Adherence to the Dialysis Prescription: Partnering with Patients for Improved Outcomes

Randee Breiterman White, MS, RN, CNN

Nonadherence is common in the U.S. dialysis population. No single strategy has been definitely proven to yield universal and/or lasting improvements in adherence. However, using a patient-centered approach, including the removal of barriers to adherence, ongoing education, and cognitive behavioral strategies, may generate increased opportunities for patients and the nephrology staff to improve both adherence and outcomes.

Nonadherence to recommended and potentially life-preserving behavioral patterns and therapies is a challenge of epidemic proportions in the United States. Most Americans do not eat properly or exercise regularly, despite the proven life-threatening ramifications of high-fat diets and inactivity. Moreover, people find it difficult to adhere to therapeutic interventions, whether they are in the form of a 10-day course of antibiotics for an acute infection or the chronic use of insulin to ensure proper control of diabetes (Valdez, 2003). By the time a typical patient reaches end-stage renal disease (ESRD), an individual pattern of nonadherence has been developed and refined for over 50 years. With this lifelong backdrop of nonadherent behavior, patients are asked to immediately and permanently modify their diet and fluid intake, remember to take a host of daily medications, and change their lifestyle to accommodate dialysis. It is not surprising, then, that many patients occasionally do not adhere to their prescribed diet, fluid restrictions, or time on dialysis and that some demonstrate flagrant, ongoing nonadherence (Valdez, 2003).

This article examines current data on the status of nonadherence among dialysis patients, the reasons for it, and interventions that might help improve and optimize adherence. A case study highlights the nurse's role in educating patients while encouraging improvements in behavior.

Prevalence and Consequences of Nonadherence

Randee Breiterman White, MS, RN, CNN, is a Clinical Nurse Specialist and Case Manager in Nephrology at Vanderbilt University Medical Center.

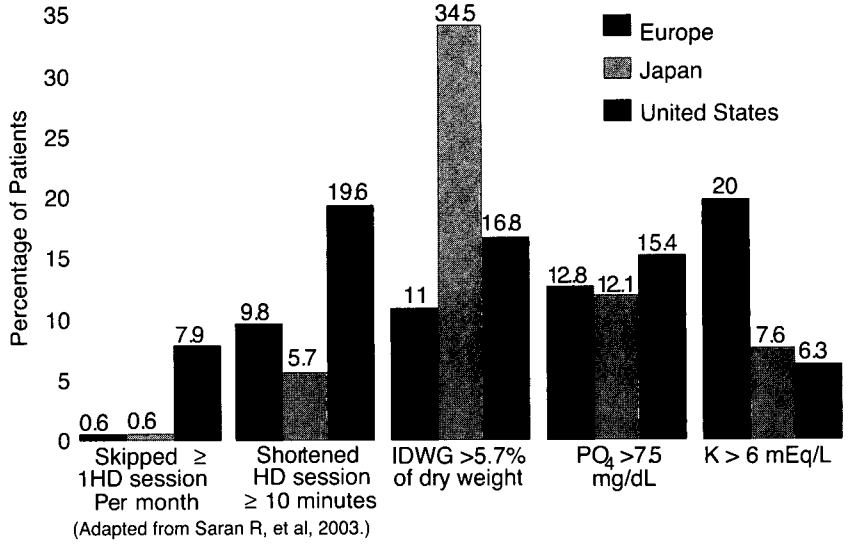
Note: *This article is supported by a financial grant from Amgen. The manuscript has undergone an anonymous peer review. The information does not necessarily reflect the opinions of ANNA or the sponsor.*

Depending on the particular component of care that is being examined, estimates of the prevalence of nonadherence in the dialysis population have ranged from 2% to over 50%. In one report, for example, only 20% to 30% of patients adhered to fluid restrictions, while 80% to 90% adhered to dietary potassium restrictions (Leggat, et al., 1998; Molzahn, 1998). Overall, it has been estimated that about 50% of hemodialysis patients do not adhere to at least part of their dialysis regimen (Kuther, 2001).

