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Journal

Neprho Nurs J, 37(3)

Authors

Evangelista, LS
Kim, Y
Evangelista, L
et al.

Publication Date

2010

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Peer reviewed



Published in final edited form as:

Nephrol Nurs J. 2010 ; 37(3): 271–281.

Relationship between Illness Perceptions, Treatment Adherence, And Clinical Outcomes in Patients On Maintenance Hemodialysis

Youngmee Kim, PhD, RN, FNP-C[Post-Doctorate Fellow] and
UCLA School of Nursing, Los Angeles, CA, and a member of ANNA's Los Angeles Chapter at the time this article was written. She currently works as an Associate Professor, Red Cross College of Nursing, Seoul, Korea. She may be contacted via email at youngkim234@gmail.com

Lorraine S. Evangelista, PhD, RN[Associate Professor]
UCLA School of Nursing, Los Angeles, CA

Abstract

Previous data indicate that negative perception of disease and non-adherence to recommended treatment may lead to unfavorable clinical outcomes in patients on maintenance hemodialysis (HD). However, a paucity of research addresses clinical outcomes in the end stage renal disease (ESRD) population as a function of patients' illness perceptions and their degree of adherence to recommended treatment. The study was conducted to examine illness perceptions and treatment adherence rates in patients on maintenance HD, and to determine if illness perceptions and adherence behaviors influence clinical outcomes. One hundred fifty-one patients completed the Revised Illness Perception Questionnaire and the ESRD-Adherence Questionnaire. Illness perceptions did not independently predict any clinical outcomes in patients on maintenance HD; however, specific adherence behaviors affected clinical outcomes. Therefore, strategies to enhance adherence should be rigorously pursued in this population to improve clinical outcomes.

Patients with ESRD require lifetime commitment to their renal replacement therapy (RRT) and the medical treatment for their underlying disease for survival, and are faced with many challenges related to adherence to their treatment (National Kidney Foundation [NKF], 2002). Treatment adherence of patients on maintenance hemodialysis (HD), the most common RRT (United States Renal Data System [USRDS], 2009), classically consists of four components, including attendance at HD sessions, adherence to prescribed medications, and fluid and diet restrictions.

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Statement of Disclosure: The authors reported no actual or potential conflict of interest in relation to this continuing nursing education article.

***Nephrology Nursing Journal* Editorial Board Statements of Disclosure**

In accordance with ANCC-COA governing rules *Nephrology Nursing Journal* Editorial Board statements of disclosure are published with each CNE offering. The statements of disclosure for this offering are published below.

Paula Dutka, MSN, RN, CNN, disclosed that she is a consultant for Hoffman-La Roche and Coordinator of Clinical Trials for Roche. Patricia B. McCarley, MSN, RN, NP, disclosed that she is on the Consultant Presenter Bureau for Amgen, Genzyme, and OrthoBiotech. She is also on the Advisory Board for Amgen, Genzyme, and Roche and is the recipient of unrestricted educational grants from OrthoBiotech and Roche.

Karen C. Robbins, MS, RN, CNN, disclosed that she is on the Speakers' Bureau for Watson Pharma, Inc.

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The reported non-adherence rates in this population have been strikingly wide. For example, according to previous studies, non-adherence rates to attendance at HD, medications, and fluid and diet restrictions were from 0 to 32.3%, 1.2% to 81%, 3.4% to 74%, and 1.2% to 82.4%, respectively (Bame, Petersen, & Wray, 1993; Bleyer et al., 1999; Block, Hulbert-Shearon, Levin, & Port, 1998; Durose, Holdsworth, Watson, & Przygodzka, 2004; Hecking et al., 2004; Kutner, Zhang, McClellan, & Cole, 2002; Lee & Molassiotis, 2002; Leggat et al., 1998; Lin & Liang, 1997; Sherman, Cody, Matera, Rogers, & Solanchick, 1994). This wide range of non-adherence in the literature is likely to be related to inconsistency in the measures used to investigate patient adherence and lack of clinically relevant operational definitions of non-adherence.

Poor adherence to treatment recommendations is associated with poor clinical outcomes. For example, skipping one or more dialysis sessions per month increased mortality by 25% to 30%, an interdialytic weight gain (IDWG) greater than 5.7% increased mortality by 12% to 35%, more than 7.5 mg/dL of serum phosphorous increased mortality by 13% to 17%, and more than 6 mEq/L of serum potassium increased mortality by 9% (Leggat et al., 1998; Saran et al., 2003).

Since the degree of treatment adherence of patients with ESRD is directly related to poor clinical outcomes (Block et al., 2004; Leggat et al., 1998; Saran et al., 2003; Sezer et al., 2002; Szczech et al., 2003), many researchers have tried to identify factors that influence treatment adherence in the ESRD population. In particular, negative illness perceptions related to disease conditions have been shown to affect adherence among persons with ESRD (Christensen, Wiebe, Edwards, Michels, & Lawton, 1996; Karamanidou, Weinman, & Horne, 2008; Welch & Thomas-Hawkins, 2005). Therefore, clinical outcomes in patients with ESRD may differ according to the patient's illness perceptions and their degree of adherence to treatment. However, no single study appears to have been conducted to address clinical outcomes in the ESRD population as a function of both patients' illness perceptions and their degree of treatment adherence.

The purpose of the study was to 1) describe illness perceptions, adherence behaviors, and clinical outcomes in a sample of patients with ESRD on maintenance HD; 2) assess the relationships between illness perceptions, adherence behaviors, and clinical outcomes; and 3) determine if illness perceptions and adherence behaviors predict clinical outcomes in a sample of patients with ESRD on maintenance HD.

