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Association of Patient-Perceived Difficulty in Adherence and Actual Non-Adherence with Hemodialysis Treatment Recommendations

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Abstract

Association of Patient-Perceived Difficulty in Adherence and Actual Non-Adherence with Hemodialysis Treatment Recommendations

By Rachel Lee Snyder

Background: Non-adherence to recommendations is common among patients on in-center hemodialysis and is associated with increased risk for poor outcomes. Patient-reported difficulty in adherence may predict non-adherent behaviors. We used data from a cohort of in-center hemodialysis patients to determine whether patients' perceived difficulty with adherence to dialysis recommendations are associated with actual non-adherence to recommendations.

Methods: We included 799 in-center hemodialysis patients initiating treatment 2/10-10/16 at Emory Dialysis clinics. Patient-perceived difficulty with adherence across multiple domains (coming to dialysis, completing dialysis sessions, fluid restrictions, diet restrictions, taking medications) was obtained from baseline social worker assessments (yes vs. no). Actual adherence in coming to dialysis, completing dialysis sessions, fluid restrictions (interdialytic weight gain), diet restrictions (potassium levels, phosphorus control), and taking medications (phosphorus control) was estimated over the 12 weeks following social worker assessment, using medical record data. Crude agreement was assessed via percent agreement and kappa estimates. Multivariable logistic regression was used to estimate the associations between these measures with adjustment for potential confounders.

Results: In our cohort of 799 patients, agreement between perceived difficulty and non-adherence was generally poor across all domains [percent agreement (kappa): coming to dialysis, 65.3% (0.06); completing dialysis sessions, 52.9% (-0.02); fluid restrictions, 65.1% (0.07); diet restrictions, 61.1% (0.01); and taking medications/diet restrictions, 58.1% (-0.01) and 62.2% (0.04)]. After adjustment, patients reporting difficulty with fluid restrictions were 62% more likely to be actually non-adherent than those not reporting difficulty (OR: 1.62, 95% CI: 1.08, 2.43). Patients reporting difficulty with coming to dialysis were 41% more likely to have actual non-adherence in this measure; however, this association was not statistically significant (OR: 1.41, 95% CI: 0.96, 2.07). The magnitudes of associations between perceived difficulty and actual non-adherence in other categories were close to null and not statistically significant.

Conclusion: Our findings show that perceived difficulty with only fluid restrictions and coming to dialysis appear to be associated with actual non-adherence. These results suggest that using patient-reported measures of difficulty may not be sufficient to target interventions to the patients most at risk for non-adherence.

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BACKGROUND

In 2018, there were over 700,000 patients in the United States living with end-stage renal disease (ESRD), with 63.2% of these patients being treated with hemodialysis (1). Patients on in-center hemodialysis must adhere to strict restrictions on diet and fluid intake and to complex medication regimens, as well as attend prescribed dialysis sessions in a dialysis facility three times a week, until death, transplantation, or switch to another dialysis modality.

Because patients receiving hemodialysis do not have healthy kidneys to regulate the amount of potassium and phosphorus in their blood, restrictions on the intake of foods high in these substances are needed in order to maintain overall health. Potassium-rich foods include many fruits and vegetables, whole grains, and nuts. Consuming too many of these foods can lead to high potassium (hyperkalemia) and, in turn, serious heart issues, such as abnormal heart rates and heart failure (2). Phosphorus-rich foods include dairy products, whole grains, seafood, and many processed foods. Consuming too many of these foods can cause high blood phosphorus (hyperphosphatemia) and the drawing of calcium from bones, leading to bone disease, skin itchiness (pruritis), and the hardening of blood vessels (2). In addition to limiting the intake of high phosphorus foods, many patients are also prescribed phosphate-binding medications in order to further control the amount of phosphorus in the blood between dialysis sessions (3). Non-adherence to these medications also contributes to hyperphosphatemia.

Another important aspect of dialysis treatment recommendations is the fluid intake restriction, often the consumption of less than 32 ounces of fluid per day, in order to limit the amount of fluid which builds up in the body between dialysis sessions and avoid hypervolemia. The effects of hypervolemia include swelling, changes in blood pressure, and increased strain on the heart, including exacerbations of coexisting heart failure (4).

In addition to adhering to these diet and fluid restrictions, in-center hemodialysis patients must attend dialysis sessions 3 times a week for around 4 hours at a time (5). Missing or shortening these sessions can also lead to hypokalemia, high blood phosphorus, and hypervolemia (6). In addition to short-term consequences of treatment non-adherence, studies have shown that non-adherence to dialysis treatment recommendations can increase the risk of mortality. Skipping dialysis sessions has been associated with as much as 30% increased mortality, up to 35% higher interdialytic weight gain (IDWG), up to 17% higher serum phosphorus, and up to 9% higher serum potassium (6). Additionally, treatment non-adherence has also been shown to be associated with increased risk of hospitalizations in patients (7). Despite these risks, 50% of patients are estimated to be non-adherent to at least one aspect of their treatment recommendations (8).