While many components of patient behavior have been assessed, Leggat, et al. (1998) established a benchmark for assessing easily measurable and reproducible components of adherence. In this analysis of 6,251 U.S. hemodialysis patients, an individual was determined to be nonadherent if one or more of the following occurred during a month: (a) skipping one or more dialysis sessions, (b) shortening a session by ≥ 10 minutes, (c) gaining > 5.7% of dry weight between sessions (a 4-kg weight gain for a 70-kg patient), or (d) having a serum phosphate (PO_4) level > 7.5 mg/dL. Results of this analysis showed that 8.5% of patients skipped hemodialysis sessions, 20% shortened their sessions, 10% had more than a 5.7% interdialytic weight gain, and 22% had a PO_4 that exceeded 7.5 mg/dL.

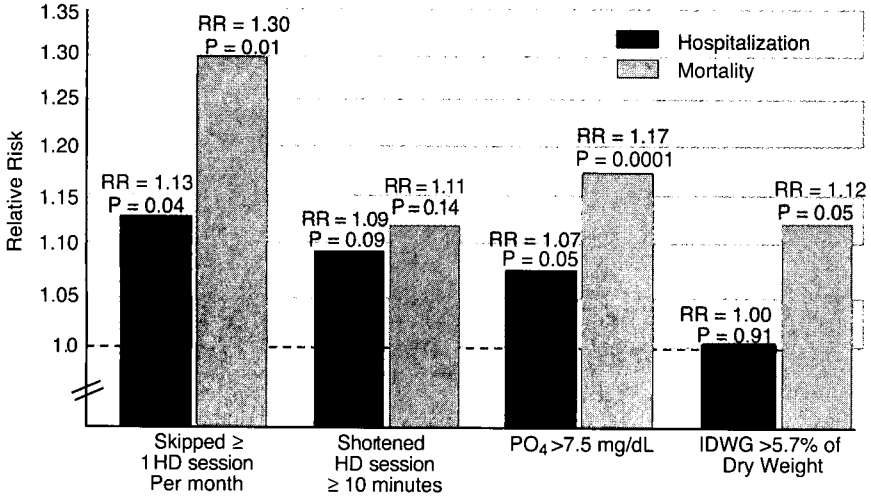
A more recent analysis using the same measures of nonadherence was reported by the Dialysis Outcomes and Practice Patterns Study (DOPPS). This study revealed interesting and significant differences in patterns of nonadherence among patients in Europe, Japan, and the United States (Figure 1), indicating that undefined cultural or practice pattern factors may affect adherence. More importantly, the DOPPS analysis found that nonadherence significantly increases the risk of hospital-

Figure 1: International Differences in Adherence to Prescribed Regimens



(Adapted from Saran R, et al, 2003.)

Figure 2: Relationship Between Adherence and Outcomes



(Adapted from Saran R, et al, 2003.)

ization and mortality (Figure 2) (Saran, et al., 2003).

Causes of Nonadherence

Patterns of nonadherence are often established early in the course of dialysis. For example, shortening or skipping sessions typically manifests in the first 6 months of treatment and remains stable thereafter (McKinley, 2000). In an excellent review of why hemodialysis treatments are shortened or skipped, Gordon, Leon, & Sehgal (2003) grouped the reasons into five general categories: medical problems, technical problems, life tasks, transportation, and patient decisions (Table 1). These authors found that the most common reasons for shortening sessions were medical problems (38%) and life tasks (21%), while the most common reasons for skipping sessions were life tasks (33%) and transportation (22%). After adjusting for multivariate patient characteristics, technical problems were more common among women; life tasks were more common among men, younger patients, and those with hypertension; and transportation problems were more common among African-Americans.

A common theme in the adherence literature is the patient's desire to exert a measure of control over the disease and the dialysis process. One study, for example, found that dialysis patients with a low level of perceived control frequently had poor adherence to dietary and fluid restrictions and that problem often worsened following educational sessions. Conversely, patients with a higher level of perceived control had improved adherence, even when incremental education was not provided (Cvengros, Christensen, & Lawton, 2004). A corroborating author observed that patients who shortened dialysis treatments were more likely to be bothered by the effects of kidney disease and have a perceived lack of control over their own health. Therefore, nonadherence may be one way that patients attempt to exert some control over their own lives (Kuther, 2001).

