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The End-Stage Renal Disease Adherence Questionnaire (ESRD-AQ): Testing The Psychometric Properties in Patients Receiving In-Center Hemodialysis

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Abstract

Reported treatment adherence rates of patients with end stage renal disease (ESRD) have been extremely varied due to lack of reliable and valid measurement tools. This study was conducted to develop and test an instrument to measure treatment adherence to hemodialysis (HD) attendance, medications, fluid restrictions, and diet prescription among patients with ESRD. This article describes the methodological approach used to develop and test the psychometric properties (such as reliability and validity) of the 46-item ESRD-Adherence Questionnaire (ESRD-AQ) in a cohort of patients receiving maintenance HD at dialysis centers in Los Angeles County. The ESRD-AQ is the first self-report instrument to address all components of adherence behaviors of patients with ESRD. The findings support that the instrument is reliable and valid, and is easy to administer. Future studies are needed in a larger sample to determine whether additional modifications are needed.

This study was conducted to develop and psychometrically test an instrument designed to measure adherence behaviors of patients with end stage renal disease (ESRD) receiving maintenance hemodialysis (HD) at dialysis centers in Los Angeles County. Maintenance HD is the most common renal replacement therapy (RRT) for the many individuals who suffer from ESRD (United States Renal Data System [USRDS], 2009). When RRT is initiated, patients' lives change completely. Patients requiring in-center HD must regularly travel to a dialysis center, consistently take prescribed medications, and extensively modify their diets. Successful treatment of ESRD depends largely on patients adhering to their very demanding

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recommended treatment regimens. Despite the importance of adherence, which is defined as following medical or health advice (Denhaerynck et al., 2007), many patients with ESRD who are on HD fail to adhere to their recommended treatment regimens. Reports concerning adherence vary widely, and the non-adherence rates to attendance at HD, prescribed medications, fluid restrictions, and dietary intake range 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, & Przygrodzka, 2004; Hecking, Bragg-Gresham, Rayner, Lützén, & Clyne, 2004; Kutner, Zhang, McClellan, & Cole, 2002; Lee & Molassiotis, 2002; Leggat et al., 1998; Lin & Liang, 1997; Sherman, Cody, Matera, Rogers, & Solanchick, 1994). Unfortunately, non-adherence to these four behaviors can have disastrous results in terms of quality of life, increased morbidity, healthcare costs, and mortality (Block et al., 2004; Leggat et al., 1998; Saran et al., 2003; Sezer et al., 2002; Szczech et al., 2003).

Adherence to treatment regimens in patients with ESRD is measured by a variety of methods, with no one method being superior (Denhaerynck et al., 2007; Loghman-Adham, 2003; Morgan, 2000). Clinical measures used to evaluate treatment non-adherence in patients with ESRD on maintenance HD include biological measures, such as interdialytic weight gain (IDWG) calculated as the difference between the patient's weight obtained at the onset of a dialysis treatment and the weight obtained at the end of the previous dialysis (Bame et al., 1993; Christensen, Benotsch, Wiebe, & Lawton, 1995; Leggat et al., 1998); and biochemical markers, such as pre-HD serum potassium or phosphorous levels (Bame et al., 1993; Betts & Crotty, 1998; Cummings, Becker, Kirscht, & Levin, 1982; Durose et al., 2004; Hecking et al., 2004; Kutner et al., 2002; Lee & Molassiotis, 2002; Leggat et al., 1998; Lin & Liang, 1997; Weed-Collins & Hogan, 1989). In general, biological and biochemical markers can be regarded as objective measures; however, the lack of a universally accepted cutoff value for each marker raises the question of whether these measures are reliable tools to assess nonadherence rates in the ESRD population. These measures have been used not only to assess treatment adherence but to evaluate clinical outcomes in the ESRD population. However, these biological and biochemical markers may be more effective or reliable measures of clinical outcomes and may not necessarily be adequate for measuring non-adherence (Bame et al., 1993; Bleyer et al., 1999; Block et al., 1998; Christensen et al., 1995; 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).

Direct questioning of patients is frequently used to measure adherence; however, few adherence scales have been developed and tested for use with patients with ESRD (Coyne et al., 1995; Gordon, Leon, & Sehgal, 2003; Lee & Molassiotis, 2002; Lin & Liang, 1997). Self-report instruments, such as questionnaires, are valuable for measuring adherence if they are well validated and reliable. Further, they might be the most cost-effective measures. However, the wide variations in the reported non-adherence rates are mainly due to lack of reliable measurement tools that address the four classical components of treatment adherence behavior of patients with ESRD on maintenance HD: attending HD sessions, taking prescribed medications, and following prescribed fluid restrictions and dietary intake. One of the few instruments with established validity and reliability to evaluate treatment adherence in ESRD population is the Dialysis Diet and Fluid Non-Adherence Questionnaire (DDFQ) (Vlaminck, Maes, Jacobs, Reyntjen, & Evers, 2001). The DDFQ consists of four questions that assess frequency and degree of adherence to fluid restriction and to dietary guidelines for the past 14 days. However, because the DDFQ does not address HD attendance and medication use, measurement of adherence is limited (Vlaminck et al., 2001). Additionally, some concerns may surface because of the DDFQ's over-simplified design. In addition, the DDFQ has never been tested with American populations.

Therefore, a valid and reliable instrument is needed to determine the degree of adherence to treatment and to identify non-adherent patients who would benefit from interventions to prevent adverse events. This study was conducted to develop and test the reliability and validity of a self-report instrument developed to assess treatment adherence behaviors of patients with ESRD receiving maintenance HD.

Methods

Item Generation and Scoring System

The End-Stage Renal Disease-Adherence Questionnaire (ESRD-AQ) for patients requiring in-center HD was designed to measure treatment adherence behaviors in four dimensions: HD attendance, medication use, fluid restrictions, and diet recommendations. Items were initially generated based on in-depth literature reviews and in consultation with clinical experts, such as nephrologists and nephrology researchers, HD nurses, and renal dieticians. The final version of the ESRD-AQ consists of 46 questions/items divided into five sections (see Table 1). The first section pursues general information about patients' ESRD and RRT-related history (5 items), and the remaining four sections ask about treatment adherence to HD treatment (14 items), medications (9 items), fluid restrictions (10 items), and diet recommendations (8 items). These four final sections directly measure adherence behaviors (14, 17, 18, 26, 31, and 46), and patients' knowledge and perceptions about treatment (11, 12, 22, 23, 32, 33, 41, and 42). Responses to the ESRD-AQ utilize a combination of Likert scales and multiple choice, as well as “yes/no” answer format.

