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## Rates and Correlates of Therapy Non-Adherence in Adult Hemodialysis Patients

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*This article examines the rate of non-adherence (NA) and the relationship of demographic and psychosocial variables on NA with treatment, fluid, diet and medications in adult hemodialysis patients. We used a cross-sectional, longitudinal design, and included 107 adult hemodialysis patients. NA rates were variable depending on the outcome examined. Fluid NA rate was the highest, with 40% of participants categorized into this group. Significant differences and correlations were found between race and albumin, months on dialysis and Kt/V, and skipped treatments and Kt/V. No significant differences were found between sex, smoking, locus of control, depression, social support, general health, self-efficacy and co-morbid conditions. The influence of environmental factors, such as health care team and system factors, on adherence should be considered in future research.*

### INTRODUCTION

In-center hemodialysis (HD) is the most common End Stage Renal Disease therapy, as the disease (ESRD) has progressively increased in prevalence in the United States (U.S. Renal Data System, 2007). Rates of non-adherence (NA) to HD ranging from 2 to 80% have been documented (Bame et al., 1993; Leggat et al., 1998). Adherence is defined as “the extent to which a person’s behavior (taking medications, following a recommended diet and/or executing life-style changes) corresponds with the *agreed* recommendations of a health care provider” (Sabate, 2003). Adherence to HD therapy requires complex, lifelong behaviors related to dialysis treatment, fluids, diet and medications. Successful adherence is critical for maintaining health, decreasing disease symptoms and preventing negative patient outcomes, such as hospitalization and mortality (Bame et al., 1993; Chan & Greene, 1994; Saran et al., 2003). The purposes of this study were to describe the rate of NA with dialysis treatment, fluids, diet and medications in adult HD patients and examine the relationship of demographic and psychosocial variables to NA with dialysis treatment, fluids, diet and medications in adult HD patients.

### METHODS

#### *Design*

Using a cross-sectional longitudinal design, we drew a random sample of 149 HD patients from 6 outpatient

HD centers in the Midwest region of the United States. The following criteria were used for inclusion: 21 years of age or older, receiving HD for at least 6 months, able to speak and read English and cognitively intact as defined by a score of 24 and above on the Mini-Mental Status Exam. Those with a guardian or durable power of attorney, which indicate cognitive deficits, were excluded. Dialysis nurses initially obtained permission from the patient for the research nurse to discuss the study. If permission was granted, a research nurse with dialysis experience and training in the data collection protocol discussed the study with potential participants. We randomly selected a sample of 149 potential participants from the available pool. Of the 149, 11% ( $n = 17$ ) were either deceased or did not meet eligibility criteria. Of the remaining 132 eligible potential participants, 113 participants agreed to participate in the study, representing an 86% consent rate. Of the 113 participants who consented, 6 participants were lost to attrition due to death, transfer to another facility or change in dialysis modality. The final analyses were completed on 107 participants. A summary of sample demographic characteristics are delineated in Table 1. Co-morbid conditions were obtained from the participants’ medical records. The most prevalent co-morbid condition was hypertension ( $n = 92$ ; 73%), followed by diabetes ( $n = 57$ ; 45%), congestive heart failure ( $n = 46$ ; 37%), peripheral vascular disease ( $n = 17$ ; 14%), cerebrovascular disease ( $n = 15$ ; 12%) and chronic obstructive disease ( $n = 10$ ; 8%).

**Table 1****Demographic Characteristics of the Sample (n = 107)**

Demographic factor	Demographic detail	n*	Percent**
Age	Mean 54.38 years; SD = 16.83; range, 20–85 years		
Months on dialysis	Mean 51.12 months; SD = 54.07 ; range, 6–288 months		
Sex	Male	56	52
	Female	51	48
Education level	High school/some high school	62	58
	Some college/college graduate	38	36
Ethnicity	Caucasian	67	63
	African American	37	35
	Other/missing	3	2
Marital status	Divorced/never married/widowed	55	52
	Married	52	48
Employment status	Disabled/retired	56	52
	Retired due to age/preference	32	30
	Employed full/part time/other	19	18
Co-morbid conditions	Mean = 2.56 (SD ± 1.51; range, 0–8)		
Depression score	Mean = 11.42 (SD ± 8.86; range, 0–41)		

\*May not always total 107 due to missing data.

