Life Options

Renal Rehabilitation Report

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INSIDE

Partnering in Dialysis Care

Compliance/Adherence Forms Foundation for Self-Management

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

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Focus on Adherence

For people on dialysis, active self-management of renal disease and its treatments is key to living long and living well. While the concept of self-management is complex and multifaceted, it is founded on the basic principle that patients must strive for ownership of their disease and full partnership in their care. This process begins with compliance, or adherence, to the full range of prescribed therapies.

People on dialysis may sometimes view adherence as a loss of power—as a threat to their control over their own lives. However, in the Life Options view, adherence is just the opposite. In fact, it is the first and best chance that patients have to gain control over their condition and its treatment.

The concept of adherence is so important that it should be considered the foundation upon which good clinical care is built. In turn, good clinical care is the foremost prerequisite to renal rehabilitation. With these important relationships in mind, Life Options has devoted this issue of the *Renal Rehabilitation Report* to the topic of adherence.

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RENAL REHABILITATION REPORT

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Contact:
Life Options Rehabilitation Program
603 Science Drive
Madison, Wisconsin 53711-1074
TEL: (800)468-7777
FAX: (608)238-5046
E-mail: lifeoptions@medmed.com
www.lifeoptions.org

Living Long and Well on Dialysis

Examining the Long-Term Benefits of Adherence

"I tend not to mince words," says 40-year-old renal patient, Mary Demick. "When I talk to new patients, I tell them, 'If you want to live on dialysis for any length of time, there are certain things you have to do.'"

Demick's straightforward approach comes, in part, from her own 17 years on dialysis. In that time, she has learned a lot about coping with the long-term effects of end-stage renal disease—and the dialysis treatment regimen.

"Even though you might feel pretty good today or tomorrow, you have to remember that the decisions you make—good or bad—accumulate over time," says Demick. "Your long-term health depends on what you do in the short-term." Much of her own success, she says, has to do with her decision to adhere to the dialysis treatment plan.

A LIFETIME OF EXPERIENCE

For Demick, adjusting to renal disease and it treatments has been a lifelong process. She was just 2 years old when she was first diagnosed with nephritis. When she was 12, her kidneys began to fail, and she started hemodialysis less than a year later.

After a short time on dialysis, Demick received a living-related transplant from her mother. When that kidney failed after nearly 10 years, Demick went back on dialysis, until her second transplant in July of 1999, nearly 17 years later.

CHOOSING ADHERENCE

Demick feels that, in her dealing with dialysis and its treatments, the seeds of success were planted early on. "When I was first starting on dialysis, my care team really stressed the importance of adherence," she says. "Perhaps even more importantly, they gave *me* the primary responsibility for my own care." This, she feels, helped her in many ways. "I think I was more motivated as far as my healthcare was concerned," she recalls. "I wasn't perfect, but I knew that my health and my future were up to me."

As a result, Demick made choices that were good for her health and for her lifestyle. "I have always followed the dialysis prescriptions and treatments," she says. "I just have never seen a point in not optimizing my possibilities for good health."

For Demick, this began with maximizing her time on dialysis. "Dialysis is an imperfect process compared to the work of a healthy kidney, so it's very important to dialyze as much as possible," she says. "In 17 years, I missed only one treatment—and that was with my doctor's permission."

"I have always followed the dialysis prescriptions and treatments. I just have never seen a point in not optimizing my possibilities for good health."

—Mary Demick

Demick knows, however, that this is not the case for all patients. "For some people, the goal seems to be to get out of the chair as fast as possible," she says. "Cutting 15 minutes off your treatment may not seem like much, but it adds up."

The benefits of getting adequate dialysis, she says, are well worth it. "When you receive all of your treatments, dialysis is gentler to your system, and you feel better afterward," she explains. "Plus, it helps to reduce your restrictions, in terms of diet and fluid intake. And, it's just much better for you in the long-term."

LEARNING TO MAKE ADJUSTMENTS

To be sure, the dialysis care regimen can be complex and demanding, often extending into nearly all aspects of a patient's life. Demick admits that, for her, certain parts have been more challenging than others. "I would say the diet is the biggest thing," she says. "There are so many family routines and cultural connections to diet." With this in mind, she used several strategies to incorporate the renal diet into her lifestyle.