The adherence behavior subscale is scored by summing the responses to questions 14, 17, 18, 26, and 46. The weighting system for scores was determined based on the degree of importance relevant to clinical outcome of each dimension. For example, missing or shortening HD has been reported to have a stronger association with mortality of patients with ESRD than other components of adherence behavior; therefore, it was given more weight in computing the adherence scores (Leggat et al., 1998; Saran et al., 2003). In addition, the ESRD-AQ adjusts scores for question numbers 14 (“During the last month, how many complete dialysis treatments did you miss?”), 18 (“During the last month, when your dialysis treatment was shortened, what was the average numbers of minutes?”), and 26 (“During the past week, how often have you missed your prescribed medicines?”), depending on the reasons for not adhering. For example, patients with medical reasons for missing or shortening the HD treatment (such as having HD access problems or physical symptoms during HD) obtained a full score (see Table 2).

The attitude/perception subscale is scored by summing the responses to questions 11, 12, 22, 23, 32, 33, 41, and 42. The remaining questions obtain information about patients' ESRD and RRT related history. The ESRD-AQ is designed such that higher scores indicate better adherence.

Validating the Instrument: Use Of Content and Face Validities

Seven experts (two nephrologists, a nurse practitioner, two HD nurses, and two renal dieticians) with extensive clinical and research experience in the care for patients with ESRD on maintenance HD were invited to assess content validity of the ESRD-AQ. To ensure that the instrument had an appropriate sample of items to represent the construct of interest, experts were asked to review the content relevance of questions, appropriate use of language, domain coverage of adherence, and the scoring system (Polit, Beck, & Owen, 2007). Further modifications to the ESRD-AQ were made based on input from the seven experts. Finally, they were asked to rate each item using a 4-point scale (1 = not relevant; 2 = somewhat relevant; 3 = quite relevant; 4 = highly relevant).

Five patients from the target population were then asked to complete the questionnaire and provide feedback on whether each item was relevant and appropriately written. These patients were asked to evaluate each item on whether potential participants would be able to respond to questions about their adherence behaviors (face validity). The investigator modified the ESRD-AQ based on input from the patients. A final version of the modified instrument was given to the five patients who subsequently agreed that the final instrument was appropriate to address their adherence behaviors.

Data Collection

Potential study participants were recruited through the use of flyers posted at eight chronic outpatient dialysis centers in Los Angeles between August 2008 and January 2009 as approved by each center's Institutional Review Board. Patient eligibility was determined by the researcher after the participants signed the Health Insurance Portability and Accountability Act (HIPAA) consent form. The inclusion criteria were 1) diagnosed with ESRD and treated with HD for at least three months; 2) received HD for three to four hours per session, three times per week; 3) at least 18 years old (which is the age of consent in California); 4) is independent and performs self-care activities (such as ability to walk and eat without assistance); 5) lived in a home setting; and 6) able to give informed consent. Patients on peritoneal dialysis were excluded. Individuals who agreed to participate and met the eligibility criteria signed the informed consent and completed the questionnaire. The ESRD-AQ is a paper-and-pencil instrument. Completion of the instrument took approximately 20 to 40 minutes. Fifty-eight (58) patients who consented to participate completed the questionnaire.

Statistical Analysis

All statistical analyses were performed using the SPSS (Version 15, SPSS, Inc. Chicago, IL). Test-retest reliability was evaluated using intraclass correlation coefficients (ICC) between frequencies of responses endorsed at time 1 and time 2 (with a two-day gap between the two time points) in a random sample of 10% of the patients (n = 6) (Yen & Lo, 2002).

The content validity of the ESRD-AQ was assessed by calculating the content validity index (CVI) (Lynn, 1986; Polit & Beck, 2006b; Polit, Beck, & Owen, 2007; Schilling et al., 2007) for each item (total 46 items) based on the expert panel's ratings of item relevance. The CVI was used to obtain item-level content validity, which was computed as the number of experts assigning a rating of 3 (quite relevant) or 4 (highly relevant) among total number of experts. Then, the average item-level CVI (I-CVI) was obtained. Experts proposed that an I-CVI of 1.00 is ideal when there are five or fewer experts, while an I-CVI of 0.83 or higher is recommended when there are more than five experts. However, an I-CVI greater than 0.78 would be acceptable overall (Lynn, 1986; Polit & Beck, 2006b; Polit et al., 2007; Schilling et al., 2007).

Construct validity was assessed by employing a known group analysis comparing adherers and non-adherers (Polit & Beck, 2004, 2006a). Two nurses working in in-center HD and one renal dietician at each dialysis center rated each patient's adherence behaviors based on dialysis attendance, IDWGs, and serum potassium and phosphorous levels over the preceding one month. Patients were considered non-adherent if they skipped or shortened their HD treatment more than once-monthly (for nonadherence to HD), if serum phosphorus was higher than 7.5 mg/dL (for non- adherence to medication and diet), if IDWGs were greater than 5.7% higher than the previous weight more than once- weekly (for nonadherence to fluid restrictions), and/or if serum potassium was higher than 6.0 mmol/L (for non-adherence to diet restrictions) on monthly laboratory results (Leggat et al., 1998;

Lòpez-Gòmez, Villaverde, Jofre, Rodriguez-Benítez, & Pérez-García, 2005; Saran et al., 2003). These criteria were used separately to distinguish between adherer and non-adherer in each of the four dimensions of adherence behavior to assess construct validity of ESRD-AQ. Non-parametric *t*-tests (Mann-Whitney U) were utilized to compare mean scores between the two groups (known adherent group vs. known non-adherent group) (Creedy et al., 2003; Klem, Sybrandy, Wittens, & Bot, 2008; Wan et al., 2008).