Because of the complexity of dialysis care and the clinical importance of treatment adherence, as well as the association between psychosocial factors and treatment adherence, social workers play an important role in helping to educate patients about their treatment and access resources that might help them improve adherence (9). However, in

order to provide the best care to patients, non-adherent patients must be reliably identified by clinicians. Definitions of non-adherence have varied across studies, with both lab-based as well as patient-reported measures being utilized (10). To our knowledge, only one previous study in the United States assessed crude correlations between patient-reported measures of adherence and clinical measures for phosphate-binding medications, diet restrictions, and fluid restrictions in 116 hemodialysis patients; however, this study did not account for demographic, social, or clinical factors that may be possible confounders (11). Additionally, no studies appeared to assess association between patient-perceived difficulty with adherence (which might serve as a marker of increased risk of subsequent actual non-adherence and related poor outcomes) and non-adherence defined by clinical measures.

In order to better understand the causes of non-adherence, as well as the best ways to plan interventions to increase adherence to treatment among dialysis patients, it is important to understand any discrepancies or association between patient-reported difficulty with adherence and actual non-adherence, as defined by medical record data and laboratory measures. Thus, in this study, we aimed to use medical record data from a cohort of in-center hemodialysis patients at Emory Dialysis clinics, along with social worker assessment data, to determine whether patients' perceived difficulty with adherence to dialysis recommendations is associated with actual non-adherence to recommendations, independent of potential confounders.

METHODS

Data Sources and Study Population

This retrospective cohort study consists of a population of patients receiving in-center hemodialysis at Northside, Candler, and Greenbrier Emory Dialysis Clinics in the metropolitan Atlanta area between February 2010 and October 2016. Data on patient-perceived difficulty with adherence to dialysis recommendations along with information on depression/anxiety, current employment, and memory impairment were extracted from the baseline (first available) psychosocial assessments conducted by social workers at the time of patient initiation of dialysis at Emory Dialysis, upon change of modality, or annually. Data from a total of 1443 social worker assessments were available. Emory Dialysis electronic medical record (EMR) data for a study period of 84 days (12 weeks) post-psychosocial assessment date were linked to psychosocial data through the use of unique chart identifiers. These data included information on patient demographics, dialysis session flowsheets, laboratory records, hospital admissions, treatment modality, vascular access, and comorbid conditions (problem list).

Patients were excluded if they did not remain on in-center hemodialysis at Emory Dialysis for 84 days post-psychosocial assessment date (n=402), if they did not answer all five assessment questions related to perceived ease of adherence (n=232), or did not have available laboratory data (n=10), leaving a sample of 799 patients (Figure 1). The study was approved by the Emory University Institutional Review Board.

Study Variables

Patient-Reported Difficulty with Adherence: Exposures of Interest

Self-reported difficulty with adherence was dichotomized (yes vs no) into variables with yes defined as a response of Very Difficult, Difficult, or Neither Easy nor Difficult (vs. Easy or Very Easy) to questions in the social worker assessment regarding ease in coming to dialysis sessions, completing dialysis sessions, fluid restrictions, diet restrictions, and taking medications (Table 1). For the examination of phosphate control (related to both diet and medication adherence), a 4-level variable was created, indicating perceived difficulty with neither diet restrictions nor taking medications, perceived difficulty with just medications, perceived difficulty with just diet, and perceived difficulty with both diet and medications.

Actual Non-Adherence: Outcomes of Interest

Emory Dialysis EMR data were utilized to create four dichotomous variables (yes vs no) indicating actual non-adherence in coming to dialysis, completing dialysis sessions, fluid restrictions, diet restrictions, and phosphate control, a combined indicator of taking medications and diet restrictions. Non-adherence to coming to dialysis was defined as missing ≥3 expected sessions during the 84-day study period. A total of 36 sessions (based on 3 sessions per week) were expected over the study period; for every 2 days a patient was hospitalized during the study period, 1 expected session was subtracted from the patient's total expected sessions. Non-adherence to completing dialysis was defined as shortening a session by 15+ minutes in >3 sessions during the study period. Non-adherence to fluid restrictions was defined as an average IDWG of ≥3 kg over the 84-day

period. Non-adherence to diet restrictions was defined as a mean serum potassium of ≥5.0 mEq/L over the study period. Non-adherence to phosphate control was defined as a mean serum phosphorus of >5.5 mg/dl over the study period.

Other Covariates:

Employment Status

Employment status as self-reported by patients in psychosocial assessment was categorized as employed (including full-time and part-time), unemployed disabled (including unemployed disabled and medical leave of absence), unemployed other (including unemployed by choice, unemployed looking for work and retired), or other/missing.

Depression or Anxiety

Presence of patient depression or anxiety (yes vs no) was defined as social worker-reported current signs or symptoms for depression or anxiety problems reported on the social worker assessment.

Memory Impairment

Memory impairment (yes vs no) was defined as social worker reported appearance of problems with either short-term or long-term memory as reported on the social worker assessment.

Attributed Cause of ESRD

Attributed cause of ESRD was ascertained from Emory Dialysis EMR data and was categorized into diabetes, hypertension, glomerulonephritis, or unknown/other.

Race

Race was ascertained using demographic data from EMR data and was dichotomized into black versus not black, due to small sample sizes for other racial groups.

Comorbid Conditions

Comorbid conditions were ascertained from EMR data including conditions reported at any time during the 84-day study period and were dichotomized as present vs. absent; these included diabetes, hypertension, heart failure, cancer, pain, chronic obstructive pulmonary disease, and cardiovascular disease.

Vascular Access

Patient vascular access in use at time of psychosocial assessment was defined using EMR data and categorized into fistula, graft, or catheter.