\*\*May not always total 100% due to missing data.

### **Instruments**

Participants were asked to complete a series of psychosocial surveys to determine the psychosocial factors correlated with NA. The unit of analysis for all instruments was the individual. The 18-item Multidimensional Health Locus of Control (MHLC) Scale-Form C was used to measure the expectancies for internal-versus-external control beliefs. People with an internal locus of control believe that their own actions determine the rewards that they obtain, while those with an external locus of control believe that their own behavior does not impact rewards and that rewards in life are generally outside of their control. Three concepts of internal, chance and doctors/other people are measured with 6 questions each. Psychometrics have been established in the dialysis population with Cronbach alphas in the 0.60 to 0.75 range and test-retest reliability coefficients ranging from 0.60 to 0.70 (Wallston et al., 1976).

Depression was measured using the Beck Depression Inventory (BDI; Beck et al., 1961). This 21-item self-administered, self-report scale addresses mood, pessimism, sense of failure, lack of satisfaction, guilty feeling, sense of punishment, self-hate, self-accusation, self-punitive wishes, crying spells, irritability, social withdrawal, indecisiveness, body image, work inhibition, sleep disturbance, fatigability, loss of appetite, weight loss, somatic preoccupation and loss of libido. The BDI has high internal consistency with ranges from 0.73 to 0.92 with a mean of 0.86 (Beck et al., 1961). The BDI has a split-half reliability co-efficient of 0.93 (Beck et al., 1961).

Medication self-efficacy was measured using the Long-Term Medication Behavior Self-Efficacy Scale (LTMBSES), developed specifically for renal transplant patients (De Geest et al., 1994). This 27-item self-administered, self-report scale measures confidence in taking immunosuppressive medications. It was effectively used with other chronic illness populations with good validity. The tool was modified with permission from the developers to measure long-term medication self-efficacy related to HD therapy. The question specific to immunosuppressive medication side effects, "Taking my medication even if it causes spots and excessive hair growth," was changed to "Taking my medication even if it causes side effects." The question specific to every other day dosing of steroids, common in transplantation, was removed (e.g., "Taking my medication even if it is prescribed to be taken every other day.") The tool addresses side effects, physical discomfort, emotional distress, distraction and being observed. Internal consistency reliability has been reported to be

0.94 (De Geest et al., 1995). Construct validity was determined with a median explained variance of 6% and area under the Receiver Operating Characteristic curve of 0.67 (Denhaerynck et al., 2003).

Social support was measured using the Social Support Appraisals Index (SSAI; Vaux, 1988). This is 23-item self-administered, self-report scale measures the degree of feeling cared for, respected and involved with family and friends (Vaux, 1988). The scale had good internal reliability with alpha scores ranging from 0.80 to 0.90 (Vaux et al., 1986). Stability was established with reliability scores of 0.80 (Vaux et al., 1986). Convergent validity has been demonstrated with significant associations to seven other appraisal measures (Vaux, 1988). Moreover, adequate concurrent and divergent validity with other perceived support measures was demonstrated and showed predicted associations with support network resources and psychological well-being (Vaux, 1988).

The Medical Outcomes Study (MOS) 36-item Short Form Health Survey (SF-36) was used to measure health status. The profile assesses 8 concepts, including physical activities, social activities, role limitations due to physical health, bodily pain, general mental health, role limitations due to mental health, vitality and general health perceptions. The median reliability coefficients for each of the eight scales was 0.80 or higher, except for social function, which had a median reliability across studies of 0.76 (Ware et al., 1993).

The Dialysis Diet and Fluid Questionnaire (DDFQ) was used to obtain the patient's perspective of diet and fluid adherence. The tool was designed and validated in Flanders, Belgium, to evaluate HD patients' NA behavior (Vlaminck et al., 2001). The DDFQ is a self-report instrument consisting of 4 subscales: 2 regarding NA to diet (frequency and intensity) and 2 about fluids (frequency and intensity). The intensity of NA is scored on a Likert-type scale from "no" to "very severe" deviation (Kugler et al., 2005).