As with most patients, Demick was given a list of foods that she could eat frequently, in moderation, or rarely. This helped her to make her initial dietary choices. "I'm very detail-oriented," she explains. "When I first went on dialysis, I used a USDA counter to measure everything I ate."

It wasn't long before this process began to pay off for Demick. "It took a lot of time and effort, but it helped me learn to make adjustments," she explains. "I began to integrate the numbers in my head. After 3 or 4

weeks, I knew the values of things that I ate regularly." Armed with information, Demick eventually started making more decisions about her diet. "If I ate something that was high in potassium, I would make sure not to eat anything else with potassium in it for the rest of the day," she says. "Being able to make decisions made me feel less restricted."

Over time, Demick also learned to make careful, informed dietary substitutions. "A lot of the things that I love to eat are not considered good for people on dialysis," she explains. "For example, I'm a cheese addict. So, I learned to eliminate other high phosphorus foods if I wanted to eat a bit of cheese."

Demick is quick to point out, however, that even minor adjustments should be made with great care. "I think it's really important to do as you are instructed at first, until you have a thorough understanding of things—food make-up, cause-and-effect, etc." she says.

IMPORTANT PARTNERSHIPS

When it comes to adherence, Demick feels that dialysis care providers play an important role, especially when it comes to educating patients. "Every patient should be taught about cause-and-effect," she explains.

The rest, Demick says, is up to patients themselves. "If you have been given all of the information, you understand it, and you are of sound mind, then you should be able to make your own choices without being harassed." Demick understands that this isn't an easy thing to do. "I know that dialysis caregivers want you to do what is best for you," she says. "But, you can't force people to do something they don't want to do."

Demick feels there are subtle things caregivers can do to encourage adherence. "As a patient, it helps to hear, 'You have the information, you've made your choices. If you'd like to talk to me about anything, let me know.'" She adds, "What isn't so helpful is hearing, 'Your bloodwork is terrible—what are you doing wrong?'"

FOSTERING ADHERENCE

Demick also feels that patient-to-patient communication is very valuable. "We should provide as many opportunities as possible for patients to talk with each other," she says. "It is often easier to take advice from someone who has been through it all before."

Overall, Demick feels that choosing adherence is the first step in taking control of the dialysis treatment regimen—a process that goes a long way toward helping people on dialysis live long and full lives. "Being informed and active in decision making is very empowering," she says. "It helps you to realize that, while the dialysis team does provide care, ultimately, it's really in your own hands." ◆

LIFE OPTIONS UPDATES

New Year, New Look for Renal Rehabilitation Report

If you are a devoted reader of the Life Options *Renal Rehabilitation Report* (*RRR*), you may have noticed some changes in this issue of the newsletter. Why the new design? Some of it has to do with simply updating the look of the *RRR*, and some of it reflects feedback we have received from our readers.

Several features have been added to make the *RRR* more reader-friendly. For example, on page 1, a *Focus* column now summarizes the theme for each issue, and a table of contents highlights specific topics that will be covered inside. A new *Life Options Updates* section will provide information about new Life Options products and services. In addition, the newsletter margins have been adjusted to provide room for a 3-hole punch, so that issues may be stored in a binder for easy reference.

While our look has changed, our dedication to providing important information for dialysis patients and care providers remains the same. We hope you continue to read and enjoy. If you have comments or questions, please contact the Life Options Rehabilitation Resource Center (RRC) at (800)468-7777, or e-mail us at lifeoptions@medmed.com. ◆

A Different Approach to Adherence

Information and Support Open Doors to Reasoned Compliance

"Patients who want *complete* autonomy don't do well. But those who take on more and more responsibility know when and how to make changes."

—Dr. Bryan Becker

Compliance with prescribed therapies plays an important role in survival, rehabilitation, and quality of life for people on dialysis. Such findings point to a link between patients' sense of independence and control, their level of information, their compliance behaviors, and their overall well-being.[1,2] On the other hand, in some instances, patients who make small, informed, and very careful adjustments to some aspects of their regimen continue to do well.