Age

Age at psychosocial assessment was ascertained using patient age at the date the demographic data were pulled, along with the social worker assessment date.

Statistical Analysis

Patient demographic, social, and clinical information were summarized overall and by response to the five self-reported adherence questions using *t* tests for continuous variables and chi-square or exact tests for categorical variables, as appropriate. Chi-square tests were also conducted comparing the percentage of patients with actual non-adherence in each category by perceived difficulty in each category. Percent agreement between the two measures and kappa statistics were also calculated for each category. Odds ratios (ORs) and 95% CIs were calculated for the associations between patient-perceived difficulty in adherence and actual non-adherence using logistic regression models. In addition to an unadjusted model, we performed sequential adjustment for those potential confounding demographic and clinical variables (age, sex, and vascular access type) and psychosocial variables (depression) that were associated with the exposures in crude analyses.

RESULTS

Patient Characteristics

Overall as shown in Table 2, the mean age at psychosocial assessment date of the 799 patients included in the cohort was 57.1 years and 54.8% of patients were male (Table 2). The majority of patients were black (95.3%). Hypertension was the attributed caused of ESRD in 57.3% of patients, diabetes in 19.3% of patients, and glomerulonephritis in 5.3% of patients. Most patients had comorbid conditions noted on their problem list, with 74.8% having hypertension, 20.1% having cardiovascular disease, 10.3% having diabetes, 8.4% having pain, 5.9 having chronic obstructive pulmonary disease, and 5.2% having heart failure. Additionally, 9.2% of the cohort had symptoms of depression/anxiety and 13.7% had memory impairment. More than half of patients were unemployed because of disability (56.7%), while 31.8% were unemployed for other reasons; only 8.5% were employed. Catheters were the most common vascular access (45.2%), followed by fistulas (30.8%) and grafts (24.0%).

Several patient characteristics differed significantly by patient-reported difficulty with adherence. In each of the five categories of non-adherence, patients reporting difficulty were statistically significantly more likely to have symptoms of depression/anxiety and to be using a catheter for vascular access, compared to patients not reporting difficulty (Tables 2a-2e). Patients reporting difficulty with fluid restrictions were also statistically significantly more likely to be male (Table 2c).

Association Between Perceived Difficulty and Actual Non-Adherence.

As shown in Table 3, 30.4% of patients who reported difficulty in coming to dialysis were found to be actually non-adherent in this category, in comparison to 24.2% who did not report difficulty in adherence; however, this difference was not statistically significant (p=0.09). These measures had a percent agreement of 65.3% with a kappa value of 0.06 (95% CI: -0.01, 0.13). For fluid restrictions, 21.6% of patients reporting difficulty were actually non-adherent, which differed significantly from actual adherence among those not reporting difficulty (15.1%, p=0.02). The two measures had a percent agreement of 65.1% and a kappa value of 0.07 (95% CI: 0.01, 0.14). Among the other categories of non-adherence there were no differences in proportion of patients actually non-adherent by patient-reported perceived difficulty and there was poor agreement (percent agreement 52.9%-62.2%; kappa values -0.02-0.04) between perceived difficulty and actual non-adherence (Table 3).

Patients reporting perceived difficulty with fluid restrictions were 55% more likely to be actually non-adherent to these restrictions, compared to those not reporting difficulty, which was a statistically significant association (OR: 1.55, 95% CI: 1.06, 2.27) (Table 4). Adjusting for age, sex, and vascular access, there was a similar association (OR: 1.53, 95%: 1.03, 2.29). Including adjustment for depression along with the previously mentioned covariates led to a slightly increased magnitude for the association (OR: 1.62, 95% CI: 1.08, 2.43). Patients reporting difficulty with coming to dialysis were 37% more likely to have actual non-adherence in this measure; however, this association was not statistically significant (OR: 1.37, 95% CI: 0.95,1.97). This association was similar in

magnitude after adjustment for age, sex, vascular, access, and depression. The magnitudes of associations between perceived difficulty and actual non-adherence in other categories were close to null and not statistically significant. These associations were not changed by adjustment for age, sex, vascular access, or depression (Table 4).

DISCUSSION

In this retrospective study of a cohort of 799 in-center hemodialysis patients at Emory Dialysis Clinics, patient-perceived difficulty with adherence to dialysis recommendations was not consistently associated with actual non-adherence, as defined by medical record- and laboratory-based measures. Agreement between perceived difficulty of adherence and actual non-adherence was low across all domains examined (percent agreement, 53%-65%; kappa values all <0.1). Patient-perceived difficulty with fluid restrictions was statistically significantly associated with 55% greater likelihood of actual non-adherence, as defined by an average IDWG of >3 kg over 12 weeks. Perceived difficulty with coming to dialysis also appeared to be positively associated with actual non-adherence (missing >1 session per month), with patients perceiving difficulty being 37% more likely to be actually non-adherent; however, this association was not statistically significant. Among the other categories of adherence (completing dialysis, diet restrictions, and phosphorus control), associations between perceived difficulty and actual non-adherence were close to null and not statistically significant. All associations were similar in magnitude and statistical significance after adjustment for age, sex, vascular access type, and depression. Overall, this study shows that patient-reported difficulty in coming to dialysis and fluid restrictions on psychosocial assessments may be somewhat predictive of behavior regarding adherence to these recommendations. However, patient-reported difficulty with completing dialysis, diet restrictions, and taking medications may not be reliable indicators of actual patient behavior in these areas.