Nurses should also realize that chronic nonadherence may be a sign of emotional or psychological problems. One representative study, for example, investigated the relationship between stress/depression and interdialytic weight gain in hemodialysis patients (n = 42). This study found that major life events, daily stressful events, and depression can independently affect adherence to the dialysis prescription, with the minor stresses of daily life correlating directly and depression correlating indirectly with nonadherent behavior (Everett, Brantley, Sletten, Jones, & McKnight, 1995).

Data also indicate that a facility's practice patterns may affect nonadherence. The DOPPS, for example, found a greater likelihood of nonadherence in facilities with more than 60 patients. Each incremental gain of 10 patients above the 60-patient threshold was associated with an increased likelihood of skipping dialysis (odds ratio [OR] = 1.03; P = 0.05), shortening a dialysis session (OR = 1.03; P = 0.05), and experiencing interdialytic weight gain (OR = 1.02, P = 0.07). Conversely, the odds of skipping hemodialysis sessions decreased by 16% (OR = 0.84; P = 0.02) for each 10% increase in highly trained staff hours (defined as hours worked by staff with 2 or more years of formal nursing training) (Saran, et al., 2003).

Table 1: Reasons for Shortening or Skipping Dialysis

Reasons for Nonadherence	% Shortening	% Skipping
Medical problems	38	20
Technical problems	19	16
Life tasks	21	33
Transportation	10	22
Patient decisions	19	19
Other	18	11

(Adapted from Gordon, Leon, & Sehgal, 2003)

Nursing Approach to Nonadherence

Many methods for improving adherence have been suggested, but few rigorous interventional studies have been conducted. Reports of adherence strategies in the literature can be broadly divided into three categories: (a) removal of barriers, (b) educational efforts, and (c) targeted attention.

An initial step to improving adherence is to remove any barriers that may be contributing to a specific

patient's nonadherence. Barriers can be identified by interviewing the patient and completing a detailed psychosocial history to discover whether issues such as transportation, conflicting family obligations, troubled personal relationships, loss of income, or an illness in the family may be contributing to nonadherence. In addition, the patient should be engaged in a frank discussion about the dialysis procedure to determine whether barriers such as scheduling, restless leg syndrome, pain, cold, friction with staff or other patients, the desire to eat or smoke, or the inability to go to the restroom are interfering with adherence (Valdez, 2003). Targeted programs to remove such barriers can be very successful. For example, a representative study showed that the average number of days of unplanned dialysis absences dropped to 0.5 per patient per year when transportation assistance was provided, compared with a mean of 2.5 when limited or no transportation assistance was offered (Kuther, 2001).

A second strategy that nurses can use is ongoing education to stress the link between adherence and short- and long-term outcomes. Nurses typically believe that good teaching is the key to adherence and often become frustrated when nonadherent behavior persists despite an excellent educational program. However, while education is the cornerstone for promoting adherence, traditional educational programs alone have yielded mixed results, with some studies showing significant and immediate improvement in adherence following targeted programs and others finding that education alone provides short-lived benefits (McKinley, 2000). These divergent results illustrate a practical observation that nephrology nurses experience every day–simply telling patients something often does little to ensure adherence.

The mixed results derived from traditional educational methods have given rise to a more targeted approach in which individualized education is combined with cognitive behavioral strategies, encouragement, support, and psychological counseling. Classic behavioral strategies have focused on rewarding specific behaviors. For example, many facilities have conducted low-pressure competitions to reward patients with the best control of a specific measure of adherence, while others have attempted to incorporate education into a signed patient contract that outlines particular behavioral expectations (Laidlaw, Beeken, Whitney, & Reyes, 1999). While these peer pressure or individually driven behavioral strategies have been shown to be successful for some patients, the improvement may be short-lived unless the effort is continually renewed. Further, these techniques may leave behind those patients who are noncompetitive or not fully engaged with their care providers.