Sense of Control

The excellent quality of life scores reported by ESRD patients who rely on the more "autonomous" therapies like home dialysis, peritoneal dialysis, and in-center self-care dialysis are often attributed to the patients' greater independence and increased sense of control.[3] According to Dr. Bryan Becker, ESRD Medical Director at the University of Wisconsin, the desire for control may also explain many cases of noncompliance. "Patients sometimes say to themselves, 'I will change this regimen to voice my independence and individuality,'" he observes.

Patients who seek independence through noncompliance risk serious consequences. However, those who practice reasoned compliance, sometimes called rational noncompliance, may sometimes be able to maximize their autonomy and quality of life without seriously risking their health.[1,2] There is even some evidence that the sense of control and well-being gained from "a little bit" of careful noncompliance promotes increased compliance with more important aspects of treatment.[4]

Reasoned Compliance

Patients who make minor changes to their treatment plan to meet individual physical, social, and/or emotional needs may not be "noncompliant," in the strictest sense of the word. Rather, they practice a reasoned compliance that fits their needs.[2] Over time, they learn to safely adjust some minor elements of their regimen to better cope with life on dialysis. Dr. Becker would like to see all his patients practice reasoned compliance. For that to happen, he says, patients have to be informed and motivated enough to manage some aspects of their own care. Experience has taught him several lessons.

"There's a pattern," he notes. "About 6 months after starting treatment, patients begin to get over their fears of dialysis and death. They feel better and they show a desire to test the system." At this point, Dr. Becker supports his patients' needs for independence. "I try to comply with their nonadherence," he says. "If I do, they are more willing to work harder when it's really important." Flexibility is another key. "I tend not to be rule-driven," Dr. Becker says. "If it's possible, I am liberal with diet, fluid, and activity guidelines."

Finally, Dr. Becker encourages people on dialysis to become part of the healthcare team. "I offer patients the opportunity to make decisions on their own. I give them the information, and then I respect their choices." Overall, he has found that the best strategy for improving overall compliance is encouraging independence. "Patients who want *complete* autonomy don't do well," he says. "But those who take on more and more responsibility know when and how to make changes. They do well, and they are the best patients to care for." ◆

Reasoned Compliance

Guidelines for Success

Not all renal patients can successfully practice reasoned compliance. Those who do share some common characteristics:

- **Knowledge.** An in-depth understanding of ESRD, dialysis, and the reasons behind every aspect of the treatment regimen.

  "*I think it's really important to do as you are instructed at first, until you have a thorough understanding of things—the make-up of foods, cause-and-effect, etc.*" *—Mary Demick*

- **Responsibility.** A belief that following the dialysis treatment regimen is one way of taking control.

  "*I am not on written fluid, sodium, potassium, or phosphorus restrictions. I restrict myself so there is a lot less for me to be 'compliant' about.*" *—Lee Deuell*

- **Involvement.** Active participation in decisions about their care.

  "*I do what I need to do to be healthy. I always end up doing what my doctor recommends because I trust him and he knows me, but I am always included in the decision.*" *—Elizabeth Schumacher*

References

1. Curtin RB, Oberley E, Sacksteder P: Compliance and rehabilitation. *Semin Dial* 10(1):52-54, 1997
2. O'Brien ME: Compliance behavior and long-term maintenance dialysis. *Am J Kidney Dis* 15(3):209-214, 1990
3. Latham CE: Is there data to support the concept that educated, empowered patients have better outcomes? *J Am Soc Nephrol* 9(12):S141-144, 1998
4. Leggat JE, Orzol SM, Hulbert-Shearon TE, Golper TA, Jones CA, Held PJ, Port FK: Noncompliance in hemodialysis: Predictors and survival analysis. *Am J Kidney Dis* 32(1):139-145, 1998

Partnering in Dialysis Care

Compliance/Adherence Forms Foundation for Self-Management

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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

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Q&A ASK THE EXPERTS

An Interview with Richard A. Sherman, MD
Department of Medicine, Division of Nephrology
UMDNJ-Robert Wood Johnson Medical School, New Brunswick, NJ

Q *Some people use the term "compliance," and some use the term "adherence." What is the debate about?*

A The difference is semantic. Using the term compliance really is a statement regarding the nature of the physician-patient relationship, whereby the doctor is the boss in charge and thus the patient should comply with the doctor's orders. These days, the term adherence is more often used, to suggest that the patient is a part of the process and has some understanding and input into what is going on.