In our study, 23% of patients reported a perceived difficulty with coming to dialysis, 24% in completing dialysis, 31% with fluid restrictions, 35% with diet restrictions, 22% with either diet or taking medications, and 15% with both diet restrictions and taking medications. While no previous studies assessed patient-perceived difficulty with dialysis adherence, Kugler et al. utilized the Dialysis Diet and Fluid Non-Adherence Questionnaire to assess patient-perceived non-adherence in diet and fluid restrictions in 113 hemodialysis patients across six clinics in the United States (12). This questionnaire captures non-adherent behavior by asking patients "How many times in the last 14 days did you not follow your diet/fluid guidelines?" and " To what degree did you deviate from diet/fluid guidelines?" (12). The study found that 74% of patients self-reported some non-adherence to diet and 65% of patients self-reported some non-adherence to fluid, percentages that were much higher than the 35% and 31% found in our study (12). While differences in the study population may explain some of this difference, these results likely highlight that there is likely an important distinction in assessing patient-perceived difficulty with adherence (a measure of attitudes and/or beliefs) and patient-perceived non-adherence (a measure of behavior).

Using medical record data, we found that 26% of patients were non-adherent in coming to dialysis, 43% were non-adherent in completing dialysis, 15% were non-adherent in diet restrictions, 17% were non-adherent in fluid restrictions, and 35% were non-adherent in phosphorus control. In a study of the association between hemodialysis treatment non-adherence and mortality, hospitalization, and practice patterns in 7676 hemodialysis patients from the Dialysis Outcomes and Practice Patterns Study (DOPPS) conducted in

the United States, Europe, and Japan, Saran et al. defined nonadherence as skipping ≥1 dialysis sessions per month, shortening a session by >10 minutes each month, a serum potassium concentration of >6.0 mEq/L, a serum phosphorus concentration of 7.5 mg/dL, and an IDWG of 5.7% of body weight (7). The study found that 7.9% of the 3359 U.S. patients were non-adherent in coming to dialysis, 19.6% of patients were non-adherent in completing dialysis, 16.8% were non-adherent for IDWG, 15.4% were non-adherent in phosphorus control, and 6.3% were non-adherent in potassium (7). These percentages were lower than our findings. However, our cutoffs for non-adherence were lower than those used in the DOPPS study, which likely explains at least some of this discrepancy. Because there is no standard for evaluating adherence, other studies have used varying clinical measures to define non-adherence in patients undergoing hemodialysis and found that proportions of patients non-adherent to coming to dialysis, fluid restrictions, diet restrictions, and taking medications have been highly variable (0%-32%, 3.4%-74%, 1.2%-82.4%, and 1.2%-81%, respectively), making comparisons of measures of actual adherence to dialysis and its management across populations difficult (6).

When assessing the crude correlations between patient-reported measures of adherence and clinical measures for phosphate-binding medications, diet restrictions, and fluid restrictions in 116 U.S. hemodialysis patients across two clinics, Cummings et al defined phosphate medication non-adherence as an average serum phosphorus level >5.5 mg/dl, potassium non-adherence as an average serum potassium level of >5.5 mEq/L, and fluid non-adherence as a mean IDWG >3.0 kg, which were similar to definitions used in our study (11). The authors compared these measures to patient-reported compliance during

interviews with study staff. Similar to the results of our study, the authors found only weak correlations between the measures in all 3 categories (r=0.36, r=0.17, and r=0.06, respectively). However, their study did not account for potential confounding demographic, social, or clinical factors (11).

Our study's results highlight the discrepancy between patient-perceived difficulty with adherence and actual non-adherence to dialysis treatment recommendations. There are various possible explanations for this lack of congruence. Because our study relied on patient-reported difficulty with adherence by social worker assessment, the length and quality of the relationship between social worker and patient (which is likely to be short at initial assessment at the clinic), or problems with general mistrust of the medical system, could affect patient responses (13). Additionally, social desirability bias could cause patients to underreport difficulty in adherence, with the hope of being viewed favorably by the social worker (14).

Previous efforts to improve adherence have included automated messaging to decrease communication barriers and missed sessions, education on the importance of adhering to treatment recommendations, and cognitive behavioral therapy (15-17). However, if an intervention is to be targeted to the highest-risk patients, the first step is to identify patients who are risk for poor adherence, and subsequently, at increased risk for both hospitalization and mortality (7, 12). Due to the discrepancy between patient-perceived ease of adherence and actual adherence, future methods for identifying those most at risk should likely include measures other than patient-reported difficulty with adherence.

Future studies on this topic could involve investigating the relationships between coping styles, reported difficulty with adherence, reported non-adherence, and actual non-adherence; the association of discrepancies between these measures with clinical outcomes; and determining better methods of identifying risk for non-adherence.