### **Outcome Data**

The outcome data, including missed or shortened dialysis treatments, Kt/V, IDWG, serum phosphorus, serum calcium and serum albumin, were extracted from the dialysis medical records for 6 months after the participants' completion of the psychosocial instruments.

The outcome measures represent the following adherence parameters: treatment adherence measured by missed or shortened treatments and Kt/V, fluid adherence measured by IDWG, medication adherence measured by serum phosphorus and diet adherence measured by

**Table 2***Adherence Outcome Parameters*

Measure	Good	Moderate	Poor
Kt/V	>1.3	1.0 to 1.3	<1.0
IDWG	<2.0 kg	2.0 to 3.0 kg	>3.0 kg
Serum phosphorus	3.5 to 5.0 mg/dL	2.0 to <3.5 mg/dL or >5.0 to 6.5 mg/dL	>6.5 or <2.0 mg/dL
Serum albumin	>3.0 g/dL	3.0 to 4.0 g/dL	<3.0 g/dL
Serum calcium	8.4 to 9.5 mg/dL	7.3 to <8.4 mg/dL or >9.5 to 10.4 mg/dL	<7.3 or >10.4 mg/dL

serum albumin and serum calcium. The Kidney Disease Outcomes Quality Initiative (KDOQI) standards parameters were used to guide adherence ranges. The adherence categories are listed in Table 2.

**Procedure**

Institutional review board and dialysis center approval were obtained prior to initiation of the study. Once a participant consented to the study, a trained research assistant administered the following scales while the participant received dialysis: the BDI, MHLC Scale-Form C, the MOS SF-36, the LTMBSES, the SSAI and the DDFQ. If participants' preferred, the surveys were read to them. The surveys took an average of about 60 minutes to complete. Following completion of the surveys, the following outcome data were extracted from each participant's medical record monthly for a total of 6 months: missed or shortened dialysis treatments, Kt/V, IDWG, serum phosphorus, serum calcium and serum albumin.

**Data Analysis**

Descriptive statistics including means, standard deviations and ranges for continuous variables and percentages for categorical variables were calculated. The Wilcoxon Rank Sum test was used for analyzing nominal variables. Spearman correlations were calculated due to the ordinal nature of the majority of the other variables. A conservative alpha level of 0.005 was used because 70 to 75 correlations were considered. Using a traditional alpha level of 0.05 would have likely resulted in finding significant correlations due to chance alone because of the large number of correlations calculated in the study.

**RESULTS**

The rate of treatment adherence included 42% ( $n = 45$ ) of participants who attended all HD treatments over the 6-month tracking period, 30% ( $n = 32$ ) who skipped one, 11% ( $n = 12$ ) who skipped two and 17% ( $n = 18$ ) who skipped three or more treatments. Shortened HD treatments showed a similar pattern with 52% ( $n = 56$ ) of participants adherent with all HD treatments, 18% ( $n = 19$ ) shortening one, 9% ( $n = 10$ ) shortening two and 20% ( $n = 21$ ) shortening three or more times in the 6-month period. The mean Kt/V for the group ( $n = 106$ ) was 1.31 (SD = 0.223; range 0.74–2.05). Using the good, moderate and poor adherence Kt/V categories to classify individual adherence levels over 6 months, 59% ( $n = 63$ ) were classified as good adherers, 34% ( $n = 36$ ) were moderate adherers and 6% ( $n = 7$ ) were poor adherers.

The mean IDWG was 2.68 kg (SD = 1.14; range -0.37–6.06). When the IDWG adherence categories were used to determine poor, moderate and good adherence over the 6-month period, 29% ( $n = 31$ ) were classified as good adherers, 30% ( $n = 32$ ) as moderate adherers and 40% ( $n = 43$ ) as poor adherers.