Methods

Study Design, Setting, and Study Participants

A total of 151 patients who spoke English, Spanish, or Korean were recruited between August 2008 and January 2009 from eight outpatient dialysis centers in Los Angeles County, California. The appropriate Institutional Review Boards approved the study. The principal investigator explained the study to patients who contacted her after reading the flyers posted at the dialysis centers. If patients were interested in participating in the study, they were asked to sign the Health Insurance Portability and Accountability Act (HIPAA) and informed consent form to allow the investigator to screen him or her for study eligibility.

Inclusion criteria for study participation were as follows: 1) a diagnosis of ESRD and currently receiving HD for more than three months; 2) receives HD for three to four hours, three times per week; 3) age 19 years or older; 4) independent with self-care activities (for example, able to walk and eat without assistance); 5) lives in a home setting; 6) understands, reads, and writes English, Spanish, or Korean; and 7) able to give informed consent. Patient-

informed consent to participate in the study was obtained after eligibility for the study was confirmed. A stratified sampling approach was used to obtain an equal number of English-, Spanish- and Korean-speaking participants.

One hundred fifty-six patients who met the inclusion criteria for study participation signed informed consent forms and agreed to participate in the study. However, five patients did not return their completed questionnaires and were lost to follow up. A total of 151 patients completed the questionnaire packet in English, Spanish, or Korean as determined by their primary language. The self-administered questionnaire packet contained questions concerning their socio-demographic characteristics and clinical history, illness perceptions, and adherence behaviors. The time to complete the questionnaire completion averaged 40 to 60 minutes. The principal investigator was available at all times to assist the patients with questionnaire completion (for example, question clarification and administering questionnaire).

Instruments

Illness perceptions were assessed using the Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002). The IPQ-R is divided into three dimensions: the identity dimension, the control dimension, and the causal dimension. The identity and control dimensions were used for this study.

The identity dimension, which consists of 14 items asking different physical symptoms in a yes or no format, addresses the number of symptoms attributed to the illness. The control dimension is composed of 38 five-point, Likert-scale items asking the personal view of the patient's current illness and include the sub-dimensions of timeline (6 items), timeline cyclical (4 items), consequences (6 items), personal control (6 items), treatment control (5 items), illness coherence (5 items), and emotional representations (6 items). High scores on the dimensions of timeline and consequences indicate patients perceive their illness to be chronic and there are likely to be adverse consequences of the illness. High scores on the personal control, treatment control, and coherence dimensions indicate patients believe they cannot control the negative consequences of their illness and symptoms, and they do not have a clear understanding of their medical condition. A high score on emotional representations indicate a higher degree of emotional distress due to the illness. In addition to obtaining scores from each dimension, the total score on the control dimension was calculated to assess overall illness perception of the patient. To compute a total score, the scores on the personal and treatment control were reverse-scored so higher total scores represented stronger overall negative perceptions. Total scores were utilized when doing univariate and multivariate tests and correlations with adherence behaviors and clinical outcomes. The validity of IPQ-R has been supported in many other studies (Jayne & Rankin, 2001; O'Neill, 2002; Yoos et al., 2007). Cronbach's alphas for the current study ranged from 0.71 to 0.88.

A newly developed, 46-item instrument, the End-Stage Renal Disease Adherence Questionnaire (ESRD-AQ), was used to measure adherence behaviors of attendance at dialysis sessions, medications, and fluid and diet restrictions (Bame et al., 1993; Kugler, Vlaminck, Haverich, & Maes, 2005; Leggat et al., 1998; Lin & Liang, 1997; Vlaminck, Maes, Jacobs, Reyntjens, & Evers, 2001). Higher scores on the ESRD-AQ denote higher adherence to the measured behavior. The validity and reliability of the ESRD-AQ were confirmed prior to use in this study. Demographic information was collected from the ESRD-AQ.

The measured clinical outcomes for the previous three-month period include the number of hospitalizations, days in hospital, and adverse graft/fistula events (for example, incidents of

clotting or infection), IDWG (mean of IDGW for the 12 HDs during the four weeks preceding the day the questionnaire was completed), and biochemical markers obtained on the day closest to the questionnaire (single-pool Kt/V_{urea} [urea kinetic modeling], serum urea nitrogen [SUN], creatinine, phosphorus, calcium, potassium, normalized protein catabolic rate [nPCR], albumin, lymphocyte count, hemoglobin, and hematocrit) (Bame et al., 1993; Christensen, Benotsch, Wiebe, & Lawton, 1995; Denhaerynck et al., 2007; Leggat et al., 1998; Mallick, Hutchinson, Patel, & Harty, 1998; Vlaminck et al., 2001).

Statistical Analysis

Statistical analyses were done using the SPSS version 15 (SPSS Inc. Chicago, IL). Descriptive statistics were used to characterize the study population and to calculate mean illness perception scores and adherence rates. Pearson product moment correlations or Spearman rho coefficients were calculated depending on the level of measurements to identify variables that were significantly correlated with each of the four treatment behaviors. Four stepwise multivariate linear regression models were examined to identify the independent determinants of clinical outcomes. Demographic information, including and gender, were entered into Step 1. Medical information (such as comorbidity and HD vintage in months, illness perception, and adherence to HD), medication, and fluid and diet restrictions were entered into Steps 2, 3, and 4, respectively. Criteria for entry and removal of variables were based on the likelihood ratio test, with enter and remove limits set at $p \leq 0.05$ and $p \geq 0.100$, respectively. The adequacy of each model was examined, and all assumptions of multiple regressions (normality, linearity, and equality of variance) were met.