Our study design had several limitations. Actual measures of non-adherence for diet, fluid, and medications were indirect and simplified. The design did not account for the fact that sodium intake from diet could also affect IDWG or that other aspects of dietary restrictions exist beyond potassium intake. However, these measures were similar to those used by previous studies (7, 8, 10, 12). Additionally, patients only reported perceived difficulty with adherence to recommendations, and it is possible that patients are non-adherent for reasons other than finding them difficult. Because our population was limited to patients receiving dialysis at Emory Dialysis clinics, there was little variation in race, which limited the ability to control for race as a possible confounder of the association between perceived difficulty and actual non-adherence or examine differences in the associations by race. As with any observational study, residual confounding is possible; for example, our analysis did not account for dialysis vintage. We also did not include home hemodialysis or peritoneal dialysis patients.

Despite these limitations, this study provides valuable information on the association between patient-perceived difficulty with adherence to dialysis recommendations and actual adherence, as defined by medical record and laboratory information. Our findings that only perceived difficulty with fluid restrictions and coming to dialysis appear to be

associated with actual non-adherence, while perceived difficulty with completing dialysis, diet restrictions, and taking medications do not appear to be as associated with actual non-adherence. These results suggest that only using patient-reported measures of difficulty may not be the best way to target interventions aimed at increasing adherence to the patients most at risk for nonadherence.

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FIGURES AND TABLES

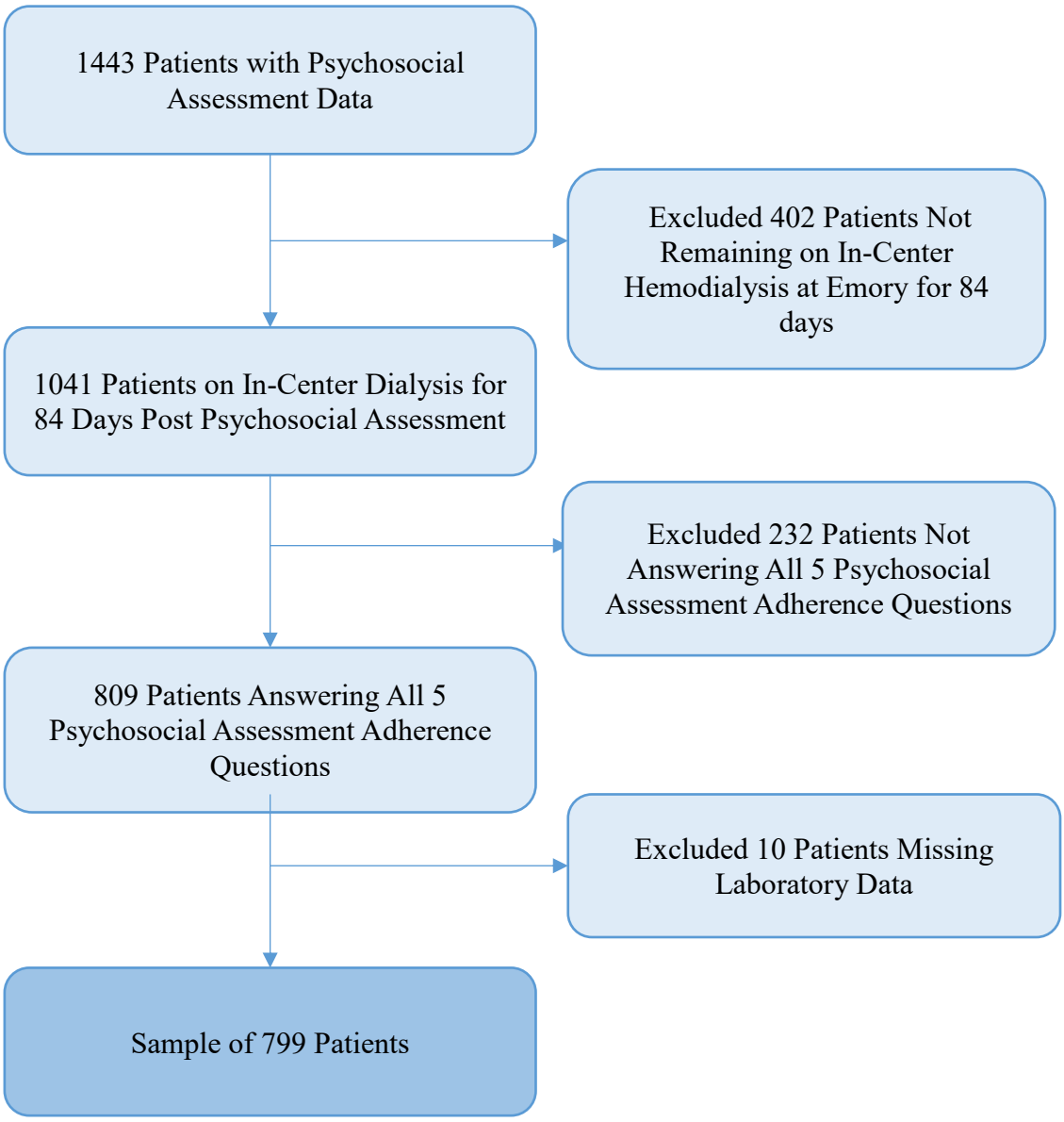

Figure 1. Summary of Sample Selection

Table 1. Social Worker Assessment Adherence Questions

Category	Question
Coming to Dialysis	Over the past month, how easy or difficult has it been for you to come to each hemodialysis treatment?
Completing Dialysis	Over the past month, how easy or difficult has it been for you to complete the full-prescribed hemodialysis treatment time?
Fluid Restrictions	Over the past month, how easy or difficult has it been for you to follow fluid restrictions?
Diet Restrictions	Over the past month, how easy or difficult has it been for you to follow dietary restrictions?
Taking Medications	Over the past month, how easy or difficult has it been for you to follow dietary restrictions?