The mean serum phosphorus was 5.73 mg/dL (SD = 1.51; range 3.04–12.30). Using the serum phosphorus criteria as a classification, 32% ( $n = 34$ ) were good adherers, 43% ( $n = 46$ ) were moderate adherers and 25% ( $n = 27$ ) were poor adherers over the 6-month period. The mean serum albumin was 3.82 g/dL (SD = 0.31; range 2.82–4.59). There were 24% ( $n = 25$ ) classified as good adherers, 75% ( $n = 79$ ) as moderate adherers and 2% ( $n = 2$ ) as poor adherers. Mean serum calcium was 9.05 mg/dL (SD = 0.63; range 7.49–10.50). Sixty percent ( $n = 64$ ) were good adherers and 40% ( $n = 43$ )

were moderate adherers. There were no poor adherers using calcium as an outcome.

Significant differences were found between race and albumin ( $p = 0.004$ ) with caucasians having lower mean serum albumin levels (3.77 versus 3.94 g/dL for African Americans). No significant differences were found between health locus of control, gender or smoking and the outcomes. Significant correlations were found between months on dialysis and Kt/V ( $r = 0.325$ ;  $p = 0.0012$ ) and skipped treatments and Kt/V ( $r = -0.371$ ;  $p < 0.0001$ ). These correlations indicate that those with longer length of time since initiating dialysis had higher Kt/V values and those who skipped more treatments had lower Kt/V values. No correlations were found between depression, social support, general health score from the MOS SF-36, self-efficacy or number of co-morbid conditions and the outcomes. The mean depression score for this sample indicates minimal depression levels in the group.

## DISCUSSION

The results of this study indicate that rates of NA in this sample of adult HD patients are variable depending on the outcome examined. The majority of participants were categorized as having good adherence when skipped treatments, shortened treatments, Kt/V and calcium were explored. However, when adherence to serum phosphorus and serum albumin parameters were assessed, most participants (75% in both groups) were classified as only moderately adherent. NA to fluid restrictions, measured by IDWG  $>3.0$  kg, showed the highest NA, with 40% of participants categorized into this group. Comparison of results with other published studies is difficult due to varied operational definitions of adherence outcomes (Russell et al., 2007). Future use of KDOQI guidelines for measuring adherence parameters will certainly minimize this comparison barrier.

The mean Kt/V was 1.3 for all patients, suggesting that most patients had adequate HD. Only 6 out of the 107 patients had Kt/V  $<1.0$ . Presently, greater efforts are made to maintain better clearances for patients. By today's standards, poor Kt/V values  $<1.0$  would have been adequate values years ago. In this study, adherence may have little effect on Kt/V, as nephrologists have many more ways to manage non-adherent patients through increasing the number of sessions, dialysis time, dialysis frequency (e.g., nocturnal home HD) or reducing flow pressure.

The difference in NA outcomes between Caucasians and African Americans is generally not supported by other studies (Russell et al., 2007). Only one study found

that serum albumin significantly contributed to predicting patients' diet adherence behaviors ( $b = 0.102$ ;  $p = 0.003$ ) but did not examine race differences (Zrinyi et al., 2003).

The statistically significant positive correlation between length of time since initiating dialysis and NA found in this study has been documented by about 30% of other studies (7 of 27) (Russell et al., 2007). However, the opposite has also been found—that shorter time on dialysis is statistically significantly correlated with NA. Other confounding factors, not yet explored, must be involved to explain this wide variability in results.

The correlation found between skipped treatments and Kt/V is consistent with our understanding of dialysis therapy. If patients skip treatments, they will not receive adequate dialysis therapy, resulting in lower Kt/V levels. The finding that those who had been on dialysis longer had higher Kt/V levels is also expected. Those who did not have adequate dialysis might have been more likely to die and were not included in the study (Lowrie & Lew, 1990).

A significant finding of this study is that many of the hypothesized predictor variables were indeed not significantly correlated with NA. Sex, smoking, depression, health locus of control, social support, general health score from the MOS SF-36, self-efficacy and number of co-morbid conditions were not correlated with treatment, fluid, diet or medication NA.