Q *What is "rational noncompliance," and what are your thoughts on the subject?*

A "Rational noncompliance" is when a patient decides in a rational way not to adhere to caregiver recommendations, such as the downsides of the renal diet or fluid restriction. These patients may not have experienced adverse outcomes from non-adherence, so they decide "it's not worth it to me."

This can be a big problem. The consequences of non-adherence are long-term—consequences that can kill you in a year or two or three, rather than next week. Patients sometimes think in the short-term: "Life is tough. I want to eat pizza today." Five years down the road, serious dietary non-adherence can lead to such problems as high blood pressure, chronic fluid overload, cardiac arrhythmias and other cardiac problems, and bone disease.

Non-adherence issues can be compounded by dire warnings caregivers give: "You have to do this, or you will die." If the patient doesn't die, then the doctor must be wrong. This can diminish the credibility of the care provider because it increases the patients' beliefs that they are

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Partnering in Dialysis Care

Compliance/Adherence Forms Foundation for Self-Management *(continued from page 5)*

"If patients don't understand why they are being asked to do something, particularly things that are difficult and ongoing, they aren't very likely to do it."

—Dr. Richard Sherman

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

Q&A Ask the Experts *(continued from page 5)*

right, and that they don't need to adhere to care provider recommendations and prescriptions.

Q *What is the best way to approach patients on the subject of adherence?*

A The best thing to do is to approach patients with education, not confrontation. Provide them with information on the importance of having full treatments—the fact that shorter treatments will result in lower Kt/V, and that non-adherence can result in higher blood pressure, more strokes, and even death.

This works for a limited number of patients. Mostly, patients are already afraid of renal disease and its consequences. Bringing it up is often non-productive, even counterproductive.

Q *How do you see self-management and adherence fitting together?*

A I very much agree with the philosophy of self-management, if the patient has the wherewithal and enough understanding of the issues—which most patients do. Take PD patients, for example. We see them once a month, we educate them about problems they may have. Other than that, they are at home, in charge of their lives. It's a different kind of relationship.

If we could help hemodialysis patients use this approach, their outcomes would probably be much better. We need to get patients interested in their own outcomes and lab values, because that will help them to regulate their diet. Care providers should become a source of information, not a source of admonition.

Q *How can healthcare providers encourage adherence and self-management?*

A The *Know Your Numbers* program is a good example. It helps patients understand the meaning and importance of URR and

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] ◆

REFERENCES

1. Elixhauser A, Eisen, S, Romeis J, Homan S: The effects of monitoring and feedback on compliance. *Med Care* 28(10):882-893, 1990
2. Kimmel PL, Peterson RA, Weihs KL, Simmens SJ, Alleyne S, Cruz I, Veis JH: Psychosocial factors, behavioral compliance and survival in urban hemodialysis patients. *Kidney Int* 54(1):245-254, 1998
3. Leggat JE, Orzol SM, Hulbert-Shearon, TE, Golper TA, Jones, CA, Held PJ, Port FK: Noncompliance in hemodialysis: Predictors and survival analysis. *Am J Kidney Dis* 32(1):139-145, 1998
4. Sherman RA: Noncompliance in dialysis patients. *Nephrol News Issues* 10(6):36-38, 1996
5. Life Options Rehabilitation Advisory Council: *Renal Rehabilitation Report* 7(5):5, 1999
6. Cummings KM, Becker MH, Kirscht JP, Levin NW: Psychological factors affecting adherence to medical regiments in a group of hemodialysis patients. *Med Care* 20(6):567-580, 1982
7. Curtin RB, Oberley E, Sacksteder P: Compliance and rehabilitation in ESRD patients. *Semin Dial* 10(1):52-54, 1997
8. Meichenbaum D, Turk DC: Factors Affecting Adherence. In: *Facilitating Treatment Adherence: A Practitioner's Guidebook*. New York: Plenum Press, 1987, pp 41-55
9. O'Brien ME: Compliance behavior and long-term maintenance hemodialysis. *Am J Kidney Dis* 15(3):209-214, 1990
10. Curtin RB, Svarstad BL, Andress D, Keller T, Sacksteder P: Difference in older versus younger hemodialysis patients' noncompliance with oral medications. *Geriatr Nephrol Urol* 7:35-44, 1997
11. King K: Noncompliance in the chronic dialysis population. *Dial Transplant* 20(2):67-68, 1991
12. Currier H: Case management of the anemic patient: Epoetin alfa-focus on compliance. *ANNA J* 20(6):470-473, 1993