Table 2. Patient Characteristics

Characteristic	**Overall (N=799)**
Mean (SD) age, years	57.10 (14.10)
Sex % (N)	
Male	54.82% (438)
Female	45.18% (361)
Race, % (N)[a]	
Black	95.31% (711)
Not Black	4.69% (30)
Cause of ESRD, % (N)	
Diabetes	19.27% (154)
Hypertension	57.32% (458)
Glomerulonephritis	5.26% (42)
Unknown/Other	18.15% (145)
Depression/Anxiety, % (N)[b]	
Yes	9.20% (72)
No	90.80% (711)
Memory Impairment, % (N)[c]	
Yes	13.65% (107)
No	86.35% (677)
Employment Status, % (N)[d]	
Employed	8.47% (53)
Unemployed Disabled	56.71% (355)
Unemployed Other	31.79% (199)
Other	3.04% (19)
Comorbid Conditions, % (N)[e]	
Diabetes	10.30% (82)
Hypertension	74.75% (595)
Heart Failure	5.15% (41)
Cancer	2.01% (16)
Pain	8.42% (67)
COPD	5.90% (47)
CVD	20.10% (160)
Vascular Access, % (N)	
Fistula	30.79% (246)
Graft	24.03% (192)
Catheter	45.18% (361)

a N= 741

b N=783

c N=784

d N=626

e N=796

Table 2a. Characteristics By Perceived Difficulty with Coming to Dialysis

Characteristic	Difficult (N=184, 23%)	Not Difficult (N=615, 77%)	P*
Mean (SD) age, years	57.93 (13.81)	56.85 (0.57)	0.36
Sex			
Male	57.61% (106)	53.98% (332)	0.39
Female	42.39% (78)	46.02% (283)	
Race, % (N)[a]			
Black	94.74% (162)	95.48% (549)	0.69
Not Black	5.26% (6)	4.52% (24)	
Cause of ESRD, % (N)			
Hypertension	59.78% (110)	56.59% (348)	0.42
Diabetes	16.30% (30)	20.16% (124)	
Glomerulonephritis	3.80% (7)	5.69% (35)	
Unknown/Other	20.11% (37)	17.56% (108)	
Depression/Anxiety, % (N)[b]			
Yes	16.76% (30)	6.95% (42)	<0.0001
No	83.28% (149)	93.05% (562)	
Memory Impairment, % (N)[c]			
Yes	16.67% (30)	12.75% (77)	0.40
No	83.35% (150)	87.25% (527)	
Employment Status, % (N)[d]			
Employed	7.10% (11)	8.92% (42)	0.09
Unemployed Disabled	58.71% (91)	56.05% (264)	
Unemployed Other	28.39% (44)	32.91% (155)	
Other	5.81% (9)	2.12% (10)	
Comorbid Conditions, % (N)[e]			
Diabetes	9.34% (17)	10.59% (65)	0.63
Hypertension	76.37% (139)	74.27% (456)	0.57
Heart Failure	4.95% (9)	5.21% (32)	0.89
Cancer	3.85% (7)	1.47% (9)	0.07
Pain	7.69% (14)	8.63% (53)	0.69
COPD	8.24% (15)	5.21% (32)	0.13
CVD	23.63% (43)	19.06% (117)	0.18
Vascular Access, % (N)			
Fistula	21.74% (40)	33.50% (206)	0.001
Graft	21.74% (40)	24.72% (152)	
Catheter	56.52% (104)	41.79% (257)	

*using t-test for continuous variables and chi-square or exact test for categorical variables.

a N= 741, b N=783, c N=784, d N=626, c N=784, e N=796

Table 2b. Characteristics By Perceived Difficulty with Completing Dialysis

Characteristic	Difficult (N=192, 24%)	Not Difficult (N=607, 76%)	P*
Mean (SD) age, years	58.63(14.05)	56.62 (14.09)	0.08
Sex			
Male	49.48% (95)	56.51% (343)	0.09
Female	50.52% (97)	43.49% (264)	
Race, % (N)[a]			
Black	93.37% (169)	95.93% (542)	0.16
Not Black	6.63% (10)	4.07% (20)	
Cause of ESRD, % (N)			
Hypertension	55.73% (107)	57.83% (351)	0.6
Diabetes	17.71% (34)	19.77% (120)	
Glomerulonephritis	5.21% (10)	5.27% (32)	
Unknown/Other	21.35% (41)	17.13% (104)	
Depression/Anxiety, % (N)[b]			
Yes	16.67% (31)	6.87% (41)	<0.0001
No	83.33% (155)	93.13% (556)	
Memory Impairment, % (N)[c]			
Yes	17.117% (32)	12.56% (75)	0.11
No	82.89% (155)	87.44% (522)	
Employment Status, % (N)[d]			
Employed	6.41% (10)	9.15% (43)	0.09
Unemployed Disabled	57.69% (90)	56.38% (265)	
Unemployed Other	30.13% (47)	32.34% (152)	
Other	5.77% (9)	2.13% (10)	
Comorbid Conditions, % (N)[e]			
Diabetes	10.47% (20)	10.25% (62)	0.93
Hypertension	76.96% (147)	74.05% (448)	0.42
Heart Failure	4.19% (8)	5.45% (33)	0.49
Cancer	3.66% (7)	1.49% (9)	0.08
Pain	7.85% (15)	8.60% (52)	0.75
COPD	7.85% (15)	5.29% (32)	0.19
CVD	21.47% (41)	19.67% (119)	0.59
Vascular Access, % (N)			
Fistula	20.83 (40)	33.94% (206)	0.0001
Graft	21.35% (41)	24.88% (151)	
Catheter	57.81% (111)	41.19% (250)	