Histograms of standardized residuals for illness perceptions and adherence behaviors examined in the study were normally distributed. Standardized partial regression scatter plots between dependent variables and variables that entered the model demonstrated weak linearity, which supports equality of variance. There were no influential outliers identified. Likewise, multicollinearity was not detected among the independent variables.

Results

One hundred fifty-one (151) patients (male $n = 87$, 57.6%) with the mean age of 51.9 ± 15.6 years participated in the study (English-speaking, $n = 58$; Spanish-speaking, $n = 52$; Korean-speaking, $n = 41$) (see Table 1). Most participants were unemployed ($n = 128$, 84.8%) because of retirement (20.6%) or medical conditions (64.2%) and had annual incomes below \$15,000 ($n = 109$, 72.2%). The most common causes of kidney failure were diabetes mellitus (43.0%) and hypertension (26.5%). HD vintage was 51.31 ± 49.73 months.

Illness Perception of Patients On Maintenance Hemodialysis

Among 14 symptoms to define the identity dimension of IPQ-R, fatigue (78.8%), loss of strength (77.5%), and dizziness (62.9%) were the most common symptoms reported by study participants. Illness perception scores of patients are summarized in Table 2. Mean scores were higher in the dimensions of timeline (acute/chronic), consequences, personal and treatment controls, and emotional perceptions than scores from other dimensions. The high mean scores on the dimensions of timeline and consequences indicate that most study participants understood their kidney disease was likely to be permanent rather than temporary and were aware of the seriousness of their condition. In addition, a majority of patients believed they could control the disease course by pursuing treatment to some extent, and were angry or frustrated at their disease, as reflected in the high mean scores on the dimensions of personal control and emotional representations, respectively.

Some significant differences appeared in illness perceptions according to demographic parameters. Older patients (age 65 years and older) had lower identity dimension scores (4.69 ± 3.51 , mean \pm SD) than younger patients (6.83 ± 3.40), indicating that older patients perceived less physical symptoms related to ESRD ($t = -3.24$, $p < 0.001$). In addition, older patients perceived chronicity of ESRD more, as evidenced by higher scores in the timeline dimension (23.49 ± 4.67 vs. 20.73 ± 5.32 , $t = 2.755$, $p = 0.007$). Female patients perceived more physical symptoms, as reflected in higher identity dimension scores than male patients (7.73 ± 3.27 vs. 5.30 ± 3.37 , $t = -4.47$, $p < 0.001$), and more emotional disturbances related to ESRD, as represented in higher emotional representation dimension scores (20.17 ± 5.82 vs. 17.44 ± 6.12 , $t = -2.770$, $p = 0.006$). Patients with higher education (above high school) tended to perceive they can control the negative consequences of their illness based on lower scores in the personal control dimension (20.84 ± 4.76 vs. 22.44 ± 4.81 , $t = 2.05$, $p = 0.043$).

Adherence Behaviors to HD Medications, and Fluid and Diet Restrictions

Most patients (98.7%) were aware of the importance of HD because they were knowledgeable about their disease (95.4%). Several patients (2.6%) reported learning of the importance of HD from personal experiences of being non-adherent, and 79.5% of study participants did not describe much difficulty in remaining for their entire dialysis session. Overall, the attendance rate to HD during the month they were evaluated was 90.7%, and the percentage of completed sessions without having any shortening episode of HD was 84.1%. These rates are equivalent to the ESRD-AQ mean scores of 284.80 ± 52.80 , 186.70 ± 34.50 , and 91.40 ± 21.80 in HD attendance, episode of shortening HD, and duration of shortening HD, respectively (see Table 3).

Most patients (98.0%) perceived the importance of taking medicine as scheduled, and they were knowledgeable about their disease (95.4%). Some patients (19.9%) had difficulty taking medications as prescribed, whereas most participants (80.1%) reported no such difficulty. The adherence rate to medicine intake during the previous week was 68.2%, which led to the ESRD-AQ mean score of 179.47 ± 30.15 . The primary reason reported for not taking medications among those who had missed doses was because patients simply forgot (75.0%).

Adherence to fluid restriction during the previous week was 79.5%, resulting in the ESRD-AQ mean score of 154.97 ± 48.56 (see Table 3). Ninety-five percent (95%) of patients were aware of the importance of fluid restriction mainly because they were knowledgeable about their disease (88.1%). Sixty-two percent (62%) of patients reported some difficulty following fluid restriction guidelines, and 36% of these 62% complained of much or extreme difficulty with their restricted fluid intake. Two participants stated they were completely unable to follow their recommended fluid restriction. The most commonly reported reason for non-adherence to fluid restriction was inability to control their desire for fluid (43.7%). Eleven patients claimed they did not understand how to restrict fluid intake.

About two-thirds (68.2%) of patients claimed to be adherent to their dietary restrictions during the previous week, and the measured ESRD-AQ mean score in dietary restriction adherence in study participants was 143.38 ± 47.50 (see Table 3). Most patients were aware of the importance of dietary recommendations mainly because they were knowledgeable about their disease (92.1%). More than half of the patients (57.6%) had difficulty following their dietary prescription; the primary reason for non-adherence to diet was inability to resist their favorite foods (56.3%).

Some significant differences were shown in adherence behaviors according to sociodemographic factors. Older patients (age 65 years and older) (297.14 ± 16.90 vs. 281.03 ± 58.48 , $t = 2.63$, $p = 0.01$) and married or living with a partner (295.52 ± 27.15 vs.

