confronted with physical symptoms such as restless legs syndrome (RLS), itching, pain, nausea, rashes, mood changes and lack of energy and fatigue. Additional psychological stressors include feelings of uncertainty about the future as well as feelings of guilt towards family members; and with problems in the social domain (Timmers, et. al., 2008; Harwood & Wilson, 2008; Logan, Pelletier, & Hodgins, 2006; Tyrell, et. al., 2005).

Challenges may lead to a *negative* perception of illness.

We know this because Timmers, et. al. (2008) observed 91 HD and 42 peritoneal dialysis (PD) patients) participating in the NECOSAD-study. The authors used the Illness Perceptions Questionnaire – Revised (IPQ-R) to measure illness perceptions and the Short Form – 36 (SF-36) to measure quality

of life (QoL). They found that illness perceptions impairment contributes significantly to aspects of QoL in HD patients with Type 2 DM. Perceptions of more symptoms, more negative consequences, strong illness identity, and lower personal control were associated with lower well-being and a diminished QoL.

While there are multiple theories to address illness perceptions, the Common Sense Model (CSM) (Figure 1) based on Leventhal's Self-Regulation Model (SRM) provides a theoretical framework for the concept of illness perceptions in relation to coping behaviors and measurable outcomes such as well-being, QoL, and self-management (Cameron, 2003). There are five (5) domains to the CSM (Figure 2). They include: 1) identity; 2) cause; 3) timeline; 4) consequences; and 5) controllability. The CSM was used to develop three (3) tools: 1) Illness Perceptions Questionnaire (IPQ); 2) Illness Perceptions Questionnaire – Revised (IPQ-R); and 3) Brief Illness Perceptions Questionnaire (Brief IPQ).

Table 1 illustrates a comparative overview of the 3 tools noted in the literature regarding illness perceptions (Weinman, et. al., 1996; Moss-Morris, et. al., 2002; Broadbent, et. al., 2005). Although the Brief IPQ has the lowest Cronbach's alpha compared to the IPQ and IPQ-R, it is still good and acceptable (Cronbach's alpha value = 0.75), especially given the rapid assessment format for both respective tools.

Another area that has been looked at is empowerment and how the same aforementioned challenges affect a person's empowerment.

Challenges may lead to a *decrease* in empowerment.

What is meant by empowerment is best described by Funnel & Weiss's (2009) definition that helping patients discover and use their innate ability to gain mastery over their disease. Patients clearly understand this tenet, as evidenced when they make statements like, "You can teach me, but you can't make me." Empowerment has been associated with positive outcomes such as improved diabetic control in children of empowered mothers; and improved self-care, self-efficacy and depression in HD patients.

Tsay & Hung (2004) observed 50 patients (empowerment group, $n = 25$; control group, $n = 25$) on dialysis, which demonstrated the potential benefits of a concentrated, nurse-coordinated program to encourage patient self-management and empowerment using the Diabetes Empowerment Scale (DES) to measure empowerment.

There are two (2) tools related to empowerment noted in the literature: 1) Diabetes Empowerment Scale (DES); and 2) Diabetes Empowerment Scale – Short Form (DES-SF). The three (3) subscales for both tools are as follows: 1) managing the psychosocial aspects of DM; 2) assessing dissatisfaction and readiness to change; and 3) setting and achieving goals.

Table 2 illustrates a comparative overview of the two (2) tools noted in the literature regarding empowerment. The DES-SF has a good validity/reliability characteristic given the Cronbach's alpha value is $= 0.85$; and has the strength of a rapid assessment format.

Based on the literature, we know that: 1) challenges may lead to a *negative* perception of illness; and 2) challenges may lead to a *decrease* in

empowerment. However, what we do not know is whether there is an association between illness perceptions and perceptions of empowerment and why this may be important? It is important to study this concept because if we can identify an association between illness perceptions and perceptions of empowerment – we can examine how to modify illness perceptions impairment. Therefore, indirectly address empowerment.

Purpose of the Study

The purposes of this dissertation study were: 1) to examine if there is an association between illness perceptions and perceptions of empowerment in HD patients with Type 2 DM; and 2) to investigate what differences in illness perceptions and perceptions of empowerment exist between HD patients with Type 2 DM and non-dialysis patients with Type 2 DM.

Figure 3 provides the schematics for the theoretical framework for the pilot study, which ultimately served as the foundation of this dissertation study, which suggests that illness perceptions and perceptions of empowerment may influence one another. The primary investigator (PI) hypothesized that there is an association between illness perceptions and perceptions of empowerment. In addition, the PI hypothesized that if a HD patient with Type 2 DM has poor illness perceptions, then he or she also has a decrease in empowerment. Surprisingly, this was not the case – as will be covered within the dissertation findings section.

Research Questions

Five (5) principal research questions frame this study, as follows: 1) Is there a difference in empowerment between HD patients with Type 2 DM (Group 1) and non-dialysis patients with Type 2 DM (Group 2)?; 2) Is there a difference in illness perceptions between HD patients with Type 2 DM (Group 1) and non-dialysis patients with Type 2 DM (Group 2); 3) Is there an association between illness perceptions and empowerment in HD patients with Type 2 DM (Group 1)?; 4) Is there an association between illness perceptions and empowerment in non-dialysis patients with Type 2 DM (Group 2)?; and 5) Is there a difference in association between illness perceptions and empowerment in patients with Type 2 DM who are receiving HD treatment (Group 1) and non-dialysis patients (Group 2) who are not?

Study Implications

This dissertation study provides a better understanding of illness perceptions of HD patients with Type 2 DM and their association with perceptions of empowerment and how this association impacts QoL – to the current body of literature available. Since there is not enough literature on this topic, the outcomes of this dissertation study, therefore, provide a foundation for and insight regarding HD patients with Type 2 DM.

Findings from this dissertation study may positively impact educational threads by bringing attention to the need for nephrology healthcare providers to identify HD patients' (with Type 2 DM) illness perceptions and their association with perceptions of empowerment. By modifying illness perceptions

impairments, empowerment can, therefore, be indirectly addressed. Educational interventions for this patient population may then be designed, specifically for identification and coping strategies, ultimately increasing QoL. Subsequently, this can provide a basis for developing interventions aimed at altering patients' illness perceptions to improve perceptions of empowerment.

Chapter II

REVIEW OF LITERATURE

The purposes of this dissertation study were: 1) to examine if there is an association between illness perceptions and perceptions of empowerment in HD patients with Type 2 DM; and 2) to investigate what differences in illness perceptions and perceptions of empowerment exist between HD patients with Type 2 DM and non-dialysis patients with Type 2 DM.

The first section of this chapter explores challenges that HD patients with Type 2 DM face and how they may negatively affect illness perceptions, which result in lack of ability to self-manage their disease (for example, diabetes self-care, adhere to fluid restrictions, etc.). The underlying theoretical framework guiding the study, research related to illness perceptions, and the survey instruments will be discussed. The second section explores the previously discussed challenges that HD patients with Type 2 DM face and how they may decrease empowerment. Subsequent sections explore how nephrology healthcare providers observe negative illness perceptions and decreased empowerment separately (in isolation) in HD patients with Type 2 DM. A summary of the review of literature concludes the need to observe illness perceptions and perceptions of empowerment via dissertation study to explore whether there is an association between illness perceptions and perceptions of empowerment in this patient population.

Challenges HD Patients with Type 2 DM Face

Diabetes mellitus is a chronic illness caused by an error in carbohydrate metabolism that affects over 16 million individuals in the U.S. The chronic nature of DM¹ presents considerable physiological and psychological concerns. This study explores illness perceptions in HD patients with Type 2 DM and whether there is an association with perceptions of empowerment.

In addition, daily challenges and adjustments in lifestyle are required by patients with DM, who are continuously interacting with some aspect of the chronic illness. Diabetes is a self-managed disease with the patient providing 95% or more of their own daily care (Anderson, et. al., 2000). Patients make daily decisions involving nutrition, physical activity, medication, blood glucose monitoring, and stress management. Patients interact with healthcare professionals, family, friends, and employers for continued support to manage the disease.

In adults 20 – 74 years of age, DM is the leading cause of ESRD, blindness, non-traumatic limb amputations and cardiovascular morbidity and mortality in the U.S. (ADA, 2001). Diabetes contributes to increased risk of stroke, by 2 to 4 times higher than adults without DM.

¹ There are two types of DM, namely Type 1 and Type 2 DM. Type 1, previously known as juvenile-onset diabetes, is caused by the destruction of the beta cells at the pancreatic level resulting in insulin deficiency. Type 1 accounts for 5 percent of the DM patient population (ADA, 2001).

Type 2 DM, previously known as adult onset diabetes, is characterized as insulin deficient and/or insulin resistance. Type 2 DM accounts for 95 percent of the DM patient population. The risk of developing this form of DM increases with age, obesity, and lack of exercise (ADA, 2001). In addition, there is a strong genetic predisposition for developing Type 2 DM. This type is more frequently seen in individuals with a history of gestational diabetes, hypertension, and/or dyslipidemia. Type 2 DM frequently goes undiagnosed for many years because there is a gradual onset of signs and symptoms of hyperglycemia, which may not be recognized by the individual or brought to the attention of a healthcare professional (NCCDPHP, 2009).

The challenge of DM is tackled on three (3) fronts: 1) primary prevention; 2) secondary prevention (of complications associated with DM); and 3) tertiary prevention of morbidity and mortality from established complications (associated with DM). The complications of diabetes are preventable through tight metabolic control and comprehensive risk reduction (Dagogo-Jack, 2002). The challenge is to empower the individual through promotion of lifestyle and self-care practices to improve glycemic control²; and ultimately, decrease the risks of DM related complications. Education and empowerment are critical to the successful self-management of DM (Anderson, et. al., 1995).

As of December 31, 2007, nearly 111,000 people living in the U.S. have ESRD³. Of those ESRD patients, 44% (48,871) also have DM (either Type 1 or Type 2) (USRDS, 2009).

² Among patients beginning ESRD therapy in 2007, the average glycemic control appears to be at a glycosylated hemoglobin (HbA_{1c}) level of 7.3 percent. This suggests that one in every two patients with ESRD and DM has less than optimal glycemic control, based on guidelines from the American Diabetes Association, which target a HbA_{1c} level of less than 7 percent. Nearly 4 in 10 diabetic patients starting ESRD therapy in 2007 had an HbA_{1c} level of 7 percent or above (USRDS, 2009). Glycemic control appears to be an issue in the population starting HD with Type 2 DM as a primary or complicating condition. (USRDS, 2009).

³ End stage renal disease occurs when the kidneys *irreversibly* fail to carry out normal function. Kidney failure has many causes, including cancer, diabetes, hypertension, inflammation, infection, lupus, an arteriosclerosis (Faris, 1994). Symptoms include: poor appetite, vomiting, bone pain, headache, insomnia, itching, dry skin, malaise, fatigue with light activity, muscle cramps, high urine output or no urine output, recurrent urinary tract infections, urinary incontinence, pale skin, bad breath, hearing deficit, detectable abdominal mass, tissue swelling, irritability, poor muscle tone, change in mental alertness, metallic taste in mouth, and restless legs syndrome (RLS) (Sakkas, et. al., 2008; Smith & Tolson, 2008; NKDEP, 2008; Davison, 2007).

How to test for ESRD. Glomerular filtration rate (GFR) is a test used to measure the level of kidney function and determine the appropriate stage of kidney disease. Most commonly, GFR is a calculation based on results of patients': 1) blood creatinine test; 2) age; 3) race; and 4) gender. Glomerular filtration rate is expressed in milliliters per minute (ml/min), which is a measure of rate at which kidneys filter blood; therefore, ESRD is essentially defined by GFR (<15ml/min) (Lucas, et. al., 2008; NKDEP, 2008).

5 stages of chronic kidney disease (CKD). There are 5 stages of CKD. Stage 5 (or ESRD) is defined as kidney failure (in which dialysis or kidney transplant is necessary) - with a GFR of <15ml/min (Davison, 2007).

In 2007, the calculated rate of new ESRD cases was 354 per million patient population. Diabetes mellitus was the primary cause of ESRD for 54 percent of all new patients in 2007 (USRDS, 2009). The overall adjusted rate of ESRD due to DM was 155 million per population in 2007; 36 percent higher than a decade before.

Patients on HD are subjected to an ongoing onslaught of therapies and lifestyle changes that affect their psychological and psychosocial well-being. Patients are asked to make daily decisions about adhering to scheduled appointments, taking prescribed medicine, limiting the intake of fluid and certain foods, and managing the symptoms of chronic kidney disease (CKD). The challenges associated with living with CKD are significant and may contribute to patients feeling that they have lost control of their lives (McCarley, 2009). Sample challenges include: 1) maintaining meaningful life roles (such as job, family, friends); 2) coping with fear, anger, frustration, sadness of a chronic condition; 3) accepting disruption in routines; 4) confronting their own mortality; 5) ensuring adequate dialysis care; 6) adhering to described therapies; and 7) adjusting to lifestyle changes (McCarley, 2009; Bodenheimer, et. al., 2002; Curtin, et. al., 2002; Shatell & Witten, 2005).

Primary treatment of kidney disease. Dialysis is a procedure that is performed routinely on patients with kidney disease (especially in its final stage, ESRD). Dialysis is an artificial way of filtering the blood. It is a necessary treatment for patients diagnosed with ESRD (unless kidney transplantation is available). Kidneys are the organs that filter out waste products and water from

the blood. In ESRD, kidney function has decreased to 10% to 15% of its original functioning, which is life-threatening without treatment. There are two dialysis modalities. When kidneys fail to function, dialysis can clean waste products artificially. There are 2 forms of dialysis: 1) hemodialysis (HD): a kidney machine that filters the blood; the blood is purified by an external artificial kidney; and 2) peritoneal dialysis (PD): an exchange process that uses the lining of the inside of the abdomen as a filter (Yung, 2008; Brodin, 2001); the peritoneal membrane functions as an artificial kidney. For this dissertation study's purposes, the focus will be on those patients being treated via HD (vs. PD).

Challenges May Lead to a Negative Perception of Illness

Illness Perception Impairment in HD Patients with Type 2 DM

The enormous impact of HD treatment and diabetes care on quality of life (QoL) has been emphasized in many studies (Timmers, et. al., 2008; Morsch, Goncalves, & Barros, 2006; Cleary & Drennan, 2005; Hagren, et. al., 2005; Iliescu, et. al., 2003; Lindqvist, Carlsson, & Sjoden, 1998). From previous studies it is known that QoL in HD patients with Type 2 DM is dramatically lower than that of the general population. Illness perceptions impairment contributes significantly to aspects of QoL in HD patients with Type 2 DM.

Theories of Illness Perceptions

Self-Regulation Theories and the Common Sense Model (CSM). In recent years, the term "self-regulation" has been applied to many theories. Therefore, there has been speculation about how self-regulation theories differ from other models of health and illness behavior. What differentiates self-regulation

theories from other models of health and illness are the elements of feedback, motivation, and the goal of pursuit. Self-regulation theories suggest that people have two inherent overarching goals: 1) survival; and 2) coherence. When illness threatens one's survival and sense of coherence, cognitive, motivational, and behavioral patterns that develop during illness may determine how one will adapt to the illness (Cameron & Leventhal, 2003). Managing an illness: 1) challenges the integrity of self; 2) requires regulation of emotional and physical states; and 3) requires understanding of the personal meaning connected to health related goals and behaviors. Self-regulation of illness often occurs within a dynamic social context of family members and friends that allow for the sharing of ideas and emotions. The Common Sense Model (CSM) of self-regulation developed by Leventhal, et. al., (1984) was developed specifically to understand and explain health and illness behavior (Cameron & Leventhal, 2003).

The CSM of self-regulation is based on a parallel processing system consisting of two (2) pathways: 1) abstract cognitions (feelings of vulnerability); and 2) concrete experience (symptoms) (Figure 1). These pathways interact as an individual adapts to an illness by creating coping procedures to manage the emotions and the symptoms (Leventhal, Brissette & Leventhal, 1992; Whitmarsh, Koutantji, & Sidell, 2003). Individuals construct representation of illness based on these pathways for which they generate goals of self-management and then derive feedback criteria to evaluate the response efficacy. According to the CSM there are five (5) domains of illness representation including: 1) identity; 2) timeline; 3) consequences; 4) control; and 5) cause (Figure 2).

Each domain is comprised of countless variables that stem from a complex social biological system. Individual appraisals of social and cultural factors as well as the experiences of their disease such as pain, fatigue, nausea, rashes, disruptions in cognitive or physical functioning, and mood changes are powerful contributors to the illness representation (Leventhal, et. al., 1992). Illness representations evaluating the acute, chronic, or cyclic nature of the disease are often based on communications with healthcare professionals, family members, and other patients rather than the actual biology of the disease. A patients' perspective on aspects such as his or her age, expected longevity, assessment of overall health, and immune strength interacts with his or her perception of each of the five domains of illness representation (respectively, identity, timeline, consequences, control, and cause). The association between patients' perspective and illness representations then plays a role in determining which coping procedure will be most helpful to him or her to manage illness (Leventhal, et. al., 1984; Leventhal, Diefenback, & Leventhal, 1991; Leventhal, et. al., 1992).

Understanding why patients do not adhere to medical regimen has been conceptualized using the CSM and illness representations. Individuals seek coherence between their illness representations and the procedures to cope with their disease, which includes their perceptions of treatment necessity (Horne, 2003). These evaluations are influenced by the information individuals receive about types and classes of treatment, past treatment experiences of one's self and others as well as societal and cultural norm about treatment. Horne (2003)

explained the unique relationship each of the CSMs' five illness representations including: 1) identity; 2) timeline; 3) consequences; 4) control; and 5) cause, has with the perception of treatment necessity⁴.

Although the theoretical framework of the CSM suggests that self-efficacy (one component of empowerment), or the ability to engage in various situation-specific self-management tasks (Anderson, et. al., 2000) (such as meal planning, adhering to scheduled appointments or blood glucose monitoring) to medical regimens is a form of coping procedure (Llewellyn, et. al., 2003), no research projects have evaluated the CSM with patients' empowerment (as of date; to the best of the authors' knowledge).

Illness perceptions are also related to perceptions of treatment necessity, which in turn, may influence empowerment, which will be discussed in subsequent sections.

Research Related to Illness Perceptions

Timmers, et. al. (2008) conducted a study titled, "Illness perceptions in dialysis patients and their association with quality of life." Their study explored illness perceptions of patients with ESRD (on both HD and PD), and their association with quality of life (QoL). Leventhal's self-regulation model (SRM)

⁴ *Identity* – assesses the symptoms experienced by the patient. Perceptions of treatment necessity are influenced by symptoms and the absence of severe symptoms or side effects may lead to the perception that treatment is not necessary or not working properly (Leventhal, et. al., 1984). *Consequences* and *timeline* – symptoms often used in determining illness representations about timeline and personal consequences of a condition. Treatment necessity is more convincing if it is consistent with the individual's representations of his or her illness. *Causal attribution* – causal beliefs have not been found to be strongly relations to the patients' sense of treatment necessity. Horne (2003) suggests that causal beliefs do not vary much between patients with the same illness. *Control/Cure* – treatment necessity is correlated with efficacy belief, or the belief that the illness will be controlled by the treatment but not with other types of beliefs such as chance or personal control.

was used as a theoretical framework. Illness perceptions and QoL were assessed with the Illness Perceptions Questionnaire – Revised (IPQ-R) and the Short Form – 36 (SF-36) in 91 HD and 42 PD patients participating in the NECOSAD-study. Compared to HD patients, PD patients experienced more personal control and had a better understanding of the illness. Illness perceptions explained from 17 to 51 percent of the variance in QoL scores. Perception of more symptoms, more consequences, strong illness identity, many negative consequences, and lower personal control were associated with lower well-being. Higher identity and higher control are associated with a better outcome, and more perceived outcomes, higher emotional representations and less control being associated with worse outcomes (Timmers, et. al., 2008).

The concept of illness perceptions is useful in understanding the impact of ESRD and of dialysis treatment on QoL. The above authors concluded that interventions aimed at providing more knowledge about ESRD and dialysis, and provision of skills to coping with the illness and its consequences may improve QoL in dialysis patients.

With the increasing interest in the CSM based on Leventhal's SRM, Weinman, et. al., (1996) created the Illness Perception Questionnaire (IPQ). The IPQ was utilized by the aforementioned research to assess the five dimensions of the CSM (i.e., identity, timeline, consequences, cure/controllability, and cause) and the patients' overall illness perception. Since its construction, the IPQ has been utilized to examine adherence in chronic illnesses such as asthma, diabetes, heart disease, breast cancer, and Huntington's disease.

One of the first studies conducted using the IPQ was in 1999 by two of the authors of the IPQ, Horne and Weinman. They examined patients' beliefs about treatment adherence in chronic physical illness. This study found considerable variation within and between chronic illness groups on patients' self-reported adherence and their beliefs about medication (Horne & Weinman, 1999). One of the limitations of this study included having a cross sectional design of chronic illnesses. Because each illness was unique in terms of its symptomology and etiology and each patient had differing perceptions of their illnesses, it was difficult for the authors to conclude how the patients' illness perceptions influenced treatment adherence. This limitation had not been a problem for the majority of studies utilizing the IPQ because these other studies focused on research using a single illness population rather than multiple illnesses.

In 2000, Byer and Meyer utilized the IPQ to look at medication adherence in asthma patients. The authors found patients' beliefs about the necessity of medication, duration of illness, and identity about illness all influenced patients' adherence to medication. The generalization of their findings was limited by the fact that their participants were drawn from one primary care setting. In contrast, Horne and Weinman (2002) examined adherence to asthma medication from patients attending asthma clinics from multiple sites. Their results suggested that illness perception and treatment beliefs were the strongest predictors of adherence. In this study, adherence was measured by self-report, which is a subjective measure (Horne & Weinman, 2002). The authors acknowledged that

although self-reported adherence was a commonly used method in medical research, an objective measure offered a different perspective on adherence.