Results

Fifty-eight (58) patients completed the instrument; they had a mean age of 47.64 ± 15.11 (standard deviation [SD]; age range = 21 to 83 years) and an average HD vintage of 56.01 ± 60.94 months (vintage range = 3 to 281 months) since initiation of maintenance HD. The primary causes of kidney failure included diabetes mellitus, hypertension, and others (such as glomerulonephritis, congenital anomalies, and polycystic kidney disease). The sociodemographic details of study participants as determined by two nurses working in in-center HD and one renal dietician according to adherence to HD attendance, medications, fluid restrictions, and diet restrictions are summarized in Table 3.

Validity

The item-level content validities for the 46 items ranged between 0.86 and 1.00, which resulted in the average of I-CVI of 0.99 (see Table 4). The fairly high level of CVI for each item implies that the content for the construct is adequately represented by the items.

Using the Mann-Whitney U test, the mean scores from the questions directly measuring adherence behaviors on four different areas of treatment adherence were compared between adherers and non-adherers. This comparison indicated that the ESRD-AQ clearly distinguished adherers and non-adherers (see Table 5). However, there were no differences in mean scores on the questions asking about perceptions and understanding levels of patients on four different areas of treatment adherence between adherers and non-adherers (see Table 6).

Reliability

Internal consistency reliability (Cronbach's alpha) was omitted since the instrument's design does not possess homogeneous items to address internal consistency reliability. As shown in Table 5, strong test-retest stability existed across all items of the ESRD-AQ, with ICCs ranging from 0.83 to 1.00. Phi correlations indicated that self-reported adherence behaviors and perceptions were consistent across the two administrations of the ESRD-AQ (see Table 6).

Discussion

The ESRD-AQ is a brief instrument that captures important aspects of patients' treatment history: self-reported treatment adherence (such as HD attendance, medications, fluid restrictions, and diet recommendations); perceptions related to adherence behaviors; and reasons for nonadherence. Results of this initial investigation of its psychometric properties suggest that the ESRD-AQ is a valid and reliable tool. A panel of expert clinicians and patients confirmed content and face validity of the tool. In addition, all scale scores were able to discriminate clearly between adherent and non-adherent patients, indicating that the instrument is a valid measure of adherence behaviors. Likewise, the ESRD-AQ showed strong test-retest reliability, suggesting it can be used reliably over time.

Content validity of the ESRD-AQ was evaluated by an expert panel. There is no universally accepted standard indicator of content validity. However, calculating CVI is one of the most

popular ways to evaluate content validity (Polit et al., 2007). Data from the current study showed that the ESRD-AQ demonstrated excellent content validity. Face validity of ESRD-AQ was also assessed. Although face validity is less important than content, criterion, and construct validities, face validity is often useful for new instruments (Polit & Beck, 2004). Construct validity of ESRD-AQ was examined by adopting a known group analysis. Given the lack of a well-established and standardized measurement tool for comparison, the known group analysis was considered to be an appropriate approach. The questions which specifically assessed patients' adherence behaviors were able to distinguish between adherers and nonadherers, which provide support for the content validity of ESRD-AQ. Intriguingly, the questions that inquired about patients' knowledge and perceptions about adherence behaviors did not distinguish between the two groups. This can be explained, in part, by the fact that patient grouping was conducted based on behavior and not based on perceptions or levels of understanding. Group determination was decided by HD nurses and a renal dietician at each dialysis center based on a combination of dialysis attendance, biochemical, and biological markers.

The minor drawback of construct validity of the ESRD-AQ evaluated by a known group analysis was the unequal sizes of two groups (adherent vs. non-adherent group) for some items. However, using non-parametric tests to compare the two groups minimized the potential effects of the data on construct validity. Previous studies showed that skipping or shortening dialysis sessions was directly related to increased mortality risk. For example, Leggat and colleagues (1998) reported that skipping one or more HD sessions or shortening sessions more than three times per month (more than 10 minutes each session) was associated with an increase in mortality of 25% and 20%, respectively. In addition, the Dialysis Outcomes and Practice Patterns Study (DOPPS), a prospective, international, and observational study conducted among 14,930 ESRD patients, showed that skipping one or more dialysis sessions a month was associated with increase in relative mortality risk of 1.30 (Saran et al., 2003). Therefore, the score of adherence to HD was given more weight on the overall adherence score.

To verify the reliability of the ESRD-AQ, the test-retest reliability method was employed. The target patients took part in the survey twice with a two-day interval between the two test times. It has been shown that if the time gap is too short, the learning effect may be reflected on the survey, and if it is too long, treatment adherence might be altered. Two to fourteen-day intervals are recommended by previous researchers (Streiner & Norman, 2003). Questionnaire completion took approximately 20 to 40 minutes, and some individuals required more time due to decreased visual acuity from their underlying diseases, such as diabetic retinopathy or due to decreased health literacy. However, about 90% of the participants took the survey within 20 to 40 minutes without major difficulty.

Some limitations were identified in the psychometric testing of the ESRD-AQ. First, reliability of ESRD-AQ completely depends on the credibility of the patient's answer since it is designed to ask one item to address one variable. Although a sample of five patients with ESRD who were representative of the target population was used to review and provide feedback of instrument's readability, as well as their ability to comprehend each statement/question, researchers failed to measure readability using a reliable and valid measure (such as a SMOG readability test). Thus, there may be limitations in using the ESRD-AQ in patients with low health literacy. Furthermore, traditional reliability tests for internal consistency, such as Cronbach's alpha, were not useful due to lack of similar items addressing one aspect of adherence. Adding companion items to direct questions in particular should be considered for future use. Second, even though most patients enjoyed answering the ERSD-AQ, spending 20 to 40 minutes to answer the questions can still be a

burden to patients. Therefore, reducing the number of the indirect questions should be considered.

Conclusion

The newly developed ESRD-AQ is easy to administer with acceptable validity and reliability. Furthermore, the ESRD-AQ is the first self-report instrument to address all components of adherence behaviors of patients with ESRD on maintenance HD. The ESRD-AQ also provides researchers and clinicians with comprehensive information, such as patients' clinical history related to their ESRD, and patients' perception and understanding level about their medical recommendations. Thus, the instrument is potentially valuable for researchers and clinicians working in the field of advanced chronic kidney disease. Future studies are needed in a larger sample to determine whether additional modifications would be helpful.