276.19 ± 64.69 , $t = -2.22$, $p = 0.028$) were related to better adherence to HD. In addition, married or living with a partner (186.57 ± 23.97 vs. 173.81 ± 33.36 , $t = -2.73$, $p = 0.007$) were associated with higher adherence to prescribed medications, while patients with higher income (\$15,000 and higher) (154.76 ± 34.59 vs. 138.79 ± 51.08 , $t = 2.20$, $p = 0.030$) showed better adherence to prescribed dietary intake.

Correlations between Illness Perceptions, Adherence Behaviors, and Clinical Outcomes

Clinical outcome parameters of the study population are summarized in Table 4, and results of the correlations of key variables are presented in Table 5. Among sociodemographic data, age was negatively correlated with phosphorous ($r = -0.274$, $p < 0.001$) and potassium levels ($r = -0.224$, $p < 0.001$), implying older patients were more likely to have lower phosphorous and potassium levels. In addition, older patients had positive correlations with higher adherence to HD treatment ($r = 0.297$, $p < 0.001$) and medications ($r = 0.227$, $p < 0.001$). Female gender was negatively correlated with Kt/V_{urea} ($r = -0.362$, $p < 0.001$) and positively correlated with post-SUN ($r = 0.231$, $p < 0.001$); female patients were more likely to have lower Kt/V_{urea} and higher post-SUN levels. Other demographic characteristics, such as educational levels and use of different languages (English, Spanish, Korean), did not have significant correlations with clinical outcomes. Higher comorbidity scores were correlated with greater IDWG ($r = 0.213$, $p < 0.001$) and higher post-SUN ($r = 0.201$, $p < 0.05$) levels. Longer HD vintage was associated with higher Kt/V_{urea} ($r = 0.257$, $p < 0.001$), lower phosphorous ($r = -0.176$, $p < 0.005$), and lower post-SUN ($r = -0.249$, $p < 0.001$) levels, implying that patients who had longer lengths of time on HD were more likely to have higher Kt/V_{urea} and lower phosphorous and post-SUN levels in this current study.

Only “treatment control” among seven dimensions of illness perception’s control dimension was correlated with non-adherence to diet restrictions ($r = -0.171$, $p < 0.05$), implying patients with more negative illness perceptions were more likely to be non-adherent to their diet restrictions. However, no dimensions of illness perceptions were correlated with clinical outcomes. Self-reported adherence to HD treatment was positively correlated with Kt/V_{urea} ($r = 0.169$, $p < 0.05$) but negatively correlated with post-SUN ($r = -0.161$, $p < 0.05$) levels, explaining adherers to HD were more likely to show higher Kt/V_{urea} and lower post-SUN levels. Self-reported adherence to medications was negatively correlated with phosphorous levels ($r = -0.272$, $p < 0.001$), meaning that patients adherent to medications were more likely to have lower phosphorous levels. In addition, being adherent to fluid restrictions was negatively correlated with IDWG, implying adherent patients were more likely to have lower IDWG. However, adherence to diet restrictions did not show correlations with any parameters of clinical outcomes, such as phosphorous and potassium levels, in this current study.

Predictors of Clinical Outcomes

Stepwise multivariate linear regression analyses were used to test if illness perceptions and adherence behaviors predicted clinical outcomes. Significant regression models predicting clinical outcomes are summarized in Table 6. Illness perception did not predict clinical outcomes. However, as shown in Table 6, adherence behaviors predicted certain clinical outcomes (Kt/V_{urea} , post-HD SUN, phosphorous, and IDWG).

Higher Kt/V_{urea} levels were predicted by the effects of adherence to HD treatment ($\beta = 0.206$, $p < 0.01$), gender ($\beta = -0.370$, $p < 0.001$), and longer HD vintage ($\beta = 0.235$, $p < 0.01$), explaining 21% of the variance in the Kt/V_{urea} levels. Lower post-SUN levels were predicted by the combined effects of adherence to HD ($\beta = -0.210$, $p < 0.01$), gender ($\beta = 0.250$, $p < 0.01$), higher co-morbidity scores ($\beta = -0.190$, $p < 0.05$), and longer HD vintage ($\beta = 0.195$, $p < 0.05$), explaining 16% of the variance in the post-SUN levels. In addition,

lower phosphorous levels were predicted by the combined effects of adherence to medications ($\beta = -0.203, p < 0.05$), older age ($\beta = -0.224, p < 0.01$), and longer HD vintage ($\beta = -0.142, p < 0.05$), explaining 12% of the variance in the phosphorous levels. Further, lower IDWG was predicted by the effects of adherence to fluid restrictions ($\beta = -0.198, p < 0.05$), gender ($\beta = 0.202, p < 0.01$), lower co-morbidity scores ($\beta = 0.256, p < 0.01$), and shorter HD vintage ($\beta = 0.172, p < 0.05$), explaining 13% of the variance in IDWG. Other clinical outcomes, such as number of hospitalizations and days in hospital, number of HD graft/fistula problems, and other biochemical markers (creatinine, calcium, potassium, nPCR, albumin, lymphocyte count, hemoglobin, and hematocrit), were not predicted by either illness perceptions or adherence behaviors.

Discussion

This study was conducted to describe adherence behaviors and disease perceptions of patients on maintenance HD in a comprehensive way and to assess the relationships between illness perceptions, adherence behaviors, and clinical outcomes in patients on maintenance HD. Based on the demographic findings, the majority of the study sample had poor socioeconomic status, as reflected in high levels of unemployment, low annual incomes, and low educational levels. Ward (2008) examined the incidence in 747,556 adults with ESRD in the U.S. population from January 1, 1996, to June 30, 2004, and reported that incidence of ESRD was different according to socioeconomic status. The incidence of ESRD caused by all primary kidney diseases was greatest in those in the lowest socioeconomic score quartile and decreased with higher socioeconomic status. Thus, the current sample adequately reflects the general U.S. population from the socioeconomic standpoint where individuals with lower socioeconomic status were at greater risk for ESRD.