Griva, Myers, and Newman (2000) examined patient HbA_{1c} levels in addition to patients' self-report of adherence. HbA_{1c} levels are blood samples that measure diabetic patients' metabolic control over a 6 to 12 week time period and are an excellent physiological indicator of treatment adherence. The participants were insulin dependent diabetic patients recruited from multiple clinics to examine their illness perceptions and adherence. The researchers found a different pattern of associations between self-reported adherence and the HbA_{1c} levels. *Perceived Illness Identity* was the only scale from the IPQ found to be associated with patients' self-reported adherence whereas *Perceived Consequences* was the only scale from the IPQ to be significantly correlated with the objective measure of adherence (i.e., the HbA_{1c} levels). These results demonstrated how different adherence measures are related to different dimensions of illness perceptions and they caution that interpretation of results is necessary.

Another study conducted by Llewellyn, et. al. (2003) with hemophilia patients utilized treatment records as an objective measure of adherence and did not include a self-report measure. In their results, only *Identity* from the IPQ was found to be a predictor of adherence in hemophilia patients. As with the previously mentioned hemodialysis (HD) adherence literature, a major limitation of these IPQ research projects was lack of design and statistical procedures to examine the direction of causation between IPQ dimensions and adherence.

The aforementioned IPQ studies used cross sectional designs, retrospective adherence measures, and correlation statistics.

In 2003, Whitmarsh, et. al. conducted a prospective study using illness perceptions to evaluate attendance to cardiac rehabilitation. They found that lower perception of symptoms and *Controllability/Curability* of illness was the best predictors of poor attendance records at rehabilitation sessions. While patients' illness perceptions were measured before the start of the rehabilitation program, the researchers did not account for other psychosocial influences that may have contributed to poor attendance. The utility of the IPQ as a prospective assessment instrument for poor attendance has been developed by this research for cardiac rehabilitation programs.

In addition to the IPQ being utilized with traditional Western medicine adherence, Searle and Murphy (2000) examined cognitive representations of new homeopathic patients and the extent of their adherence to recommended treatment. The patients presented with a myriad of medical concerns. The study found that patients' *Causation* beliefs were found to be the best predictor of illness understanding and treatment adherence.

In addition to the research examining illness perception as a predictor for treatment adherence, other researchers have used the IPQ to examine patients' illness perceptions as mediating and/or moderating psychosocial variables. Rees, et. al. (2003) also included illness perception in a study examining distress in women with an increased risk for breast cancer. They compared samples of women with an increased risk of breast cancer and those who are not at risk, and

compared their illness perception and distress. There were no discernable differences between the two risk groups' illness perceptions and their levels of distress.

The IPQ has also been modified to address caregivers' illness perceptions as well as the patients with Huntington's disease. In two separate but related studies, Helder, et. al. (2002) examined how illness perception contributed to caregivers' QoL and patients' well-being. *Illness Identity, Consequences, and Timeline* were found to be correlated to caregiver coping, however, did not significantly explain the caregivers' QoL. In the second study, Helder, et. al. (2002) focused on the illness perception of Huntington's disease patients and found that patients' *illness Identity* was negatively related to their well-being. Inclusion of the IPQ in the Huntington's disease studies allowed the IPQ to assess patients whose illness is virtually untreatable.

The ability to treat a patients' condition and how this relates to their perception of illness was also examined by Fortune, et. al. (2002) in a study of psoriasis. Psoriasis is a chronic, skin disease that is incurable. The authors used the IPQ with this difficult to treat and incurable patient population. This study found that illness perceptions as measured by the IPQ explained the most amount of variance for stress, distress, and disability in patients with psoriasis.

Tools Related to Illness Perceptions

There are three (3) tools related to illness perceptions that can be used for this study: 1) Illness Perceptions Questionnaire (or IPQ); 2) Illness Perceptions

Questionnaire – Revised (or IPQ-R); and 3) Brief Illness Perceptions

Questionnaire (or Brief IPQ). See Table 1.

Based on the utilization and adaptability of the IPQ with different patient population and illnesses, Moss-Morris, et. al. (2002) re-evaluated the IPQ and decided to revise it to make it more accurate to the theoretical tenets of CSM based on Leventhal's SRM, and improve the psychometric properties of the *Cure/Control* and *Timeline* subscales. The IPQ-R increased the Cronbach's alpha score to 0.89 for the *timeline* subscale and separated the *Cure/Control* subscale into three (3) separate subscales that more accurately assessed the patient's perceptions of: 1) cure; 2) illness control; and 3) treatment control (Moss-Morris, et al., 2002).

Fowler and Baas (2006) used the IPQ-R to examine the illness representation of patients on HD. The authors explored the relationship between illness perception and QoL for CKD patients on maintenance HD. These authors found a strong relationship between the QoL and patients' illness perceptions, suggesting further examination of illness perceptions and holistic outcomes in persons undergoing HD. This research had limitations including a 24.7% response rate, which produced a small sample size. The authors postulated that a thorough assessment of patients' perceptions may provide the medical team with substantial information about how patients perceive HD in terms of illness *Identity, Cause, Timeline, Consequences, and Controllability*. Identifying and addressing patients' perceptions may improve adherence with recommended treatment regimens.

In 2005, Broadbent, et. al. evaluated the Brief IPQ, a nine-item scale designed to rapidly assess the cognitive and emotional representations of illness. The researchers assessed the test-retest reliability of the scale in 132 renal out-patients. They assessed concurrent validity by comparing the Brief IPQ with the IPQ-R and other relevant measures in 309 asthma, 132 renal, and 119 diabetes out-patients. Predictive validity was established by examining the relationship of Brief IPQ scores to outcomes in a sample of 103 myocardial infarction (MI) patients. Discriminant validity was examined by comparing scores on the Brief IPQ between five (5) different illness groups. The findings indicated the Brief IPQ showed good test-retest reliability and concurrent validity with relevant measures. The scale also demonstrated good predictive validity in patients recovering from MI with individual items being related to mental and physical functioning at 3 months' follow-up, cardiac rehabilitation class attendance, and speed of return to work. The discriminant validity of the Brief IPQ was supported by its ability to distinguish between different illnesses. In sum, the Brief IPQ provides a rapid assessment of illness perceptions, which could be particularly helpful in ill patient populations, large-scale studies, and in repeated measures research designs (Broadbent, et. al., 2005).

The IPQ-R has over 80 items, and in some situations such a long questionnaire is prohibitive. This is particularly the case with HD patients with Type 2 DM because patients are very ill and the primary treatment is long and invasive. A shorter questionnaire such as the Brief IPQ (vs. IPQ or IPQ-R) is more suitable because it is less taxing and much quicker to complete. Also, it is

more acceptable to those patients (particularly older adults) who are limited in their reading and writing ability. The Brief IPQ offers the potential for illness perceptions to be investigated in a wider range of patient groups and would be especially useful when illness perceptions are measured as only one part of a larger set of psychological constructs (as is the case in this dissertation study) (Broadbent, et. al., 2005).

Details of the Illness Perception Questionnaire – Revised (IPQ-R). The psychometric properties of the IPQ-R have been previously tested on center-based HD patients, and the structural validity, internal reliability, test-retest reliability, and discriminant validity are within acceptable limits (Moss-Morris, et. al., 2002). The internal reliability for each dimension of the IPQ-R was demonstrated by Cronbach's alpha scores ranging from 0.79 to 0.89.

The IPQ-R assesses nine components of illness representation in three (3) sections. The first section asks about the subscale *Identity* – In which participants are asked yes/no questions about 14 different symptoms and if they believe these symptoms are related to being on HD.

The second section is comprised of 38 questions address 7 subscales (Moss-Morris, et. al., 2002). Two (2) subscales are patient's perception of control: 1) *Personal control* (beliefs about the control he/she has in controlling their symptoms and condition); and 2) *Treatment control* (beliefs about the usefulness of the treatments they are receiving). The next two scales assess *Timeline* (length of time that the patient believes HD will last) and *Timeline cyclical* (patients' perceptions about the patterns of how they are feeling). The last three

scales are: *Consequences* (patient's expected outcomes and effects of HD); *Illness coherence* (an overriding dimension of how much patients understand/comprehend about their illness); and *Emotional representation* (six affective responses which are sensitive to illness perception and to predict health related responses). All scales are scored using a 5-point Likert scale: *strongly agree, agree, neither agree nor disagree, disagree, strongly disagree*. Each subscale is scored separately with some reverse-scoring required.

High scores on *identity, timeline, consequences, and cyclical* scales demonstrate strongly held beliefs about the number of symptoms attributed to the illness, the chronicity of the condition, the negative consequences of the illness, and the cyclical nature of the condition, respectively. High scores on the *personal control, treatment control, and coherence* dimensions theoretically represent positive beliefs about the controllability of the illness and a personal understanding of the condition (Moss-Morris, et. al., 2002).

The third and final section focuses on the subscale *Causes*. This scale consists of 18 possible causes for being on dialysis (i.e., lifestyle, hereditary, chance, behavior, uncertain). This scale also uses the 5 point Likert scale.

Strengths and limitations of the IPQ-R. The IPQ-R is a subjective measure of illness representations or perceptions (Moss-Morris, et. al., 2002). Strengths include: 1) self-reporting can empower the patient; and 2) the scale has been adapted to enable the patient to respond in various languages. Limitations include: 1) the questionnaire is very long (over 80 items); and 2) the

questionnaire is difficult for patients who are limited in their reading and writing ability.

Details of the Brief Illness Perception Questionnaire (Brief IPQ). The Brief IPQ is a psychosomatic scale, which can be used to include HD patients with Type 2 DM with the permission of the authors (Appendix C; Appendix H). See Table 1.

The psychometric properties of the Brief IPQ (Appendix C) have been previously tested on center-based HD patients, and the structural validity, internal reliability, test-retest reliability, and discriminant validity are within acceptable limits (Broadbent, et. al., 2005). The internal reliability for each of the five (5) dimensions of the Brief IPQ was demonstrated by Cronbach's alpha scores ranging from 0.70 to 0.75.

The Brief IPQ has nine (9) items and is shown in Appendix C. The items were developed by forming one question that best summarized the items contained in each subscale of the IPQ-R. Therefore, the Brief IPQ has eight (8) new items plus part of the causal scale previously used in the IPQ-R. All of the items except the causal question are rated using a 0-to-10 response scale. Five (5) of the items assess cognitive illness representations; consequences (Item 1), timeline (Item 2), personal control (Item 3), treatment control (Item 4), and identity (Item 5). Two (2) of the items assess emotional representations: concern (Item 6) and emotions (Item 8). One item assesses illness comprehensibility (Item 7). Assessment of the causal representation is by an open-ended response item adapted from the IPQ-R, which asks patients to list

the three (3) most important causal factors in their illness (Item 9). Responses to the causal item can be grouped into categories such as stress, lifestyle, hereditary, etc., determined by the particular illness studied, and categorical analysis can then be performed (Broadbent, et. al., 2005). For this dissertation study's purposes, responses to Item 9, causal factors, were collected (perhaps for future use), however, were not included in the results.

Like the IPQ and IPQ-R, the Brief IPQ uses the word 'illness', but it is possible to replace this with the name of a particular illness (such as kidney disease or ESRD and DM or Type 2 DM, specifically). Similarly, the treatment control item uses the word 'treatment', but this can be replaced by a particular treatment (such as 'hemodialysis'), if researchers are interested in a particular treatment (Broadbent, et. al., 2005). For this dissertation study's purposes the words 'illness' and 'treatment' were not replaced.

Strengths and limitation of the Brief IPQ. The Brief IPQ (Appendix C) is a subjective measure of illness representations or perceptions (Broadbent, et. al., 2005). Strengths include: 1) brevity; 2) speed of completion for patients; 3) easy interpretation of scores; 4) useful for ill and elderly populations who would find completion of a long questionnaire (such as the IPQ or the IPQ-R) difficult; 5) advantageous when researchers are already using a other pencil-and-paper measures but wish to also include an assessment of illness perceptions; 6) advantageous when researchers need to assess illness perceptions repeatedly over a relatively short period, to reduce the burden on research participants; 7) valid and reliable measure of illness perceptions in a variety of illness groups

(including HD patients with Type 2 DM and non-dialysis patients with Type 2 DM); 8) easy to understand and to complete for patients; 9) results from the scale can be easily scored and are readily interpretable by researchers and clinicians; and 9) the scale has been adapted to enable the patient to respond in various languages. A limitation is self-reporting can reflect inaccurate information if the patient has difficulty understanding what is written, or cannot see or physically write out responses (however, the questionnaire can be used with an interpreter in future studies, if deemed necessary).

Challenges May Lead to a Decrease in Empowerment

Empowerment Impairment in HD Patients with Type 2 DM

Hemodialysis patients with Type 2 DM make choices each day that are affected by their emotions, thoughts, values, goals, and other psychosocial aspect of living with a chronic illness (Anderson, et. al., 1995). Type 2 DM and kidney disease (especially in combination) are complex chronic diseases to manage. In addition to its medical management, empowerment of the HD patient with Type 2 DM is required to overcome psychosocial barriers to self-management and QoL (Glasgow, Toobent & Gillette, 2001; Powers, 2003; McCarley, 2009).

Theories of Empowerment

Empowerment of patients supports “a path that has a patient-centered approach in collaboration with the medical regimen” (Simmons, 2001, p. 12).

The literature on the theoretical underpinnings of empowerment has proliferated during the last 15 years, however, there has been less emphasis on

the development of instruments to measure empowerment (Herbert, et. al., 2009). Instruments that have been developed tend to be tailored for use in specific populations or contexts. Questionnaires measuring empowerment in adults focus on the individual. To contextualize this research, the origins and meaning of empowerment theory are discussed, as it relates to this study.

Empowerment theory. Empowerment is a multidimensional construct applicable to individuals (as well as to organizations and neighborhoods). It is viewed as a construct (vs. a concept) because it is not directly observable. One of the earliest references to empowerment describes it as "...the possibility for people to control their own lives" (Herbert, et. al., 2009). Empowerment is commonly described as a contextual, participatory process, which enables individuals to achieve a sense of control over their own lives. Empowerment processes are essential to achieving empowerment outcomes. These processes are transactional in that they involve interactions with others (Herbert, et. al., 2009).

Empowerment is a coercive strategy that is justified by its outcomes and creates dependent patient populations (Powers, 2003). Empowerment has been associated with positive outcomes such as improved diabetic control in children of empowered mothers; more active decision making and lower anxiety levels in men with prostate cancer; increased self-efficacy, skill, and knowledge in women learning about breast cancer control; and improved empowerment, self-care, self-efficacy, and depression in those with ESRD (Herbert, et. al., 2009; Tsay & Hung, 2004; Little, et. al., 2004).

In the context of HD patients with Type 2 DM, empowerment is defined as helping patients discover and use their innate ability to gain mastery over their disease (Funnel & Weiss, 2009). Patients clearly understand this tenet, as evidenced when they make statements like, “You can teach me, but you can’t make me.” Moreover, interest in empowerment grew out of recognition that the traditional compliance or adherence models of care for ESRD patients undergoing HD treatment and education does not always work. Thus, this is not a new way of looking at adherence or a new method of trying to get patients to follow their treatment plan, but a different paradigm for providing multi-disciplinary care for those patients undergoing HD treatment.

The term empowerment has been used to refer to other similar constructs, and in particular to self-efficacy (Anderson, et. al., 2000; Herbert, et. al., 2009), even though empowerment has a more broad theoretical perspective (vs. self-efficacy) (Herbert, et. al., 2009). Perceived self-efficacy is defined as the belief in one’s own capabilities to organize and execute the actions that are required to produce goals. Self-efficacy has been characterized as both a component and an outcome of empowerment (Herbert, et. al., 2009).

The literature on empowerment has evolved from a primarily theoretical perspective, to theory testing and redefinition, with a greater focus on measurement (Herbert, et. al., 2009). The context-specific nature of empowerment and increased emphasis on its measurement has resulted in the development of questionnaires designed for specific populations (such as

diabetes). An overview of self determination theory and its relevance to empowerment theory follows.

Self-determination theory. Patient empowerment is based on the tenets of self-determination theory, which states that individuals are naturally motivated to improve their own well-being. This theory predicts improved outcomes among patients who approach the regulation of their own health from the perspective of autonomous self-regulation, competence, control, and self-determination; similar to self-efficacy. Self-determination theory has been consistently supported by study results, which show that patients are much more likely to adhere to recommended therapeutic approaches if they have internalized the need for a behavioral change and value it personally (vs. others that try to force them to behave in a way that is contrary to their nature) (McCarley, 2009).

Self-determination is a term used to describe respect for a patient as an individual and that patients should have some control of the dialysis process in which the patient and healthcare professional share. This means that the patient is an integral part of their own care and the decision-making required. Self-determination in a dialysis unit recognizes who owns the “body”; therefore, who has the right to make choices (Tims, Kling, & Bennett, 2007).

Research Related to Empowerment

Several landmark studies have noted that effective management of DM by patients who have the chronic disease is essential to prevent complications (ADA, 2001; Anderson, et. al., 2000; Rubin, Peyrot, & Saudek, 1991; The Diabetes Control and Complication Trial Research Group, 1993; United Kingdom

Prospective Study Group, 1998). In these studies, it was found that effective management goals were established through the patient having control and effective self-care behaviors. Hemodialysis patients with DM need to understand the disease and treatment, which includes implementing changes in lifestyle (Hunt, Arar, & Larme, 1998).

Healthcare professionals typically spend a significant amount of time trying to convince HD patients with Type 2 DM to change potentially harmful behaviors. Data have consistently indicated that behavior cannot be successfully modified unless patients set their own goals and internalize the need for change (McCarley, 2009).

The need for empowered patients is highlighted by the fact that HD patients spend 92% of their time outside the confines of the dialysis facility. Therefore, self-management is necessary to ensure improved outcomes (McCarley, 2009).

In one randomized controlled study titled, "Empowerment of patients with end-stage renal disease: a randomized controlled trial" conducted by Tsay and Hung (2004), 50 patients (empowerment group, n = 25; control group, n = 25) on dialysis demonstrated the potential benefits of a concentrated, nurse-coordinated program to encourage patient self-management and empowerment. Qualified participants from two (2) dialysis centers of major hospitals in southern Taiwan were randomly assigned into control and experimental groups. Each group received identical packets of information on CKD, potential therapies, coping strategies, and other components of care. In addition, the experimental group

participated in twelve one-on-one consulting sessions in which nurses fostered empowerment by helping patients develop self-management skills (including goal setting, problem solving, stress management, coping techniques, social support, and motivation). A patient-led behavioral change program encouraged patient identification of problem areas that could be addressed through self-management, exploration of emotions, development of goals and strategies to achieve these goals, and a self-care plan for behavioral change and stress management. Patient-reported outcomes were assessed through several validated survey instruments. Patients' perceptions of their own empowerment was measured using the Diabetes Empowerment Scale (DES; please see below for details), which included subscales on managing the psychosocial aspects of disease, assessment of dissatisfaction and readiness to change, and how goals were set and achieved. The Strategies Used by People to Promote Health Scale was used to assess patients' perceptions of self-care and self-efficacy (Tsay & Hung, 2004).

Data for both groups were collected at baseline and 6 weeks after completion of the intervention in the experimental group. Primary statistical analysis was performed by means of t-test and analysis of covariance. Results indicated significant improvements in empowerment $\{t(48) = 6.54; p < 0.0001\}$ among patients in the experimental group compared with those in the control group (Tsay & Hung, 2004). The results of this study highlight the complexities in attempting to quantify the concept of empowerment (Tims, King, & Bennet, 2007) for this patient population.

Limitations noted in this study include: 1) small sample size ($n = 50$); and 2) non-generalizable (may not be applicable to diverse sociodemographic HD patient populations to include variables such as race or ethnicity). The sample for this study was drawn from two (2) dialysis centers of major hospitals in southern Taiwan.

Therefore, based upon limitation, future work will incorporate the aforementioned Common Sense Model (CSM) based on Leventhal's Self-Regulation Model (SRM) within the context of this dissertation study.

Tools Related to Empowerment

A patients' degree of empowerment should be assessed like any other component of therapy, and healthcare professionals should be trained to consult with patients to refine self-management and empowerment skills (McCarley, 2009).

Details of the Diabetes Empowerment Scale – Short Form (DES-SF). The DES-SF is an empowerment scale, which can be used for HD patients with Type 2 DM with the permission of the Michigan Diabetes Research and Training Center (MDRTC) (Appendix D). See Table 2. The MDRTC developed the DES-SF in part for the use by healthcare professionals. By downloading the forms, the PI agreed to acknowledge the MDRTC as the source of the items in the survey instruments in any written instruments, reports, or publications resulting from their use or reproduction.

In 2000, Anderson, et. al. developed the Diabetes Empowerment Scale (DES) to measure the psychosocial self-efficacy of people with diabetes. The

original questionnaire contained 37 items representing eight (8) conceptual dimensions including: 1) assessing the need for change; 2) developing a plan; 3) overcoming barriers; 4) asking for support; 5) supporting oneself; 6) coping with emotion; 7) motivating oneself; and 8) making diabetes care choices appropriate for one's priorities and circumstances. Using factor analyses the questionnaire was reduced to the current 28-item DES ($\alpha = 0.96$) containing three (3) subscales. The three (3) subscales are: 1) managing the psychosocial aspects of diabetes with 9 items ($\alpha = 0.93$); 2) assessing dissatisfaction and readiness to change with 9 items ($\alpha = 0.81$); and 3) setting and achieving goals with 10 items ($\alpha = 0.91$). In addition to providing an overall assessment of diabetes-related psychosocial self-efficacy, the three (3) subscales of the DES allow for an examination of its underlying components.

