

ACCEPTANCE

This dissertation, PREDICTING FLUID ADHERENCE IN HEMODIALYSIS PATIENTS VIA AN ILLNESS PERCEPTION QUESTIONNAIRE, by TAVA LYNN ARNOLD, was prepared under the direction of the candidate's Dissertation Advisory Committee. It is accepted by the committee members in partial fulfillment of the requirements for the Degree of Doctor of Philosophy in the College of Education, Georgia State University.

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ABSTRACT

PREDICTING FLUID ADHERENCE IN HEMODIALYSIS PATIENTS VIA THE ILLNESS PERCEPTION QUESTIONNAIRE - REVISED

by
Tava L. Arnold

The Illness Perception Questionnaire – Revised (IPQ – R; Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002) was utilized in the current research to better understand and predict fluid adherence in hemodialysis patients. A sample of patients was recruited from three hemodialysis centers in the Los Angeles area and 116 participants completed the Illness Perception Questionnaire – Revised. The Illness Perception Questionnaire – Revised (Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002), is based on the common sense model (CSM) of self regulation by Leventhal (1984). Fluid adherence was measured by the Interdialytic Weight Gain (IWG). IWG is determined by subtracting the postdialytic weight for the previous session from the predialytic weight for the current session. To obtain a more representative indicator of adherence over time the mean IWG was calculated over a 12 session period (approximately 4 weeks). Patients with a mean IWG weights over 2.5 Kg were considered non-adherent to fluid restrictions. In addition, a self-report demographic information questionnaire was administered. Block logistic regression demonstrated that non adherence to fluid restrictions accounted for 65% of the prediction equation and gender was the only identified variable as being a significant predictor of fluid adherence in this hemodialysis patient population. The results of this study suggested that patient

illness perceptions as measured by the Illness Perception Questionnaire did not predict adherence to fluid restrictions. However, in this sample, women were significantly more likely to adhere to fluid restrictions than men. Possible modifications for future research, including a subjective measure of adherence as well as the objective measure are evaluated and discussed.

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VIA THE ILLNESS PERCEPTION QUESTIONNAIRE - REVISED
by
Tava L. Arnold, M.A.

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ABBREVIATIONS

CSM	Common Sense Model
ESRD	End Stage Renal Disease
IPQ	Illness Perception Questionnaire
IPQ-R	Illness Perception Questionnaire – Revised
IWG	Interdialytic Weight Gain

CHAPTER 1

THE ROLE OF ILLNESS PERCEPTION ON FLUID ADHERENCE WITH HEMODIALYSIS PATIENTS: A REVIEW OF THE LITERATURE

Introduction

Overview of kidney functioning and hemodialysis

Kidneys are vital organs that filter the blood of extra water, salt, and waste products to keep the body chemically stable (Faris, 1994). The excess water and waste are excreted from the body in the form of urine. Kidney failure has many causes, including cancer, diabetes, hypertension, inflammation, infection, lupus, and arteriosclerosis (Faris, 1994). End Stage Renal Disease (ESRD), or irreversible chronic kidney failure, is the stage at which the body requires the use of dialysis or kidney transplant to maintain life. ESRD occurs when at least 95% of normal kidney functioning has been lost. Dialysis is a type of medical treatment that removes the excess water and waste from the blood (Faris, 1994). The most common form of dialysis is hemodialysis, which is performed by a machine that connects through the patient's veins to filter the blood, removing waste and excess fluid (Christensen, Wiebe, Benotsch, & Lawton, 1996; Cvangros, Christensen, & Lawton, 2004; Faris, 1994). Most hemodialysis patients receive dialysis at a center two to three times a week for up to four hours per session (Faris, 1994). Unlike healthy kidney functioning which occurs on a continuous basis, individuals receiving hemodialysis are placed on stringent dietary and medical

regimen to control the build up of toxins and fluids in the blood (Christensen, Smith, Turner, & Cundick, 1994; Faris, 1994).

An important part of patients' dietary restrictions is their fluid intake. Since hemodialysis patients cannot excrete excess fluid from their bodies, careful attention is given to the amount of fluids they intake. Fluids are considered anything that is liquid at room temperature, including foods such as Jell-O™ and ice cream, and patients are typically recommended to keep intake to 1 liter a day (Cvengros et al., 2004; Faris, 1994). Research suggests that 30 to 60 percent of patients fail to adhere to recommended fluid restrictions (Christensen, Moran, Weibe, Ehlers, & Lawton, 2002; Christensen et al., 1996; Wolcott, Maida, Diamond, & Nesenson, 1986). Failure to adhere to fluid restrictions can lead to complications such as hypertension, congestive heart failure, pulmonary edema, and increased risk of mortality (Wolcott et al., 1986).

The amount of fluid ingested between sessions is measured by the patient's Inter-dialytic Weight Gain (IWG; Cvengros et al., 2004). The IWG is considered to be a valid and reliable measure of fluid adherence, and is utilized in both clinical and research settings (Cvengros et al., 2004; Wolcott et al., 1986). Patients are routinely weighed at the start and after completing each dialysis session, therefore IWG is calculated based on the individual's post-dialysis weight or dry weight of the previous session subtracted from the pre-dialysis weight for the subsequent session (Khechane & Mwaba, 2004; Cvengros et al., 2004). Adherence can be evaluated based on the average weight gain over a 12-session period, with IWG values over 2.5kg interpreted as poor or problematic fluid adherence (Christensen, Benotsch, Lawton, & Wiebe, 1995; Cvengros et al., 2004). Even with the incidence and clinical importance of patient fluid adherence, research

examining adherence outcomes in hemodialysis patients is limited (Christensen et al., 1996).