Fowler and Baas (2006) used the IPQ-R to examine illness perception on patients on maintenance HD. The mean scores of each dimension from 42 patients on maintenance HD in their study were similar to those in the current study. Most participants in their study had low socioeconomic status and were Caucasian.

Non-adherence rates to HD (missing and shortening HD), medication, and fluid and diet restrictions in the current study population were 12.6%, 31.8%, 20.5%, and 31.8%, respectively. Previous studies reported non-adherence rates to attendance at HD, medications, and fluid and diet restrictions from 0 to 32.3%, 1.2% to 81%, 3.4% to 74%, and 1.2% to 82.4%, respectively (Bame et al., 1993; Bleyer et al., 1999; Block et al., 1998; Durose et al., 2004; Hecking et al., 2004; Kutner et al., 2002; Lee & Molassiotis, 2002; Leggat et al., 1998; Lin & Liang, 1997; Sherman et al., 1994). Since the previously reported adherence rates have been extremely varied, it is difficult to compare measured adherence rates in this study to those reported by others. When compared to the reported adherence rates using self-report instruments, the study conducted by Kugler and colleagues (2005) reported non-adherence rates as high as 74.6% and 81.4% to fluid and diet restrictions from 916 patients in Germany and Belgium, respectively. They used the Dialysis Diet and Fluid Non-Adherence Questionnaire (DDFQ), the only available self-report instrument with proven validity and reliability. Overall adherence rates in this study population are thought to be higher than the previous study. Perhaps this is related to the different study settings, measurement instruments, and/or the recruitment procedures employed for the study, which resulted in 100% of participants volunteering to take part in the survey.

The reported adherence rate to HD for the current sample was high, but the rates of adherence to medications and fluid and diet restrictions were relatively low. It is speculated that these findings are related to the increased degree of difficulty following treatment

recommendations for medications and fluid and diet guidelines; perhaps fluid and dietary restrictions require more willpower of patients.

Hemodialysis vintage was the most important predictor among all predictor variables, explaining variance in four different outcomes in this study. Among sociodemographic variables, age was the only demographic variable that had a correlation with adherence and clinical outcomes. Age was positively correlated with adherence to HD and medications, and was negatively correlated with phosphorous and potassium levels. Older age has been reported as the predictor of higher adherence in the ESRD population (Kimmel et al., 1995; Kugler et al., 2005; Kutner et al., 2002), and such findings were confirmed in this current study.

Illness perceptions were negatively correlated with adherence to diet; patients who reported stronger negative perceptions about their disease were more non-adherent with dietary restrictions. Previous studies showed that illness perceptions affect either adherence behavior or clinical outcomes in patients on maintenance HD (Christensen et al., 1996; Karamanidou et al., 2008; Welch & Thomas-Hawkins, 2005). However, in contrast, illness perceptions did not predict any clinical outcomes in this study. When Christensen and colleagues (1996) investigated the relationships between private body consciousness (PBC) and clinical parameters, such as IDWG and phosphorous level over a one-month period in 52 patients on maintenance HD, patients with higher PBC scores indicating higher perception of body processes had a negative disease perception and poorer clinical outcomes. The only difference between the two studies was the measurement tool used to assess perception of disease. Compared to the PBC scale, the IPQ-R covers broader aspects of disease perceptions, including emotional perceptions.

Adherence to fluid restrictions with certain demographic and medical factors was a predictor of lower IDWG, and adherence to HD was a predictor of higher Kt/V_{urea} levels. In addition, adherence to medication was a predictor of lower phosphorous levels; patients with higher adherence to medication had lower phosphorous levels. Most patients with ESRD are on phosphate binders, and results from the current study strongly support that adherence behaviors can affect clinical outcomes in the ESRD population; however, phosphorous level is related to not only medication adherence but also diet adherence. Therefore, this study provides a clear rationale to emphasize importance of treatment adherence in this population.

Findings from the current study are limited; participants were from a specific geographical location and recruited from eight dialysis centers in Los Angeles County, California, which has a high number of ethnic minorities. Generalization of study results may be limited by the homogeneous nature of this sample because half of the patients with ESRD in the U.S. are Caucasians (USRDS, 2009). In addition, even though the sample size was determined through a power analysis, a larger sample may be needed to adequately describe illness perceptions and adherence behaviors. Socio-demographics, medical factors, and adherence behaviors appear to explain less than 30% of the variance of clinical outcomes. Therefore, further investigations are required to verify which additional factors are responsible in determining critical clinical outcomes in patients on maintenance HD. Finally, the ESRD-AQ is a newly generated self-report instrument used for this study. Although its validity and reliability were supported in prior research, it may require further modification depending on future studies, such as its application to a more diverse population in different experimental settings.

Conclusions and Clinical Implications

This study examined relationships between illness perceptions, adherence behaviors, and clinical outcomes using a valid and comprehensive questionnaire with four areas of treatment adherence in the ESRD population on maintenance HD. Illness perceptions did not independently predict any clinical outcomes in patients on HD; however, these current findings suggest that specific adherence behaviors affect clinical outcomes. Thus, strategies to enhance adherence should be rigorously pursued in this population. Likewise, clinicians and researchers should focus on developing interventions to educate and counsel patients on maintenance HD; older persons and individuals with lower socio-economic status warrant increased scrutiny.