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Table 1
End-Stage Renal Disease Adherence Questionnaire (ESRD-AQ)

This survey asks for your opinion about how well you follow your dialysis treatment schedule and about medical recommendations related to medication, diet, and fluid intake. This information will help us to understand if you have difficulty following your dialysis treatment, medication regimen, fluid restriction, and recommended diet. Please answer every question by marking the appropriate box. If you are unsure about how to answer, please choose one best answer that applies to you.
Note: Numbers in parentheses are the response codes.

I. General Information		
1.	When did you begin or restart your hemodialysis treatment?	Beginning Date: _____/_____ Month/Year (Restarting date if you restarted hemodialysis: _____/_____ Month/Year)
2.	Have you ever had chronic peritoneal dialysis treatment?	No$_{(1)}$ Yes$_{(2)}$ (Please answer below) I had peritoneal dialysis from _____/_____ Month/Year to _____/_____ Month/Year
3.	Have you had a kidney transplant?	No$_{(1)}$ Yes$_{(2)}$ (Please answer below) I had a kidney transplant once from _____/_____ Month/Year to _____/_____ Month/Year Or I had kidney transplants twice from _____/_____ Month/Year to _____/_____ Month/Year and from _____/_____ Month/Year to _____/_____ Month/Year If you have had transplants more than twice, please write the dates in the spaces above for the last two transplants.
4.	What type of transportation do you use to go to the dialysis center?	□ Personal transportation$_{(1)}$ □ Bus$_{(2)}$ □ Taxi$_{(3)}$ □ Medical transportation van$_{(4)}$ □ Other (Specify)$_{(5)}$: _____
5.	Who accompanies you to the dialysis center?	□ Myself$_{(1)}$ □ Parent$_{(2)}$ □ Spouse (Husband or wife)$_{(3)}$ □ Child$_{(4)}$ □ Friend$_{(5)}$ □ Other (Specify the person)$_{(6)}$: _____

II. Hemodialysis Treatment

6.	How many days a week do you receive hemodialysis treatment?	□	2 days or less$_{(1)}$
		□	3 days$_{(2)}$
		□	4 days$_{(3)}$
		□	More than 4 days$_{(4)}$
		□	More than 5 days$_{(5)}$
7.	How many hours are you treated for each hemodialysis?	□	Less than 3 hours$_{(1)}$
		□	3 hours$_{(2)}$
		□	3 hours and 15 minutes$_{(3)}$
		□	3 hours and 30 minutes$_{(4)}$
		□	3 hours and 45 minutes$_{(5)}$
		□	4 hours$_{(6)}$
		□	More than 4 hours$_{(7)}$
		□	Other (Specify the hours)$_{(8)}$: _____
8.	Is your dialysis schedule convenient for you? (Please choose one best answer that applies to you.)	□	Yes$_{(1)}$
		□	No, because I have to come to the dialysis center too early$_{(2)}$
		□	No, because I have to come to the dialysis center too late$_{(3)}$
		□	No, because of my work schedule$_{(4)}$
		□	No, because it is my meal time and I get hungry during dialysis treatment$_{(5)}$
		□	No, because it is my medication time and I have to take medicines/insulin$_{(6)}$
		□	No, because of (Other)$_{(7)}$: _____
9.	When was the last time a medical professional (your doctor, nurse, dietician, or other medical staff) talked to you about the importance of not missing your dialysis treatment?	□	This week$_{(1)}$
		□	Last week$_{(2)}$
		□	One month ago$_{(3)}$
		□	More than a month ago$_{(4)}$
		□	When I first began dialysis treatment$_{(5)}$
		□	Never$_{(6)}$
		□	Other (Specify)$_{(7)}$: _____
10.	How often does a medical professional (your doctor, nurse, dietician, or other medical staff) talk to you about the importance of staying for the entire dialysis time during your dialysis treatment?	□	Every dialysis treatment$_{(1)}$
		□	Every week$_{(2)}$
		□	Every month$_{(3)}$
		□	Every 2 to 3 months$_{(4)}$
		□	Every 4 to 6 months$_{(5)}$
		□	When I have abnormal blood or other test results$_{(6)}$
		□	Rarely$_{(7)}$

		□	Irregularly$_{(8)}$
		□	Never$_{(9)}$
		□	Other (Specify)$_{(10)}$: _____
11.	How important do you think it is to follow your dialysis schedule?	□	Highly important$_{(1)}$
		□	Very important$_{(2)}$
		□	Moderately important$_{(3)}$
		□	A little important$_{(4)}$
		□	Not important$_{(5)}$
12.	Why do you think it is important to follow your dialysis schedule? (Please choose one best answer that applies to you.)	□	Because I fully understand that my kidney condition requires dialysis as scheduled$_{(1)}$
		□	Because following the dialysis schedule is important to keep my body healthy$_{(2)}$
		□	Because medical professional (my doctor, nurse, or dietitian) told me to do so$_{(3)}$
		□	Because I had an experience that I was sick after I missed dialysis$_{(4)}$
		□	Because I had an experience that I was hospitalized after I missed dialysis$_{(5)}$
		□	I don't think following the dialysis schedule is very important to me$_{(6)}$
		□	Other (Specify)$_{(7)}$: _____
13.	How much difficulty have you had staying for your entire dialysis treatment as ordered by your doctor?	□	No difficulty$_{(1)}$
		□	A little difficulty$_{(2)}$
		□	Moderate difficulty$_{(3)}$
		□	A lot of difficulty$_{(4)}$
		□	Extreme difficulty$_{(5)}$
14.	During the *last month*, how many dialysis treatments did you miss completely?	□	None (I did not miss any treatments)$_{(1)}$
		□	Missed one dialysis treatment$_{(2)}$
		□	Missed two dialysis treatments$_{(3)}$
		□	Missed three dialysis treatments$_{(4)}$
		□	Missed four or more dialysis treatments$_{(5)}$
15.	What was the main reason you missed your dialysis treatment *last month*?	□	Not applicable: I did not miss any treatment$_{(1)}$
		□	Transportation problems$_{(2)}$
		□	I had other things to do (Please explain)$_{(3)}$:
		□	Hemodialysis access (graft, fistula, or catheter) clotted$_{(4)}$
		□	Physician (medical or surgical) appointment$_{(5)}$
		□	I had to go to the emergency room$_{(6)}$
		□	I was hospitalized$_{(7)}$
		□	Forgot$_{(8)}$