Fluid adherence research with hemodialysis patients

In one of the earliest research projects on fluid adherence with hemodialysis patients, Cummings, Decker, Kirscht, and Levin (1982) surveyed 116 participants about their knowledge of treatment, health beliefs, treatment history, social support, personal characteristics, and adherence. The results indicated that patients' perceptions about the effects of their illness on their families were significantly correlated with IWG, suggesting that the more disruptive the effects of their illness on their family, the less likely they were to adhere to fluid restrictions. In a seminal article written by Rosenbaum and Ben-Ari Smira (1986), the researchers examined the cognitive and personality factors of hemodialysis patients. These researchers found that hemodialysis patients who demonstrated higher resourcefulness (i.e., self-control skills) were able to lower their weight increases between dialysis sessions. Furthermore, resourcefulness was demonstrated to be mediated by patients' perceived self-efficacy. More self-efficacious individuals' reported higher resourcefulness (or self-control) about their past adherence, and perceived themselves to be well able to maintain their adherence to fluid restrictions in the future. Schneider, Friend, Whitaker, and Wadhwa (1991) followed up on Rosenbaum and Ben-Ari Smira's (1986) research by further investigating the relationship between cognitive variables and adjustment to fluid adherence. Schneider et al. (1991) assessed cognitive variables such as locus of control, self-evaluation of compliance and self-efficacy, as well as the emotional variables of depression, anger, and anxiety in fluid adherence. Schneider et al. (1991) found that the cognitive variables accounted for past

and future fluid adherence. Emotional variables such as depression were not related to adherence, but patients reporting high negative emotions were significantly more symptomatic and distressed.

Christensen, Smith, Turner, Holman, and Gregory (1992) measured patients' perception of familial social support and adherence. Patients' who perceived a more cohesive, expressive, and lower intra-family conflict had significantly more favorable adherence to fluid intake restrictions in both center base and home hemodialysis programs. Sensky, Leger, and Gilmour (1996) also examined social support and fluid adherence with similar findings to Christensen et al. 1992; namely, good social support was related to much lower levels of interdialytic weight gain.

Everett, Brantley, Sletten, Jones, and McKight (1995) evaluated stress (major and minor life events), depression, and adherence to fluid restrictions. Their results suggested that minor stress directly related to fluid adherence; as minor stress increases, fluid adherence decreases. Additionally, there was a direct inverse correlation between depression and nonadherence (i.e., higher levels of depression was not associated with nonadherence). Additionally, major life events were not found to be directly related to adherence.

In the mid to late 1990's Christensen and his research team, published a string of articles addressing the effects of different psychosocial conditions on fluid adherence. Christensen et al. (1995) utilized the Ways of Coping Questionnaire and found that the use of planful problem solving as a coping strategy was associated with more favorable adherence when used in response to stressors involving relatively controllable aspects of dialysis. Less controllable stressors involving emotional self-control were associated

with more favorable adherence. Seeking informational support in response to uncontrollable encounters was associated with poorer adherence. Confrontive coping was also associated with poorer adherence for both high and low control situations.

In 1996, Christensen, Wiebe, Edwards, Michels, and Lawton examined bodily self-focusing tendencies and the degree of illness related physical impairment to determine if they were associated with fluid adherence. Body self focusing tendencies were described as an increased attention to physical sensations. A preliminary forward entry regression analysis and a liberal confidence interval ($p < .10$), was conducted to examine demographic and clinical characteristics with patients IWG. Age was the only significant predictor of adherence, suggesting that younger patients have more favorable fluid adherence. In the primary regression analyses, bodily self focus failed to explain a significant amount of IWG variance. Moran, Christensen, and Lawton (1997), published an article examining the five factor personality model and social support. Hierarchical regression analysis (controlling for demographic, clinical, and other personality variables) revealed a significant interaction between social support and conscientiousness. However, high support among patients with low conscientiousness was associated with poorer fluid intake adherence while social support had little effect on fluid intake adherence among high conscientiousness patients. Christensen, Moran, Lawton, Stallman, and Voigts (1997) focused on monitoring attentional style, trait anxiety, coping strategies, and perceived control. Interestingly, IWG was only significantly correlated to the demographic variable of age, which was the same finding reported by Christensen et al. (1996). Additionally, higher monitoring of adverse information and information seeking behaviors were related to higher interdialytic weight

gains. The effect of monitoring on fluid intake adherence was partially mediated by individual differences in perceived control. Lastly, Christensen, Wiebe, and Lawton (1997) examined the concept of Cynical Hostility, as evaluated by the Cook-Medley Hostility Scale, which reflects suspiciousness, cynical mistrust, disparaging views of others, and easily aroused anger and “powerful other” (e.g., health care providers) control expectancies. Participants completed the Cook-Medley Hostility Scale and “Powerful Others” Health Locus of Control (PHLC). The PHLC measure the extent to which an individual will base their health related expectations on the actions or advice of powerful others. Results from a hierarchical regression analysis suggested there was no significant interaction between hostility and “powerful others” locus of control in explaining patients’ IWG.

Utilizing the Health Belief Model, Welch (2001) examined benefits, barriers, seriousness, susceptibility and self-efficacy. Instead of using IWG to assess for fluid adherence, the research applied the Stages of Changes model to determine fluid adherence by determining patient’s adherence into one of three categories: 1) precontemplation, which was defined by the authors as patients that were not currently limiting fluids to 1 kg and were not planning on making changes to limit fluids in the future 2) contemplation, which were not limiting but thinking about making changes within the next month, and 3) action/maintenance, who were limiting fluids to 1 kg and planning on continuing to limit fluids in future. Results demonstrated that the precontemplation stage had lower benefits associated with adherence than patients in the action/maintenance stage. Additionally, patients in the action/maintenance stage perceived higher susceptibility to pulmonary edema than those in the contemplation

stage. Welch suggested using stage appropriate interventions to address specific health beliefs.

In addition to research in the United States examining fluid adherence in hemodialysis patients, researchers in China and South Africa examined patient's beliefs about fluid adherence. For example, Pang, Ip, and Chang, (2001) used a depression scale, health locus of control scale, and a social support questionnaire. Their results found satisfaction with social support and higher monthly family incomes were associated with greater fluid adherence and lower IWG. Lee and Molassiotis (2002) examined dietary knowledge, health beliefs, and self-reported compliance. Results from this study found that knowledge and health beliefs were not significant predictors of adherence with this population. Interestingly, patients who worked full time had higher levels of non-adherence to fluid restrictions than unemployed patients. Khechane and Mwaba (2004) investigated if treatment related to stress and coping was related to fluid adherence in South African patients. Results suggested that avoidance and social support seeking were the most commonly utilized coping strategies for this population. However, problem solving was the only strategy found to be significantly correlated with fluid adherence.