*using t-test for continuous variables and chi-square or exact test for categorical variables.

a N= 741, b N=783, c N=784, d N=626, c N=784, e N=796

Table 2c. Characteristics By Perceived Difficulty with Fluid Restrictions

Characteristic	Difficult (N=250, 31%)	Not Difficult (N=549,69%)	P*
Mean (SD) age, years	56.45 (14.33)	57.40 (13.99)	0.38
Sex			
Male	60.40% (151)	52.28% (287)	0.03
Female	39.60% (99)	47.72% (262)	
Race, % (N)[a]			
Black	95.28% (222)	95.32% (489)	0.98
Not Black	4.72% (11)	3.83% (24)	
Cause of ESRD, % (N)			
Hypertension	58.40% (146)	56.83% (312)	0.3
Diabetes	15.60% (39)	20.95% (115)	
Glomerulonephritis	5.60% (14)	5.10% (28)	
Unknown/Other	20.40% (51)	17.12% (94)	
Depression/Anxiety, % (N)[b]			
Yes	13.88 % (34)	7.06% (38)	0.002
No	86.12% (211)	92.94% (500)	
Memory Impairment, % (N)[c]			
Yes	13.06% (32)	13.91% (75)	0.75
No	86.94% (213)	86.09% (464)	
Employment Status, % (N)[d]			
Employed	9.84% (19)	7.85% (34)	0.09
Unemployed Disabled	57.51% (111)	56.35% (244)	
Unemployed Other	27.46% (53)	33.72% (146)	
Other	5.18% (10)	2.08% (9)	
Comorbid Conditions, % (N)[e]			
Diabetes	7.66% (19)	11.50% (63)	0.1
Hypertension	77.82% (193)	73.36% (402)	0.18
Heart Failure	5.24% (13)	5.11% (28)	0.94
Cancer	2.02% (5)	2.01% (11)	0.99
Pain	5.24% (13)	9.85% (54)	0.03
COPD	5.65% (14)	6.02% (33)	0.83
CVD	20.56% (51)	19.89% (109)	0.83
Vascular Access, % (N)			
Fistula	27.20% (86)	32.42% (178)	0.005
Graft	19.20% (48)	26.23% (144)	
Catheter	53.60% (134)	41.35% (227)	

*using t-test for continuous variables and chi-square or exact test for categorical variables.

a N= 741, b N=783, c N=784, d N=626, c N=784, e N=796

Table 2d. Characteristics By Perceived Difficulty with Diet Restrictions

Characteristic	Difficult (N=278, 35%)	Not Difficult (N=521, 65%)	P*
Mean (SD) age, years	56.87 (13.97)	57.22 (14.18)	0.74
Sex			
Male	56.12% (156)	54.13% (282)	0.59
Female	43.88% (122)	45.87% (239)	
Race, % (N)[a]			
Black	97.31% (253)	94.24% (458)	0.06
Not Black	2.16% (6)	5.76% (24)	
Cause of ESRD, % (N)			
Hypertension	58.27% (162)	56.81% (296)	0.67
Diabetes	17.99% (50)	19.96% (104)	
Glomerulonephritis	4.32% (12)	5.76% (30)	
Unknown/Other	19.42% (54)	17.47% (91)	
Depression/Anxiety, % (N)[b]			
Yes	15.19% (41)	6.04% (31)	<0.0001
No	84.81% (229)	93.96% (482)	
Memory Impairment, % (N)[c]			
Yes	14.71% (40)	13.09% (67)	0.53
No	85.29% (232)	86.91% (445)	
Employment Status, % (N)[d]			
Employed	9.71% (20)	7.86% (33)	0.12
Unemployed Disabled	59.71% (123)	55.24% (232)	
Unemployed Other	26.21% (54)	34.52% (145)	
Other	4.37% (9)	2.38% (10)	
Comorbid Conditions, % (N)[e]			
Diabetes	10.87% (30)	10.00% (52)	0.7
Hypertension	76.45% (211)	73.85% (384)	0.42
Heart Failure	5.07% (14)	5.19% (27)	0.94
Cancer	2.90% (8)	1.54% (8)	0.19
Pain	6.88% (19)	9.23% (48)	0.26
COPD	6.16% (17)	5.77% (30)	0.82
CVD	20.65% (57)	19.81% (103)	0.78
Vascular Access, % (N)			
Fistula	26.26% (73)	33.21% (173)	0.05
Graft	23.02% (64)	24.57% (128)	
Catheter	50.72% (141)	42.23% (220)	

*using t-test for continuous variables and chi-square or exact test for categorical variables.

a N= 741, b N=783, c N=784, d N=626, c N=784, e N=796

Table 2e. Characteristics By Perceived Difficulty with Taking Medications and Diet Restrictions