		□	"Didn't want to go" or "Couldn't go" *(Go to the next question: Question #16)*(9)
		□	Other (Please specify)(10): _____
16.	(Answer this question when you marked the above question as *"Didn't want to go Couldn't go."*) Why didn't you want to go to the dialysis center? (Please choose one best answer that applies to you)	□	Because dialysis treatment makes me anxious(1)
		□	Because I had vomiting/diarrhea(2)
		□	Because I had cramping(3)
		□	Because I often get hungry during dialysis treatment(4)
		□	Because I was physically uncomfortable (Specify the condition)(5)
		□	Because I was sick due to other conditions (Specify the conditions)(6)
		□	Because I was emotionally depressed(7)
		□	Other(8): _____
17.	During the *last month*, ***how many times*** have you ***shortened*** your dialysis time?	□	Not applicable: I have not shortened my dialysis time(1)
		□	Once(2)
		□	Twice(3)
		□	Three times(4)
		□	Four to five times(5)
		□	Other (Specify frequency)(6): _____
18.	During the *last month*, when your dialysis treatment was shortened, what was the ***average number of minutes?***	□	Not applicable: I have not shortened my dialysis time(1)
		□	Less than 10 minutes or 10 minutes(2)
		□	11 to 20 minutes(3)
		□	21 to 30 minutes(4)
		□	More than 31 minutes(5)
		□	Other (Specify)(6) (If you need to write two or more different time because you shortened dialysis more than once, please use this space): _____
19.	What was the main reason you have shortened your dialysis treatment?	□	Not applicable: I have not shortened my dialysis time(1)
		□	Cramping(2)
		□	Bathroom use(3)
		□	Restlessness(4)
		□	Low blood pressure(5)
		□	Access (graft, fistula, or catheter) clotted(6)
		□	Physician (medical or surgical) appointment(7)
		□	Personal business or emergency(8)
		□	Work schedule(9)
		□	Transportation problems(10)

	□	Staff decision (**Why? Please explain:** For example, poor blood flow, clotting dialyzer, machine malfunction, etc.)$_{(11)}$: _____
	□	Did not feel like staying$_{(12)}$
	□	Other (Please specify)$_{(13)}$: _____

III. Medication

20. When was the last time a medical professional (your doctor, nurse, dietician or other medical staff) spoke to you about your medicines?	□	This week$_{(1)}$
	□	Last week$_{(2)}$
	□	One month ago$_{(3)}$
	□	More than a month ago$_{(4)}$
	□	When I first began dialysis treatment$_{(5)}$
	□	Never$_{(6)}$
	□	Other (Specify)$_{(7)}$: _____
21. How often does a medical professional (your doctor, nurse, dietician or other medical staff) talk to you about the importance of taking medicines as ordered?	□	Every dialysis treatment$_{(1)}$
	□	Every week$_{(2)}$
	□	Every month$_{(3)}$
	□	Every 2 to 3 months$_{(4)}$
	□	Every 4 to 6 months$_{(5)}$
	□	When I have abnormal blood or other (for example, blood pressure) test results$_{(6)}$
	□	Rarely$_{(7)}$
	□	Irregularly$_{(8)}$
	□	Never$_{(9)}$
	□	Other (Specify)$_{(10)}$: _____
22. How important do you think it is to take your medicines as scheduled?	□	Highly important$_{(1)}$
	□	Very important$_{(2)}$
	□	Moderately important$_{(3)}$
	□	A little important$_{(4)}$
	□	Not important$_{(5)}$
23. Why do you think it is important to take your medicines as scheduled? (Please choose one best answer that applies to you.)	□	Because I fully understand that my kidney condition requires to take medicines as scheduled$_{(1)}$
	□	Because taking medicines is important to keep my body healthy$_{(2)}$
	□	Because a medical professional (my doctor, nurse, dietician, or other medical staff) told me to do so$_{(3)}$
	□	Because I had an experience that I was sick after I missed medicines$_{(4)}$
	□	Because I had an experience that I was hospitalized after I missed medicines$_{(5)}$
	□	I don't think taking medicines is very important to me$_{(6)}$

		□	Other (Specify)$_{(7)}$: _____
24.	Have you had any difficulty with taking your medicines?	□	No$_{(1)}$
		□	Yes$_{(2)}$
25.	How much difficulty have you had with taking your prescribed medicines?	□	No difficulty$_{(1)}$
		□	A little difficulty$_{(2)}$
		□	Moderate difficulty$_{(3)}$
		□	A lot of difficulty$_{(4)}$
		□	Extreme difficulty$_{(5)}$
26.	During the *past week*, ***how often*** have you missed your prescribed medicines?	□	None of the time: I did not miss my medicines$_{(1)}$
		□	Very seldom$_{(2)}$
		□	About half of the time$_{(3)}$
		□	Most of the time$_{(4)}$
		□	All of the time$_{(5)}$
27.	What was the main reason for not taking your prescribed medicines this *past week*?	□	Not applicable: I did not miss medicines$_{(1)}$
		□	Forgot to take medicines$_{(2)}$
		□	Forgot to order medicines$_{(3)}$
		□	Medicine cost$_{(4)}$
		□	Inconvenience$_{(5)}$
		□	I was hospitalized$_{(6)}$
		□	Side effects$_{(7)}$ *(Go to question #28)*
		□	Other$_{(8)}$: _____
28.	(Answer this question when you have marked the above question as "*Side effects.*") What kind of side effect(s) to the medication(s) did you have? (Please choose one best answer that applies to you.)	□	Loss of appetite$_{(1)}$
		□	Nausea/vomiting/diarrhea/constipation$_{(2)}$
		□	Stomach pain$_{(3)}$
		□	Dizziness$_{(4)}$
		□	Headache$_{(5)}$
		□	Itching/skin problems$_{(6)}$
		□	Other (Specify symptoms)$_{(7)}$: _____
IV. Fluid			
29.	When was the last time a medical professional (your doctor, nurse or dietician or other medical staff) spoke to you about your fluid restrictions?	□	This week$_{(1)}$
		□	Last week$_{(2)}$
		□	One month ago$_{(3)}$
		□	More than a month ago$_{(4)}$
		□	When I began dialysis treatment$_{(5)}$
		□	Never$_{(6)}$
		□	Other (Specify)$_{(7)}$: _____