Goal

To provide an overview of the success rate of treatment options for patients with ESRD on maintenance hemodialysis based on treatment adherence versus non-adherence.

Objectives

1. List the purposes of this study measuring the treatment adherence of patients with ESRD.
2. Describe how patient perceptions of their disease and adherence vs. non-adherence to treatment of ESRD affect their clinical outcomes.

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References

- Bame SI, Petersen N, Wray NP. Variation in hemodialysis patient compliance according to demographic characteristics. *Social Science & Medicine*. 1993; 37(8):1035–1043. [PubMed: 8235736]
- Bleyer AJ, Hylander B, Sudo H, Nomoto Y, de la Torre E, Chen RA, Burkart JM. An international study of patient compliance with hemodialysis. *Journal of the American Medical Association*. 1999; 281(13):1211–1213. [PubMed: 10199431]
- Block GA, Hulbert-Shearon TE, Levin NW, Port FK. Association of serum phosphorus and calcium \times phosphate product with mortality risk in chronic hemodialysis patients: A national study. *American Journal of Kidney Disease*. 1998; 31(4):607–617.
- Block GA, Klassen PS, Lazarus JM, Ofsthun N, Lowrie EG, Chertow GM. Mineral metabolism, mortality, and morbidity in maintenance hemodialysis. *Journal of American Society of Nephrology*. 2004; 15(8):2208–2218.

- Christensen AJ, Benetsch EG, Wiebe JS, Lawton WJ. Coping with treatment-related stress: Effects on patient adherence in hemodialysis. *Journal of Consulting and Clinical Psychology*. 1995; 63(3): 454–459. [PubMed: 7608358]
- Christensen AJ, Wiebe JS, Edwards DL, Michels JD, Lawton WJ. Body consciousness, illness-related impairment, and patient adherence in hemodialysis. *Journal of Consulting Clinical Psychology*. 1996; 64(1):147–152.
- Denhaerynck K, Manhaeve D, Dobbels F, Garzoni D, Nolte C, De Geest S. Prevalence and consequences of nonadherence to hemodialysis regimens. *American Journal of Critical Care*. 2007; 16(3):222–235.
- Durose CL, Holdsworth M, Watson V, Przygodzka F. Knowledge of dietary restrictions and the medical consequences of noncompliance by patients on hemodialysis are not predictive of dietary compliance. *Journal of the American Dietetic Association*. 2004; 104(1):35–41. [PubMed: 14702581]
- Fowler C, Baas LS. Illness representations in patients with chronic kidney disease on maintenance hemodialysis. *Nephrology Nursing Journal*. 2006; 33(2):173–174. 179–186. [PubMed: 16613412]
- Hecking E, Bragg-Gresham JL, Rayner HC, Pisoni RL, Andreucci VE, Combe C, Friedrich KP. Haemodialysis prescription, adherence and nutritional indicators in five European countries: results from the Dialysis Outcomes and Practice Patterns Study (DOPPS). *Nephrology Dialysis Transplantation*. 2004; 19(1):100–107.
- Jayne RL, Rankin SH. Application of Leventhal 19s self-regulation model to Chinese immigrants with type 2 diabetes. *Journal of Nursing Scholarship*. 2001; 33(1):53–59. [PubMed: 11253580]
- Karamanidou C, Weinman J, Horne R. Improving haemodialysis patients' understanding of phosphate-binding medication: A pilot study of a psycho-educational intervention designed to change patients' perceptions of the problem and treatment. *British Journal of Health Psychology*. 2008; 13(Pt. 2):205–214. [PubMed: 18302808]
- Kimmel PL, Peterson RA, Weihs KL, Simmens SJ, Boyle DH, Verme D, Cruz I. Behavioral compliance with dialysis prescription in hemodialysis patients. *Journal of the American Society of Nephrology*. 1995; 5(10):1826–1834. [PubMed: 7787151]
- Kugler C, Vlaminc H, Haverich A, Maes B. Nonadherence with diet and fluid restrictions among adults having hemodialysis. *Journal of Nursing Scholarship*. 2005; 37(1):25–29. [PubMed: 15813583]
- Kutner NG, Zhang R, McClellan WM, Cole SA. Psychosocial predictors of non-compliance in haemodialysis and peritoneal dialysis patients. *Nephrology Dialysis Transplantation*. 2002; 17(1): 93–99.
- Lee SH, Molassiotis A. Dietary and fluid compliance in Chinese hemodialysis patients. *International Journal of Nursing Studies*. 2002; 39(7):695–704. [PubMed: 12231026]
- Legat JE Jr, Orzol SM, Hulbert-Shearon TE, Golper TA, Jones CA, Held PJ, Port FK. Non-compliance in hemodialysis: Predictors and survival analysis. *American Journal of Kidney Diseases*. 1998; 32(1):139–145. [PubMed: 9669435]
- Lin CC, Liang CC. The relationship between health locus of control and compliance of hemodialysis patients. *Kaohsiung Journal of Medical Sciences*. 1997; 13(4):243–254. [PubMed: 9177086]
- Mallick NP, Hutchinson A, Patel M, Harty J. Factors influencing dialysis outcome: The dialysis dose in perspective. *Nephrology Dialysis Transplantation*. 1998; 13 Suppl. 6:152–157.
- Moss-Morris R, Weinman J, Petrie KJ, Horne R, Cameron LD, Buick D. The revised illness perceptions questionnaire (IPQ). *Psychology and Health*. 2002; 17(1):1–16.
- National Kidney Foundation (NKF). K-DOQI clinical practice guidelines for clinical kidney disease: Evaluation, classification, and stratification. *American Journal of Kidney Diseases*. 2002; 39 Suppl. 1:S45–S75.
- O'Neill E. Illness representations and coping of women with chronic obstructive pulmonary disease: A pilot study. *Heart & Lung*. 2002; 31(4):295–302. [PubMed: 12122393]
- Saran R, Bragg-Gresham JL, Rayner HC, Goodkin DA, Keen ML, Van Dijk PC, Port FK. Nonadherence in hemodialysis: Associations with mortality, hospitalization, and practice patterns in the DOPPS. *Kidney International*. 2003; 64(1):254–262. [PubMed: 12787417]

