



Partnering in Dialysis Care: Compliance and Self Management

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Years of research and clinical experience have shown that the right combination of treatment, medication, and diet can save dialysis patients' lives. Simply knowing what to do is not enough, however. Actually following, or adhering to, the full treatment plan remains one of the greatest challenges for dialysis patients and professionals alike.



Essential to Long Life

In medical terms, compliance is "the degree to which patient behavior corresponds to the recommendations of a healthcare provider."⁽¹⁾ Compliance includes a variety of actions, such as taking medicines as prescribed (the right dose, at the right time, in the right way); receiving treatments (like dialysis, chemotherapy, or surgery); performing certain actions (such as exercise or physical therapy); modifying diet; and in some cases, refraining from certain actions (like smoking or drinking).

Regardless of the specific actions recommended, optimal results cannot be achieved if treatments aren't carried out as prescribed. Therefore, compliance is important in every medical situation, and especially so for people on dialysis. "The level of intensity associated with compliance is increased for ESRD patients," notes Bryan Becker, MD, Assistant Professor of Medicine and ESRD Medical Director at the University of Wisconsin, "because if they stop their (dialysis) treatments, they will die."

For those on dialysis, even lesser degrees of noncompliance can have negative effects. One recent study of 295 dialysis patients showed that frequent skipping and/or shortening of dialysis treatments was associated with poor survival.⁽²⁾ Another study reported that skipping even one dialysis session per month is

associated with an increased risk of death.⁽³⁾

Even patients who never miss a dialysis session can have problems with other aspects of treatment. Failure to comply with fluid restrictions, for example, can result in excessive weight gain that complicates dialysis treatment and may cause serious heart problems.⁽⁴⁾ Lapses in dietary compliance can lead to electrolyte imbalances that produce a range of conditions, from life-threatening heart rhythm problems to bone disease and severe itching.

Compliance is so important to positive, long-term health outcomes for people on dialysis that 10 of 15 nephrologists interviewed in a recent Life Options opinion study ranked compliance "essential" to patients' ability to live long and productive lives.⁽⁵⁾

Widespread Noncompliance

Despite overwhelming evidence of the benefits of compliance and the dangers of noncompliance, a large number of people on dialysis do not follow treatment recommendations completely. Estimates of the rate of noncompliance vary, depending on how it is measured. There is no question, however, that noncompliance is widespread.

One summary of studies on compliance in hemodialysis patients found that nearly one-third did not follow dietary and fluid restrictions, and one-half were noncompliant in taking phosphate-binding medication.⁽⁶⁾ When the complete dietary, fluid, medication, and treatment regimen is studied, noncompliance rates as high as 86% have been reported.⁽⁷⁾

Why is noncompliance so common? There are many reasons. Research has identified more than 50 factors that influence compliance. These factors fall into five categories:⁽⁸⁾

- Patient characteristics
- Disease characteristics
- Treatment regimen characteristics
- Relationship between patient and care provider
- The clinical setting

In the ESRD population, most patient demographic characteristics, like gender, race, occupation, educational level,

and income cannot be consistently linked to compliance.⁽⁹⁾ Age is the single exception; older patients are more likely to be compliant than younger patients.^(3, 10)

Patients' mental health characteristics, however, often affect compliance. Depression, for example, has been linked to noncompliance, whereas social support and positive perceptions of well-being are likely to foster compliance.⁽²⁾ Patient characteristics alone cannot account for the high rates of noncompliance among dialysis patients. To understand noncompliance, other factors must be explored.

A Demanding Regimen

Several characteristics of end-stage renal disease and dialysis treatment contribute to difficulties with compliance:⁽⁷⁾

- ESRD is a disease that requires lifelong treatment.
- Many different medications are required.
- The medication/treatment schedule is complex.
- Reasons for some therapies may be difficult to understand.
- Short-term consequences of noncompliance may not be obvious.



"Dialysis patients face an uphill battle in complying with their prescribed medications and diet," says Richard Sherman, MD.⁽⁴⁾ Most patients take 7 to 10 different medications,⁽⁴⁾ they spend 12 or more hours per week doing dialysis, and they must severely modify what they eat and drink 24 hours a day, 7 days a week.

Making Adjustments

Long-time dialysis patient Irma Williams knows first-hand the effort it takes to follow the treatment regimen. "At first, it seems all you hear is 'stop,' 'no,' and 'don't,'" she says. "It is hard to stick with it, but you know your body is not like it was before, so you have to comply." After 15 years, Williams has found that it does get better. "You make adjustments and take on new habits," she says. "But it changes your life tremendously."

The pervasive impact of ESRD and its treatment almost certainly

results in noncompliance. "It's a lot to ask," says Dr. Becker. "So, if I can, I try to pare down the demands—not in treatment sessions, but in fluids, medications, or diet." Dr. Becker believes this flexible approach is one way that physicians and staff can help promote improved compliance, better outcomes, and quality of life.

The Influence of Staff

Many factors that affect compliance are beyond the scope of staff influence, including patient characteristics, disease characteristics, and the realities of dialysis treatment. Nevertheless, the dialysis team can exert a powerful influence on compliance through education and encouragement.



Education and support are key elements in promoting compliance. "If patients don't understand why they're being asked to do something, particularly things that are difficult and ongoing," says Dr. Sherman, "they aren't very likely to do it."⁽⁴⁾ Why, then, have several studies failed to show a link between knowledge and compliance?⁽¹¹⁾ Because education alone is not

sufficient. It provides a foundation for compliance, but not the motivation to follow through.

Encouragement—from family members and from dialysis staff - can supply the motivation that patients need. Encouragement takes many forms, including:

- **Setting expectations for success.** Some patients are more likely to respond to staff expectations than to family expectations.⁽⁹⁾
- **Avoiding labels.** Patients should not be thought of as "compliant" or "noncompliant." A negative label is likely to produce a negative effect, making the patient defensive, uncooperative, even rebellious. Some caregivers feel so strongly about labels that they don't even use the term "compliance." They prefer the more neutral term "adherence." "Adherence is the act of being consistent...This subtle word choice can help [staff] and patients view nonadherence as a symptom of a larger problem to be solved than a behavior to which blame must be assigned."⁽¹²⁾

- **Staying positive.** Praise for good results will likely produce greater benefits than criticism for errors.
- **Individualizing.** Plans to address noncompliance should be based on an individualized review of the patient's psychological, social, and medical situation.⁽¹²⁾

The dialysis team has the responsibility to teach and encourage, but "it is important to avoid assuming responsibility for the patient's adherence."⁽¹²⁾ It is unrealistic to try to control the behavior of other adults. Communication should be kept on an adult-to-adult basis, and patients should be treated as part of the dialysis care team. "We do need someone to cheer us on," admits Williams, "but don't treat us like children."

The Next Step

Successful renal rehabilitation depends, in large part, on the ability of patients to comply with their treatment plans. The first 25 years of the ESRD program have been devoted to defining what those treatment plans should be. The next step is to work on the many factors that will enable patients to follow—and live with—their regimens.⁽²⁾

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