As with all research studies, there were several limitations of this work. Generalization to other areas of the United States and beyond is cautioned because the sample was drawn from a rather limited geographic region. Additionally, the resulting sample was small. However, inclusion of only one predictor variable for every 10 participants in the total sample when conducting the analysis minimizes concern. Although the consent rate was quite high, there is a possibility that those who chose not to participate may be different than those who consented to the study. For example, more NA individuals may have decided not to participate. Another possible limitation is that participants may have provided socially desirable answers to the survey questions. However, an attempt to address this threat to internal validity was made by using a trained research assistant to administer the surveys and not the dialysis staff members.

## FUTURE RESEARCH

The present study's findings, when placed in the context of mixed findings from other published literature, suggest that other influences must be examined in future

adherence research in adult HD patients (Hailey & Moss, 2000; Hoover, 1989; Morgan, 2000). The World Health Organization, in a 2003 landmark evidence-based report on adherence in chronic illness, emphasized that adherence to medical therapy is influenced by a multitude of factors (Sabate, 2003). These factors include social and economic, health care system, health care team, disease/disease therapy and patient-related factors. The report also stresses that health care providers and researchers continue to focus on patient-related factors for remedying adherence problems, when factors in the patient's environment, such as health care team and health care system, may have an even greater influence. If adherence is to be improved, each of these factors must be addressed in future research studies.

### IMPLICATIONS FOR PRACTICE

This study's findings support prior research in that adherence to HD medical regimens is a problem in the adult population and that patient-related factors as predictors for adherence are not robust. As such, health care providers must utilize the broader adherence evidence for practice guidance until results are available from the adult HD population. The adherence evidence suggests that adherence-enhancing interventions must be designed for each patient based on routine assessment of individual needs, as no one intervention or groups of interventions have been effective (Haynes et al., 2005; Roter et al., 1998; Sabate, 2003). Utilizing the clinical assessment and intervention skills of the dialysis center's qualified social worker is critical. Adherence assessment and support must be an ongoing process because adherence behavior occurs in a person's dynamic and changing environment (Sabate, 2003). Health care professionals can provide helpful support to patients, yet little training on adherence has been integrated into health care preparation and continuing education (Sabate, 2003). Consequently, intervention programs addressing information about adherence, clinical decision-making processes and the use of behavioral tools are greatly needed both in the practice and health care education systems (Sabate, 2003). Those based on individual needs, family, community and patient organizations can be important in supporting adherence (Sabate, 2003). Finally, multidisciplinary teams must collaborate to enhance adherence (Sabate, 2003). Collaboration should occur at the patient, peer, health care professional, dialysis unit and health care delivery system level.

### CONCLUSION

Adherence to medical therapies by adult HD patients continues to challenge health care professionals. Demographic and patient psychosocial factors are not strong predictors. Health care providers must use adherence evidence from the broader chronic illness research in practice. Nephrology social workers are able to utilize their training and skills related to psychosocial assessment to determine barriers and risks for each individual patient upon initiation of dialysis, as well as on an ongoing basis. Future research must focus beyond adherence influencing patient factors and instead explore adherence influencing health care team, system and social and economic factors.

### REFERENCES

- Bame, S. I., Peterson, N., & Wry, B. (1993). Variation in hemodialysis patient compliance according to demographics characteristics. *Social Science Medicine*, 37, 1035–1043.
- Beck, A. T., Ward, C. H., Mendelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry*, 4, 53–63.
- Chan, C. & Greene, G. (1994). Dietary compliance among young hemodialysis patients. *Dialysis and Transplantation*, 23(4), 184–189.
- De Geest, S., Abraham, I., Gemoets, H., & Evers, G. (1994). Development of the Long-Term Medication Behaviour Self-Efficacy Scale: Qualitative study for item development. *Journal of Advanced Nursing*, 19(2), 233–238.
- De Geest, S., Borgermans, L., Gemoets, H., Abraham, I., Vlamincx, H., Evers, G., et al. (1995). Incidence, determinants, and consequences of subclinical noncompliance with immunosuppressive therapy in renal transplant recipients. *Transplantation*, 59(3), 340–347.
- Denhaerynck, K., Abraham, I., Gourley, G., Drent, G., De Vleeschouwer, P., Papajcik, D., et al. (2003). Validity testing of the Long-Term Medication Behavior Self-Efficacy Scale. *Journal of Nursing Measurement*, 11(3), 267–282.
- Hailey, B. J. & Moss, S. B. (2000). Compliance behaviour in patients undergoing haemodialysis: A review of the literature. *Psychology, Health & Medicine*, 5(4), 395–406.