- Sezer S, Ozdemir FN, Arat Z, Perim O, Turan M, Haberal M. The association of interdialytic weight gain with nutritional parameters and mortality risk in hemodialysis patients. *Renal Failure*. 2002; 24(1):37–48. [PubMed: 11921697]
- Sherman R, Cody R, Matera J, Rogers M, Solanchick J. Interdialytic weight gain and nutritional parameters in chronic hemodialysis patients. *American Journal of Kidney Diseases*. 1994; 24:921–923. [PubMed: 7985669]
- Szczzech LA, Reddan DN, Klassen PS, Coladonato J, Chua B, Lowrie EG, Owen WF Jr. Interactions between dialysis-related volume exposures, nutritional surrogates and mortality among ESRD patients. *Nephrology Dialysis Transplantation*. 2003; 18(8):1585–1591.
- United States Renal Data System (USRDS). USRDS annual data report. 2009. Retrieved from <http://www.usrds.org/adr.htm>
- Vlaminck H, Maes B, Jacobs A, Reyntjens S, Evers G. The dialysis diet and fluid nonadherence questionnaire: Validity testing of a self-report instrument for clinical practice. *Journal of Clinical Nursing*. 2001; 10(5):707–715. [PubMed: 11822521]
- Ward MM. Socioeconomic status and the incidence of ESRD. *American Journal of Kidney Diseases*. 2008; 51(4):563–572. [PubMed: 18371532]
- Welch JL, Thomas-Hawkins C. Psycho-educational strategies to promote fluid adherence in adult hemodialysis patients: A review of intervention studies. *International Journal of Nursing Studies*. 2005; 42(5):597–608. [PubMed: 15921991]
- Yoos HL, Kitzman H, Henderson C, McMullen A, Sidora-Arcoleo K, Halterman JS, Anson E. The impact of the parental illness representation on disease management in childhood asthma. *Nursing Research*. 2007; 56(3):167–174. [PubMed: 17495572]

Table 1Sociodemographic Data of Study Participants ($N = 151$)

Descriptor	Number	Percentage
Gender		
Male	87	57.6%
Female	64	42.4%
Age		
Less than 65 years	116	76.8%
65 years and older	35	23.2%
Race/Ethnicity		
Caucasian	2	1.3%
African American	19	12.6%
Asian American	58	38.4%
Native American	1	0.7%
Hispanic/Latino	71	47.0%
Education Level		
High school or less	85	56.3%
Vocational school	7	4.6%
Some college	22	14.6%
College graduate or more	37	24.5%
Marital Status		
Never married	43	28.5%
Married/living with partner	67	44.3%
Separated, divorced, widowed	41	27.2%
Currently Employed		
Yes	23	15.2%
No	128	84.8%
Income		
Less than \$15,000	109	72.2%
\$15,000 to \$60,000	39	25.8%
Greater than \$60,000	3	2.0%
Causes of Kidney Failure		
Diabetes mellitus	65	43.0%
Hypertension	40	26.5%
Glomerulonephritis	8	5.3%
Others (congenital kidney anomalies, polycystic kidney)	19	12.6%
Unknown	19	12.6%
HD Vintage in Months		
12 months or less	30	19.9%
13 to 36 months	47	31.1%

Descriptor	Number	Percentage
37 to 60 months	28	18.5%
60 months or greater	46	30.5%
HD Treatment Duration		
3 hours	39	25.8%
More than 3 and less than 4 hours	65	43.1%
4 hours	47	31.1%

Table 2Score on the IPQ-R Subscales of the Subjects ($N = 151$)

Scale (Number of Items)	Possible Score Range	Mean \pm SD	Cronbach's Alpha
Identity Dimension			
Identity (14)	0 to 14	6.33 \pm 3.53	0.88
Control Dimension			
Timeline (acute/chronic) (6)	6 to 30	21.37 \pm 5.30	0.75
Timeline (cyclical) (4)	4 to 20	11.68 \pm 4.48	0.84
Consequences (6)	6 to 30	22.75 \pm 4.96	0.72
Personal control (6)	6 to 30	21.54 \pm 4.83	0.71
Treatment control (5)	5 to 25	17.86 \pm 4.43	0.75
Illness coherence (5)	5 to 25	11.56 \pm 4.90	0.83
Emotional representations (6)	6 to 30	18.60 \pm 6.13	0.82

Note: High scores of Identity = complaining of more physical symptoms; high scores on the dimensions of timeline and consequences = higher degree of perceptions of chronicity and adverse *consequences* of the illness; high scores on the personal control, treatment control and coherence dimensions = higher degree of perceptions of uncontrollability over negative consequences of their illness and lower understanding of their medical condition. A high score on emotional representations = higher degree of emotional distress due to the illness.

Table 3Adherence Behavior Scores ($N = 151$)

ESRD-AQ ^a Question Number	Possible Score Range	Score Mean \pm SD
#14: HD ^b attendance	0 to 300	284.80 \pm 52.80
#17: Episode of shortening HD	0 to 200	186.70 \pm 34.50
#18: Duration of shortening HD if shortened	0 to 100	91.40 \pm 21.80
#26: Adherence to medication	0 to 200	179.47 \pm 30.15
#31: Adherence to fluid restriction	0 to 200	154.97 \pm 48.56
#46: Adherence to dietary restriction	0 to 200	143.38 \pm 47.50

^a End-stage renal disease adherence questionnaire.