Characteristic	Neither Difficult (N=502, 63%)	Medications or Diet Difficult (N=175, 22%)	Both Difficult (N=122, 15%)	P*
Mean (SD) age, years	57.37 (14.07)	56.94 (14.49)	56.23 (13.70)	0.71
Sex				
Male	53.98% (271)	54.86% (96)	58.20% (71)	0.7
Female	46.02% (231)	45.14 (79)	41.80% (51)	
Race, % (N)				
Black	94.43% (441)	95.76% (158)	98.25% (112)	0.21
Not Black	5.57% (23)	4.24% (5)	1.75% (20)	
Cause of ESRD, % (N)				
Hypertension	56.97% (286)	56.00% (98)	60.66% (74)	0.74
Diabetes	19.92% (100)	21.14% (37)	21.15% (33)	
Glomerulonephritis	5.58% (28)	4.00% (7)	5.74% (7)	
Unknown/Other	17.53% (88)	18.86% (33)	19.67% (24)	
Depression/Anxiety, % (N)[a]				
Yes	5.67% (28)	10.53% (18)	22.03% (26)	<0.0001
No	94.33% (466)	89.47% (153)	77.97% (92)	
Memory Impairment, % (N)[b]				
Yes	12.37% (61)	18.50% (32)	11.86% (14)	0.11
No	87.63% (432)	81.50% (141)	88.14% (104)	
Employment Status, % (N)[c]				
Employed	8.15% (33)	10.00% (11)	8.11% (9)	0.11
Unemployed Disabled	54.32% (220)	60.91% (67)	61.26% (68)	
Unemployed Other	35.06% (142)	27.27% (30)	24.32% (27)	
Other	2.47% (10)	1.82% (2)	6.31% (7)	
Comorbid Conditions, % (N)[d]				
Diabetes	9.98% (50)	13.14% (23)	7.50% (9)	0.27
Hypertension	73.45% (368)	73.71% (129)	81.67% (98)	0.17
Heart Failure	5.19% (26)	5.14% (9)	5.00% (6)	0.99
Cancer	1.20% (6)	3.43% (4)	3.33% (4)	0.1
Pain	9.18% (46)	6.86% (12)	7.50% (3)	0.59
COPD	5.99% (30)	3.43% (6)	9.17% (11)	0.12
CVD	19.96% (100)	16.00% (28)	26.67% (32)	0.08
Vascular Access, % (N)				
Fistula	33.67% (169)	32.57% (57)	16.39% (20)	0.002
Graft	24.70% (124)	21.71% (38)	24.59% (30)	
Catheter	41.63% (209)	45.71% (80)	59.02% (72)	

*using ANOVA for continuous variables and chi-square or exact test for categorical variables.
a N= 741, b N=783, c N=784, d N=626, c N=784, e N=796

Table 3. Actual Non-Adherence by Patient-Reported Perceived Difficulty with Adherence

Among those with perceived difficulty with:	**% Actual Non-Adherence as defined by:**	**P***	**% Agreement**	**Kappa (95% CI)**
Coming to Dialysis	Missing ≥ 3 sessions during study period			
Yes	30.43	0.09	65.33%	0.06 (-0.01, 0.13)
No	24.23			
Completing Dialysis	Shortening sessions by 15+ minutes in >3 sessions			
Yes	41.15	0.59	52.94%	-0.02 (-0.08, 0.05)
No	43.33			
Fluid Restrictions	IDWG ≥ 3 kg			
Yes	21.6	0.02	65.08%	0.07 (0.01, 0.14)
No	15.12			
Diet Restrictions	Serum Potassium > 5.0			
Yes	15.83	0.69	61.08%	0.01 (-0.05, 0.07)
No	14.78			
Diet Restrictions & Taking Medications	Serum Phosphorus > 5.5			
Neither	33.86	0.4		
Either	33.71		58.07%	-0.01 (-0.08, 0.05)
Both	40.16		62.20%	0.04(-0.02, 0.10)

*Using chi-square

Table 4. Associations Between Perceived Difficulty with Adherence and Actual Non-Adherence to Recommendations

	OR (95% CI) for Actual Non-Adherence by Adherence Recommendation		
Perceived Difficulty in:	**Model 1[a]**	**Model 2[b]**	**Model 3[c]**
Coming to Dialysis (yes vs. no)	1.37 (0.95, 1.97)	1.40 (0.96, 2.03)	1.41 (0.96, 2.07)
Completing Dialysis (yes vs. no)	0.91 (0.66, 1.27)	1.00 (0.71, 1.41)	1.03 (0.73, 1.46)
Fluid Restrictions (yes vs. no)	1.55 (1.06, 2.27)	1.53 (1.03, 2.29)	1.62 (1.08, 2.43)
Diet Restrictions (yes vs no)	1.08 (0.73, 1.62)	1.12 (0.74, 1.68)	1.13 (0.74, 1.72)
Taking Medications/Diet Restrictions			
Neither	Referent	Referent	Referent
Either	0.99 (0.69, 1.43)	0.98 (0.67, 1.43)	0.97 (0.66, 1.43)
Both	1.31 (0.87, 1.97)	1.28 (0.83, 1.96)	1.39 (0.89, 2.16)

a unadjusted

b adjusted for age, sex, vascular access

c adjusted for age, sex, vascular access, and depression/anxiety