To allow for a brief overall assessment of diabetes-related psychosocial self-efficacy, Anderson, et. al. (2000) developed an eight-item short form of the DES (the DES-SF; Appendix D). The DES-SF was created by choosing the item from the remaining 28 items with highest items to subscale correlation from each of the original eight (8) conceptual domains. The reliability of the DES-SF using the original dataset was $\alpha = 0.85$. The authors subsequently administered the DES-SF to 229 participants in a study. The reliability of the DES-SF using the data from the sample was $\alpha = 0.84$. The content validity of the DES-SF was supported in the study by DES-SF scores and HbA_{1c} levels changed in a positive direction after the 229 participants completed a 6-week problem-based patient education program. The change in DES-SF scores and HbA_{1c} levels

were not correlated, suggesting that these two measures vary independently (Anderson, et. al., 2000). These data provide evidence that the DES-SF is a valid and reliable measure of overall diabetes-related psychosocial self-efficacy.

Strengths and limitation of the DES-SF. The DES-SF (Appendix D) is a subjective measure of empowerment for HD patients with Type 2 DM (Anderson, et. al., 2000). Strengths include: 1) brevity; 2) speed of completion for patients; 3) easy interpretation of scores; 4) useful for ill and elderly populations who would find completion of a long questionnaire (such as the DES) difficult; 5) advantageous when researchers are already using a other pencil-and-paper measures but wish to also include an assessment of empowerment; 6) advantageous when researchers need to assess empowerment repeatedly over a relatively short period, to reduce the burden on research participants; 7) valid and reliable measure of empowerment in a variety of illness groups (including HD patients with Type 2 DM); 8) easy to understand and to complete for patients; 9) results from the scale can be easily scored and are readily interpretable by researchers and clinicians; and 9) the scale has been adapted to enable the patient to respond in various languages. A limitation is self-reporting can reflect inaccurate information if the patient has difficulty understanding what is written, or cannot see or physically write out responses (however, the questionnaire can be used with an interpreter in future studies, if deemed necessary).

Is There an Association between Illness Perceptions and Perceptions of Empowerment?

Based on the literature, we know that: 1) challenges may lead to a *negative* perception of illness; and 2) challenges may lead to a *decrease* in empowerment. However, what we do not know is whether there is an association between illness perceptions and empowerment and why this may be important? It is important to study this concept because if we can identify an association between illness perceptions and perceptions of empowerment – we can examine how to modify illness perceptions impairment. Therefore, indirectly address empowerment.

Traditionally, the nephrology team (consisting of various healthcare professionals) focuses educational efforts on providing patients with the knowledge needed to comply with the prescribed treatment regimen. However, studies have consistently indicated that patients cannot be forced to follow a lifestyle that is decided by others. Therefore, patient empowerment and self-management are crucial to ensure that patients know they are still in control of their lives and are motivated to become engaged partners with their nephrology healthcare team (McCarley, 2009).

This dissertation study will provide a better understanding of illness perceptions of HD patients with Type 2 DM and their association with perceptions of empowerment and how this association impacts QoL. Since there is not enough literature on this topic, the outcomes of this dissertation study will provide a foundation for and insight regarding HD patients with Type 2 DM.

Findings from this dissertation study may positively impact educational threads by bringing attention to the need for nephrology healthcare providers to identify HD patients' (with Type 2 DM) illness perceptions and their association with perceptions of empowerment. By modifying illness perceptions impairments, empowerment can, therefore, be indirectly addressed. Educational interventions for this patient population may then be designed, specifically for identification and coping strategies, ultimately increasing QoL. Subsequently, this can provide a basis for developing interventions aimed at altering patients' illness perceptions to improve perceptions of empowerment.

Chapter III

METHODS

Study Design

Pilot phase. The pilot study design was an exploratory one. Data was used to determine the sample size for this dissertation study based on power analysis (Erdfelder, Faul, & Buchner, 1996). Methodology was reviewed to ensure technical and logistical aspects were capable of being achieved. The pilot study confirmed the methodology including procedures was sound. Ultimately, the dissertation study findings were supported by the pilot study findings.

Definitive study. In this dissertation study (prospective, cohort-nested, case-control, quantitative), a cohort (N = 101) of 51 HD patients with Type 2 DM (Group 1; case) was developed from among the patients of one out-patient dialysis center {St. Joseph's Regional Medical Center (SJPMC) located at 703 Main Street in Paterson, NJ; Chief Nephrologist: Chandra B. Chandran, MD} in addition to 50 non-dialysis patients with Type 2 DM (Group 2; control) from one family medicine clinic at SJPMC.

Tools

The Brief-IPQ is a psychosomatic scale, which was used to measure illness perceptions of HD patients with Type 2 DM with the permission of the authors (Appendix C; Appendix H).

The DES-SF is an empowerment scale, which was used to measure empowerment of HD patients with Type 2 DM with the permission of the Michigan Diabetes Research and Training Center (Appendix D).

Sociodemographic information. A General Information Form (GIF) (Appendix E) questionnaire with seven (7) dimensions of sociodemographic information was developed for this research including: 1) gender; 2) age; 3) length of time on dialysis; 4) primary language spoken at home; 5) race or ethnicity; 6) years of basic schooling; and 7) employment status. The Paterson public schools public report from the New Jersey Department of Education was used to develop the GIF, specifically regarding race, ethnicity, and primary language spoken at home (Glascoe, 2009).

Coding of all research materials. Coding of all returned research packets (including all of their survey contents) was performed as follows. Each survey form – for each participant to be surveyed – was numbered using a gently pressed pencil mark on the back of each survey within the research packet (to be administered by administrative personnel). The contents of surveys within each research packet had the same number. The following numbering system was developed to track the results (Sexton, et. al., 2004). The tracking number incorporated the month and year of the survey, which was helpful in keeping data organized, especially when the pilot study was approved and extended for use within the dissertation study, as obtained data was useful in application for the dissertation study (as an example of how surveys would be conducted multiple times). Please note codes that may obviously identify participants were not

used. Using the criteria previously described within the initial IRB Application form, the PI determined that the proposed pilot study required 40 research packets. The PI began conducting the pilot study in May 2010, so the research packets (and all of their survey contents) were numbered sequentially as 0510-01 through 0510-40. A good response rate was essential for meaningful results; therefore, the PI had a response rate of at least 65 percent ($n = 26$) before analyzing and presenting the results. The PI began conducting the dissertation study in December 2010, so the research packets (and all of their survey contents) were numbered sequentially as 1210-01 through 1210-80. By using a numbering system with ranges, the PI was able to determine how many surveys have been returned; and to better maintain organization for possible future use.

Study Participants

All relevant permissions and ethical approval to conduct this research were obtained from the organizations (SHU as well as SJRMC, respectively) concerned. Anonymity of patients and confidentiality of data was preserved. Patients were informed of the purpose of the study and about the principles of voluntary and anonymous participation. Patients who returned their questionnaires were deemed to have given voluntary consent.

The target populations were HD patients with Type 2 DM (Group 1) at one out-patient dialysis center at SJRMC and non-dialysis patients with Type 2 DM (Group 2) at one family medicine clinic at SJRMC. The pilot study participants consisted of a sample of 20 HD patients with Type 2 DM from a cohort of 120 HD patients (with or without Type 2 DM). This sample size was based on the

statistic that 44% of ESRD patients will have DM. In addition, 20 non-dialysis patients with Type 2 DM from the family medicine clinic were obtained. The two (2) groups were matched based on age and gender. The dissertation study participants (N = 101) consisted of 51 HD patients with Type 2 DM and 50 non-dialysis patients with Type 2 DM from the same locations as the pilot study, stated above.

Inclusion criteria. Participants were HD or non-dialysis patients with Type 2 DM who: 1) were under a physician's care; 2) were between the ages of 18 and 85; and 3) had no previous history of renal replacement therapy (Timmers, et. al., 2008).

Exclusion criteria. Participants (HD or non-dialysis) patients with Type 2 DM) who: 1) were under 18 years of age *or* older than 85 years of age; and 2) had previous history of renal replacement therapy.

Study Site

The setting of the study was one out-patient dialysis center located at SJRMC at 703 Main Street, Paterson, New Jersey, 07503 (northeastern NJ) and one family medicine clinic located at SJRMC. St. Joseph's Regional Medical Center is a tertiary care teaching hospital in an urban community. The institution represents one of several affiliated facilities within the St. Joseph's Healthcare System (including another acute-care facility, a long-term care facility, and children's hospital). The out-patient dialysis center had a capacity of 60 HD patients per shift (3 shifts per day; 6 days per week; therefore, 360 HD

treatments per week). All records were obtained from dialysis patients at SJRMC.

Procedure

Figure 3 provides the schematics of the procedures involved in this dissertation study. Approval to conduct research was obtained from the Nephrology Council of the participating institution. Upon approval, access to participants was done in collaboration with the Directors of Nephrology, Family Medicine & Research of the participating institution. Potential participants {HD patients with Type 2 DM (Group 1) and non-dialysis patients with Type 2 DM (Group 2)} were identified by designated administrative personnel of the institution. All participants were recruited through a solicitation letter (Appendix A). This letter included an explanation of the purpose of the research study, an indication that participation is voluntary, and that confidentiality and participant anonymity will be maintained throughout the study. This letter was stapled on the research packet. The packet contained the survey questionnaires, the IRB approved informed consent (Appendix B), and a return envelope. An additional copy of the informed consent (Appendix B) was provided in the packet for participants own records. The packet was given to each participant during their normally scheduled HD treatment or family medicine clinic visit by designated administrative personnel. Eligibility was determined by the completion of 3 questions in the solicitation letter (Appendix A) including: 1) Are you between the ages of 18 and 85?; 2) Do you have Type 2 Diabetes Mellitus?; and 3) Do you have NO history of renal replacement therapy? If the participants met the

eligibility criteria they were requested to complete the Brief IPQ (Appendix C) (Broadbent, et. al., 2005) (to collect illness perceptions data), the DES-SF (Appendix D) (Anderson, et. al., 2000; Tsay & Hung, 2004) (to collect empowerment data), and the GIF (Appendix E) (to collect sociodemographic information data). See Table 4.

The PI chose to use the short forms because of their good validity and reliability, especially because they were used in combination – given the rapid assessment format.

Spanish translation. As per SHU IRB's policies and procedures, the Letter of Solicitation and Informed Consent documents were submitted in both English and Spanish. A statement of certification as to the accuracy of the translation from an authorized company (ASTA-USA) on their letterhead stationary accompanied all such documents. English and Spanish versions (Certification of Spanish Translation – Appendix I) of each instrument were provided to each participant within the research packet⁵. The collection of all data was a one-time

⁵ *Brief Illness Perception Questionnaire (Brief IPQ) (Spanish version).* The Brief IPQ has been translated into 22 different languages including Spanish. A special acknowledgement to Eliana Guic from Universidad Católica de Chile will be applied to all submissions and publications as her translation of the Brief IPQ into Spanish is copyrighted. The PI corresponded with the original author, Liz Broadbent and on December 6, 2009 received written permission via e-mail to use both the English and Spanish versions of the Brief IPQ. The accuracy of the Spanish translation of the Brief IPQ was explored by Pacheco, et. al. (2007). The aforementioned researchers designed the methodology in two (2) phases: 1) transcultural adaptation of the Brief IPQ (Spanish version) including: a) double translation; b) pilot; c) double back translation; and d) consensus and discussion with the team; and 2) cross-sectional study and assessment of psychometric characteristics. The researchers compared results (Spanish version) with original validation studies (English version). Statistical analyses included the following: 1) descriptive and response process analyses – out of 579 participants, 53% were women, with a mean age (SD) of 59.2; 2) reliability (Cronbach's coefficient alpha) at 0.668; 3) test-retest in a subgroup; and 4) validity (Principal Component Analysis – Varimax) 2 components (emotional/inside and cognitive/outside) explain 57.3% of variance. The researchers concluded that the Brief IPQ (Spanish version) is a "structurally valid and reliable instrument to identify peoples' perceptions and develop interventions that take in account cognitive representations and emotional responses to chronic diseases that can facilitate to develop a shared decision making."

collection that took approximately 45 minutes. Any questions the participants may have had was encouraged and promptly answered by the designated administrative personnel. Please note participants were able to stop offering

The Brief IPQ (Spanish version) is often used in the field. For example, in one study conducted by Mann, et. al. (2008), titled, "Misconceptions about diabetes and its management among low-income minorities with diabetes", the researchers findings demonstrated that among the 151 study participants {which were predominately Latino/a (58%) and African American (34%), with low income (89% <\$30,000 per year)} despite having longstanding disease and regular outpatient diabetes care, participants frequently hold disease and medication beliefs that are inconsistent with a chronic disease model of diabetes. Using both the English and Spanish version of the Brief IPQ, all English- or Spanish- speaking adults with type 2 diabetes mellitus (DM) were eligible and able to self-report using the validated tools (Broadbent, et. al., 2006).

Diabetes Empowerment Scale – Short Form (DES-SF) (Spanish version). The DES-SF has been translated into Spanish by the Michigan Diabetes Research and Training Center (MDRTC) (2000). The MDRTC has developed several survey instruments for diabetes patients and health professionals including the Spanish version of the DES-SF. By downloading the forms, the researcher agrees to acknowledge the MDRTC as the source of the items in the survey instruments in any written instruments, reports, or publications resulting from their use or reproduction as per MDRTC's website at <http://www.med.umich.edu/mdrtc/profs/survey.html>.

The accuracy of the Spanish translation of the instrument was confirmed in north Texas by Melancon, et. al. in 2009 when the researchers administered the survey to 82 participants in the north Texas region to measure self-efficacy (versus northern region of United States where the original Spanish version of the instrument was developed). To increase the accuracy of responses, questionnaires were provided in English and Spanish to all participants in a dual-language format (English and Spanish) by the original author (MDRTC, 2000). However, the original instrument was developed in the northern region of the United States (Michigan). To ensure the dialect was similar to that used by the populations of north Texas, back translation was completed by a bi-lingual, Mexican-American Assistant at the local university located in north Texas. The new version was also reviewed for accuracy by the lead facilitator at a church located in north Texas. Data was coded using the scoring guidelines provided by the original author (MDRTC, 2000). Based on suggestions from a member of the research team, who is also a native of Mexico and a trained linguist and instructor of ESL, the instrument was adapted from a 5-point to a 4-point Likert scale. The translator suggested the removal of phrase, "strongly disagree," as it was not culturally meaningful for this population in north Texas. To clarify answers, the term 'disagree' was used exclusively. Following this change, the modified instrument was pre-tested with a sample of six (6) participants in the community. Results from the pre-test demonstrated there were strong correlations between original and new format ($r^2 = 0.85$). The PI believes that given the proposed study location is in the northern United States (Paterson, NJ) similar to where the instrument was originally developed, the Spanish version provided by the original authors (MDRTC, 2000) is most appropriate and acceptable for use in the proposed sample population.

The DES-SF (Spanish version) is often used in the field. For example, in one study conducted by Sarkar, Fisher, & Schillinger (2006), titled, "Is self-efficacy associated with diabetes self-management across race/ethnicity and health literacy?", the researchers found an association among the 413 participants (18% Asian/Pacific Islander; 25% African American; 42% Latino/a; and 15% white) and increasing self-efficacy score and self-management with regard to diet, exercise, self-monitoring blood glucose, and foot care. Using both the English and Spanish version of the DES-SF, all English- or Spanish- speaking adults with diabetes were eligible and able to self-report using the validated tools (Anderson, et. al., 2000).

their illness perceptions and perceptions of empowerment responses at any time, without any questions or negative responses from the administrative personnel. All participants were asked to seal the completed questionnaire in the return envelope, and place the envelope in a designated drop box located on the out-patient HD unit. The PI collected all research packets from the drop boxes 2 weeks after distribution.

The return of the completed questionnaires was considered consent from the study participants. All information in this study was kept strictly confidential. Data was entered into the GraphPad Prism (Version 5.0) statistical package (Graph Pad Corp., San Diego, CA) and SPSS (Version 18.0) (SPSS, Inc., Chicago, IL) and maintained on a USB memory drive. All research data was stored in locked file cabinet drawer on the out-patient HD unit. The PI and the three (3) members of her dissertation committee are the only individuals who had access to all of the research data for a period of three (3) years. All research data will be destroyed via professional shredding services after that time.

Pilot study experience. The pilot study confirmed the methodology including procedures was sound. The logistics were worked out during the pilot phase. Ultimately, the pilot study served as the base foundation for the definitive study.

Analytical Approaches

The above pilot data collection was carried out over a 3-month period in 2010; the above dissertation study data was carried out over 6-month period beginning in 2010 as well. Sociodemographic data including race or ethnicity (obtained by the GIF; Appendix E) was group-wise compared. Any

sociodemographic variables that were significantly different between the two groups were added, in a forward step-wise fashion, to the logistic regression model to account for confounding effects.

In all tests, the level of statistical significance was set at a P value of < 0.05 (two-tailed). Calculations were performed using GraphPad Prism (Version 5.0) and SPSS (Version 18.0) on a personal computer platform.

From the data obtained from the analyses, the PI was able to address the following research questions and hypotheses using the following analytical approaches:

Research Question 1: Is there a difference in empowerment between HD patients with Type 2 DM (Group 1; case) and non-dialysis patients with Type 2 DM (Group 2; control)?

Hypothesis 1: There is a difference between empowerment between Groups 1 and 2.

Analytical Approach 1: Global sum scores from the DES-SF were used to analyze outcomes associated with empowerment. Distribution was tested by D'Agostino-Pearson Omnibus normality test. For independently assorted samples, a *t*-test was used. If not normally distributed, Mann-Whitney U-test was used (Pearson, D'Agostino, & Bowman, 1977).

Research Question 2: Is there a difference in illness perceptions between HD patients with Type 2 DM (Group 1; case) and non-dialysis patients with Type 2 DM (Group 2; control)?

Hypothesis 2: There is a difference between illness perceptions between Groups 1 and 2.

Analytical Approach 2: Global sum scores from the Brief-IPQ were used to analyze outcomes associated with perceptions of empowerment. Distribution was tested by D'Agostino-Pearson Omnibus normality test. For independently assorted samples, a *t*-test was used. If not normally distributed, Mann-Whitney U-test was used (Pearson, D'Agostino, & Bowman, 1977).

Predictor variables were treated as continuous in that the ordinal data was compiled into an overall global score {for Brief IPQ (Appendix C) as well as the DES-SF (Appendix D)}. All continuous variables were tested for normality by the D'Agostino-Pearson Omnibus normality test (Pearson, D'Agostino, & Bowman, 1977).

Research Question 3: Is there an association between illness perceptions and empowerment in HD patients with Type 2 DM (Group 1)?

Hypothesis 3: There is an association between illness perceptions and empowerment in Group 1.

Analytical Approach 3: Correlation analysis was used. If normally distributed, Pearson's Product-Moment Correlation (PPMC) was used. If not normally distributed, Spearman's Rank Correlation Coefficient was used.

Research Question 4: Is there an association between illness perceptions and empowerment in non-dialysis patients with Type 2 DM (Group 2)?

Hypothesis 4: There is an association between illness perceptions and empowerment in Group 2.

Analytical Approach 4: Correlation analysis was used. If normally distributed, PPMC was used. If not normally distributed, Spearman's Rank Correlation Coefficient was used.

Whenever the assumption of normality could be made (based on the results of the normality tests), parametric methods was used, i.e., for group-wise comparison *t*-tests were used and for correlations, Pearson's Product-Moment method was used. In the event that the results of normality tests suggested the use of non-parametric statistics, the Mann-Whitney U-test was substituted for *t*-tests.

Research Question 5: Is there a difference in association between illness perceptions and empowerment in patients with Type 2 DM who are receiving HD treatment (Group 1) and non-dialysis patients (Group 2) who are not?

Hypothesis 5: There is a difference in association between illness perceptions and empowerment in Groups 1 and 2.

Analytical Approach 5: A regression analysis was used. ANCOVA was used to determine Y slope and intercept. Details: on two lines, one representing the association between illness perceptions and perceptions of empowerment for HD patients with Type 2 DM (Group 1) and another for the association between illness perceptions and perceptions of empowerment for non-dialysis patients with Type 2 DM (Group 2). Both lines are plotted on a graph where there is one independent variable, illness perceptions (plotted on the X-axis) and one dependent variable, empowerment, on the Y-axis. Each line is the ordinary least squares (OLS) best-fit model for the association between the two variables for

each of the two groups. Using this method it is simple to examine the dispersion within the lines {using the 95% confidence bands (95% CB) to do this (Hayter, et. al., 2007)} and the dispersion between the lines (ANOVA). However, since the dispersion is on a "slant", that being the slope of the OLS model represented by the regression lines, it is suggested as another way to think about ANCOVA – a 2-way ANOVA where independent variable is group assignment and the other variable is the regression line.

In all tests, the level of statistical significance was set at a P value of < 0.05 (two-tailed). Calculations were performed using GraphPad Prism (Version 5.0) and SPSS (Version 18.0) on a personal computer platform.

Calculation of sample size. Calculation of sample size for this dissertation study was based on results from the aforementioned exploratory pilot study conducted by the same PI (based on illness perceptions means and pools standard deviations; Timmers, et. al., 2008), using G-power (Erdfelder, Faul, & Buchner, 1996) (*t*-test; $n \sim 40$); because it was powered, even a negative result was meaningful. All research questions were tested at two-sided $\alpha = 0.05$; acceptable Beta was less than or equal to 0.20 (Power = 80%). The number of participants to be included was increased by 15% ($n \sim 46$) based on the Asymptotic Relative Efficiency (ARE) (Randles & Wolf, 1979) for non-parametric analysis and use of the Mann-Whitney U-test. In other words, the ARE allowed the PI to go from a parametric analysis (*t*-test) to a non-parametric statistic (Mann-Whitney U-test). In terms of number of participant needs (vs. *t*-test), the Mann-Whitney U-test never can be more than a 15% difference. Expecting as

much as a 25% dropout rate (or “no response”), 58 participants per group were needed in the sample population. Clearly, the PI reached the appropriate pre-determined sample size (based on the pilot study findings) for this dissertation study given a cohort (N = 101) of 51 HD patients with Type 2 DM (Group 1; case) and 50 non-dialysis patients with Type 2 DM (Group 2; control) (for a total of 101 participants) was achieved.