Evens, Wagner, and Welch (2004) examined the role of cognitive functioning in 147 hemodialysis patients, using a brief screening instrument, Cognistat, which assesses level of consciousness, orientation, attention, language, construction, memory, calculations, and reasoning to determine if cognitive performance was related to fluid adherence. For all of the Cognistat subtests except calculations there were no significant differences in cognitive performance found between patients who did and did not adhere

to fluid restrictions. On calculations, nonadherent patients performed significantly better than adherent patients. The most recent article examining fluid adherence of hemodialysis patients focuses on the role of perceived control and preference of control. Cvenegros et al. (2004) found that the relationship between preference for information and perceived control over dialysis explained a significant proportion of the IWG. Specifically, patients with low levels of perceived control and high preference for information concerning one's health were found to have poorer adherence to fluid restrictions, suggesting that assessing patients' levels of preference for information and perception of control may be beneficial in determining intervention strategies for patients likely to be nonadherent.

In summary, although the methodologies and findings have differed throughout fluid adherence research, certain variables have been demonstrated to have a correlation or predictive relationship with hemodialysis patients' fluid adherence. Self-efficacy, perception of impact of illness on family, perception of control, consciousness, coping strategies, social support, and age, were found to be correlated with or predictive of patients' fluid adherence (Brady, Tucker, Alfino, Tarrant, & Finlayson, 1997; Christensen et al., 1995; Christensen et al., 1997; Lee & Molassiotis, 2002; Moran et al., 1997; Rosenbaum & Ben-Ari Smira, 1982; Schneider et al., 1991). Because most of the aforementioned studies were limited to correlation analyses of psychosocial variables and adherence, they offer little help in identifying promising interventions aimed at increasing fluid adherence.

Interventions designed to facilitate fluid adherence in hemodialysis patients have had varying degrees of success. Some of these interventions have used self-monitoring,

behavioral interventions, counseling sessions, rewards, stages of change, and positive reinforcement to improve patients' adherence (Christensen et al., 1997; Christensen et al., 2002; Hegel, Ayllon, Thiel, & Oulton, 1992; Molaison & Yadrick, 2003; Welch, & Thomas-Hawkins, 2005). These interventions mostly reflected short-term changes. In order to create interventions that have more lasting effects in improving the fluid adherence of patients, research regarding the influence of psychological constructs on fluid adherence is needed (Christensen et al., 2002; Hegel et al., 1992; Molaison & Yadrick, 2003). A relatively recent theoretical model, referred to as the Common Sense Model of Self-Regulation (Leventhal, Nerenz, & Steele, 1984), has drawn considerable attention and seems promising.

Self-Regulation Theories and the Common Sense Model (CSM)

In recent years, the term "self-regulation" has been applied to many theories and therefore, there is speculation about how self regulation theories differ from other models of health and illness behavior (Cameron & Leventhal, 2003). What differentiates self-regulation theories from other models of health and illness are the elements of feedback, motivation, and the goal of pursuit (Cameron & Leventhal, 2003). Self regulation theories suggest that humans have two inherent overarching goals: survival and 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 challenges the integrity of self, requires regulation of emotional and physical states, and an 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 (Cameron & Leventhal, 2003). 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 pathways 1) abstract cognitions (feelings of vulnerability) and 2) concrete experience (symptoms). 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 representations 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 domains of illness representation: *identity*, *timeline*, *consequences*, *control*, and *cause*.

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 and are often based on communications with medical professionals, family members, and other patients rather than the actual biology of the disease. A patient's perspective on aspects such as his/her age, expected longevity, assessment of overall health, and immune strength interacts with their perception of each of the five domains of illness representation. The relationship between patient's

perspective and illness representations then plays a role in determining which coping procedure will be most helpful to them to manage their illness or condition (Leventhal, et al., 1984; Leventhal, Diefenback, & Leventhal, 1991; Leventhal et al., 1992). Illness perceptions also relate to perceptions of treatment necessity which in turn influences adherence. Nonadherence is not only a waste of resources but a missed opportunity for therapeutic benefit (Horne, 2003).

Common Sense Model and Adherence

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 norms about treatment. Horne (2003) explained the unique relationship each of the CSM ' five illness representations, *identity*, *timeline*, *consequences*, *control*, and *cause*, has with the perception of treatment necessity.

Identity – assesses the symptoms experiences 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). *Consequence 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 her/his illness. *Causal Attribution* – causal beliefs have not been found

to be strongly related to the patient's 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. Although the theoretical framework of the CSM or the Self-Regulatory Theory suggests that adherence to medical regimens is a form of coping procedure (Llewellyn, Miners, Lee, Harrington, & Weinman, 2003), relatively few research projects have evaluated the CSM Self-Regulatory Theory with treatment adherence (Horne & Weinman, 1999).

With the increasing interest in the CSM or Self-Regulatory Theory, Weinman, Petrie, Moss-Morris, and Horne (1996) created the Illness Perception Questionnaire (IPQ). The IPQ was utilized by the aforementioned research to assess the five dimensions of the CSM of self-regulatory theory (i.e., *identity, timeline, consequences, cure/controllability, and cause*) and the patient's 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.