30.	How often does a medical professional (your doctor, nurse, dietician or other medical staff) talk to you about the importance of fluid restriction?	□ Every dialysis treatment$_{(1)}$ □ Every week$_{(2)}$ □ Every month$_{(3)}$ □ Every 2 to 3 months$_{(4)}$ □ Every 4 to 6 months$_{(5)}$ □ When I have abnormal blood or other (for example, blood pressure) test results$_{(6)}$ □ Rarely$_{(7)}$ □ Irregularly$_{(8)}$ □ Never$_{(9)}$ □ Other (Specify)$_{(10)}$: _____
31.	During the *past week*, how often have you followed the ***fluid restriction*** recommendations?	□ All of the time$_{(1)}$ □ Most of the time$_{(2)}$ □ About half of the time$_{(3)}$ □ Very seldom$_{(4)}$ □ None of the time$_{(5)}$
32.	How important do you think it is to limit your fluid intake?	□ Highly important$_{(1)}$ □ Very important$_{(2)}$ □ Moderately important$_{(3)}$ □ A little important$_{(4)}$ □ Not important$_{(5)}$
33.	Why do you think it is important for you to limit your fluid intake? (Please choose one best answer that applies to you.)	□ Because I fully understand that my kidney condition requires limiting fluid intake$_{(1)}$ □ Because limiting fluid intake is important to keep my body healthy$_{(2)}$ □ Because a medical professional (my doctor, nurse, dietician, or other medical staff) told me to do so$_{(3)}$ □ Because I got sick after I drank lots of fluid$_{(4)}$ □ Because I was hospitalized after I drank lots of fluid$_{(5)}$ □ I don't think limiting fluid is very important to me$_{(6)}$ □ Other (Specify)$_{(7)}$: _____
34.	Have you had any difficulty with limiting your fluid intake?	□ No$_{(1)}$ □ Yes$_{(2)}$
35.	How much difficulty have you had following your fluid restriction recommendations?	□ No difficulty$_{(1)}$ □ A little difficulty$_{(2)}$ □ Moderate difficulty$_{(3)}$ □ A lot of difficulty$_{(4)}$

		□	I was unable to follow any recommendations at all$_{(5)}$
36.	If you had difficulty following your fluid restriction recommendations, ***what type of difficulty*** have you had?	□	No difficulty$_{(1)}$
		□	Not interested$_{(2)}$
		□	I was unable to control fluid intake$_{(3)}$
		□	I don't understand how to follow the fluid restriction$_{(4)}$
		□	Other$_{(5)}$: _____
37.	During the past week, how many times have you weighed yourself ***at home*** (outside dialysis center)?	□	More than 3 times$_{(1)}$
		□	3 times$_{(2)}$
		□	Twice$_{(3)}$
		□	Once$_{(4)}$
		□	None of the time$_{(5)}$
		□	Other$_{(6)}$: _____
38.	How important do you think it is to weigh yourself daily?	□	Highly important$_{(1)}$
		□	Very important$_{(2)}$
		□	Moderately important$_{(3)}$
		□	A little important$_{(4)}$
		□	Not important$_{(5)}$
V. Diet			
39.	When was last time a medical professional (your doctor, nurse, dietician, or other medical staff) talked to you about your diet?	□	This week$_{(1)}$
		□	Last week$_{(2)}$
		□	One month ago$_{(3)}$
		□	More than a month ago$_{(4)}$
		□	When I first began dialysis treatment$_{(5)}$
		□	Never$_{(6)}$
		□	Other (Specify)$_{(7)}$: _____
40.	How often does a medical professional (your doctor, nurse, dietician or other medical staff) talk to you about the importance of following a proper diet?	□	Every dialysis treatment$_{(1)}$
		□	Every week$_{(2)}$
		□	Every month$_{(3)}$
		□	Every 2 to 3 months$_{(4)}$
		□	Every 4 to 6 months$_{(5)}$
		□	When I have abnormal blood or other (for example, blood pressure) test results$_{(6)}$
		□	Rarely$_{(7)}$
		□	Irregularly$_{(8)}$
		□	Never$_{(9)}$
		□	Other (Specify)$_{(10)}$: _____

41.	How important do you think it is to watch the types of food you eat each day?	□	Highly important$_{(1)}$
		□	Very important$_{(2)}$
		□	Moderately important$_{(3)}$
		□	A little important$_{(4)}$
		□	Not important$_{(5)}$
42.	Why do you think it is important for you to watch your diet daily? (Please choose one best answer that applies to you.)	□	Because I fully understand that my kidney condition requires to watch my diet$_{(1)}$
		□	Because watching my diet is important to keep my body healthy$_{(2)}$
		□	Because a medical professional (my doctor, nurse, or dietician) told me to do so$_{(3)}$
		□	Because I got sick after eating certain food that I was not supposed to eat$_{(4)}$
		□	Because I was hospitalized after eating certain food that I was not supposed to eat$_{(5)}$
		□	I don't think watching my diet is important to me$_{(6)}$
		□	Other (Specify)$_{(7)}$: _____
43.	Have you had any difficulty following your dietary recommendations?	□	No$_{(1)}$
		□	Yes$_{(2)}$
44.	How much difficulty have you had following your dietary recommendations?	□	No difficulty$_{(1)}$
		□	A little difficulty$_{(2)}$
		□	Moderate difficulty$_{(3)}$
		□	A lot of difficulty$_{(4)}$
		□	I was unable to follow any recommendations at all$_{(5)}$
45.	What type of difficulty have you had keeping your dietary recommendations?	□	Not applicable: No difficulty$_{(1)}$
		□	I was not willing to control what I want to eat$_{(2)}$
		□	I was unable to avoid certain unrecommended food$_{(3)}$
		□	I don't understand what type of diet to follow$_{(4)}$
		□	Other (Specify)$_{(5)}$: _____
46.	During the *past week*, how many times have you followed the diet recommendations?	□	All of the time$_{(1)}$
		□	Most of the time$_{(2)}$
		□	About half of the time$_{(3)}$
		□	Very seldom$_{(4)}$
		□	None of the time$_{(5)}$