Ultimately, what the PI hoped to find was an association with illness perceptions and perceptions of empowerment in HD patients with Type 2 DM – so that in future works this dissertation study may lay the foundation and provide insight.

Chapter IV

RESULTS

The purposes of this dissertation study were: 1) to examine if there is an association between illness perceptions and perceptions of empowerment in HD patients with Type 2 DM; and 2) to investigate what differences in illness perceptions and perceptions of empowerment exist between HD patients with Type 2 DM and non-dialysis patients with Type 2 DM. In this prospective, cohort-nested, case-control study (by nature, it is a quantitative one) (N = 101), 51 HD patients with Type 2 DM (Group 1; case) and 50 non-dialysis patients with Type 2 DM (Group 2; control) were developed. In all tests, the level of statistical significance was set at a P value of < 0.05 (two-tailed). Calculations were performed using GraphPad Prism (Version 5.0) and SPSS (Version 18.0) on a personal computer platform. This dissertation study findings were supported by the pilot study.

Description of Sample Findings

The baseline characteristics of participants in each group are presented in Table 3. Similarities and differences in demographics of participants were reviewed based on findings via General Information Form (GIF) data for both groups. All baseline characteristics were equivalent except for 3 of the 7. These 3 (age, gender, and years of basic schooling) will later be examined as potential confounders. The data indicated homogeneity {respectively, (languages, P

Value = 0.230); (ethnicity/race, P Value = 0.148); and (employment status, P Value = 0.068)} and non-homogeneity {respectively, (median age, P Value = 0.0004); (gender, P Value = 0.046); and (years of basic schooling, P Value = 0.013)} of participants across the groups. Any differences that were less than or equal to P Value = 0.05 (respectively, age, gender, and years of basic schooling) were included in a logistic regression model to determine adjusted odds ratio.

From the data obtained from the analyses, the PI was able to address the following research questions and hypotheses using the following analytical approaches:

Description of Research Question 1 Findings.

Research Question 1: Is there a difference in empowerment between HD patients with Type 2 DM (Group 1; case) and non-dialysis patients with Type 2 DM (Group 2; control)?

Hypothesis 1: There is a difference between empowerment between Groups 1 and 2.

Analytical Approach 1: Global sum scores from the DES-SF were used to analyze outcomes associated with empowerment. Distribution was tested by D'Agostino-Pearson Omnibus normality test. For independently assorted samples, a *t*-test was used. Individual values of data are ordinal; however, global sum scores are interval. Non-parametric analyses are used for ordinal data or non-normally distributed data. The PI used the Mann-Whitney U-test because the data was not normally distributed (Pearson, D'Agostino, & Bowman, 1977).

Figure 5 illustrates the spread of DES-SF total scores is consistent between both groups (P Value = 0.722). It makes sense that the spread of DES-SF total scores is consistent between both groups because both groups have Type 2 DM. Similarities between the 2 groups may include the following: 1) managing the psychological aspects of DM; 2) assessing dissatisfaction and readiness to change; and 3) setting and achieving goals.

Research Question 1 Finding: There is no difference between empowerment between Groups 1 and 2. This dissertation finding is consistent with the pilot study finding (pilot; P Value = 0.969).

Description of Diabetes Empowerment Scale – Short Form (DES-SF) Findings.

Description of Research Question 2 Findings.

Research Question 2 had the same set up as Research Question 1; however, the other parameter, illness perceptions, was examined.

Research Question 2: Is there a difference in illness perceptions between HD patients with Type 2 DM (Group 1; case) and non-dialysis patients with Type 2 DM (Group 2; control)?

Hypothesis 2: There is a difference between illness perceptions between Groups 1 and 2.

Analytical Approach 2: Global sum scores from the Brief-IPQ were used to analyze outcomes associated with perceptions of empowerment. Distribution was tested by D'Agostino-Pearson Omnibus normality test. For independently assorted samples, a *t*-test was used. Individual values of data are ordinal;

however, global sum scores are interval. Non-parametric analyses are used for ordinal data or non-normally distributed data. The data was not normally distributed, therefore, the Mann-Whitney U-test was used (Pearson, D'Agostino, & Bowman, 1977).

Predictor variables were treated as continuous in that the ordinal data was compiled into an overall global score {for Brief IPQ (Appendix C) as well as the DES-SF (Appendix D)}. All continuous variables were tested for normality by the D'Agostino-Pearson Omnibus normality test (Pearson, D'Agostino, & Bowman, 1977).

The PI was able to take a look at the Brief-IPQ at the macroscopic level via the use of the global sum scores. However, the PI used the item scores of the Brief-IPQ (specifically, the 8 characteristics) to examine the phenomenon at the microscopic level. Figure 6 illustrates the compilation of Brief-IPQ item scores for both groups (P Value = 0.076). Looking at the Brief-IPQ total scores to see if there was a difference in illness perceptions between the 2 groups, the data did not quite achieve statistical significance based on the pilot study. As a reminder, the calculation of sample size was based on total scores of Brief-IPQ in the pilot study. The fact remains a larger sample might have rendered this statistically significant. A future study, perhaps including a multi-center approach may yield statistically significant results.

Research Question 2 Finding: There is no difference between illness perceptions between Groups 1 and 2. This dissertation study finding is consistent with the pilot study finding as well (pilot; P Value = 0.081).

Characteristic findings of Brief-IPQ. No statistically significance was found of 5 (out of a possible 8) characteristics of the Brief-IPQ (including *personal control, treatment control, identity, concern, and coherence*).

There was no statistical significance between the 2 groups related to *personal control* when asked, "How much control do you feel you have over your illness?" Figure 7 (*personal control* scores) illustrates participants' perception of how much personal control over illness (P Value = 0.450); absolutely no control to extreme amount of control.

There was no statistical significance between the 2 groups related to *treatment control* when asked, "How much do you think your treatment can help your illness?" Figure 8 (*treatment control* scores) illustrates participants' perceptions of how much treatment can help illness (P Value = 0.838); not at all to extremely helpful.

There was no statistical significance between the 2 groups related to *identity* when asked, "How much do you experience symptoms from your illness?" Figure 9 (*identity* scores) illustrates participants' perceptions of how many illness symptoms experienced (P Value = 0.213); no symptoms at all to many severe symptoms.

There was no statistical significance between the 2 groups related to *concern* when asked, "How concerned are you about your illness?" Figure 10 (*concern* scores) illustrates participants' perceptions of concern about illness (P Value = 0.428); not at all concerned to extremely concerned.

There was no statistical significance between the 2 groups related to *coherence* when asked, “How well do you feel you understand your illness?” Figure 11 (*coherence* scores) illustrates participants’ perception of how well illness is understood (P Value = 0.368); don’t understand at all to understand very clearly.

The other 3 (out of a possible 8), which were statistically significant, characteristic findings of the Brief-IPQ included *consequences*, *timeline*, and *emotional representation*. These characteristics are shown as categorical data, which was derived from ordinal data using Receiver Operating Characteristic (ROC) curve analyses; ROC curve analyses determines a “cut-off” score that best separated the 2 groups (Barnabei, Marazia, & De Caterina, 2007). First, we will look at the 3 statistically significant characteristics, which were analyzed in an univariate fashion. Later, we will look at this in light of the affect of potential confounders amongst the baseline characteristics (specifically, age, gender, and years of basic schooling).

There was statistical significance between the 2 groups related to *consequences* when asked, “How much does your illness affect your life?” Figure 12 (*consequence* scores) illustrates non-dialysis participants perceived illness affects their lives more severely (vs. dialysis participants) (P Value = 0.005), when analyzed in an univariate fashion (1 dependent variable, group; and 1 independent variable, consequences scores); not severe to severe. Based on ROC curve analyses, a consequences score ≥ 6 = perception of life more severely affected; < 6 = perception of life less severely affected. Later on, the PI

examines the affect of potential confounders amongst the baseline characteristics.

There was statistical significance between the 2 groups related to *timeline* when asked, “How long do you think your illness will continue?” Also, an univariate analysis, Figure 13 (*timeline* scores) illustrates dialysis participants perceived illness will more likely last forever (vs. non-dialysis participants) (P Value = 0.040); not forever to forever. Based on ROC curve analyses, a timeline score ≥ 9 = perception of illness will most likely last forever; < 9 = perception of illness will less likely last forever.

There was statistical significance between the 2 groups related to *emotional representation* when asked, “How much does your illness affect you emotionally (for example, does it make you angry, scared, upset or depressed?)” Figure 14 (*emotional representation* scores) illustrates non-dialysis participants perception of emotion affecting their lives is greater (vs. dialysis participants) (P Value = 0.0002); not extreme to extreme. Based on ROC curve analyses, an emotional representation score ≥ 4 = perception of emotions more extremely affected; < 4 = perception of emotions less extremely affected.

Multivariate analyses. It was necessary to adjust for potential confounders, specifically, age, gender, and years of basic schooling, using multivariate analyses, which was performed by logistic regression. Table 4, highlights the potential confounders, extracted from the baseline characteristics of the study groups (as previously seen within Table 3).

In all tests, the level of statistical significance was set at a P value of < 0.05 (two-tailed). Calculations were performed using GraphPad Prism (Version 5.0) and SPSS (Version 18.0) on a personal computer platform.

Gender affects the significance of consequences. Table 5 presents consequences as adjusted for potential confounders. Unadjusted consequences (as a characteristic of the Brief-IPQ) had a statistically significant P Value = 0.005. Using logistic regression, the odds ratio (OR) = 3.29 and the 95% confidence interval (95% CI) = 1.45 to 7.47. Consequences, adjusted for age, had a significant P Value = 0.0004 (OR = 5.04; 95% CI = 2.05 to 12.40). Consequences, adjusted for gender, was not significant (P Value = 0.712; OR = 1.17; 95% CI = 0.51 to 2.67). Consequences, adjusted for years of basic schooling, was significant (P Value = 0.023; OR = 2.62; 95% CI = 1.14 to 6.03). Gender affects the significance of consequences. Although non-dialysis participants perceived illness affects their lives more severely (vs. dialysis participants) (P Value = 0.005) (as shown in Figure 12), Table 6 indicates that female dialysis patients, as a group, perceived illness affects their lives more severely (vs. male, non-dialysis; female, non-dialysis; and male, dialysis groups); 13 out of 17 female dialysis participants (78%). Consequences is not a completely independent association – it depends on gender. Further exploration is needed in future studies.

Age and gender affects the significance of timeline. Table 7 presents timeline as adjusted for potential confounders. Unadjusted timeline (as a characteristic of the Brief-IPQ) had a statistically significant P Value = 0.040.

Using logistic regression, the OR = 0.36 and the 95% CI = 0.14 to 0.94.

Timeline, adjusted for age, did not have a significant P Value = 0.095 (OR = 0.44; 95% CI = 0.17 to 1.15). Timeline, adjusted for gender, was not significant (P Value = 0.138; OR = 0.49; 95% CI = 0.19 to 1.26). Timeline, adjusted for years of basic schooling, was significant (P Value = 0.023; OR = 0.37; 95% CI = 0.15 to 0.87). Table 8 indicates 81% (34 out of 42) dialysis patients, 56 years of age or older, perceived illness will more likely last forever (vs. non-dialysis, ≥56 years of age; non-dialysis, <56 years of age; and dialysis, <56 years of age patients). Table 9 shows 79% of male dialysis patients (27 out of 34) perceived illness will more likely last forever (vs. male, non-dialysis; female, non-dialysis; and female, dialysis patients). Timeline is not a completely independent association – it depends on age and gender. Further exploration is needed in future studies.

Through the use of multivariate analyses, the PI was able to confirm emotional representation is a significant characteristic finding and remains an independent variable – regardless of the 3 potential confounders (age, gender, and years of schooling, respectively). Table 10 presents emotional representation as adjusted for potential confounders. Unadjusted emotional representation (as a characteristic of the Brief-IPQ) had a statistically significant P Value = 0.0002. Using logistic regression, the OR = 6.52 and the 95% CI = 2.36 to 17.99. Emotional representation, adjusted for age, was significant (P Value = 0.011; OR = 3.60; 95% CI = 1.35 to 9.62). Emotional representation, adjusted for gender, was significant (P Value = 0.022; OR = 2.96; 95% CI = 1.17

to 7.48). Emotional representation, adjusted for years of basic schooling, was significant (P Value = 0.0002; OR = 7.0; 95% CI = 2.55 to 19.28).

Description of Brief Illness Perception Questionnaire (Brief-IPQ) Findings.

In order to look at an association between illness perceptions in 2 different groups (respectively, HD patients with Type 2 DM; and non-dialysis patients with Type 2 DM), Research Question 3 and 4 must be addressed.

Description of Research Question 3 Findings.

Research Question 3: Is there an association between illness perceptions and empowerment in HD patients with Type 2 DM (Group 1)?

Hypothesis 3: There is an association between illness perceptions and empowerment in Group 1.

Analytical Approach 3: Correlation analysis was used. If the data was normally distributed, Pearson's Product-Moment Correlation (PPMC) would have been used, however, it was not normally distributed. Therefore, the Spearman's Rank Correlation Coefficient was used because the data was not normally distributed. In the event that the results of normality tests suggested the use of non-parametric statistics, the Mann-Whitney U-test was substituted for *t*-tests. Therefore, the Mann-Whitney U-test was used because the data was not normally distributed.

Table 11 indicates a high negative association between illness perceptions and empowerment in HD patients with Type 2 DM (Group 1) ($r_s = -0.493$; P Value = 0.0007).

Research Question 3 Finding: There is a *negative* association between illness perceptions and empowerment in Group 1. As illness perceptions impairment improves, empowerment decreases. The more HD patients with Type 2 DM understood their illness, the less empowered they felt. This goes along with Timeline findings.

Description of association between illness perceptions and empowerment in dialysis participants (DES-SF vs. Brief-IPQ).

Description of Research Question 4 Findings.

Research Question 4: Is there an association between illness perceptions and empowerment in non-dialysis patients with Type 2 DM (Group 2)?

Hypothesis 4: There is an association between illness perceptions and empowerment in Group 2.

Analytical Approach 4: Correlation analysis was used. If the data was normally distributed, the PPMC would have been used. However, the data was not normally distributed, therefore, the Spearman's Rank Correlation Coefficient was used. In the event that the results of normality tests suggested the use of non-parametric statistics, the Mann-Whitney U-test was substituted for *t*-tests. Therefore, the Mann-Whitney U-test was used because the data was not normally distributed.

Table 11 indicates no association was found between illness perceptions and empowerment in the non-dialysis group ($r_s = -0.233$; P Value = 0.108).

Research Question 4 Finding: There is no association between illness perceptions and empowerment in Group 2.

Description of association between illness perceptions and empowerment in non-dialysis participants (DES-SF vs. Brief-IPQ).

Description of Research Question 5 Findings.

This leads us to the 5th and final research question, with an inkling of how it turned out.

Research Question 5: Is there a difference in association between illness perceptions and empowerment in patients with Type 2 DM who are receiving HD treatment (Group 1) and non-dialysis patients (Group 2) who are not?

Hypothesis 5: There is a difference in association between illness perceptions and empowerment in Groups 1 and 2.

Analytical Approach 5: The Analysis of Covariance (ANCOVA), based on linear regression, was used to determine Y slope and intercept. Details: on two lines, one, representing the association between illness perceptions and perceptions of empowerment for HD patients with Type 2 DM (Group 1), and another, for the association between illness perceptions and perceptions of empowerment for non-dialysis patients with Type 2 DM (Group 2). Both lines are plotted on a graph where there is one independent variable, empowerment, (plotted on the X-axis) and one dependent variable, illness perception, on the Y-axis. Each line is the ordinary least squares (OLS) best-fit model for the association between the two variables for each of the two groups. Using this method it is simple to examine the dispersion within the lines {using the 95% confidence bands (95% CB) to do this (Hayter, et. al., 2007)} and the dispersion between the lines (ANOVA). However, since the dispersion is on a "slant", that

being the slope of the OLS model represented by the regression lines, it is suggested as another way to think about ANCOVA – a 2-way ANOVA where independent variable is group assignment and the other variable is the regression line.

Figure 15 compares dialysis vs. non-dialysis participant and whether there is an association between illness perceptions and empowerment. Figure 15 illustrates there is an association between illness perceptions and empowerment in dialysis participants (P Value = 0.004; $r^2 = 0.179$); also, it illustrates there is no association between illness perceptions and empowerment in non-dialysis participants (P Value = 0.122; $r^2 = 0.050$).

Results of ANCOVA are illustrated in Figure 16, whereas, there is an association between illness perceptions and empowerment in dialysis and non-dialysis participants (DES-SF vs. Brief-IPQ) ($P_{\text{slopes}} = 0.198$; $P_{\text{intercept}} = 0.017$).

Research Question 5 Finding: There is a difference in the association between illness perceptions and empowerment in Groups 1 and 2.

Description of association between illness perceptions and empowerment in dialysis and non-dialysis participants (DES-SF vs. Brief-IPQ).

Summary of research question findings. The summary of the 5 research question findings are as follows: 1) There is no difference between empowerment between Groups 1 and 2; 2) There is no difference between illness perceptions between Groups 1 and 2; however, the PI found 3 statistically significant characteristics (specifically, consequences, timeline, and emotional representation) from the Brief-IPQ via univariate analyses; **3) There is a**

negative association between illness perceptions and empowerment in Group 1; 4) There is no association between illness perceptions and empowerment in Group 2; and 5) There is an association between illness perceptions and empowerment in Groups 1 and 2.

Summary of significant characteristic findings. Univariate analyses indicated differences between 3 characteristics of the Brief-IPQ. First, the non-dialysis group perceived illness affects their lives more severely (consequences; P Value = 0.005). However, via multivariate analyses, the PI discovered 78% of female dialysis patients perceived illness affects their lives more severely (vs. any other group). Secondly, the dialysis group perceived illness will more likely last forever (timeline; P Value = 0.040). However, via multivariate analyses, the PI discovered both age and gender affects the significance of timeline. Lastly, the non-dialysis groups perception of emotion affecting their lives is greater (emotional representation; P Value = 0.0002), which turned out to be insensitive to any of the 3 potential confounders (age, gender, and years of schooling, respectively).

Chapter V

DISCUSSION

Theoretical Application

There is an Association between Illness Perceptions and Perceptions of Empowerment

Prior to the completion of this dissertation study, based on the literature, we knew that: 1) challenges may lead to a *negative* perception of illness; and 2) challenges may lead to a *decrease* in empowerment. Prior to this dissertation, what we did not know is whether there is an association between illness perceptions and empowerment. But, now we know there is. There is an association between illness perceptions and empowerment in non-dialysis and dialysis participants.

It was important to examine this theoretical concept because if we could identify an association between illness perceptions and perceptions of empowerment – we could examine how to modify illness perceptions impairment (such as consequences, timeline, and emotional representations). Therefore, we are now able to indirectly address empowerment. We have been successful, through this work, at suggesting the associations to formulate practice application based on our theoretical framework.

Let's revisit the Empowerment Theory and look at how it relates to these dissertation findings. Traditionally, the nephrology team (consisting of various

healthcare professionals including Registered Dietitians) focused educational efforts on providing patients with the knowledge needed to comply with the prescribed treatment regimen. However, studies have consistently indicated that patients cannot be forced to follow a lifestyle that is decided by others.

Therefore, patient empowerment and self-management are crucial to ensure that patients know they are still in control of their lives and are motivated to become engaged partners with their nephrology healthcare team (McCarley, 2009).

Patient education is an important component in the management of dialysis patients (Rantanen, et. al., 2008; Klang, et. al., 1998). Good quality patient education is based on patients' individual needs (Rantanen, et. al., 2008; Leino-Kilpi & Vuorenheimo, 1994); therefore, it is important to focus educational efforts based on individual perceptions of empowerment.

The empowerment approach suggests that patients have the capacity to make choices and be responsible for the consequences of their actions (Rantanen, et. al., 2008; Curtin, Johnson, & Schatell, 2004; Feste & Anderson, 1995).

This dissertation study provides a better understanding of illness perceptions of HD patients with Type 2 DM and their association with perceptions of empowerment and how this association impacts QoL. Since, previously, there was not enough literature on this topic, the outcomes of this dissertation study, therefore, have provided a foundation for and insight regarding HD patients with Type 2 DM.

Findings from this dissertation study may positively impact educational threads by bringing attention to the need for nephrology healthcare providers to identify HD patients' (with Type 2 DM) illness perceptions and their association with perceptions of empowerment. By modifying illness perceptions impairments, empowerment can, therefore, be indirectly addressed. Educational interventions for this patient population may then be designed, specifically for identification and coping strategies, ultimately increasing QoL. Subsequently, this can provide a basis for developing interventions aimed at altering patients' illness perceptions to improve perceptions of empowerment.

Implications for Practice

Let's review some practical applications for these dissertation findings. The results of this dissertation study have important implications related to the attention that healthcare professionals pay to the perceptions of empowerment of HD patients with Type 2 DM. In addition, results are valuable in planning individualized patient education and can be used to increase the patient's input in the treatment planning phase.

Consequences and patient education. Patient education is an important component in the management of dialysis patients (Rantanen, et. al., 2008; Klang, et. al., 1998). Good quality patient education is based on patients' individual needs (Rantanen, et. al., 2008; Leino-Kilpi & Vuorenheimo, 1994); therefore, it is important to focus educational efforts based on individual perceptions of empowerment. The empowerment approach suggests that patients have the capacity to make choices and be responsible for the

consequences of their actions (Rantanen, et. al., 2008; Curtin, Johnson, & Schatell, 2004; Feste & Anderson, 1995).

Non-dialysis participants perceived illness affects their lives more severely (vs. dialysis participants) (P Value = 0.005) as illustrated in Figure 12 (consequences scores). Diabetes care is not only to maintain stable levels of blood sugar, but also to avoid the consequences it may bring to the various body systems (NKF, 2011). Patient education for those with Type 2 DM within a clinic setting may focus on the following topics: 1) diabetic neuropathy (decreased limb sensitivity, ulcers, reduced blood supply, amputation); 2) heart disease (altered levels of sugar in blood, heart works beyond capacity, weakened heart muscle); 3) renal failure (damage to the filter system of the kidneys); and 4) diabetic retinopathy (damage to retina because of circulatory failure, macular degeneration, blindness). Providing patient education regarding how to prevent consequences, via the empowerment approach, may reduce non-dialysis participants' perception that illness affects their lives more severely. As determined via multivariate analyses, consequences is not a completely independent association – it depends on gender, specifically females. Further exploration is needed in future studies.