Research utilizing the Illness Perception Questionnaire (IPQ)

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 patient's 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 Illness Perception Questionnaire 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 HbA1c levels in addition to patients' self-report of adherence. HbA1c 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 (Griva et al., 2000). The participants were insulin dependent diabetic patients recruited from multiple clinics to examine their illness perceptions and adherence. Griva et al. (2000) found a different pattern of associations between self-reported adherence and the HbA1c 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 HbA1c 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 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 were the best predictors of poor attendance records at rehabilitation sessions. While patient's 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 homoeopathic 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, Fry, Cull and Sutton (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. For patients with irritable bowel syndrome (IBS), Rutter and Rutter (2002) found that depression was predicted by the IPQ scale, Consequences. Additionally, Cure/Control and Consequences scales were mediated by different coping strategies and were important predictors of quality of life and psychological adjustment of patients with IBS. 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, Kaptein, Van Kempen, Weinman, Van Houwelingen, and Roos (2002) examined how illness perception contributed to caregivers' quality of life and patient's well being. Illness Identity, Consequences, and Timeline were found to be correlated to caregiver coping but did not significantly explain the caregivers' quality of life. 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 patient's condition and how this relates to their perception of illness was also examined by Fortune, Richards, Griffiths, and Main's (2002) 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. Based on the utilization and adaptability of the IPQ with different patient population and illnesses, Moss-Morris, Weinman, Petrie, Horne, Cameron, and Buick (2002) re-evaluated the IPQ and decided to revise it to make it more accurate to the theoretical tenets of CSM or self-regulatory theory, and improve the psychometric properties of the *cure/control* and *timeline* subscales. The Illness Perception Questionnaire – Revised (IPQ-R) increased the Cronbach's alpha score for the *timeline* subscale and separated the *cure/control* subscale into three separate subscales that more accurately assessed the patient's perceptions of cure, illness control, and treatment control (Moss-Morris, et al., 2002).

A recent article, Fowler and Baas (2006), used the IPQ-R to examine the illness representation of patients on hemodialysis. The authors explored the relationship between illness perception and quality of life for chronic kidney disease patients on maintenance hemodialysis. These authors found a strong relationship between the quality of life and patients' illness perceptions, suggesting further examination of illness perceptions and holistic outcomes in persons undergoing hemodialysis. This research's limitations included a 24.7% response rate, which produced a small sample size. The authors postulated that a thorough assessment of patient's perceptions may provide the medical team with substantial information about how patients perceive hemodialysis in

terms of illness identity, cause, timeline, consequences, and controllability. Identifying and addressing patient's perceptions may improve adherence with recommended treatment regimens.

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CHAPTER 2

PREDICTING FLUID ADHERENCE IN HEMODIALYSIS PATIENTS VIA THE ILLNESS PERCEPTION QUESTIONNAIRE – REVISED

Introduction

More than 300,000 people are on hemodialysis in the United States (USRDS, 2006). Dialysis is necessary when the kidneys are unable to filter the blood of extra water, salt, and waste products to keep the body chemically stable (Faris, 1994). Functioning kidneys excrete the excess water and waste from the body in the form of urine. For people with kidney failure, hemodialysis is performed by a machine that connects through the patient's veins to filter the blood, removing waste and excess fluid (Christensen, Wiebe, Benotsch, & Lawton, 1996; Cvengros, Christensen, & Lawton, 2004; Faris, 1994). Kidney failure has many causes, including cancer, diabetes, hypertension, inflammation, infection, lupus, and arteriosclerosis (Faris, 1994). End Stage Renal Disease (ESRD) or irreversible chronic kidney failure, is the stage at which the body requires the use of dialysis or a kidney transplant to maintain life. ESRD occurs when at least 95% of normal kidney functioning has been lost. The most common type of dialysis is hemodialysis. Most hemodialysis patients receive dialysis at a center two to three times a week, for up to four hours per session (Faris, 1994). Unlike healthy kidney functioning, which occurs on a continuous basis, individuals receiving hemodialysis are placed on stringent dietary and medical regimens to control the build up of toxins and fluids in the blood (Christensen, Smith, Turner, & Cundick, 1994; Faris 1994).

An important part of patients' dietary restrictions is their fluid intake. Since hemodialysis patients cannot excrete excess fluid from their bodies, careful attention is given to the amount of fluids they intake. Fluids are considered anything that is liquid at room temperature, including foods such as Jell-O™ and ice cream. Patients are typically recommended to keep fluid intake to one liter a day (Cvengros et al., 2004; Faris, 1994). Research suggests that 30 to 60 percent of patients fail to adhere to recommended fluid restrictions (Christensen, Moran, Weibe, Ehlers, & Lawton, 2002; Christensen et al., 1996; Wolcott, Maida, Diamond, & Nesenson, 1986). Failure to adhere to fluid restrictions can lead to complications such as hypertension, congestive heart failure, pulmonary edema, and increased risk of mortality (Wolcott et al., 1986).

The amount of fluid ingested between sessions is measured by the Inter-dialytic Weight Gain (IWG; Cvengros et al., 2004). The IWG is considered to be a valid and reliable measure of fluid adherence and is utilized in both clinical and research settings (Cvengros et al., 2004; Wolcott et al., 1986). Patients are routinely weighed prior to the start and after each dialysis session. Therefore, IWG is calculated based on subtracting the individual's pre-dialysis weight from his/her post-dialysis weight or dry weight from the previous session (Cvengros et al., 2004; Khechane & Mwaba, 2004). Adherence can be evaluated based on the average weight gain over a 12-session period, with IWG values over 2.5kg interpreted as poor or problematic fluid adherence (Christensen, Benotsch, Wiebe, & Lawton, 1995; Cvengros et al., 2004). Even with the incidence and clinical importance of patient fluid adherence, research examining adherence outcomes in hemodialysis patients is limited (Christensen et al., 1996).

Throughout fluid adherence research with hemodialysis patients, certain variables have been demonstrated to have a correlation or predictive relationship with hemodialysis patients' fluid adherence. Self-efficacy, perception of impact of illness on family, perception of control, consciousness, coping strategies, social support, and age, were found to be correlated with or predictive of patients' fluid adherence (Brady, Tucker, Alfino, Tarrant, & Finlayson, 1997; Christensen et al., 1995; Christensen, Moran, Lawton, Stallman, & Viogets, 1997; Lee & Molassiotis, 2002; Moran, Christensen, Wiebe, & Lawton, 1997; Rosenbaum & Ben-Ari Smira, 1982; Schneider, Friend, Whitaker, & Wadhwa, 1991). Because most of the aforementioned studies were limited to correlational analyses of psychosocial variables and adherence, they offer little help in identifying promising interventions aimed at increasing fluid adherence.