An alternative method that stresses cognitive behavioral modification is based on the premise that strategies to improve nonadherence are of little value unless the patient agrees that the prescribed regimen is personally worthwhile. This approach attempts to involve patients in their own care by helping them regain a measure of control and achieve an understanding of how their behaviors affect their own health. This approach is based on the premise that most people have difficulty remembering and internalizing a series of nonpersonalized facts (traditional teaching). By contrast, helping patients learn to recognize how the facts affect their personal outcomes can promote both understanding and improved adherence (cognitive behavior). The cognitive behavioral approach has been shown to result in more sustained, long-term modifications than the behavioral approach alone (Kuther, 2001; Molzahn, 1998).

The easiest way for a nurse to begin implementing a cognitive behavioral approach is to be sensitive to the personal needs and desires of each patient. Although it may sound trite, the importance of positive interactions and relationships between providers and patients is a strong theme in the compliance literature (Kuther, 2001). Like everyone else, patients want to be valued and shown that their opinion matters and is appreciated. As a result, nurse/patient interactions that are purposefully designed to show patients that their opinion matters can be extremely effective (Molzahn, 1998). For example, greeting a patient who arrives at dialysis with fluid gain and high blood pressure with a comment such as, "You must not be taking your blood pressure medications–we'll have to adjust your time on dialysis," creates an interaction that is both negative and paternalistic. The patient may then not be receptive to educational information, even if it will help them personally. By contrast, asking a question such as, "Do you notice any difference in the way your body looks or feels on the days that you have high blood pressure?" provides the opportunity for a conversation in which patients can begin to self-assess how nonadherence affects them personally. Treating patients as individuals and equals allows them to exert some self-control over their own behaviors and outcomes and makes it more likely that they will be open to an ongoing educational dialogue (Hartwell, 2002).

When developing an individualized plan to encourage adherence, nurses should also recall that nonadherence may be a sign of emotional or psychological problems. In such cases, a psychological consult may be indicated. Some patients may be resistant to individual psychological sessions, but group sessions with other patients and/or family members, with guidance from a trusted and accepted psychiatric nurse or social worker, may be more readily accepted (Hersh-Rifkin & Stoner, 1999).

Finally, it should be noted that some patients who do not have emotional or psychological problems continue to be willfully and flagrantly nonadherent. Although the nephrology staff is still responsible for providing high-quality treatment, education, and support, patients have the right to refuse recommended treatments and behavioral modifications. However,

flagrantly nonadherent patients do not have the right to complicate clinic schedules, delay other patients, or create conflict in the dialysis facility. In such cases, the facility's conflict resolution procedure should be initiated to determine how to minimize the effect of such nonadherence on the facility and on other patients.

Case Study

RS is a 64-year-old woman with ESRD caused by long-standing hypertension. Within 2 months of initiating hemodialysis, RS has had six episodes of excessive interdialytic weight gain, averaging about 6 kg (these typically happen on Mondays). After the most recent occurrence, the nurse talked with RS to obtain a detailed psychosocial history. At the beginning of the session, the nurse complimented RS on her blood pressure, which had consistently been excellent. The nurse then asked her to perform a self-assessment of how her feet and ankles looked that day compared with other days. RS observed that she thought her feet and ankles looked swollen. She explained that she had hosted the weekly family dinner the day before, and that she continues to serve as the primary cook. She feels that she needs to set a good example for her young grandchildren by eating everything on her plate.

RS and the nurse discussed how overindulgence during these dinners is contributing to the swelling that RS observed, and the negative health ramifications that result. The nurse shared the history of the weight gains, and RS was surprised at the number of occurrences. RS and the nurse jointly devised a plan to convene a meeting with the family to solicit their understanding and support for RS's adherence to dietary and fluid restrictions.

Outcomes improved immediately, and RS had no excessive interdialytic weight gain for the next 3 weeks–the nurse continued to provide ongoing encouragement. However, at week 4 RS again arrived with severe ankle edema and a 6.5-kg weight gain. She immediately commented to the nurse that she knows she overdid it with food and fluid that weekend and does not like the way her ankles look.