Timeline and racial disparity awareness. Dialysis participants perceived illness will more likely last forever (vs. non-dialysis participants) (P Value = 0.040) as illustrated in Figure 9 (timeline scores). In one study titled, "Why don't more African-Americans on dialysis get transplants?", over 600 patients and 278 nephrologists by Harvard physician-investigators were surveyed in 2004. It is

well-known that blacks are less likely to get renal transplants than whites (QI, 2011). This is found to be true – even when they are eligible, and insurance status, as well as other illnesses, are controlled for. The survey results suggested that nephrologists were less likely to believe that transplantation improves survival for blacks than whites (69% vs. 81%). Blacks were less likely than whites to report receiving some or a lot of information about transplantation (55% vs. 74%). Raising awareness of patients' eligibility to receive renal transplants may empower dialysis participants who perceive illness will more likely last forever. Timeline is not a completely independent association – it depends on age and gender, specifically male patients, 56 years of age and older. Further exploration is needed in future studies.

Emotional representation and mental health management. Non-dialysis participants perception of emotion affecting their lives is greater (vs. dialysis participants) (P Value = 0.0002) as illustrated in Figure 14 (emotional representation scores). Greater emotional representation of DM is associated with poorer self-care and impaired metabolic control. Adults with DM are twice as likely to be depressed than similar individuals without DM; and depression is associated with poor glycemic control. Findings from a cross national survey revealed 41% of people with DM had poor psychological well-being. According to Paddison, et. al., 2010, the majority of healthcare professionals believe that psychological problems affect their patients' self-management behavior. Focusing on mental health management as a component within the multi-

disciplinary approach in treating Type 2 DM may empower patients, thereby, reduce illness perceptions of emotion negatively affecting their lives.

Chapter VI

SUMMARY AND CONCLUSION

Limitations

One limitation of this dissertation study included the use of a single-center for each group. The sample for this study was drawn from one out-patient dialysis center located at SJRMC at 703 Main Street, Paterson, New Jersey, 07503 (northeastern NJ) and one family medicine clinic located at SJRMC. St. Joseph's Regional Medical Center is a tertiary care teaching hospital in an urban community. The institution represents one of several affiliated facilities within the St. Joseph's Healthcare System (including another acute-care facility, a long-term care facility, and children's hospital). Perhaps future works could include a multiple-center approach model, thereby, increasing the likelihood of generalizability.

By using the Brief-IPQ and the DES-SF, another limitation was self-reporting, which has the potential to reflect inaccurate information, if the patient has difficulty understanding what is written, or cannot see or physically write out responses. However, the questionnaire can be used with an interpreter in future studies, if deemed necessary.

The results are generalizable to primarily urban populations given the diversity of the sample patient population from SJRMC.

Conclusions

In sum, the purposes of this dissertation study were: 1) to examine if there is an association between illness perceptions and perceptions of empowerment in HD patients with Type 2 DM; and 2) to investigate what differences in illness perceptions and perceptions of empowerment exist between HD patients with Type 2 DM and non-dialysis patients with Type 2 DM. So why was this study done? This study was done to add to the literature, knowledge concerning how to increase the QoL of dialysis patients with Type 2 DM.

Findings from this dissertation study may positively impact educational threads by bringing attention to the need for nephrology healthcare providers (including Registered Dietitians) to identify HD patients' (with Type 2 DM) illness perceptions and their association with perceptions of empowerment. By modifying illness perceptions impairments, empowerment can, therefore, be indirectly addressed. Educational interventions for this patient population may then be designed, specifically for identification and coping strategies, ultimately increasing QoL. Subsequently, this can provide a basis for developing interventions aimed at altering patients' illness perceptions to improve perceptions of empowerment.

We can address illness perceptions impairments through the empowerment approached, based on the empowerment theory, because we now know for sure there is an association.

Regarding consequences, through the empowerment theory approach we now know to educate female non-dialysis patients with Type 2 DM regarding

health topics such as heart failure and diabetic retinopathy; ultimately, to increase their QoL.

Pertaining to timeline, we now know to empower male dialysis patients with Type 2 DM, 56 years of age or older, with the knowledge they may be eligible for a renal transplant.

Also, we now know this study supports focusing on mental health management of non-dialysis patients with Type 2 DM via the empowerment theory approach.

A lot of future studies may be administered with this dissertation study serving as the foundation.

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Figure 1.
The Common Sense Model (CSM).

The Common Sense Model (CSM).

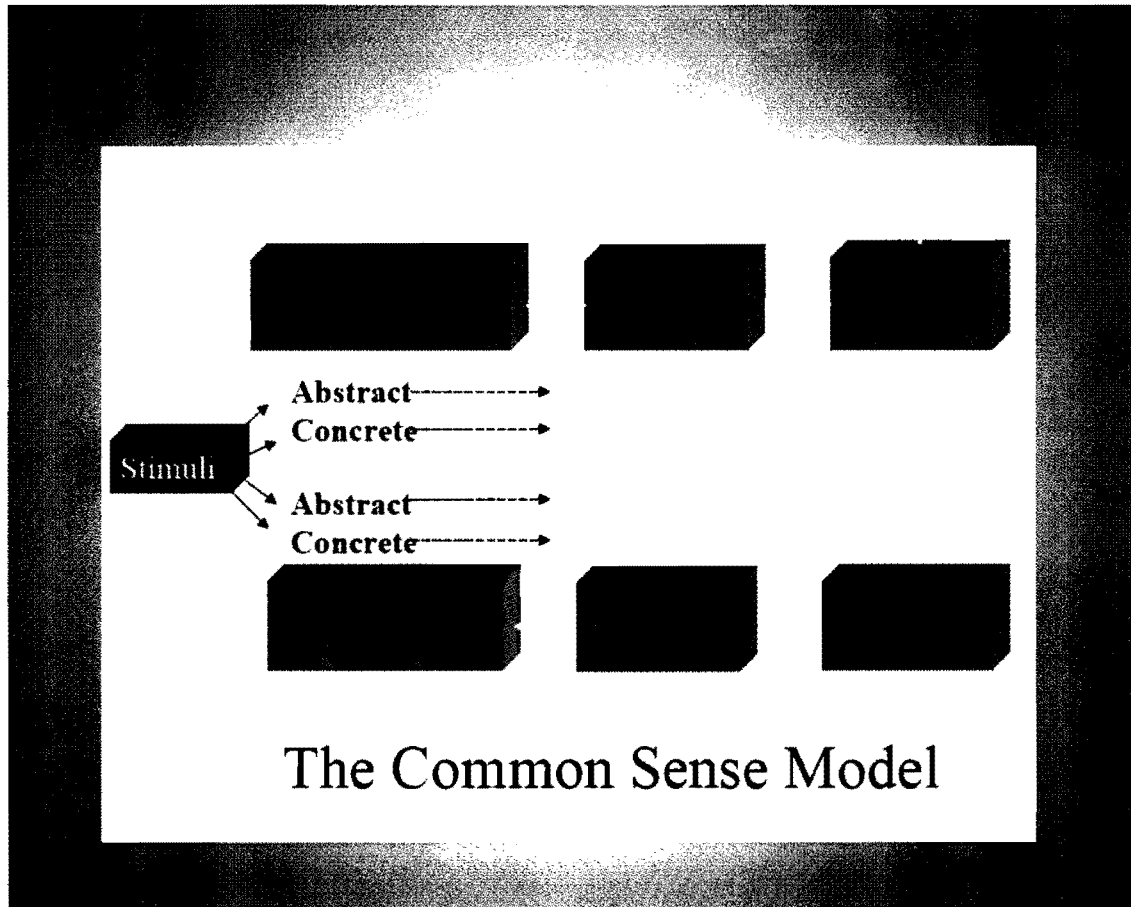


Figure 2.

The 5 domains of the Common Sense Model (CSM).

The 5 domains of the Common Sense Model (CSM).

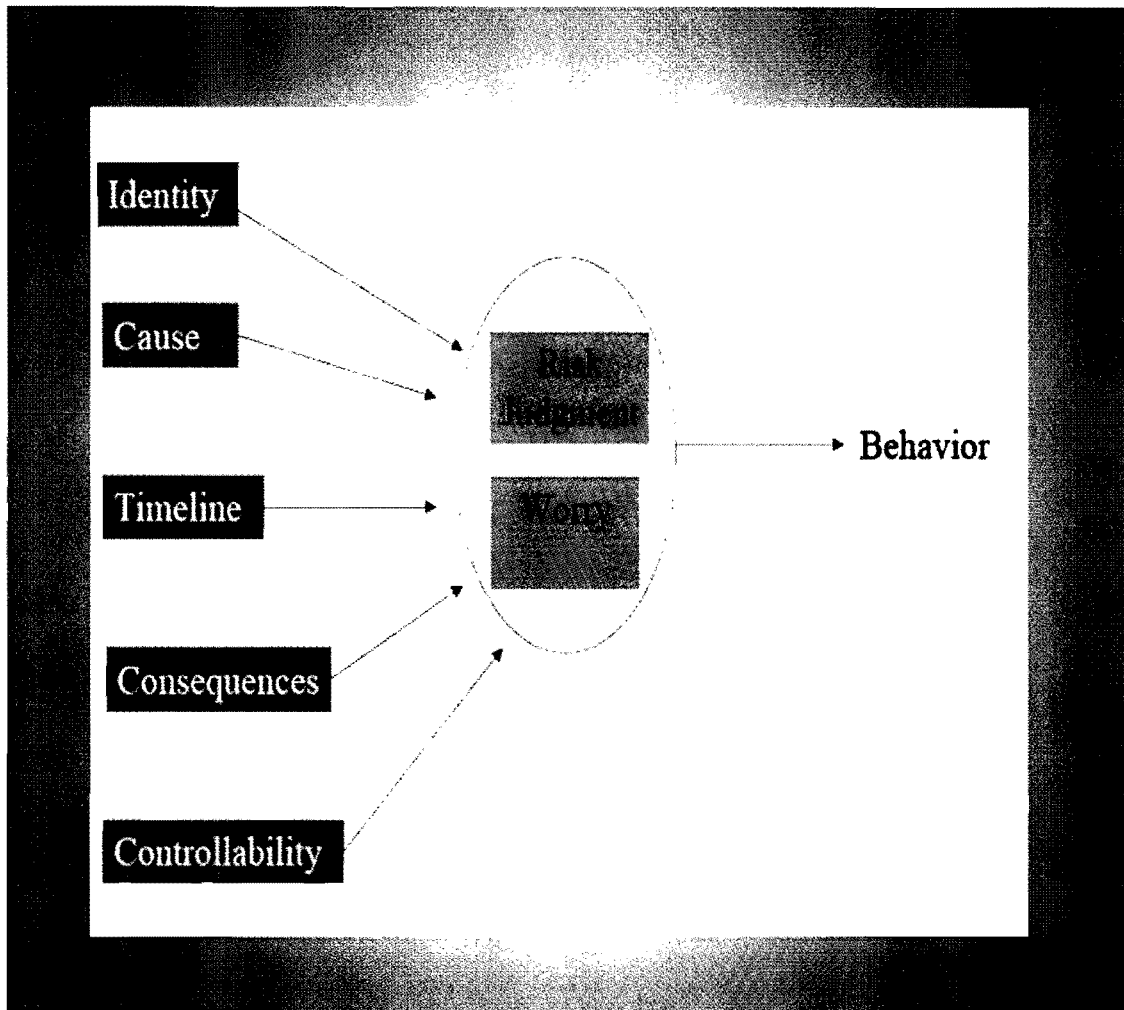


Figure 3.

**Schematics of theoretical framework for dissertation study:
illness perceptions and empowerment may influence one another.**

**Schematics of theoretical framework for dissertation study:
illness perceptions and empowerment may influence one another.**

HD Patients with Type 2 DM Face Challenges

Is there a difference in association between
and
in patients with Type 2 DM
who are receiving treatment and patients
and their age and gender controlled matches who are not?

Figure 4.

Schematics of dissertation study procedures.

Schematics of dissertation study procedures.

SJPMC's Administrative Personnel

Informed Consent
Brief IPQ
DES-SF
GIF
pencil

Figure 5.

The spread of DES-SF total scores is consistent between both groups.

The spread of DES-SF total scores is consistent between both groups.

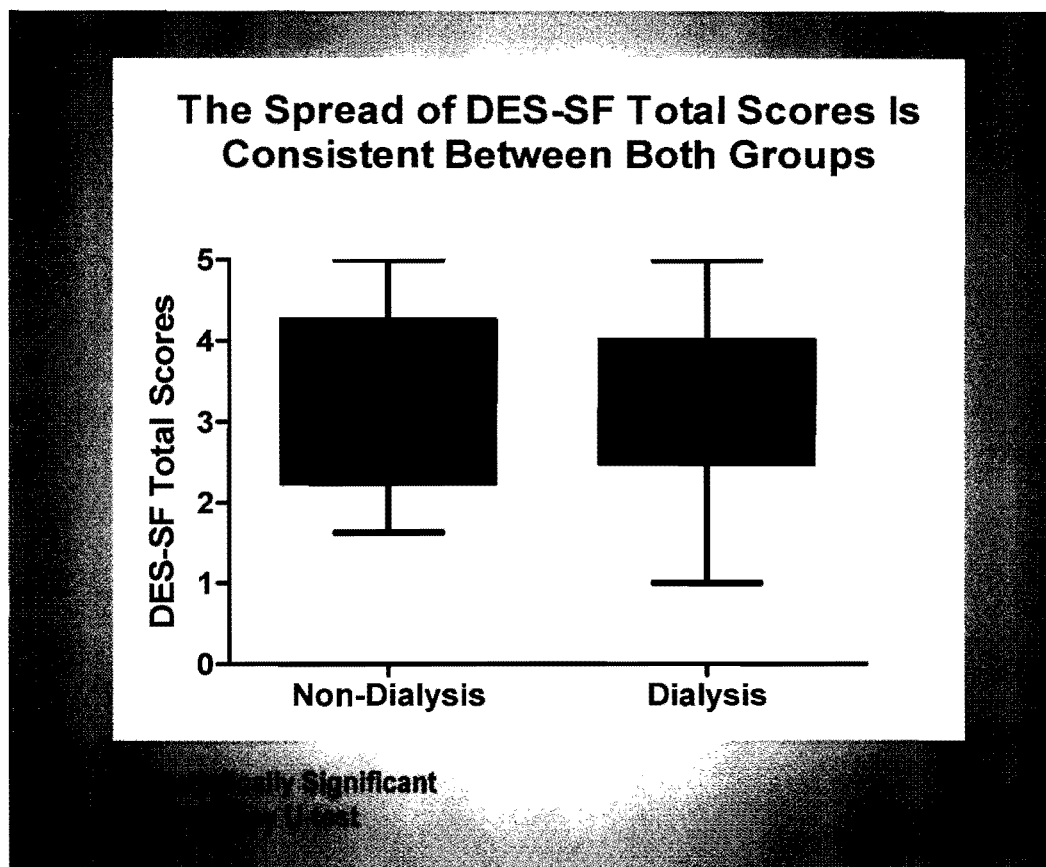


Figure 6.

The compilation of Brief-IPQ item scores for both groups.

The compilation of Brief-IPQ item scores for both groups.

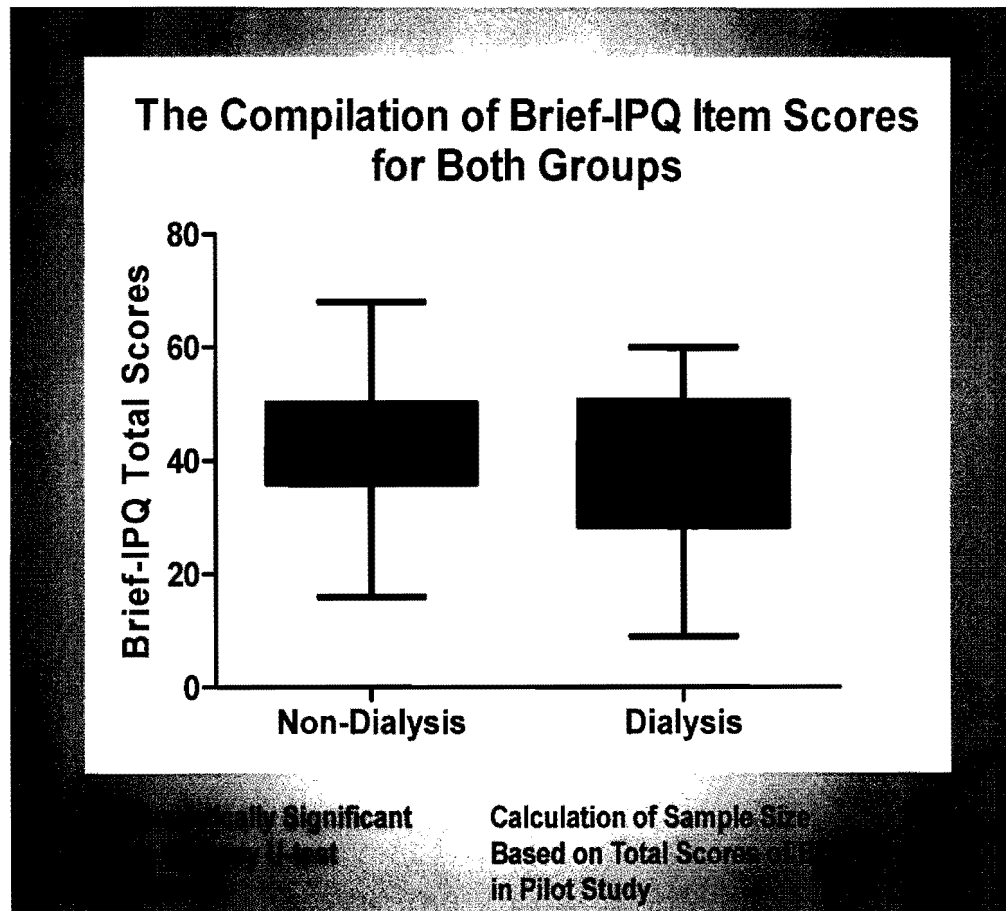


Figure 7.

Participants' perceptions of how much personal control over illness.

Participants' perceptions of how much personal control over illness.

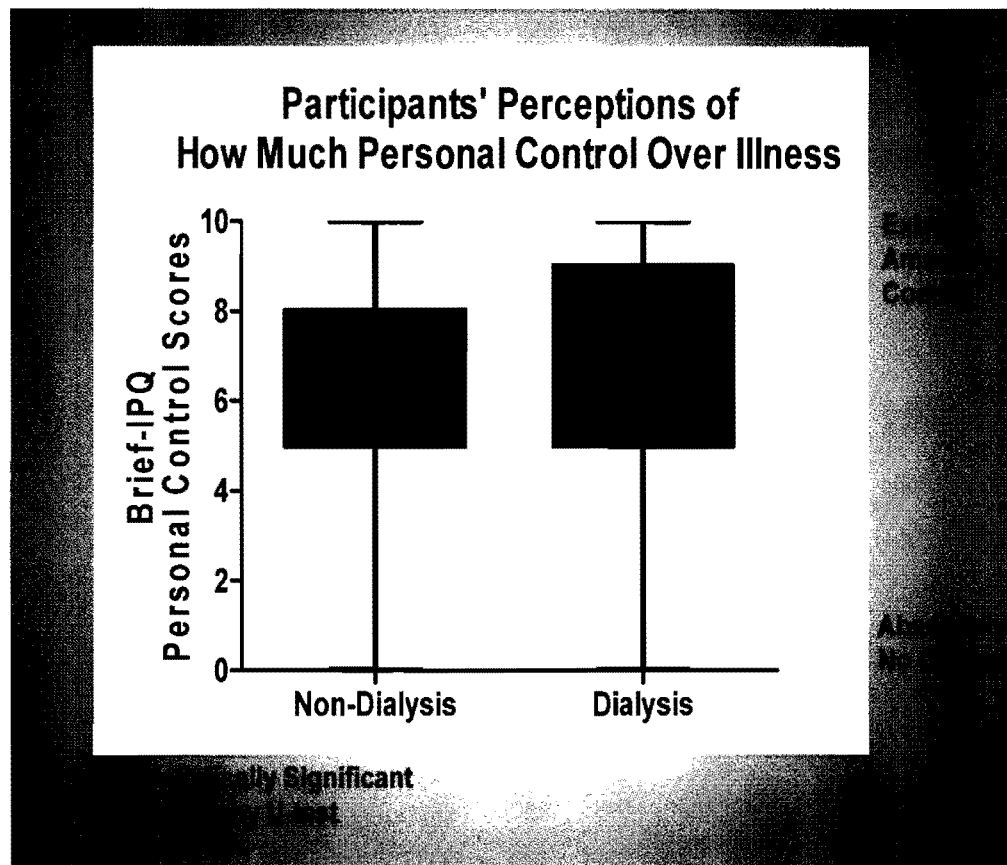


Figure 8.

Participants' perceptions of how much treatment can help illness.

Participants' perceptions of how much treatment can help illness.