Table 2
Scoring Individual Items of the End-Stage Renal Disease Adherence Questionnaire

Section Name	Question Numbers	Targeted Area in the Item	To Recorded Value of (Points)
Section 1: General Information (5 items)	1, 2, and 3	Fact related to previous RRT history	No value
	4 and 5	Fact related to transportation situation to get HD	No value
Section 2: HD Treatment (14 items)	6 and 7	Fact related to HD schedule	No value
	8	Perception of patients on HD schedule	No value
	9 and 10	Information about counseling on HD	No value
	11	Perception on importance of HD adherence	No value Analyze responses using descriptive statistics
	12	Understanding level on importance of HD	No value Analyze responses using descriptive statistics
	13	Perception of patients on HD	No value
	14	Frequency of missing HD during last month	Response category 1→300 Response category 2→200 Response category 3→100 Response category 4→50 Response category 5→0
	15	Reason for missing HD	No value (Note: If patients missed HD due to medical reasons (if the answer is 4, 6, or 7), adjust scores from question number 14 and give a full credit (300 points)
	16	Supplementary question for Question 15 (psychophysical symptoms)	No value
	17	Frequency of shortening HD during last month	Response category 1→200 Response category 2→150 Response category 3→100 Response category 4→50 Response category 5→0
	18	Duration of shortening HD during last month	Response category 1→100 Response category 2→75 Response category 3→50 Response category 4→25 Response category 5→0
	19	Reason for shortening HD treatment	No value (Note: If patients shortened HD due to medical reasons (if the answer is 2, 5, 6 or 11), adjust scores from question number 17 & 18 and give a full credit (200 and 100 points)
Section 3: Medication (9 items)	20 and 21	Information about counseling on medication	No value
	22	Perception on importance of medication adherence	No value Analyze responses using descriptive statistics
	23	Understanding level on importance of medication	No value. Analyze responses using descriptive statistics
	24 and 25	Fact related to difficulty with taking medicines	No value
	26	Frequency of missing medication during last month	Response category 1→200 Response category 2→150 Response category 3→100

Section Name	Question Numbers	Targeted Area in the Item	To Recorded Value of (Points)
			Response category 4→50 Response category 5→0
	27	Reason for missing medication	No value (Note: If patients missed medication due to medical reasons (if the answer is 6 or 7) adjust scores from the question number 26 and give a full credit (200 points).
	28	Supplementary question for Question 27 (psychophysical symptoms)	No value
Section 4: Fluid Restriction (10 items)	29 and 30	Information about counseling on fluid restriction	No value
	31	Fluid restriction: Self-monitoring (Frequency)	Response category 1→200 Response category 2→150 Response category 3→100 Response category 4→50 Response category 5→0
	32	Perception on importance of fluid restriction	No value Analyze responses using descriptive statistics
	33	Understanding level on importance of fluid restriction	No value Analyze responses using descriptive statistics
	34 and 35	Fact related difficulty with limiting fluid intake	No value
	36	Types of difficulty following fluid restriction (additional question to #35)	No value
	37 and 38	Information on weighing at home (not mandatory requirements for all ESRD patients)	No value
Section 5: Dietary Restriction (8 items)	39 and 40	Information about counseling on dietary recommendations	No value
	41	Perception on importance of dietary recommendations	No value Analyze responses using descriptive statistics
	42	Understanding level on importance of dietary recommendations	No value Analyze responses using descriptive statistics
	43 and 44	Fact related to difficulty with following dietary recommendations	No value
	45	Types of difficulty following fluid restriction (Additional question to #44)	No value
	46	Dietary restriction: Self-monitoring (Frequency)	Response category 1→200 Response category 2→150 Response category 3→100 Response category 4→50 Response category 5→0

Table 3

Sociodemographic Data of Study Participants: Adherers vs. Non-Adherers (*N* = 58)

Adherence Area / Descriptor	Hemodialysis A(*n*)/B(*n*) = 45/13		Medication A(*n*)/B(*n*) = 55/3		Fluid A(*n*)/B(*n*) = 52/6		Diet A(*n*)/B(*n*) = 51/7	
	A *n* (%)	B *n* (%)	A *n* (%)	B *n* (%)	A *n* (%)	B *n* (%)	A *n* (%)	B *n* (%)
Gender								
Male	27 (60.0)	6 (46.2)	30 (54.5)	3 (100.0)	30 (57.7)	3 (50.0)	30 (58.8)	3 (42.9)
Female	18 (40.0)	7 (53.8)	25 (45.5)	0 (0.0)	22 (42.3)	3 (50.0)	21 (41.2)	4 (57.1)
Race/Ethnicity								
Caucasian	1 (2.2)	1 (7.7)	2 (3.6)	0 (0.0)	2 (3.8)	0 (0.0)	1 (2.0)	1 (14.3)
African American	13 (28.9)	6 (46.2)	17 (30.9)	2 (66.7)	16 (30.8)	3 (50.0)	15 (29.4)	4 (57.1)
Asian American	16 (35.5)	1 (7.7)	17 (30.9)	0 (0.0)	17 (32.6)	0 (0.0)	15 (29.4)	2 (28.6)
Native American	0 (0.0)	1 (7.7)	1 (1.8)	0 (0.0)	1 (1.9)	0 (0.0)	1 (2.0)	0 (0.0)
Hispanic/Latino	15 (33.3)	4 (30.8)	18 (32.7)	1 (33.3)	16 (30.8)	3 (50.0)	19 (37.3)	0 (0.0)
Education Level								
High school or lower	15 (33.3)	3 (23.1)	17 (30.9)	1 (33.3)	16 (30.8)	2 (33.3)	16 (31.4)	2 (28.6)
Vocational school	4 (8.9)	1 (7.7)	5 (9.1)	0 (0.0)	4 (7.7)	1 (16.7)	4 (7.8)	1 (14.3)
Some college	11 (24.4)	5 (38.5)	15 (27.3)	1 (33.3)	15 (28.8)	1 (16.7)	14 (27.5)	2 (28.6)
College graduate or higher	15 (33.4)	4 (30.8)	18 (32.7)	1 (33.3)	17 (32.7)	2 (33.3)	17 (33.4)	2 (28.6)
Marital Status								
Never married	10 (22.2)	8 (61.5)	17 (30.9)	1 (33.3)	17 (32.7)	1 (16.7)	16 (31.4)	2 (28.6)
Married	20 (44.4)	2 (15.4)	21 (38.1)	1 (33.3)	19 (36.5)	3 (50.0)	19 (37.3)	3 (42.9)
Separated, divorced, widowed	15 (33.3)	3 (23.1)	17 (30.9)	1 (33.3)	16 (30.7)	2 (33.3)	16 (31.3)	2 (28.6)
Current Employment								
Yes	4 (8.9)	4 (30.8)	7 (12.7)	1 (33.3)	8 (15.4)	0 (0.0)	6 (11.8)	2 (28.6)
No	41 (91.1)	9 (69.2)	48 (87.3)	2 (66.7)	44 (84.6)	6 (100.0)	43 (88.2)	5 (71.4)
Causes of Kidney Failure								
Diabetes mellitus	12 (26.7)	3 (23.1)	15 (27.3)	0 (0.0)	12 (23.0)	3 (50.0)	14 (27.5)	1 (14.3)
Hypertension	17 (37.8)	3 (23.1)	17 (30.9)	3 (100.0)	20 (38.5)	1 (16.7)	18 (35.3)	2 (28.6)