Interventions designed to facilitate fluid adherence in hemodialysis patients have had varying degrees of success. Some of these interventions have used self-monitoring, behavioral interventions, counseling sessions, rewards, stages of change, and positive reinforcement to improve patients' adherence (Christensen et al., 2002; Hegel, Ayllon, Thiel, & Oulton, 1992; Molaison & Yadrick, 2003; Welch & Thomas-Hawkins, 2005). These interventions mostly reflected short-term changes. In order to create interventions that have more lasting effects in improving the fluid adherence of patients, research regarding the influence of psychological constructs on fluid adherence is needed (Christensen et al., 2002; Hegel et al., 1992; Molaison & Yadrick, 2003). A relatively recent theoretical model, referred to as the Common Sense Model of Self-Regulation (Leventhal, Nerenz, & Steele, 1984) has drawn considerable attention within adherence research and seems promising.

The Common Sense Model of Self-Regulation (CSM)

The common sense model (CSM) of self-regulation developed by Leventhal, Nerenz, and Steele (1984) is one of several self-regulation models (e.g., Scheier and Carver Model, and the Lazarus and Folkman stress coping model). The CSM model was developed within the context of understanding health and illness behavior, whereas the Scheier and Carver, and Lazarus and Folkman models are general models of behavioral self-regulation that focus on goal selection and behavior for all types of daily activities, which includes health related behavior (Cameron & Leventhal, 2003).

The CSM of self-regulation is based on a parallel processing system consisting of two pathways of abstract cognitions (feelings of vulnerability) and concrete experience (symptoms) that interact as an individual adapts to an illness (Leventhal, Brissette & Leventhal, 2003; Whitmarsh, Koutantji, & Sidell, 2003). One pathway involves abstract cognitions and coping procedures to manage emotions and a second pathway for concrete experiences and coping procedures to manage symptoms (Whitmarsh et al., 2003).

Patients construct representations of their illness based these two pathways. They then generate goals for self-management of behavior and feedback criteria to evaluate the efficacy of their behavior. According to the CSM, there are five domains of illness representation: *identity, timeline, consequences, control, and cause*.

Each domain is comprised of variables that stem from a complex social biological system. Individual appraisals of social and cultural factors as well as the experiences of the 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., 2003). Illness representations evaluating the acute, chronic, or cyclic

nature of the disease are often based on the communications with medical professionals, family members, and other patients rather than the actual biology of the disease. A patient's perspective on aspects such as his/her age, expected longevity, assessment of overall health, and immune strength interacts with their perception of each of the five domains of illness representation. The relationship between a patient's perspective and illness representations then plays a role in determining which coping procedure will be most helpful for managing his/her illness or condition (Leventhal et al., 1984; Leventhal & Diefenback, & Leventhal, 1991; Leventhal et al., 2003). Illness perceptions also relate to perceptions of treatment necessity which in turn influence adherence. Nonadherence is not only a waste of resources but a missed opportunity for therapeutic benefit (Horne, 2003).

Common Sense Model and Adherence

Understanding why patients do not adhere to their medical regimen has been conceptualized using the CSM and illness representations with a variety of illnesses. Individuals seek coherence between their illness representations and coping with their disease, which includes their perceptions of treatment necessity, or the evaluation that their condition warrants treatment (Horne, 2003). These evaluations are influenced by the information individuals received about types and classes of treatment, past treatment experiences of ourselves and other, and societal and cultural norms about treatment. Horne (2003) explained the unique relationship each of the five illness representations has with perception of treatment necessity. *Identity* – assesses the symptoms experiences 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). *Consequence 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 their illness. *Causal Attribution* – causal beliefs have not been found to be strongly related to treatment necessity. Horne (2003) suggests that causal beliefs do not vary much between patients with the same illness. *Control/Cure* – treatment necessity is correlated to efficacy belief or the belief that the illness will be control by the treatment but not with other types of beliefs, such as chance or personal control. In 1996, researchers wanted to create an instrument for research that was “theoretically based and psychometrically sound, but with sufficient flexibility for the user...” (Weinman, Petrie, Moss-Morris, & Horne, 1996, p. 432), and to meet that end, they created the Illness Perception Questionnaire (IPQ) as a method of assessing the cognitive representations of illness based on the CSM.

The IPQ assesses the five dimensions of the CSM (i.e., *identity, timeline, consequences, cure/controllability, and cause*). The IPQ was theoretically constructed to examine each of the five dimensions and measure the patient’s overall illness perception. The IPQ has been utilized in research assessing psychological stress in psoriasis patients (Fortune, Richards, Griffith, & Main, 2002), patients living with Huntington Disease (Helder et al., 2002), illness beliefs in vitiligo patients (Papadopoulos, Bor, Walker, Flaxman, & Legg, 2002), distress in women at risk for Breast Cancer (Rees, Cull, & Sutton, 2004), coping with Irritable Bowel Syndrome (Rutter & Rutter, 2002), asthma (Horne & Weinman, 2002), diabetes (Griva, Myers, & Newman, 2000), and hemophilia (Llewellyn et al., 2003). While the theoretical framework of the CSM suggests that

adherence to medical regimens is a form of coping (Llewellyn et al., 2003), relatively few research projects have evaluated the CSM via the IPQ and adherence (Horne & Weinman, 1999). The research that has been conducted using the IPQ focused on medical adherence for patients with hypertension (Meyer, Leventhal, & Guttman, 1985), asthma (Horne & Weinman, 2002; Byer & Meyer, 2000), homeopathic medicine (Searle & Murphy, 2000), cardiac rehabilitation (Whitmarsh et al., 2003), chronic physical illness (Horne & Weinman, 1999), hemophilia (Llewellyn et al., 2003), diabetes (Gonder-Fredrick & Cox, 1991), and predicting future adherence to rehabilitation classes (Petrie, Wienman, Sharpe, & Buckley, 1996).

Based on the utilization and adaptability of the IPQ with different patient populations and illnesses, Moss-Morris et al. (2002) re-evaluated the IPQ and decided to revise it to make it more consistent with the theoretical tenets of CSM of self-regulatory theory and to improve the psychometric properties of the *cure/control* and *timeline* subscales. The Illness Perception Questionnaire – Revised (IPQ-R) increased the Cronbach's alpha score for the *timeline* subscale and separated the *cure/control* subscale into three separate subscales that more accurately assessed the patient's perceptions of cure, illness control, and treatment control (Moss-Morris, et al., 2002).