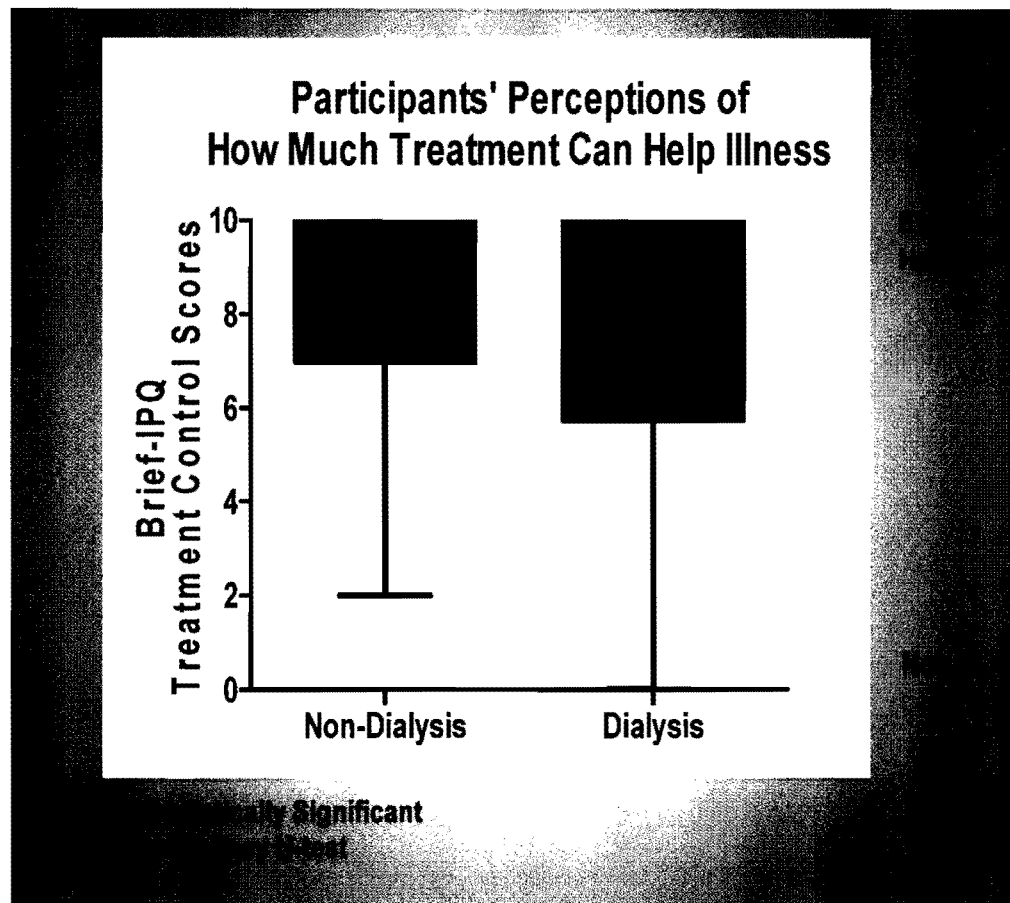


Figure 9.

Participants' perceptions of how many illness symptoms experienced.

Participants' perceptions of how many illness symptoms experienced.

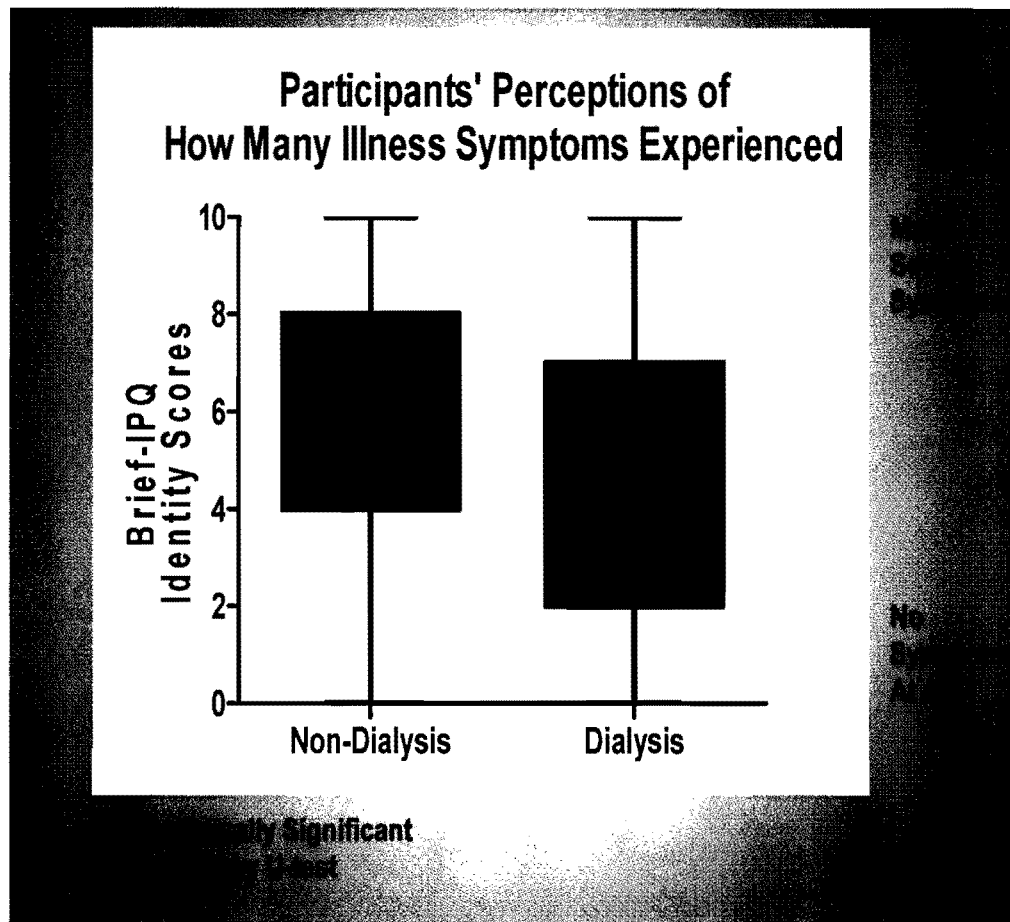


Figure 10.

Participants' perceptions of concern about illness.

Participants' perceptions of concern about illness.

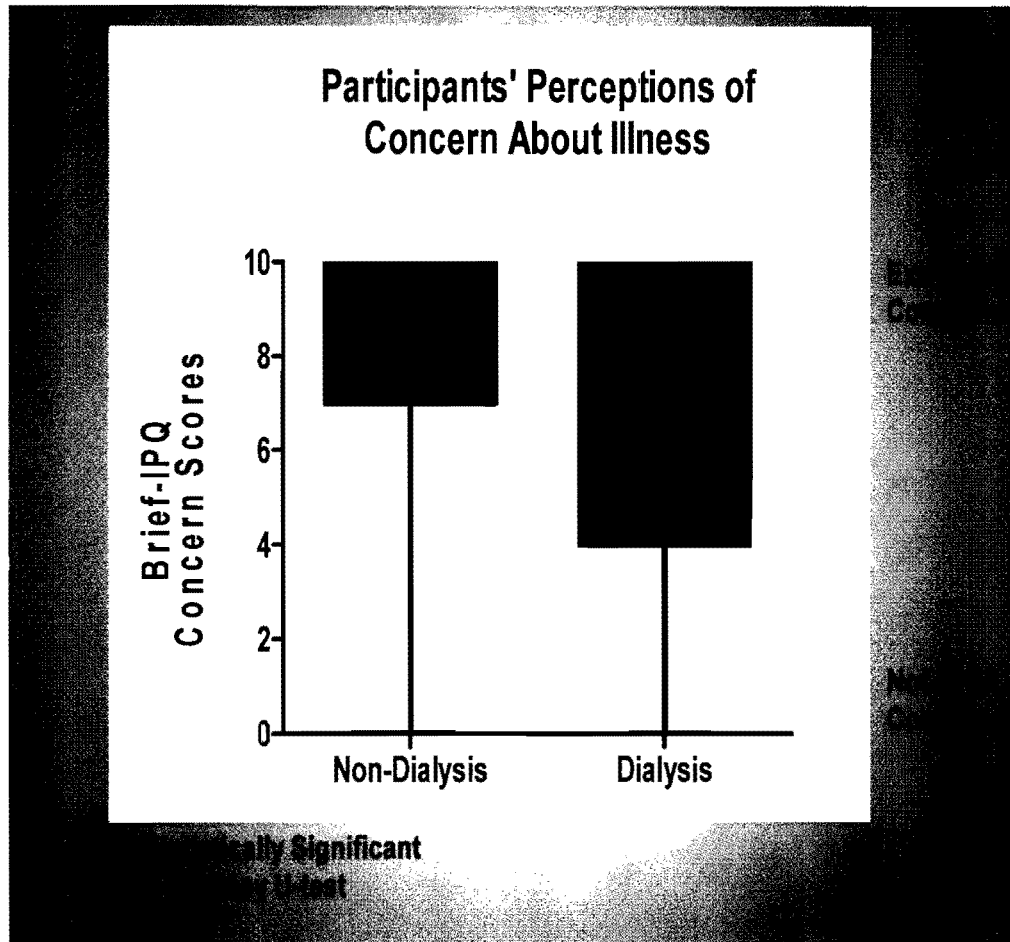


Figure 11.

Participant's perceptions of how well illness is understood.

Participant's perceptions of how well illness is understood.

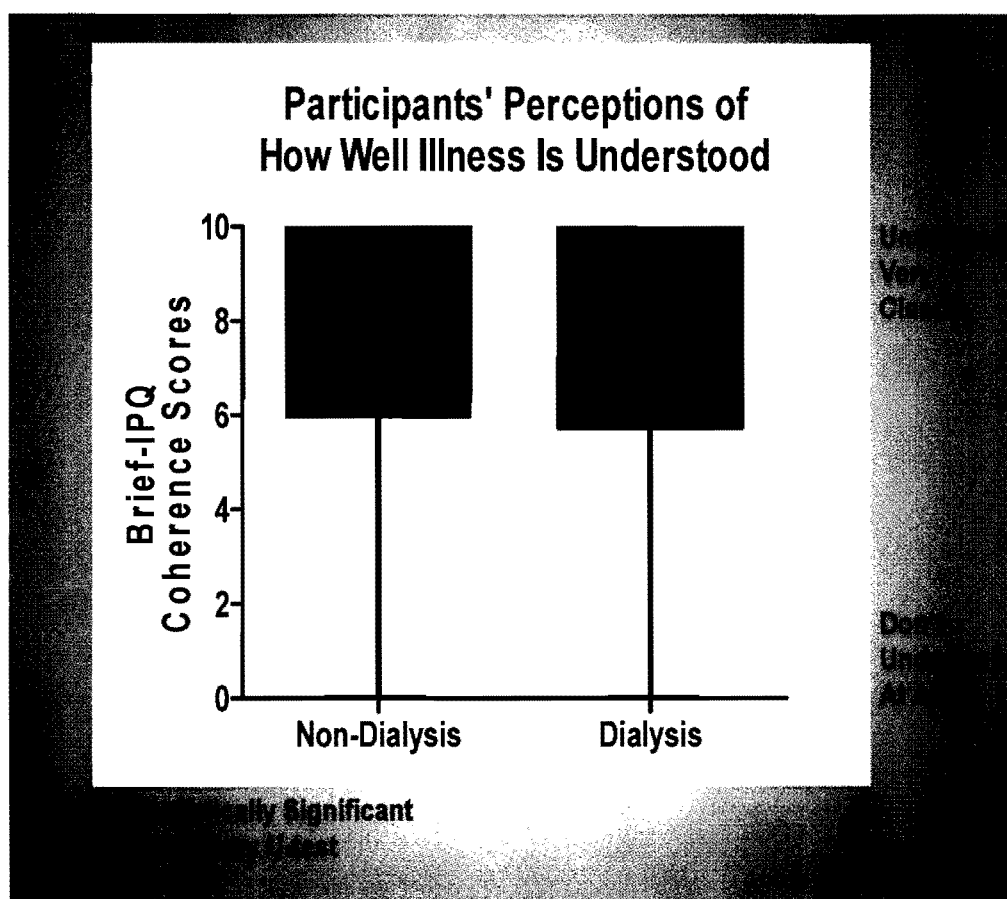


Figure 12.

Non-dialysis participants perceived illness affects their lives more severely (vs. dialysis participants).

Non-dialysis participants perceived illness affects their lives more severely (vs. dialysis participants).

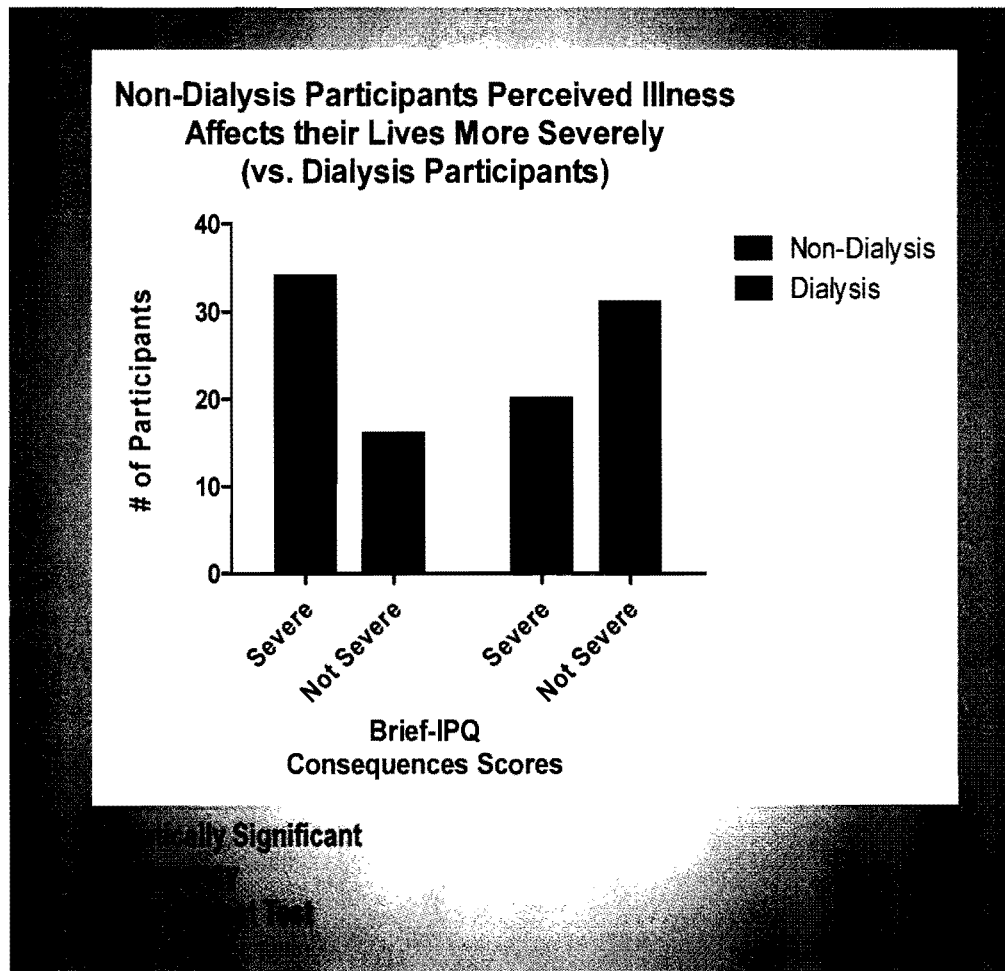


Figure 13.

**Dialysis participants perceived illness will more likely last forever
(vs. non-dialysis participants).**

**Dialysis participants perceived illness will more likely last forever
(vs. non-dialysis participants).**

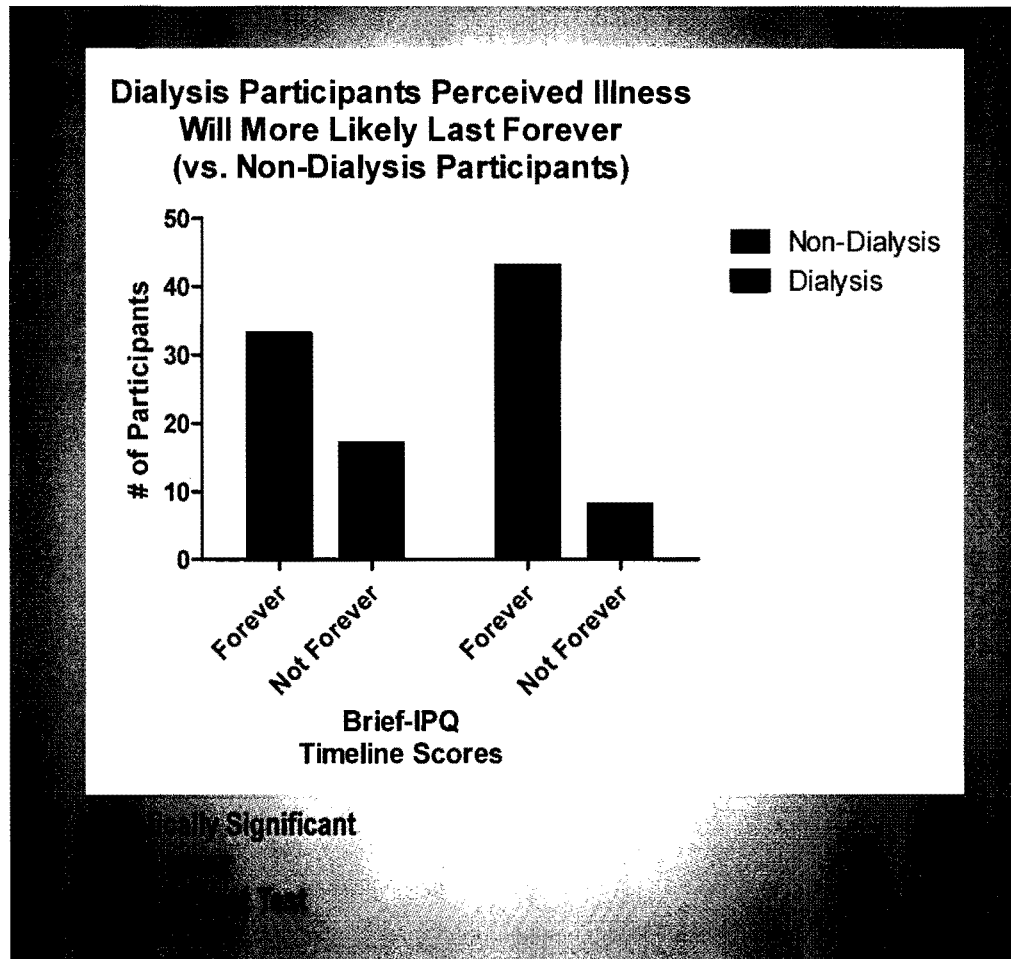


Figure 14.

**Non-dialysis participants perception of emotion
affecting their lives is greater (vs. dialysis participants).**

Non-dialysis participants perception of emotion affecting their lives is greater (vs. dialysis participants).

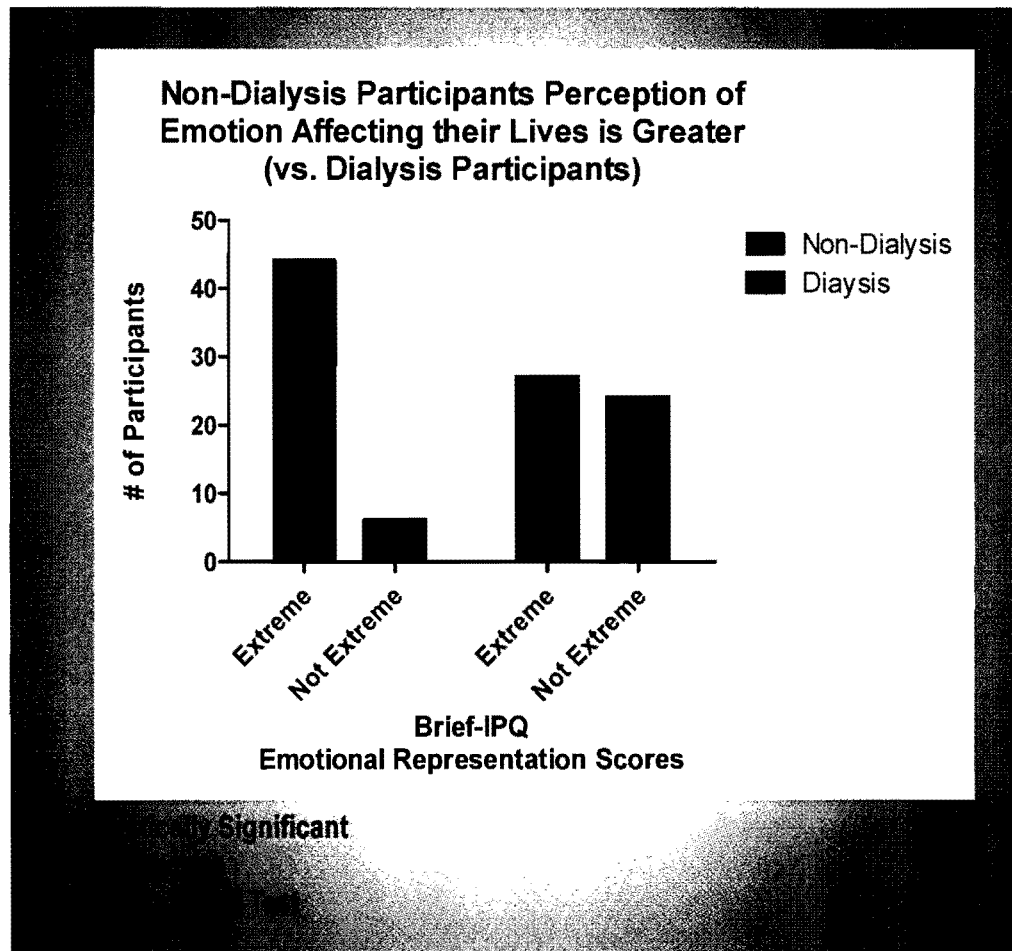


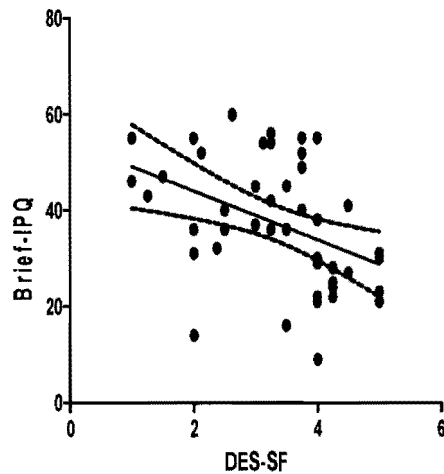
Figure 15.