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Adherence Area / Descriptor	Hemodialysis A(*n*)/B(*n*) = 45/13		Medication A(*n*)/B(*n*) = 55/3		Fluid A(*n*)/B(*n*) = 52/6		Diet A(*n*)/B(*n*) = 51/7	
	A ***n*** **(%)**	**B** ***n*** **(%)**	**A** ***n*** **(%)**	**B** ***n*** **(%)**	**A** ***n*** **(%)**	**B** ***n*** **(%)**	**A** ***n*** **(%)**	**B** ***n*** **(%)**
Others	16 (35.5)	7 (53.8)	23 (41.8)	0 (0.0)	20 (38.5)	2 (33.3)	19 (37.3)	4 (57.2)
HD Vintage (Months)								
Mean ± SD	57.96 ± 63.88	49.49 ± 51.21	56.91 ± 62.32	40.67 ± 25.01	53.02 ± 56.21	82.05 ± 95.83	51.14 ± 59.47	91.97 ± 64.09
Range	3-281	7-165	3-281	12-58	3-281	7-237	3-281	10-165

Note: A = adherers; B = non-adherers; HD = in-center hemodialysis; SD = standard deviation.

Table 4
Content Validities of ESRD-AQ (Expert *n*= 7)

ESRD-AQ Area (Item Number)	Expert 1 to 6	Expert 7	Experts in Agreement	I-CVI
General Information (1 to 5)	✓	✓	7	1.00
HD Treatment (6 to 19)	✓	✓	7	1.00
Medication (20 to 28)	✓	✓	7	1.00
Fluid (29 to 38)	✓	Rating of 1 for items 37 and 38:	Items 29 to 36=7 Items 37 and 38=6	0.86
Diet (39 to 46)	✓	✓	7	1.00
Average I-CVI				0.99

✓ = Rated 3 (quite relevant) or 4 (highly relevant)

I-CVI = Item-level content validity index

Table 5

Summary of Known Group Analysis on the Questions that Specifically Address Patients' Adherence Behaviors

Item Number/Treatment Behavior	Adherers (*n*)/Non-Adherers (*n*)	Mann-Whitney U	Z	*P* Value
#14 (HD Attendance)	45/13	97.000	-5.334	< 0.001
#17 (Shortening HD)	45/13	127.500	-3.915	< 0.001
#18 (Duration of Shortening HD)	45/13	118.000	-4.137	< 0.001
#26 (Adherence to Medication)	55/3	3.000	-3.136	0.002
#31 (Adherence to Fluid Restrictions)	52/6	76.000	-2.206	0.027
#46 (Adherence to Diet Restrictions)	51/7	59.000	-3.032	0.002

Table 6

Summary of Known Group Analysis on the Questions that Address Patients' Perception and Understanding Levels of Adherence Behaviors

Item #/Perception and Understanding on Importance of Adherence	Adherers (*n*)/Non-Adherers (*n*)	Mann-Whitney U	Z	*P* Value
#11 (Perception on HD Attendance)	45/13	222.000	-1.869	0.062
#12 (Understanding Level on Importance of HD Attendance)	45/13	276.000	-0.973	0.330
#22 (Perception on Medication Adherence)	55/3	73.500	-0.436	0.663
#23 (Understanding Level on Importance of Medication)	55/3	75.000	-0.420	0.675
#32 (Perception on Fluid Restrictions)	52/6	131.500	-0.727	0.467
#33 (Understanding Level on Importance of Fluid Restrictions)	52/6	126.000	-1.249	0.212
#41 (Perception on Diet Restrictions)	51/7	134.500	-1.181	0.238
#42 (Understanding Level on Importance of Diet Restrictions)	51/7	154.000	-0.960	0.337

Table 7
Likert Scale Scores from 14 Items for Intra-Class Correlation Coefficients (*n* = 6)

Subjects	Test Scores	Retest Scores
1	20	20
2	21	18
3	22	22
4	24	20
5	23	23
6	32	30

Table 8

Intra-Class Correlation Analysis (*n* = 6)

		95% Confidence Interval			*F* Test		
	ICC	**Lower Bound**	**Upper Bound**	***F* Value**	**df1**	**df2**	**Sig.**
Single Measures	0.915[a]	0.518	0.988	22.505	5.0	5	0.002
Average Measures	0.956[b]	0.682	0.994	22.505	5.0	5	0.002

Note: Two-way mixed effects model where people effects are random and measures effects are fixed.

[a]The estimator is the same, whether the interaction effect is present or not.

[b]This estimate is computed assuming the interaction effect is absent, because it is not estimable otherwise.