A recent article, Fowler and Baas (2006), used the IPQ-R to examine the illness representation of patients on hemodialysis. The authors explored the relationship between illness perception and quality of life for chronic kidney disease patients on maintenance hemodialysis. These authors found a strong relationship between the quality of life and patients' illness perceptions, suggesting further examination of illness perceptions and holistic outcomes in persons undergoing hemodialysis. This research's

limitations included a 24.7% response rate, which produced a small sample size. The authors postulated that a thorough assessment of patient's perceptions may provide the medical team with substantial information about how patients perceive hemodialysis in terms of illness identity, cause, timeline, consequences, and controllability. Identifying and addressing patient's perceptions may improve adherence with recommended treatment regimens. The orientation for the current research is to identify dimensions of illness perceptions that may predict fluid adherence. The primary research question is: What is the predictive utility for fluid adherence in hemodialysis patients of the seven dimensions of illness perception after controlling for demographic variables, such as gender, age, time on dialysis, race/ethnicity, years of education, caregiver status, and employment? Secondary analyses were conducted to determine the significant differences between patients who adhere to fluid restrictions and those who do not for each dimension of the Illness Perception Questionnaire - Revised that significantly contributed to the prediction of adherence.

Method

Participants and Procedure

This study is a cross-sectional design using hemodialysis patients recruited from several hemodialysis centers located in a large metropolitan area in the Western United States. A total of 129 patients on hemodialysis, ages eighteen years or older, who demonstrated no cognitive impairments and who could read and write English were invited to complete the Illness Perception Questionnaire (IPQ-R) (Moss-Morris, et al., 2002) and a demographic questionnaire. Each eligible patient was given a verbal explanation of the research, a written consent form, the IPQ-R, and demographic sheet. The participants' 12 previous Interdialytic Weight Gain (IWG) amounts were recorded

from the patients' chart by a staff member at the center. Of the 129 patients, 116 patients returned their questionnaires completed, giving a response rate of 90%. Of these participants, 71 (61%) were men and 45 were (39%) women. The average participant was 64 years old with a range of 32 to 93 years and standard deviation of 14.2 years with 14.4 years of education (range 7 to 28 years of education; standard deviation 2.8 years). Fifty-five percent of the participants were of White/Euro descent. Of the remaining participants, 8% were Latino, 27% were Black/African descent, and 9.5% were Asian descent. The average length of time on dialysis was 3.7 years. Over 52.5% of the participants had no caregiver and 41% had a family member as a caregiver. Table 1 shows the demographic information of the participants.

Table 1

Demographic Data

<i>Demographic Variables</i>	<i>f</i>
Age	
<u>M</u>	64
<u>SD</u>	14.2 years
<u>Range</u>	32 – 93
Gender	
Males	71
Females	45

Race/Ethnicity

White/Euro	64
Hispanic/Latino	10
Black/African	31
Asian	11

Education

<u>M</u>	14.42 years
<u>SD</u>	2.86 years
<u>Range</u>	7 – 28 years

Adherence

<u>M</u>	2.88 kg	
<u>SD</u>	1.4	
Adherent		42
Nonadherent		74

Years on Dialysis

<u>M</u>	3.7
<u>SD</u>	4.6

Caregiver

None	61
Family Member	48
Professional caregiver/nurse	7

This study received ethical approval by the Office of Research Integrity at Georgia State University and the permission of the participating centers to recruit participants.

Measurement Instruments

Illness Perception Questionnaire – Revised (IPQ-R; Moss-Morris et al., 2002)

The psychometric properties of the IPQ - R have been previously tested on center-based hemodialysis 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 (Table 2) was demonstrated by Cronbach's alpha scores ranging from .79 to .89. Test-Retest reliability (Table 1) of the IPQ-R with renal patients (over a 3-week period) ranged in correlations between .46 to .88. Discriminant validity was utilized to ensure that the dimensions of the IPQ-R were not a reflection of the individual's affective temperament and was evaluated by using the Positive and Negative Affect Scale (PANAS; Watson, Clark, & Tellegen, 1988). The PANAS assesses an individual's positive and negative affect as it relates to his/her medical condition. The results of the correlations between the IPQ-R and the PANAS were small to moderate ($r = .01$ to $.54$) with the smallest correlation between positive affect and timeline and the largest correlation between negative affect and emotional representation. These results indicate that the IPQ-R is not testing the patient's affective feelings about his/her illness.

The IPQ-R assesses nine components of illness representation in three 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 hemodialysis.

Table 2

Cronbach's Alpha and test-retest reliability for IPQ-R dimensions

Dimension	Alpha Level (α)	Reliability (r) (Renal patients, N = 28)
Timeline acute/Chronic	.89	.76***
Timeline Cyclical	.79	.72***
Consequences	.84	.74***
Personal Control	.81	.46**
Treatment Control	.80	.63***
Illness Coherence	.87	.60***
Emotional Representations	.88	.70***
Identity	.75	.80***

Note: ** $p < .01$; *** $p < .001$

The second section is comprised of 38 questions address 7 subscales. Two subscales are patient's perception of control both *Personal control* (beliefs about the control he/she has in controlling their symptoms and condition) and *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 hemodialysis 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 hemodialysis); *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-type 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.

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

Demographic

A *demographic questionnaire* with five dimensions of socio-demographic information was developed for this research: Age, Gender, Race or Ethnicity, Years of Education, Employment Status, and Length of Time on Dialysis.

Fluid Adherence

A *fluid adherence form* was created to measure patients' fluid gains (IWG) between sessions while also maintaining anonymity for the participants after data collection. Fluid Adherence is a commonly used dimension in treatment adherence research with hemodialysis patients (Christensen et al., 1996). Fluid adherence is

measured by the Interdialytic Weight Gain (IWG). The IWG is determined by subtracting the post-dialytic weight for the previous session from the pre-dialytic weight for the current session. To obtain a more representative indicator of adherence over time, the mean IWG can be calculated over a 12 session period (approximately 4 weeks). Mean IWG of 2.5 kg or higher indicates problematic adherence (Christensen, Weibe, Benotsch, & Lawton, 1995).