**DES-SF vs. Brief-IPQ: dialysis participants.;
DES-SF vs. Brief-IPQ: non-dialysis participants.**

DES-SF vs. Brief-IPQ: dialysis participants.;
DES-SF vs. Brief-IPQ: non-dialysis participants.

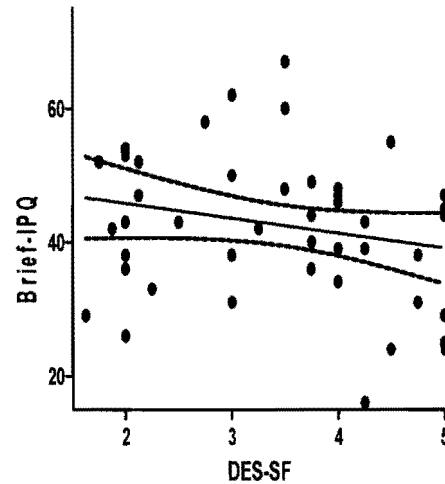
DES-SF vs. Brief-IPQ
Dialysis Participants

There is an Association Between
Illness Perceptions & Empowerment
in Dialysis Participants



DES-SF vs. Brief-IPQ
Non-Dialysis Participants

There is No Association Between
Illness Perceptions & Empowerment
in Non-Dialysis Participants



Significant

↑IP ↓E

Not Statistically Significant

Linear Regression

$r^2 = 0.050$

$P = 0.122$

Figure 16.

**DES-SF vs. Brief-IPQ: there is an association between
Illness perceptions and empowerment in
non-dialysis and dialysis participants.**

**DES-SF vs. Brief-IPQ: there is an association between
Illness perceptions and empowerment in
non-dialysis and dialysis participants.**

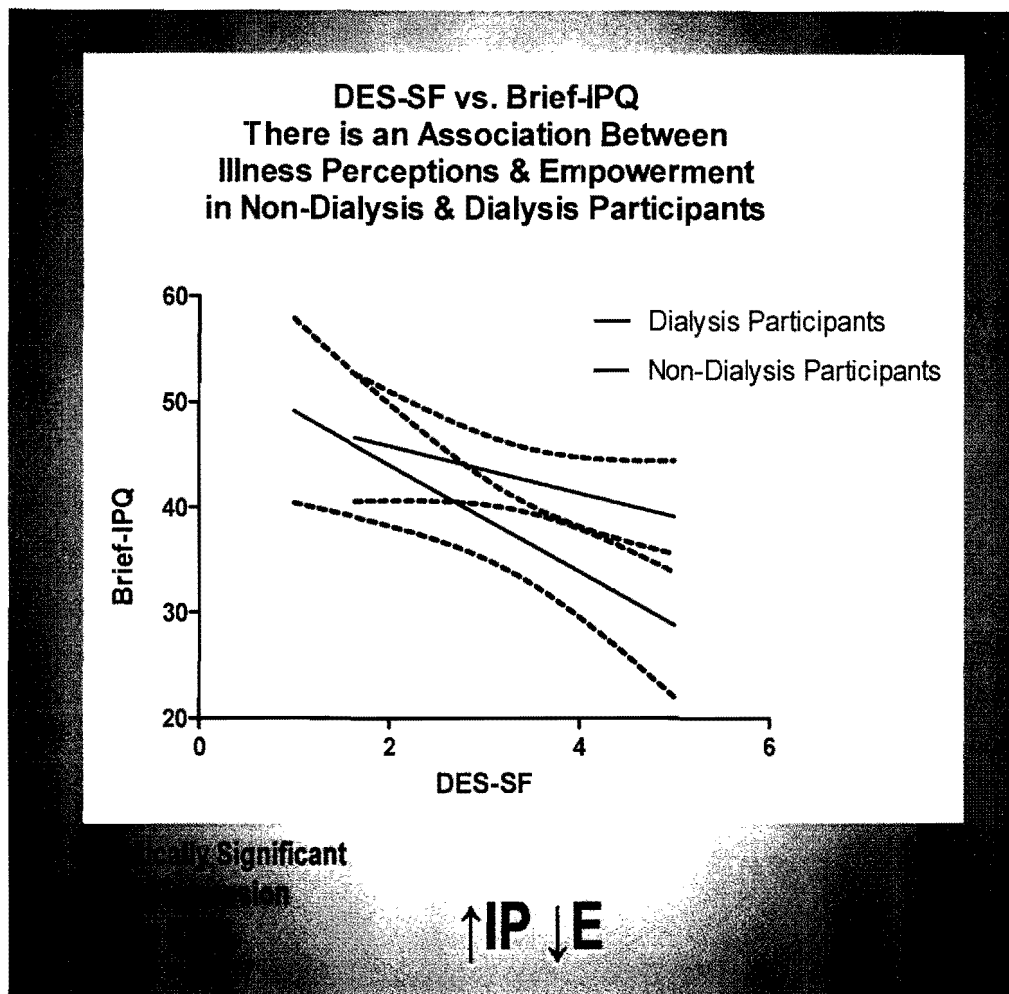


Table 1.

Comparative overview of the three (3) tools noted in the literature regarding illness perceptions.

Comparative overview of the three (3) tools noted in the literature regarding illness perceptions.

	Weinman et al., 1996	Moss-Morris et al., 2002	Broadbent et al., 2005
Number of Items	82	88	9
Validity/ Reliability	Cronbach's alpha 0.73 to 0.82	Cronbach's alpha 0.79 to 0.89	Cronbach's alpha 0.70 to 0.75
Effort/Scale	45	45	2
Strengths	Utilization & Adaptability	Revised – More Accurate to CSM	Rapid Assessment Format
Limitations	Long	Long	Self-reporting

Weinman, et. al., 1996; Moss-Morris, et. al., 2002; Broadbent, et. al., 2005

Table 2.

Comparative overview of the two (2) tools noted in the literature regarding empowerment.

Comparative overview of the two (2) tools noted in the literature regarding empowerment.

	DEA	DIS-87
Number of Items	25	8
Validity/ Reliability	Cronbach's alpha 0.81 to 0.96	Cronbach's alpha 0.85
Likert Scale	X	X
Strengths	Utilization & Adaptability	Rapid Assessment Format
Limitations	Long	Self-reporting

Anderson, et. al., 2000; Tsay & Hung, 2004; Tims, King, & Bennet, 2007

Table 3.

Baseline characteristics of study groups (N = 101).

Baseline characteristics of study groups (N = 101).

Characteristics of Study Group			
Characteristics	Non-HD	HD	P Value
Age (years) {median, (IQR)}	55.0 (47.3 to 62.8)	63.5 (58.0 to 71.0)	0.0004
Gender (Male/Female)	23/27	34/17	0.046
Time on HD (months) {median, (IQR)}	N/A	55.0 (36.0 to 72.0) Or 5 ¼ Years	N/A
Languages			0.230
English	31	30	
Spanish	14	19	
Other	5	2	
Ethnicity/Race (non-White/White)	41/9	47/4	0.148
Years of Basic Schooling (≥12/<12)	38/12	26/25	0.013
Employment Status			0.068
Employed	10	1	
Retired	10	24	
Unemployed	25	8	
Sick Leave	5	18	

GIF, General Information Form

Table 4.

Potential confounders of study groups (N = 101).

Potential confounders of study groups (N = 101).

Potential Confounders of Study Groups			
Characteristics	Non-HD	HD	P Value
Age (years) {median, (IQR)}	55.0 (47.3 to 62.8)	63.5 (58.0 to 71.0)	0.0004
Gender (Male/Female)	23/27	34/17	0.046
Years of Basic Schooling (≥12/<12)	38/12	26/25	0.013

Table 5.

Consequences: adjustments for potential confounders.

Consequences: adjustments for potential confounders.

Consequences: Adjustments for Potential Confounders

Status	P Value	Odds Ratio	95% CI
Unadjusted	0.005	3.29	1.45 to 7.47
Adjusted for Age	0.0004	5.04	2.05 to 12.40
Adjusted for Gender	0.712	1.17	0.51 to 2.67
Adjusted for Years of Basic Schooling	0.023	2.62	1.14 to 6.03

Table 6.

Gender affects the significance of consequences.

Gender affects the significance of consequences.

Gender Affects the Significance of Consequences

	Non-Dialysis (n = 50)	Dialysis (n = 51)
Male	14/23 (61%)	16/34 (47%)
Female	18/27 (67%)	13/17 (78%)

Table 7.

Timeline: adjustments for potential confounders.

Timeline: adjustments for potential confounders.

Timeline: adjustments for Potential Confounders			
Status	P Value	Odds Ratio	95% CI
Unadjusted	0.040	0.36	0.14 to 0.94
Adjusted for Age	0.095	0.44	0.17 to 1.15
Adjusted for Gender	0.138	0.49	0.19 to 1.26
Adjusted for Years of Basic Schooling	0.023	0.37	0.15 to 0.87

Table 8.

Age affects the significance of timeline.

Age affects the significance of timeline.

Age Affects the Significance of Timeline

	Non-Dialysis (n = 50)	Dialysis (n = 51)
≥56 Years Of Age	16/24 (67%)	34/42 (81%)
<56 Years Of Age	15/26 (58%)	7/9 (78%)

Table 9.

Gender affects the significance of timeline.

Gender affects the significance of timeline.

Gender Affects the Significance of Timeline

	Non-Dialysis (n = 50)	Dialysis (n = 51)
Male	13/23 (57%)	27/34 (79%)
Female	13/27 (48%)	13/17 (77%)

Table 10.

Emotional representation: adjustments for potential confounders.

Emotional representation: adjustments for potential confounders.

Emotional Representation Adjustments for Potential Confounders			
Status	P Value	Odds Ratio	95% CI
Unadjusted	0.0002	6.52	2.36 to 17.99
Adjusted for Age	0.011	3.60	1.35 to 9.62
Adjusted for Gender	0.022	2.96	1.17 to 7.48
Adjusted for Years of Basic Schooling	0.0002	7.00	2.55 to 19.28

Table 11.

Results of research question # 3 & #4.

Results of research question #3 & #4.

Results of Research Question #3 & #4

	Question #3	Question #4
	Dialysis	Non-Dialysis
r_s	-0.493	-0.233
P Value	0.0007	0.108
Statistical Significance	High Negative Association	None

Appendix A

Solicitation Letter

Solicitation Letter

Dear Participant,

My name is Jaime L. Pula, MS, RD, and I am a doctoral candidate at Seton Hall University's School of Health & Medical Sciences. I am conducting a research project titled, "*Illness perceptions in hemodialysis (HD) patients with Type 2 diabetes mellitus (DM) and their association with empowerment: a pilot study.*" This project will culminate in my dissertation.

Please read the following pages of this Solicitation Letter to further explain the purposes of this study, expected duration of your participation, description of the procedures (including specific name and contents of all surveys), statement of the voluntary nature of your participation, statement of how anonymity will be preserved, and how your information will be securely stored to maintain confidentiality.

I am inviting you to participate in this research study because you are a patient with Type 2 Diabetes Mellitus.

Please begin by answering the following questions: *Circle* your responses.

1. Are you between the ages of 18 and 85?
Yes No
2. Do you have Type 2 Diabetes Mellitus?
Yes No
3. Do you have **NO** history of renal replacement therapy?
Yes No

If you have answered **YES** to **ALL** of the above questions you **ARE ELIGIBLE** for participation in this study, please **open** the research packet and begin completing the enclosed questionnaires. Place the completed questionnaire in the enclosed return envelope. Please seal the envelope and place in the designated drop box on the unit.

If you answered **NO** to **ANY** of the above questions you are **NOT ELIGIBLE** to participate in this study. *Thank you* for your time and please return the research packet by placing it in the designated drop box on your unit.

Carta de Solicitud

Estimado participante:

Mi nombre es Jaime L. Pula, MS, RD, y soy un candidato a doctorado de la Facultad de Salud y Ciencias Médicas de la Universidad Seton Hall. Estoy llevando a cabo un proyecto de investigación que tiene el título de "*Illness perceptions in hemodialysis (HD) patients with Type 2 diabetes mellitus (DM) and their association with empowerment: a pilot study*" (Percepciones de la enfermedad en pacientes de hemodiálisis (HD, por sus siglas en inglés) con diabetes mellitus (DM) del tipo 2 y su asociación con la potenciación: un estudio piloto). El proyecto terminará con mi disertación.

Le pido que lea las siguientes páginas de esta Carta de Solicitud que explican en mayor detalle el estudio, la duración esperada de su participación, la descripción de los procedimientos (incluyendo nombre y contenidos específicos de todas las encuestas), la declaración de la naturaleza voluntaria de su participación, la declaración sobre cómo se preservará el anonimato y la manera en que su información será almacenada de manera segura para mantener la confidencialidad.

Por medio de la presente lo invito a participar en este estudio de investigación debido a que usted es un paciente con diabetes mellitus del tipo 2.

Le pido que comience respondiendo las siguientes preguntas: *marque con un círculo* sus respuestas.

4. ¿Tiene entre 18 y 85 años de edad?

Sí

No

5. ¿Sufre de diabetes mellitus del tipo 2?

Sí

No

6. ¿**NO** tiene antecedentes de terapia de reemplazo renal?

Sí

No

Si respondió **SÍ** a **TODAS** las preguntas anteriores, usted **CALIFICA** para participar en este estudio, **abra** el paquete de investigación y comience a responder los cuestionarios que se adjuntan. Coloque el cuestionario con las respuestas en el sobre que se adjunta. Cierre el sobre y colóquelo en el buzón designado de la unidad.

Si usted respondió **NO** a **ALGUNA** de las preguntas anteriores, **NO CALIFICA** para participar en este estudio. Muchas gracias por su tiempo y le pedimos que devuelva el paquete de investigación depositándolo en el buzón designado de su unidad.

Appendix B

Informed Consent

Informed Consent

Research title:

Illness perceptions of hemodialysis (HD) patients with Type 2 diabetes mellitus (DM) and their association with empowerment: a pilot study

Researchers' affiliation:

Any interested patient is invited to participate in a research study that will explore illness perceptions of patients with Type 2 DM (either undergoing HD treatment or non-dialysis patients with Type 2 DM), and their association with empowerment.

This study is being undertaken at Seton Hall University (SHU) located in South Orange, New Jersey in the Department of Graduate Programs in Health Sciences located on campus at Alfieri Hall. The primary investigator (PI) of this study is Jaime L. Pula, MS, RD, whom is a doctoral candidate in the Ph.D. program for Health Sciences, Leadership Track. The PI's Committee Chair is Vincent A. DeBari, Ph.D., Professor of Medicine. The PI has followed all policies and procedures related to this study as set forth by the SHU's Institutional Review Board (IRB).

Purposes of the study:

The purposes of this descriptive (exploratory) study are: 1) to investigate the illness perceptions of HD patients with Type 2 DM; and 2) to examine if there is an association between these illness perceptions and perceptions of empowerment.

Duration of the participant's involvement in the study:

The administrative personnel will make all interested participants aware that this study will include a one-time collection of data materials {Brief Illness Perceptions Questionnaire or Brief IPQ (Appendix C), Diabetes Empowerment Scale – Short Form or DES-SF (Appendix D), and General Information Form or GIF (Appendix E)} that will take approximately 45 minutes. .

Explanation of procedures:

All participants will continue usual nursing care during their regularly scheduled HD treatment at SJRMC, which is located at 703 Main Street in Paterson, NJ (northeastern NJ) (Chief Nephrologist: Chandra B. Chandran, MD) or family medicine clinic visit.

Potential participants (HD patients with Type 2 DM or non-dialysis patients with Type 2 DM) will be identified by designated administrative personnel of the institution. These participants will be HD patients with Type 2 DM or non-dialysis patients with Type 2 DM of the participating institution. They will be recruited through a solicitation letter (Appendix A). This letter will include an explanation of the purpose of the research study, an indication that participation is voluntary, and that confidentiality and participant anonymity will be maintained throughout the study. This letter will be stapled on the research packet. The packet will contain the survey questionnaire and a return envelope. The packet will be given to each patient during their normally scheduled HD treatment or family medicine clinic visit by administrative personnel. Eligibility will be determined by the completion of 3 questions in the solicitation letter (Appendix A): 1) Are you between the ages of 18 and 85?; 2) Do you have Type 2 Diabetes Mellitus?; and 3) Do you have NO history of renal replacement therapy? If the participants meet the eligibility criteria they will be requested to complete the Brief IPQ (Appendix B) (Broadbent, et. al., 2005) (to collect illness perceptions data), the DES-SF (Appendix C) (Anderson, et. al., 2000; Tsay & Hung, 2004) (to collect empowerment data), and the GIF (Appendix D) (to collect sociodemographic information data). The collection of all data will be a one-time collection that will take approximately 45 minutes. English and Spanish versions of all tools will be provided in the research packet. Any questions the participants may have will be encouraged and promptly answered by the administrative personnel. Please note participants will be able to stop offering their illness perceptions and empowerment responses at any time, without any questions or negative responses from the administrative personnel. All participants will be asked to seal the completed questionnaire in the return envelope, and place the envelope in a designated drop box located on the out-patient HD unit. The primary investigator (PI) will collect the boxes within two (2) weeks after distribution.

Any participant will complete these questionnaires during his or her HD treatment session or family medicine clinic visit. The time required to complete the questionnaires should be no longer than 45 minutes. Upon completion, he or she will return the completed questionnaires in a sealed envelope (enclosed) and place in a designated drop box located on the out-patient HD unit or family medicine clinic. Any participant will keep the solicitation letter, which has been provided inside the research packet, so as to ensure anonymity. Any participant will return the questionnaires to the designated drop box within 2 weeks of receipt.

Surveys. If the participants meet the eligibility criteria they will be requested to complete the Brief IPQ (Appendix B) (Broadbent, et. al., 2005) (to collect illness perceptions data), the DES-SF (Appendix C) (Anderson, et. al., 2000; Tsay & Hung, 2004) (to collect empowerment data), and the GIF (Appendix D) (to collect sociodemographic information data). The collection of all data will be a one-time collection that will take approximately 45 minutes. {Sample questions any participant is asked to answer include (but, are not limited to) what his or her

ethnicity is, his or her age, whether “(he or she) believe(s) (he or she) know(s) the positive ways (he or she) cope(s) with diabetes-related stress”, and “how much does (his or her) illness affect (his or her) life?”

Voluntary nature:

The return of the completed questionnaires will be considered consent from any study participant (HD patient with Type 2 DM or non-dialysis patient with Type 2 DM). Any participant understands he or she is able to stop offering his or her responses to *any* of the questionnaires *at any time*, without *any* questions or negative responses from the administrative personnel.

Anonymity:

Anonymity is preserved. Participant names *are not* associated with any of the collected data. You will not be identified by name or description in any reports or publications about this study. Any participant does *not* authorize his or her name to be associated with any of the collected data; therefore, he or she is assured all records remain anonymous and confidential.

Confidentiality:

Any participant is assured any information obtained in connection with this study is held in strict confidence and kept securely by the PI. All information in this study will be kept strictly confidential. Data will be entered into the SPSS statistical package (Version 17.0) and maintained on a USB memory drive. All research data will be stored in a locked file cabinet drawer on the out-patient HD unit at St. Joseph's Regional Medical center. The PI and the three (3) members of her dissertation committee are the only individuals who will have access to all of the research data for a period of three (3) years. Thereafter, all research data will be destroyed via professional shredding services.

If a participant is excluded from the study for any reason, his or her materials are discarded via professional shredding services. No video or audio tapes are involved in the study. Information will be available at the end of the study, if anyone is interested.

Contact information:

If any participant has any problems, questions or concerns, he or she does *not* hesitate to contact the PI, Jaime L. Pula, MS, RD, Primary Investigator, doctoral candidate, in the Department of Graduate Programs in Health Sciences at SHU, at (888) 728-7778. Any participant may contact the PI, the PI's Committee Chair, Vincent A. DeBari, Ph.D., at (973) 877-2813 or Dr. Mary F. Ruzicka, Director of the SHU IRB, at (973) 313-6314 or Dr. Patrick Perin, Chairman of SJRMC IRB, at (973) 754-2768 directly for answers to pertinent questions about the research and his or her rights, if necessary.

Consentimiento informado

Título de la investigación:

Illness perceptions of hemodialysis (HD) patients with Type 2 diabetes mellitus (DM) and their association with empowerment: *a pilot study* (Percepciones de la enfermedad en pacientes de hemodiálisis (HD, por sus siglas en inglés) con diabetes mellitus (DM) del tipo 2 y su asociación con la potenciación: un estudio piloto)

Afiliación del investigador:

Se invita a todo paciente interesado a participar en un estudio de investigación que explorará las percepciones de la enfermedad de los pacientes con DM del tipo 2 (bajo tratamiento de HD o pacientes sin diálisis con DM del tipo 2) y su asociación con la potenciación.

Este estudio se lleva a cabo en la Universidad Seton Hall (SHU, por sus siglas en inglés), ubicada en South Orange, Nueva Jersey, en el Departamento de Programas de Graduados en Ciencias de la Salud, ubicado en el campus de Alfieri Hall. El investigador principal de este estudio es Jaime L. Pula, MS, RD, candidato a doctorado en el programa de Doctorado de Ciencias de la Salud, Leadership Track. El Presidente del Comité del Investigador Principal es Vincent A. DeBari, Ph.D., Profesor de Medicina. El Investigador Principal ha cumplido con todas las políticas y procedimientos relacionados con este estudio, tal como lo establece el Consejo de Revisión Institucional (IRB, por sus siglas en inglés) de la SHU.

Objetivos del estudio:

Los objetivos de este estudio descriptivo (exploratorio) son: 1) investigar las percepciones de la enfermedad de los pacientes de HD con DM del tipo 2; y 2) examinar la asociación entre dichas percepciones de la enfermedad y la potenciación.