^b Hemodialysis.

Note: Higher scores indicate better adherence to treatment.

Table 4Descriptive Summary of Measured Clinical Outcome Parameters ($N = 151$, Mean \pm SD)

Number of hospitalizations in last 3 months (Total of 13 patients had hospitalizations: minimum – once; maximum – twice)	1.08 \pm 0.28
Number of days in hospital in last 3 months (Minimum 2 days and maximum 16 days among the 13 patients who were hospitalized)	4.77 \pm 3.81
Number of HD ^a access clotting in last 3 months	0
Number of HD access infection in last 3 months	0
Mean of IDWG ^b for the past 4 weeks (Kg)	2.75 \pm 1.01
Single pool Kt/V _{urea}	1.69 \pm 0.33
Pre-HD serum phosphorus (mg/dL)	5.55 \pm 1.69
Pre-HD serum potassium (mEq/L)	4.98 \pm 0.71
Pre-HD SUN ^c (mg/dL)	57.37 \pm 17.84
Post-HD SUN (mg/dL)	14.80 \pm 6.65
Pre-HD serum creatinine (mg/dL)	10.16 \pm 3.08
Pre-HD serum calcium (mg/dL)	9.22 \pm 0.80
nPCR ^d (g/kg – 1; day – 1)	1.14 \pm 0.29
Pre-HD serum albumin (g/dL)	4.44 \pm 3.44
Total lymphocyte count (1000/ μ L)	1.699 \pm 0.66
Hemoglobin (g/dL)	12.05 \pm 1.21

^a Hemodialysis,^b Interdialytic weight gain,^c Serum urea nitrogen,^d Normalized protein catabolic rate.

Table 5

Correlational Matrix of Key Variables (*N* = 151)

Variables	1	2	3	4	5	6	7	8	9	10	11	12
1. Age												
2. Comorbidity	0.421 ^{***}											
3. HD Vintage	0.031	-0.221 ^{***}										
4. Treatment Control ^a	0.156	0.000	0.086									
5. Adherence to HD	0.297 ^{***}	0.123	0.005	-0.024								
6. Adherence to Medications	0.227 ^{***}	0.066	0.133	-0.054	0.225 ^{***}							
7. Adherence to Fluid	0.111	-0.014	-0.009	0.038	0.136	0.150						
8. Adherence to Diet	-0.001	-0.023	-0.081	-0.171 [*]	0.162 [*]	0.207 [*]	0.303 ^{***}					
9. IDWG for 4 Weeks	0.013	0.213 ^{***}	0.106	0.065	0.162 [*]	-0.044	-0.205 [*]	-0.141				
10. Kt/V _{urea} , Single Pool	0.092	-0.142	0.257 ^{***}	0.095	0.169 [*]	0.154	-0.010	0.069	-0.246 ^{***}			
11. Pre-HD Serum Phosphorus	-0.274 ^{***}	-0.096	-0.176 [*]	0.034	-0.154	-0.272 ^{***}	0.042	-0.055	0.178 [*]	-0.279 ^{***}		
12. Pre-HD Serum Potassium	-0.224 ^{***}	-0.041	-0.023	-0.064	-0.115	-0.020	-0.040	-0.051	0.221 ^{***}	-0.084	0.111	
13. Post-HD SUN	-0.075	0.201 [*]	-0.249 ^{***}	0.077	-0.161 [*]	-0.120	-0.096	-0.106	0.416 ^{***}	-0.661 ^{***}	0.348 ^{***}	0.305 ^{***}

^aTreatment control = score of treatment control dimension among 7 dimensions of illness perception's control dimension; co-morbidity = Charlson comorbidity scores were used; higher illness perception scores reflect stronger negative perceptions about illness; higher adherence scores reflect better adherence level.

* Correlation is significant at the 0.05 level (2-tailed).

*** Correlation is significant at the 0.01 level (2-tailed).

Table 6

Final Models Predicting Clinical Outcomes (N = 151)

Clinical Outcomes	Variables	Beta	R ²	Adjusted R ²	F	P
Kt/V_{urea}	Gender	-0.370***	0.229	0.213	14.551	0.000
	HD Vintage in months	0.235**				
	Adherence to HD	0.206**				
Post-SUN	Gender	0.250**	0.178	0.155	7.898	0.000
	Co-morbidity	-0.190**				
	HD vintage in months	0.195**				
	Adherence to HD	-0.210**				
Pre-HD Phosphorus	Age	-0.224**	0.141	0.124	8.075	0.000
	HD vintage in months	-0.142*				
	Adherence to medications	-0.203*				
IDWG	Gender	0.202**	0.150	0.127	6.463	0.000
	Co-morbidity	0.256**				
	HD vintage in months	0.172*				
	Adherence to fluid	-0.198*				

Note: Beta (β) = standardized coefficients; female is a reference group in gender; comorbidity= Charlson comorbidity score; higher adherence score means better adherence level; demographic information, including age and gender, were entered into Step 1; medical information (such as comorbidity and HD) vintage in Step 2; illness perception in Step 3; and adherence to HD, medications, fluid, and diet in Step 4, respectively. The findings indicate β coefficients in the final step, after controlling for socio-demographic and medical information (age, gender, comorbidity, and HD vintage).

* p < 0.05

** p < 0.01

*** p < 0.001