The IWG data were collected using a two part approach. 1) After consenting to participate in the research, participants filled in their name at the top of the IWG form in a designated spot. The bottom portion of the form contained the participant's randomly assigned number that corresponded to the participant's questionnaire and spaces to input the participants last twelve pre and post dialysis weights. These weights were obtained by a staff member of the dialysis center. 2) After the form was completed, the top portion with the participant's name was removed and shredded at the center.

Results

Prediction of fluid adherence in hemodialysis patients on the seven dimensions of illness perception, after controlling for the demographic variables?

Logistic regression analysis was utilized to determine if the illness perception dimensions are influential in hemodialysis patients' adherence to fluid restrictions. The criterion variable was patient's IWG, coded for adherence (weights under 2.5 kg) and non adherence (weights over 2.5 kg). The first block of predictor variables was gender, age, race/ethnicity, years of education, employment status, years on dialysis, and caregiver status. The second block of predictor variables was the seven dimensions of illness perception (i.e., Timeline, Timeline Cyclical, Consequences, Personal Control, Treatment

Control, Emotional Representation, and Illness Coherence). Logistic regression was chosen over discriminant function analysis, in order to evaluate statistically the effects of three continuous predictors (age, years of education, and years on dialysis), one dichotomous predictor (gender), and three dummy-coded predictors (race/ethnicity, caregiver status, and employment status). Forty-two of the participants were adherent and 74 of them were nonadherent to fluid restrictions. The baseline model is calculated prior to inputting any demographic information or dimensions and predicts that all participants are in the largest group was 63% accurate overall. A test of the first model, which only included demographic variables, was statistically significant $\chi^2 (9, N=116) = 17.252, p < .05$. This model correctly classified 89% of patients who were non-adherent to fluid restrictions as being non-adherent and 38.1% of patients who were adherent as being adherent.

Table 3 shows the logistic regression coefficient, the results of the Wald test, and the significance level for each of the predictors in Block 1. With $\alpha = .05$, gender ($b = 1.278, p < .005$) was the only predictor to have a significant partial effect. The odds ratio for gender was 3.58, which indicates that when holding other variables constant, a woman is more likely to adhere to fluid restrictions than a man.

Table 3

Logistic Block Regression Predicting Fluid Adherence via the IPQ-R

Predictor	b	Wald χ^2	p
Dialysis	.008	2.134	.144
Gender	1.278	7.755	.005**
Age	-.020	1.267	.260
Education	-.013	.030	.863

A test of the full model, which included both demographic variables and illness perception dimensions, was not statically significant, $\chi^2(17, N = 116) = 20.240, p > .05$. This model correctly classified 82.4% of patients as non adherent to fluid restrictions and 35.7% of patients as adherent, for an overall rate of 65.5%. In this model, gender (b = 1.546, $p = .003$) continued to be the only predictor to have a significant partial effect.

The proposed exploratory t-tests were not conducted, since the seven hypothesized IPQ-R dimensions did not significantly contribute to the prediction model. However, a post hoc correlation matrix was created to examine the IPQ-R dimensions for multicollinearity. The results suggest that some of the dimensions demonstrate small to moderate correlations to each other but that overall, multicollinearity did not meaningfully affect these findings.

Discussion

Utilizing the CSM of self-regulation theory and the IPQ - R, the current research attempted to generate predictions about hemodialysis patients' fluid adherence. The present results suggest that patients' illness perceptions were not predictive of their

adherence to fluid restrictions. When analyzing data with logistic regression, a beginning block is generated prior to inputting any variables, and a baseline model is created. The baseline model without any predictors was 63% accurate. This high percentage was generated by the large number of nonadherent patients within this sample. Since 63% of the model was already explained by adherence alone, there was little room to improve upon the model once the demographic and IPQ-R dimensions were added.

Demographics were entered into the first block, and gender was found to be predictive of fluid adherence. In this model, being females increased the odds of adhering to fluid restrictions. In the second block, both demographics and IPQ-R dimensions were entered, and the model was 65.5% accurate with gender remaining as the only significant predictor. This significant finding, while not been mentioned in previous research, raises the question about the accuracy of having the same IWG for males and females when determining adherence. Re-evaluation the IWG for males and females may be warranted to provide a more accurate assessment of each gender's fluid adherence.

To better understand these results, examining the theory behind the IPQ-R and its application to this hemodialysis sample is warranted. The authors of the IPQ-R encourage the modification of its wording to accurately correspond to the patient population being evaluated (Moss-Morris et al., 2002). The IPQ, predecessor to IPQ-R, (Weinman et al., 1996) has been used to assess illness perception in other medical conditions, such as vitiligo, heart disease, diabetes, and Huntington's disease, which are considered to be organic to the patient's body. The focus of the current study, dialysis, is an artificial condition that results from a loss of kidney function, regardless of the cause. A possible interpretation for the current study's findings could be that hemodialysis was

considered a consequence of another medical condition by some patients, and therefore their understanding of the symptoms and side effects of dialysis were influenced or eclipsed by the pre-existing condition. Since hemodialysis is such a unique condition, the wording of the questions on the IPQ-R may not have elicited patients' perceptions of hemodialysis in a manner that would demonstrate the predictability of the dimensions, (i.e., Timeline, Consequences, Personal and Treatment Control, Emotional Representation, and Illness Coherence) with fluid adherence.

Previous research with the IPQ-R with renal patients were the validation study for the IPQ-R, in which the authors used a group of renal patients on hemodialysis to determine test-retest reliability (Moss-Morris et al., 2002), and another study examined the relationship between the IPQ-R and the Index of Well Being with hemodialysis patients (Fowler & Baas, 2006). Similar to this current research, both studies included correlation matrices and neither of them reported problems with multicollinearity and the IPQ-R.

Another possible explanation for the current findings may be in the method of assessing adherence. It is helpful to begin by placing the current study's findings in context to how other authors assessed medical adherence in their research with the IPQ. Searle and Murphy's (2000) article found *Identity*, a dimension of the IPQ, was predictive of adherence to remedies, but none of the IPQ dimensions were found to predict patient's adherence to dietary restrictions. However, the study assessed adherence by using only a single question about dietary restrictions. Additionally, Horne and Weinman (2002) examined the IPQ and self-reported adherence to asthma prevention medication. Their results suggested that while illness perceptions were not directly

linked to adherence, these perceptions played an important role in contributing to patients' beliefs about the necessity of their medications.