Duración de la participación de los participantes en el estudio:

El personal administrativo comunicará a todos los participantes interesados que este estudio incluirá una recopilación por única vez de materiales de datos {Cuestionario Breve de Percepciones de la Enfermedad o IPQ (por sus siglas en inglés) Breve (Anexo C), Escala de Potenciación de Diabetes – Versión Resumida o DES-SF, por sus siglas en inglés (Anexo D) y Formulario de Información General o GIF, por sus siglas en inglés (Anexo E)} que llevará aproximadamente 45 minutos.

Explicación de los procedimientos:

Todos los participantes continuarán con sus cuidados de enfermería normales durante su tratamiento de HD programado normalmente en SJRMC, ubicado en 703 Main Street en Paterson, NJ (noreste de NJ) (Jefe de Nefrología: Chandra B. Chandran, MD) o visita a la clínica de medicina familiar.

El personal administrativo designado de la institución identificará a los participantes potenciales (pacientes de HD con DM del tipo 2 o pacientes sin diálisis con DM del tipo 2). Dichos participantes serán pacientes de HD con DM del tipo 2 o pacientes sin diálisis con DM del tipo 2 de la institución participante. Serán reclutados a través de una carta de solicitud (Anexo A). Dicha carta incluirá una explicación del objetivo del estudio de investigación, una indicación de que la participación es voluntaria y que se mantendrá la confidencialidad y anonimato de los participantes durante el estudio. Dicha carta será abrochada al paquete de investigación. El paquete incluirá el cuestionario de la encuesta y un sobre de respuesta. El personal administrativo entregará un paquete a cada paciente durante su tratamiento de HD normalmente programado o visita a la clínica de medicina familiar. La elegibilidad será determinada a través de las respuestas a las tres preguntas en la carta de solicitud (Anexo A): 1) ¿Tiene entre 18 y 85 años de edad?; 2) Sufre de diabetes mellitus del tipo 2; y 3) ¿NO tiene antecedentes de terapia de reemplazo renal? Si los participantes cumplen con los criterios de elegibilidad, se les pedirá que respondan el IPQ Breve (Anexo B) (Broadbent, et. al., 2005) (para recopilar datos de percepción de la enfermedad), la DES-SF (Anexo C) (Anderson, et. al., 2000; Tsay & Hung, 2004) (para recopilar datos de potenciación) y el GIF (Anexo D) (para recopilar datos de información sociodemográfica). La recopilación de datos será por única vez y tomará aproximadamente 45 minutos. Se proporcionarán versiones en inglés y español de todas las herramientas en el paquete de investigación. Se alentará a los participantes a formular toda pregunta que puedan tener y las mismas serán respondidas a la brevedad por el personal administrativo. Tenga en cuenta que los participantes podrán dejar de brindar sus respuestas sobre percepciones de la enfermedad y potenciación en cualquier momento, sin ninguna pregunta o respuestas negativas por parte del personal administrativo. Se les pedirá a todos los participantes que pongan el cuestionario con las respuestas en el sobre de respuesta y que lo coloquen en el buzón designado ubicado en la unidad de HD de pacientes externos. El investigador primario recogerá los buzones dentro de dos (2) semanas después de la distribución.

Todos los participantes responderán a los cuestionarios durante sus sesiones de tratamiento de HD o visitas a la clínica de medicina familiar. El tiempo necesario para responder los cuestionarios no debería ser de más de 45 minutos. Después de responderlos, los participantes pondrán los cuestionarios con las respuestas en un sobre cerrado (que se adjunta) y lo colocarán en un buzón designado ubicado en la unidad de HD de pacientes externos o de la

clínica de medicina familiar. Todos los participantes conservarán la carta de solicitud, que fue incluida dentro del paquete de investigación, de manera de garantizar el anonimato. Todos los participantes colocarán los cuestionarios en el buzón designado dentro de las 2 semanas a partir de la recepción.

Encuestas. Si los participantes cumplen con los criterios de elegibilidad, se les pedirá que respondan el IPQ Breve (Anexo B) (Broadbent, et. al., 2005) (para recopilar datos de percepción de la enfermedad), la DES-SF (Anexo C) (Anderson, et. al., 2000; Tsay & Hung, 2004) (para recopilar datos de potenciación) y el GIF (Anexo D) (para recopilar datos de información sociodemográfica). La recopilación de datos será por única vez y tomará aproximadamente 45 minutos. {Entre las preguntas que se le pedirá que respondan a todos los participantes podemos mencionar (de forma enunciativa y no limitativa) cuál es su origen étnico, su edad, si consideran que conoce maneras positivas para hacer frente al estrés relacionado con la diabetes y en qué medida la enfermedad afecta a su vida.}

Naturaleza voluntaria:

El envío de los cuestionarios con las respuestas será considerado como consentimiento para la participación en el estudio (paciente de HD con DM del tipo 2 o paciente sin diálisis con DM del tipo 2). Todos los pacientes comprenden que pueden dejar de proporcionar sus respuestas a *cualquiera* de los cuestionarios *en cualquier momento* sin *ninguna* pregunta o respuesta negativa por parte del personal administrativo.

Anonimato:

Se preservará el anonimato. Los nombres de los participantes *no están* asociados a ninguno de los datos recopilados. Usted no será identificado por nombre o descripción en ningún informe o publicación sobre este estudio. Los participantes *no* autorizan a que su nombre quede asociado a ninguno de los datos recopilados; por lo tanto, se garantiza a los mismos que sus legajos permanecerán anónimos y confidenciales.

Confidencialidad:

Se garantiza a todos los participantes que el investigador principal mantendrá a toda la información obtenida en relación con este estudio en estricta confidencialidad y seguridad. Toda la información en este estudio será conservada en estricta confidencialidad. Los datos serán ingresados en un paquete estadístico SPSS (versión 17.0) y conservados en una unidad de memoria USB. Todos los datos de investigación serán almacenados en un cajón de armario de archivos con llave en la unidad de HD de pacientes externos del Centro Médico Regional St. Joseph. El investigador principal y los tres (3) miembros de su comité de disertación son las únicas personas que tendrán

acceso a todos los datos de investigación durante un período de tres (3) años. A partir de ese momento, todos los datos de investigación serán destruidos por medio de servicios de destrucción de documentos profesionales.

Si un participante es excluido del estudio por cualquier motivo, sus materiales serán descartados por medio de servicios de destrucción de documentos profesionales. El estudio no hace uso de cintas de video ni de audio. La información estará disponible al final del estudio, si alguien está interesado.

Información de contacto:

Si un participante tiene algún problema, pregunta o duda, no debe dudar en comunicarse con el investigador principal Jaime L. Pula, MS, RD, Investigador Principal, candidato a doctorado en el Departamento de Programas de Graduados en Ciencias de la Salud de la SHU, al teléfono (888) 728-7778. Todos los participantes pueden comunicarse con el investigador principal, el Presidente del Comité del investigador principal, Vincent A. DeBari, Ph.D., al teléfono (973) 877-2813, con el Dr. Mary F. Ruzicka, Director de SHU IRB, al teléfono (973) 313-6314 o con el Dr. Patrick Perin, Presidente de SJRMC IRB, al teléfono (973) 754-2768 directamente para obtener respuestas a preguntas pertinentes sobre la investigación y sus derechos, si es necesario.

Appendix C

Brief Illness Perception Questionnaire (Brief-IPQ)

Brief Illness Perception Questionnaire (Brief-IPQ)

For the following questions, please circle the number that best corresponds to your views:

How much does your illness affect your life?

0	1	2	3	4	5	6	7	8	9	10
no affect at all									severely affects my life	

How long do you think your illness will continue?

0	1	2	3	4	5	6	7	8	9	10
a very short time									forever	

How much control do you feel you have over your illness?

0	1	2	3	4	5	6	7	8	9	10
absolutely no control									extreme amount of control	

How much do you think your treatment can help your illness?

0	1	2	3	4	5	6	7	8	9	10
not at all									extremely helpful	

How much do you experience symptoms from your illness?

0	1	2	3	4	5	6	7	8	9	10
no symptoms at all									many severe symptoms	

How concerned are you about your illness?

0	1	2	3	4	5	6	7	8	9	10
not at all concerned									extremely concerned	

How well do you feel you understand your illness?

0	1	2	3	4	5	6	7	8	9	10
don't understand at all									understand very clearly	

How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

0	1	2	3	4	5	6	7	8	9	10
not at all									extremely	
affected									affected	
emotionally									emotionally	

Please list in rank-order the three most important factors that you believe caused your illness.

The most important causes for me:

1. _____

2. _____

3. _____

El Cuestionario Breve de Percepción de Enfermedad

En las siguientes preguntas, por favor, marque con un circulo el número que mejor representa su opinion

¿Cuánto afecta su enfermedad a su vida?

0 1 2 3 4 5 6 7 8 9 10
no la afecta absolutamente nada afecta gravemente
mi vida

¿Cuánto cree Ud. que durará su enfermedad?

0 1 2 3 4 5 6 7 8 9 10
muy poco tiempo para siempre

¿Cuánto control siente Ud. que tiene sobre su enfermedad

0 1 2 3 4 5 6 7 8 9 10
absolutamente ninguno control total

¿En que medida cree Ud. que su tratamiento ayuda a mejorar su enfermedad?

0 1 2 3 4 5 6 7 8 9 10
absolutamente nada ayuda muchísimo

¿En que medida siente Ud. síntomas debidos a su enfermedad?

0 1 2 3 4 5 6 7 8 9 10
absolutamente ningún síntoma muchos síntomas
graves

¿En que medida está Ud. preocupado por su enfermedad?

0 1 2 3 4 5 6 7 8 9 10
absolutamente nada de preocupado extremadamente
preocupado

¿En que medida siente Ud. que entiende su enfermedad?

0 1 2 3 4 5 6 7 8 9 10
no la entiendo nada la entiendo muy
claramente

¿En que medida lo afecta emocionalmente su enfermedad? (Es decir, ¿Lo hace sentirse con rabia, asustado, enojado o deprimido?)

0 1 2 3 4 5 6 7 8 9 10

Absolutamente nada de afectado emocionalmente

Extremadamente afectado
emocionalmente

Por favor, haga una lista con los tres factores más importantes que Ud. cree que causaron su enfermedad, enumérelos en orden de importancia.

Las tres causas que yo considero más importantes son:

1. _____

2. _____

3. _____

Appendix C

Diabetes Empowerment Scale – Short Form (DES-SF)

Diabetes Empowerment Scale – Short Form (DES-SF)

The 8 items below constitute the DES-SF. The scale is scored by averaging the scores of all completed items (Strongly Disagree =1, Strongly Agree = 5)

Check the box that gives the best answer for you.

- | | | | | | |
|---|---|---|--|--|--|
| 1. In general, I believe that I know what part(s) of taking care of my diabetes that I am dissatisfied with. | <input type="checkbox"/> ₁
Strongly
Disagree | <input type="checkbox"/> ₂
Somewhat
Disagree | <input type="checkbox"/> ₃
Neutral | <input type="checkbox"/> ₄
Somewhat
Agree | <input type="checkbox"/> ₅
Strongly
Agree |
| 2. In general, I believe that I am able to turn my diabetes goals into a workable plan. | <input type="checkbox"/> ₁
Strongly
Disagree | <input type="checkbox"/> ₂
Somewhat
Disagree | <input type="checkbox"/> ₃
Neutral | <input type="checkbox"/> ₄
Somewhat
Agree | <input type="checkbox"/> ₅
Strongly
Agree |
| 3. In general, I believe that I can try out different ways of overcoming barriers to my diabetes goals. | <input type="checkbox"/> ₁
Strongly
Disagree | <input type="checkbox"/> ₂
Somewhat
Disagree | <input type="checkbox"/> ₃
Neutral | <input type="checkbox"/> ₄
Somewhat
Agree | <input type="checkbox"/> ₅
Strongly
Agree |
| 4. In general, I believe that I can find ways to feel better about having diabetes. | <input type="checkbox"/> ₁
Strongly
Disagree | <input type="checkbox"/> ₂
Somewhat
Disagree | <input type="checkbox"/> ₃
Neutral | <input type="checkbox"/> ₄
Somewhat
Agree | <input type="checkbox"/> ₅
Strongly
Agree |

**DES-SF; Diabetes Research and Training Center
© University of Michigan, 2003**

Anderson, et. al., 2000

Diabetes Empowerment Scale-Short Form (DES-SF)
Versión en español.

	Muy de acuerdo	De acuerdo	Ni de acuerdo ni en desacuerdo	En desacuerdo	Muy en desacuerdo
1. En general creo que yo conozco con qué partes del cuidado de mi diabetes estoy insatisfecha(o) .					
2. En general creo que yo soy capaz de convertir mis metas en un plan de acción práctico y concreto.					
3. En general creo que yo puedo intentar hacer diferentes cosas para superar las barreras enfrente para lograr mis metas.					
4. En general creo que yo puedo decir como me estoy sintiendo viviendo con la diabetes.					
5. En general creo que yo conozco maneras positivas que uso para enfrentar el estrés que me causa la diabetes.					
6. En general creo que yo conozco en donde puedo encontrar apoyo para vivir y cuidar de mi diabetes.					
7. En general creo que yo conozco lo que me ayuda a permanecer motivado para cuidar de mi diabetes.					
8. En general creo que yo me conozco lo suficiente como persona como para tomar las decisiones que me convienen para el cuidado de mi diabetes.					

Muchas Gracias por reponder el cuestionario.

Anderson, et. al., 2000

Appendix D
General Information Form (GIF)

General Information Form (GIF)

Please mark answers by **circling** the most appropriate choice unless otherwise indicated to answer by **writing** in most accurate information. Thank you for your participating in this questionnaire.

SOCIODEMOGRAPHIC

1) I am:

Male

Female

2) My age is (in years): _____

If you do not receive hemodialysis treatments at all, please skip to Question #4.

3) I have been on hemodialysis for a total length of time of (in months): _____

4) Languages I speak at home or with my family and/or friends include:

English

Spanish

Arabic

Bengali

Turkish

Other: _____

5) My ethnicity or race is:

Black

White

Hispanic

Native American

Asian

Pacific Islander

Middle Eastern

Other: _____

6) The most years of schooling in basic education I received is:

6 years schooling

9 years schooling

12 years schooling

7) The type of vocational educations I received is:

No education

Secondary/upper secondary level

Polytechnic/college or university

8) My current employment status is:

Employment or student

Retired

Unemployed

Sick leave

9) I have Type 2 Diabetes Mellitus.

Yes

No

Thank you again for your time. Have a nice day!

Formulario de información general

Por favor elije la repuesta mas apropiada con un círculo si no indican contestar con **escribir** con la más exacta información. Gracias por participar en este cuestionario.

SOCIODEMOGRAFICAS

1) Sexo:

Masculino ____

Femenino ____

2) Edad (en anos): ____

Si nunca has recibido tratamientos por hemodiálisis, por favor siga a la pregunta #4.

3) Estoy recibiendo tratamientos por hemodiálisis para ____ meses.

4) Idiomas que hablo en casa o con mi familia y amigos son:

Ingles

Espanol

Árabe

Bengalí

Turco

Otro: _____

5) Mi origen étnico es:

Negro

Blanco

Hispano

Nativo Americano

Asiático

De las Islas del Pacifico

De Oriente Medio

Otro: _____

6) Máximo número de años en educación básica:

6 años

9 años

12 años

7) El tipo de profesional educación que e recibido es:

Ninguna educación profesional

Universidad secundaria

Politécnico/Universidad

8) Mi actual status de empleo es:

Empleado o estudiante

Retirado

Desempleado

Baja por enfermedad

9) Tengo tipo 2 Diabetes Mellitas.

Si

No

Gracias por su tiempo. ¡Que tenga un lindo día!

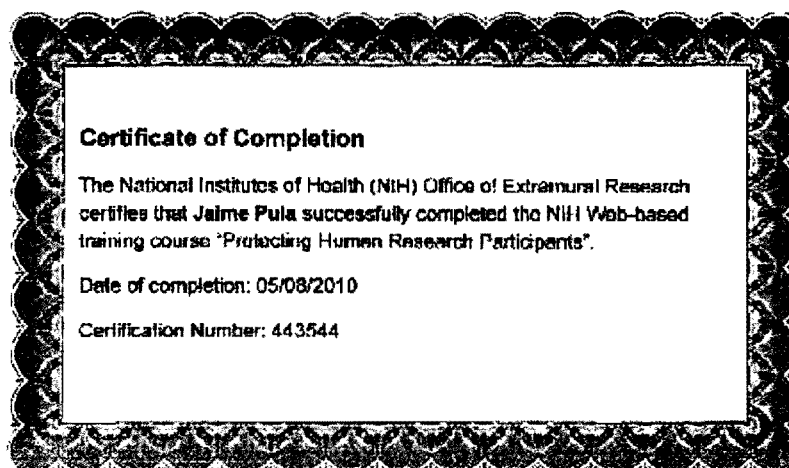
Appendix F

Completion Certificate of Human Participant Protection

Completion Certificate of Human Participant Protection

Protecting Human Subject Research Participants

Page 1 of 1

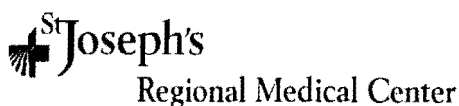


<http://phrp.nihtraining.com/users/cert.php?v=442544>

5/8/2010

Appendix G

St. Joseph's Regional Medical Center IRB Approval Letter



703 Main Street
Paterson, New Jersey 07503
973.754.2000

**INSTITUTIONAL REVIEW BOARD
(973) 754-2768 FAX (973) 754-4355
EXPEDITED REVIEW REVISION – 2010**

May 26, 2010

**Jaime L. Pula, MS, RD,
St. Joseph's Regional Medical Center
703 Main Street
Paterson, NJ 07503**

Dear Ms. Pula:

PR# 09-035 "Illness Perceptions Of Hemodialysis (HD) Patients With Type 2 Diabetes Mellitus (DM) And Their Association With Empowerment: A Pilot Study," Revisions includes the addition of Michael D. DeLisi, MD as a co-investigator; Solicitation Letter (Appendix A) to the informed consent; minor aesthetic changes to the instruments (Appendix B; Appendix C) revised (Appendix D) method of coding was approved through expedited revision review by Dr. Patrick Perin on May 26, 2010.

I have reviewed the aforementioned revision of PR #09-035: Since the revisions do not present any added risk, I have approved this revision through expedited review, 45 CFR 46, 21 CFR 50, 56.

My best wishes for your efforts in the proposed area of research you are conducting continue to be fruitful and rewarding.

Yours very truly,

A handwritten signature in black ink, appearing to read "Patrick V. Perin, MD".

**Patrick V. Perin, MD
Chairman, Institutional Review Board**

PVP/lh

Appendix H

Permission to Use the Brief IPQ

Appendix H
Permission to Use the Brief IPQ

--- On **Mon, 12/7/09, Jaime Pula** <mvprdllc@yahoo.com> wrote:

From: Jaime Pula <mvprdllc@yahoo.com>
Subject: Re: Approval to Use Brief IPQ
To: "Elizabeth Broadbent" <lizbroadbent@clear.net.nz>
Date: Monday, December 7, 2009, 2:46 PM

Thank you for your kind consideration. I will be sure to forward my findings to you.

Happy Holidays!

--- On **Sun, 12/6/09, Elizabeth Broadbent** <lizbroadbent@clear.net.nz> wrote:

From: Elizabeth Broadbent <lizbroadbent@clear.net.nz>
Subject: Re: Approval to Use Brief IPQ
To: "Jaime Pula" <mvprdllc@yahoo.com>
Date: Sunday, December 6, 2009, 1:43 AM

Dear Jaime

Yes you may

kind regards

Liz

On 6/12/2009, at 2:04 PM, Jaime Pula wrote:

Dear Ms. Broadbent,

My name is Jaime L. Pula. I am a doctoral candidate at Seton Hall University located in South Orange, NJ. I am seeking your approval to use the Brief IPQ to collect data on illness perceptions in hemodialysis patients with Type 2 DM as my dissertation topic in partial fulfillment of a Ph.D. in Health Sciences.

Please let me know what steps I need to take to obtain your permission.

Sincerely Yours,

Jaime L. Pula, MS, RD
Doctoral Candidate
Seton Hall University
(732) 207-8819
MVPRDLLC@yahoo.com

Appendix I

Certification of Spanish Translation



ASTA-USA Translation Services, Inc.
Post Office Box 25, Main Street | Hartville, Wyoming 82215 USA
Tel.: 866.446.1860 | Fax.: 866.297.0606 | www.asta-usa.com | www.LegalTranslationSolutions.com

CERTIFIED TRANSLATION

Documents Translated For:

LAST NAME: Pula	FIRST NAME: Jaime	MIDDLE NAME:
COMPANY: N/A		DIVISION: N/A

List of Materials, Documents, Forms, Transcripts, Licenses, etc., translated.


Letter of Informed Consent [IllnessPerceptionsSpanishTranslationNeededSt.JoesIRBInformedConsentUpdated52610.doc]

Source Language(s):	English
Target Languages:	Spanish

HARTVILLE, WYOMING

WITH REFERENCE TO THE ABOVE MENTIONED MATERIALS/DOCUMENTS, we at ASTA-USA Translation Services, Inc., a professional document translation company, attest that the language translation completed by ASTA-USA's certified professional translators, represents, to the best of our judgment, an accurate and correct interpretation of the terminology/content of the source document(s). This is to certify the correctness of the translation only. We do not guarantee that the original is a genuine document or that the statements contained in the original document(s) are true.

IN WITNESS WHEREOF, ASTA-USA Translation Services, Incorporated has caused the Certificate to be signed by its duly authorized officer(s).

By: 
Alain J Roy, President

Date: 14 June 2010

A copy of the translated version is attached to this statement of certification.



The National Association of
Judiciary Interpreters & Translators

ASTA-USA Translation Services, Incorporated – Member #7031
A Member in Good Standing