- Haynes, R. B., Yao, X., Degani, A., Kripalani, S., Garg, A., & McDonald, H. P. (2005). Interventions for enhancing medication adherence. *The Cochrane Database of Systematic Reviews* (4), Art. No.: CD000011. pub000012.
- Hoover, H. (1989). Compliance in hemodialysis patients: A review of the literature. *Journal of the American Dietetic Association*, 89(7), 957–959.
- Kugler, C., Vlaminc, H., Haverich, A., & Maes, B. (2005). Nonadherence with diet and fluid restrictions among adults having hemodialysis. *Journal of Nursing Scholarship*, 37(1), 25–29.
- Leggat, J. E., Jr., Orzol, S. M., Hulbert-Shearon, T. E., Golper, T. A., Jones, C. A., Held, P. J., et al. (1998). Noncompliance in hemodialysis: Predictors and survival analysis. *American Journal of Kidney Diseases*, 32(1), 139–145.
- Lowrie, E. G. & Lew, N. L. (1990). Death risk in hemodialysis patients: The predictive value of commonly measured variables and an evaluation of death rate differences between facilities. *American Journal of Kidney Disease*, 15(5), 458–482.
- Morgan, L. (2000). A decade review: Methods to improve adherence to the treatment regimen among hemodialysis patients. *Nephrology Nursing Journal*, 27(3), 299–304.
- Roter, D. L., Hall, J. A., Merisca, R., Nordstrom, B., Cretin, D., & Svarstad, B. (1998). Effectiveness of interventions to improve patient compliance: A meta-analysis. *Medical Care*, 36(8), 1138–1161.
- Russell, C. L., Knowles, N., & Peace, L. (2007). Adherence in dialysis patients: A review of the literature. *Journal of Nephrology Social Work*, 27, 11–44.
- Sabate, E. (2003). *Adherence to long-term therapies: Evidence for action*. Geneva, Switzerland: World Health Organization.
- Saran, R., Bragg-Gresham, J. L., Rayner, H. C., Goodkin, D. A., Keen, M. L., Van Dijk, P. C., et al. (2003). Nonadherence in hemodialysis: Associations with mortality, hospitalization, and practice patterns in the DOPPS. [Miscellaneous]. *Kidney International*, 64(1), 254–262.
- U.S. Renal Data System. (2007). Annual data report. Retrieved October 26, 2007, from [www.usrds.org/adr.htm](http://www.usrds.org/adr.htm)
- Vaux, A. (1988). *Social support: Theory, research, intervention*. New York: Praeger.
- Vaux, A., et al. (1986). The social support appraisals (SS-A) scale: Studies of reliability and validity. *American Journal of Community Psychology*, 14(2), 195–219.
- Vlaminc, H., Jacobs, A., & Reyntjens, S. (2001). The Dialysis Diet and Fluid Non-Adherence Questionnaire: Validity testing of a self-report instrument. *Journal of Clinical Nursing*, 1, 707–715.
- Wallston, B. S., Wallston, K. A., Kaplan, G. D., & Maides, S. A. (1976). The development and validation of the Health Related Locus of Control (HLOC) scale. *Journal of Consulting & Clinical Psychology*, 44, 580–585.
- Ware, H. E., Snow, K. K., Kosinski, M., & Gandek, B. (1993). *SF26 Health survey manual and interpretation guide*. Boston, MA: New England Medical Center Health Institute.
- Zrinyi, M., Juhasz, M., Balla, J., Katona, E., Ben, T., Kakuk, G., et al. (2003). Dietary self-efficacy: Determinant of compliance behaviours and biochemical outcomes in haemodialysis patients. *Nephrology Dialysis Transplantation*, 18, 1869–1873. **JNSW**