adequacy, and it spurs them to ask questions, to keep everyone on their toes. We need to extend this, to find programs that will get patients similarly motivated about all other aspects of dialysis, from access management, to anemia and potassium.

Q *How can people on dialysis ask questions without being seen as "difficult"?*

A That's a problem for care providers, not patients. A lot of care providers are uncomfortable with being questioned. If you question something that isn't right, then you're questioning the person.

You could tell patients to be polite and diplomatic in their questioning, but that's not really fair. Instead, we as care providers must get comfortable with our actions being questioned.

Q *What is the best way to measure adherence for people on dialysis?*

A I don't think there is a "best" way to measure adherence. Serum potassium, interdialytic weight gain, and serum phosphorus are typically used, but we know that these are not necessarily markers of adherence. For example, serum potassium varies among patients and sometimes has little to do with dietary noncompliance. Weight gain is routinely used to assess fluid and salt intake, but the measure may not be adjusted for body weight, and may not take into account such factors as fluid levels in solid foods. There are similar issues with serum phosphorus.

So we cannot assume that the usual measures of adherence are accurate indicators of non-adherence. We must talk to patients. They should tell us how they followed the diet. They may still come with apparent signs of non-adherence, but these may in fact be from other causes. Patients are often right. When looking at adherence, we are best to assess all the parameters we have. Patients showing up and staying for treatment is the most important measure. The others are auxiliary measures, which together might support our impressions of adherence/non-adherence. ◆

Focus on Adherence *(continued from page 1)*

COMMON TERMS

In healthcare, the words adherence and compliance are both used to indicate "the degree to which patients follow the recommendations of their care providers." Recently, however, some people have expressed concern that the word compliance might imply a relationship in which providers are in the position of "dictating" and patients are in the position of "obeying."

To avoid even such subtle negative undertones, many people now use the word "adherence." Indeed, the term adherence underscores patients' important role in decision making, and, in some ways, it seems to better fit the Life Options philosophy of self-management. However, for the sake of consistency, in this issue of the *Renal Rehabilitation Report*, we have opted to use whichever term was originally used in the referenced literature or quotes.

A similar situation exists with "rational noncompliance" and "reasoned compliance." Both terms are generally used to describe a process by which well-informed patients make minor, carefully considered changes to their prescribed therapies in order to adapt the dialysis regimen to their preferred lifestyle.

In most cases, such changes are related to the strict fluid and dietary restrictions that are a large part of dialysis care. However, although there is little difference in the actual definitions of the terms, some people have come to prefer the expression "reasoned compliance" as a way to emphasize the more positive aspects of patients' roles in their own care management—affirming the opportunity for informed dialysis patients to actively participate in their care and treatment decisions.

COMMON GROUND

The issues and views surrounding adherence are very important for people on dialysis. While opinions about the terminology may vary, one thing is certain—there are many changes in everyday living patterns and behaviors that are required as part of the dialysis regimen, and these changes have a major impact on the potential for people on dialysis to live long and to enjoy the best possible quality of life.

For more information about adherence or about renal rehabilitation, please contact the Life Options Rehabilitation Resource Center (RRC) at (800)468-7777. ◆

RENAL REHABILITATION REPORT

Life Options Rehabilitation Program
603 Science Drive
Madison, Wisconsin 53711-1074
(800)468-7777

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The Renal Rehabilitation Report is dedicated to identifying effective programs, projects, and people who are helping dialysis patients realize their fullest potential.

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