A noteworthy aspect of Searle and Murphy's (2000), and Horne and Weinman's (2002) research studies is that the authors used subjective self-report measures rather than objective measures of adherence. Griva et al. (2000) found that illness perception dimensions were significantly correlated to adherence but which dimensions were significantly correlated depending on the method of assessing adherence. Their study evaluated the illness perceptions of insulin dependent diabetics. Adherence was assessed using both a self-report measure and a metabolic control measure. The results found that patient's perception of symptoms (*Identity*) was predictive of adherence when assessed by metabolic control, whereas *Control* accounted for a portion of self reported adherence. Similar to Griva et al. study, Byer and Myers (2000) study, found that *Timeline* significantly predicted the number of inhaler prescriptions (objective) and *Identity* explained a small percentage of self reported adherence. As these articles highlight, illness perception dimensions have been predictive for both objective and subjective measures of adherence. Since neither the IPQ nor the IPQ-R has been used in research to predict adherence with the hemodialysis population, the current research utilized the most common method to assess fluid adherence within this population, interdialytic weight gain.

The literature review for this study demonstrated that all of the research on fluid adherence with hemodialysis patients utilized the objective measure of fluid adherence, IWG. As previously mentioned, the IWG is considered to be a valid and reliable indicator of fluid adherence (Cvengros et al., 2004; Wolcott et al., 1986). While the use

of self report as a measure of fluid adherence is less common, four studies within the hemodialysis literature have utilized this approach. Researcher pioneers in the areas of hemodialysis and adherence, Cummings, Becker, Kirscht and Levin (1982), included a self report measure for fluid adherence in addition to IWG. They found that patient's self report of fluid adherence weakly correlated with the objective measure of IWG, suggesting that how patients view their adherence may not be indicative of their actual adherence. The authors concluded that patients' perception of how they are complying does not correspond to the objective measures, and that multiple measurement approaches are recommended to ensure an accurate gauge of compliance.

However, Cummings et al. (1982) findings on the utilization of multiple adherence methods have not been supported by other research. Rosenbaum and Ben-Ari Smira (1986) and Schneider et al., (1991) utilized both the IWG as an objective measure of adherence as well as patients' self report of adherence. In neither study did the authors report differences in findings between the self reported adherence and the IWG, suggesting that both methods resulted in the same findings. Additionally, a 2002 study utilized both self report and IWG of fluid adherence and found a significant positive relationship between them (Lee & Molassiotis, 2002). The authors suggested that since patients know their IWG and it is calculated on a regular basis, the IWG influences the patient's perception and report about their adherence to fluid restrictions (Lee & Molassiotis, 2002). As noted in the literature, the IPQ-R has been successful in predicting self reported adherence in other medical populations.

When developing research within the medical community, it is important to balance between the number of questionnaires and patient participation. The inclusion of

more questionnaires may decrease the number of participants surveyed. When attempting to predict a certain medical outcome, the power of the study plays an important role in the number of variables included in any given study. Medical populations are a vulnerable group whose participation can be challenging to access. Although dialysis patients may be an ideal population for research due to the diversity of patient backgrounds, dialysis and the lifestyle of dialysis patients are extremely tiring thus limiting the time patients are willing to devote to filling out questionnaires. The current study sought to balance between patient participation and the breadth of psychosocial variables that the study included. However, it is noteworthy that this research offered one of the larger, geographically, and demographically diverse samples in current hemodialysis adherence research.

Although sample size was not a concern in the present research, the number of nonadherent patients in the sample was a limitation in this study. While research suggests anywhere from 30 to 60% of dialysis patients are nonadherent (Christensen, Moran, Weibe, Ehlers, & Lawton, 2002; Christensen et al., 1996; Wolcott, Maida, Diamond, & Nesenson, 1986), the percentage of patients who were nonadherent was not assessed during data collection and therefore no steps were taken to expand the data collection to have a more representative sample of patients that do adhere to fluid restrictions. The percentage of nonadherent patients was considerable and this may have contributed to the prediction models ineffectiveness in identifying other variables that may have predicted patients' nonadherence to fluid restrictions. Future research that is able to collect data on a more equal number of patients who are adherent and

nonadherent, might more readily identify the predictive psychosocial aspects of adherence.

Implications for Future Research

A next step in hemodialysis research may be a qualitative study to understand how hemodialysis patients conceptualize dialysis. Anecdotally, it was noteworthy from speaking with the patients during data collection, the number of patients that mentioned social isolation since being on hemodialysis. Unintentionally, the medical teams attention given to nonadherence may be a secondary reinforce to these isolated patients since less attention was observed to be given to patients who are following their medical regimen and are adherent.

Another observation was that there were many more women who accompanied their husbands to dialysis than men with their wives; incidentally only one man was seen accompanying his wife. More males indicated having a caregiver, particularly their wives than females indicated having a caregiver. In this study since more males were found to be nonadherent to their fluid restrictions, development of a psychoeducational group focused on increasing spousal or caregiver knowledge about fluid restrictions may be beneficial to increase patient's adherence.

An additional consideration with hemodialysis research is taking into account the unique circumstances under which a person becomes reliant on dialysis. Perhaps a more elaborate assessment of mediating or moderating variables of fluid adherence with instruments that assess treatment beliefs, like the Renal Adherence Attitudes Questionnaire (RAAQ; Rushe & McGee, 1998) and/or the Renal Adherence Behaviour

Questionnaire (RABQ; Rushe & McGee, 1998), may predict areas for intervention with fluid adherence.

In summary, the socio-biological systems that influence patients' adherence are complex, and there are enormous numbers of possible interactions that challenge theories and methodological approaches to conducting adherence research (Leventhal, et al., 2003). This current research has evaluated Leventhal's common sense model of self-regulation using the dimensions of the Illness Perception Questionnaire - Revised as predictors of fluid adherence. Future research designed to address the complex systems of adherence may build upon these findings and move the medical research community another step closer to accounting for the psychosocial variables that determine adherence to hemodialysis fluid restrictions.

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