Discussion

The tone for this positive patient interaction was set by the nurse's use of positive reinforcement, coupled with a willingness to have the patient assume some control for self-assessing how fluid overload was affecting her. By contrast, a negative, accusatory, and paternalistically oriented interaction would have probably resulted if the nurse had observed, "I see you gained too much weight again–we'll have to do something about that."

Nurses should also be aware that permanent change is typically not easy or quick and that it will often be accompanied by setbacks. Indeed, it is estimated that 80% of those who attempt behavioral change will fail the first time. However, relapse does not necessarily mean failure, and persistence can often bring about long-lasting change (McKinley, 2000).

Conclusions

Data from the DOPPS and similar clinical evaluations have revealed the widespread nature of nonadherence among dialysis patients, as well as its significant impact on morbidity and mortality. While no single program for improving adherence has been shown to work for everyone, a combination approach that includes removal of barriers to adherence, education, and cognitive behavioral strategies may provide the best opportunity to improve compliance. While any program may be accompanied by small incremental improvements and ongoing setbacks, the results of a program that successfully modifies behavior can be extremely rewarding and beneficial for both staff and patients.

References

Cvengros, J.A., Christensen, A.J., & Lawton, W.J. (2004). The role of perceived control and preference for control in adherence to a chronic medical regimen. *Annals of Behavioral Medicine, 27,* 155-161.

Everett, K.D., Brantley, P.J., Sletten, C., Jones, G.N., & McKnight, G.T. (1995). The relation of stress and depression to interdialytic weight gain in hemodialysis patients. *Behavioral Medicine, 21*(1), 25-30.

Gordon, E.J., Leon J.B., & Sehgal, A.R. (2003). Why are hemodialysis treatments shortened and skipped? Development of a taxonomy and relationship to patient subgroups. *Nephrology Nursing Journal, 30,* 209-217.

Hartwell, L. (2002). *Chronically Happy,* San Francisco, CA: Poetic Media Press. 25-74.

Hersh-Rifkin, M., & Stoner, M.H. (1999). Psychosocial aspects of dialysis therapy. In: Gutch, C.F., Stoner, M.H., & Corea, A.L. *Review of hemodialysis for nurses and dialysis personnel.* St. Louis, MO, Mosby, Inc. 279-287.

Kuther, N.G. (2001). Improving compliance in dialysis patients: does anything work? *Seminars in Dialysis, 14,* 324-327.

Laidlaw, J.K., Beeken, J.E., Whitney, F.W., & Reyes, A.A. (1999). Contracting with outpatient hemodialysis patients to improve adherence to treatment. *American Nephrology Nurses Association Journal, 26,* 37-40.

Leggat, J.E., Orzol, S.M., Hulbert-Shearon, T.E., Golper, T.A., Jones, C.A., Held, P.J., & Port, F.K. (1998). Noncompliance in hemodialysis: predictors and survival analysis. *American Journal of Kidney Diseases, 32,* 139-145.

McKinley, M. (2000). Missed treatments: how to help patients change problem behavior. *Nephrology News & Issues, 14,* 16-17.

Molzahn, A.E. (1998). Psychosocial impact of renal disease. In: J. Parker, (Ed.), *Contemporary Nephrology Nursing,* Pitman, NJ: Anthony J. Jannetti, Inc. 271-282.

Saran, R., Bragg-Gresham, J.L., Rayner, H.C., Goodkin, D.A., Keen, M.L., van Dijk, P.C., Durokawa, K., Piera L., Saito, A., Fukuhara, S., Young, E.W., Held, P.J., & Port, F.K. (2003). Nonadherence in hemodialysis: associations with mortality, hospitalization, and practice patterns in the DOPPS. *Kidney International, 64,* 254-262.

Valdez, R. (2003). Dealing with the noncompliant patient: 10 steps to achieving compliance. *Nephrology News & Issues, 17,* 65-68.