Editor's Note: This article is a summary of a booklet developed by Ramiro Valdez, PhD, of the Texas End Stage Renal Disease (ESRD) Network for use by dialysis facilities. The booklet, which includes sample letters, intervention techniques, various resources, references, and other information, is available free of charge on the ESRD Network of Texas website: www.esrdnetwork.org/docs/[illegible]

Dealing with the Noncompliant Dialysis Patient: 10 Steps to Achieving Compliance

Ramiro Valdez, PhD

Noncompliance, or not following the physician's orders exactly as prescribed, is almost a way of life for some Americans. Many people with diabetes, for instance, do not monitor their insulin. Many people do not take antibiotics for the full duration (usually 10 days) as instructed. Most Americans do not exercise or eat properly. Being diagnosed with end-stage renal disease (ESRD) seldom changes this pervasive behavior.

Most dialysis patients overload on fluids or cheat on their diet from time to time. While this can be a problem, in most cases the staff can see that the patients are making a genuine effort to follow their suggestions. Some patients, however, flagrantly disregard the medical regimen and make it clear to the staff that they have no intention of following the plan. For these few patients, noncompliance is not only risky, it also makes it difficult for doctors and the staff to continue to provide care.

While the temptation may be to dismiss these patients, it is important to remember that their refusal to follow the regimen may be a symptom in and of itself. These patients may have psychological or emotional problems that prevent them from developing insight.

Whatever the reason for noncompliance, it is best to do everything possible to eliminate any deterrents to compliance and to enhance those factors that will encourage it. This will take time and effort, but it can be extremely rewarding when the staff members see a change in the patient's behavior.

The following 10 steps are interventions designed to help when patients repeatedly skip treatments without a reasonable explanation or sign off before their dialysis treatments are complete. These steps are not all-inclusive, and if a staff member can envision something else, it should certainly be tried. Also, the order of these steps is dynamic. In other words, if the staff finds that doing one step prior to another is more effective, then it should be tried. Finally, the steps are not absolute; if one particular step does not apply to a particular patient, that step can be skipped.

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The goal of this intervention effort is a change in behavior leading to adequate dialysis and, therefore, an improvement in the patient's health. This is not intended as a dismissal process.

The interdisciplinary treatment team should discuss the patient's behavior during care plan review or the continuous quality improvement (CQI) meeting. Once the team agrees that the patient's behavior is a problem, the intervention can begin.

Step 1: Update the Patient's Psychosocial History

The social worker or nurse can assess the patient's psychosocial situation. Things to watch for at this time are any factors that may impede the patient's coming to the clinic. These factors include transportation problems, sudden loss of income, illness in the family, conflicting family obligations (e.g., babysitting, care giving of an elderly parent, etc.), or marital discord. An unhappy spouse may suddenly decide that he or she can no longer sit and wait for four hours. He or she may demand that the patient sign off early.

If any psychosocial problems are identified, these can be addressed immediately. Once these problems are resolved, or if no problems are identified, proceed to the next step.

Step 2: Rule Out Life Change Events

Life change events (LCEs) are situations that most people in our society experience at one time or another in their lives. These include such things as death of a spouse, divorce, marital separation, a new marriage, a jail term, personal injury, death of a close family member, or dismissal from a job. Most dialysis patients experience some LCEs when they first start dialysis. The initial psychosocial assessment addresses these issues and helps the patient adjust to life on dialysis. Thus, this step is intended for those patients who are past their initial adjustment. Patients who are noncompliant from the start require intensive patient education and help with adjusting to dialysis, not an assessment for LCEs.

Although LCEs are common, they can still adversely affect our lives in various ways. They may result in our inability to handle daily problems. Routines frequently become disrupted, and things that were previously important may take a back seat. The stress of an LCE may continue for a few days or a few weeks. Because our usual coping skills do not work for a short time, our daily stressors, which would usually not disrupt our daily lives, may now do so.

It is anticipated that within a few days to a few weeks, the stress of the LCE will wear off, or the patient will achieve a new level of functioning that will allow him or her to cope once again with daily problems. If the stress and inability to cope with the LCE continue for longer than a few weeks, a referral for psychological help is recommended.

The treatment team can help the patient cope and find ways to fit dialysis into his or her current situation. Once this is done,

it is anticipated that the patient will return to regular functioning, which includes keeping regular dialysis appointments. If the patient does not cope with the LCE or if none can be identified, proceed to the next step.

Step 3: Eliminating (Where Possible) the Discomforts of Dialysis

Patients often hate to come to dialysis or else cut the treatment short because they are uncomfortable during the treatment. Assess for such intradialytic problems as restless legs syndrome, pain, being too cold, patient/staff friction, the need to eat (especially for people with diabetes), the desire to smoke, and restroom use.

These discomforts can be addressed by the treatment team on a case-by-case basis. Once the physician knows the patient has restless legs syndrome or pain, he or she can address it. Once the clinic manager knows that the patient is too cold during the treatment or that there is friction between the patient and staff, it may be appropriate to switch the patient to another shift or even another chair on the same shift.

Patients who need to eat during dialysis can have their meal schedule assessed by the dietitian or may be given permission to eat an apple or candy bar during dialysis. Better to allow an appropriate snack than to have a patient signing off early to go eat.

A heavy smoker may have problems going four hours without smoking. It may be appropriate to attempt smoking cessation at this time. If the patient is adamant that he or she is not going to stop smoking and cannot go four hours without a cigarette, the staff may need to consider chewing gum or other such interventions. If eliminating the discomforts of dialysis does not work or if none can be identified, proceed to step four.

Step 4: Convene a Meeting

The meeting needs to include the patient and the entire treatment team. It is appropriate to invite the patient's family or significant other, if the patient agrees. At this time, the treatment team can have a frank discussion with the patient about the problem(s) and ask the patient if there is anything the staff can do to help.

Often involving the family, especially the spouse, is very significant. Once the spouse knows that the problem exists and that the patient is endangering his or her health, the family support system can be mobilized. With the help of the patient's family, the staff can address the problem from multiple angles. Sometimes an angry spouse can be much more effective than a caring staff.

If the patient or the family does not have any ideas as to what can be done to resolve the problem, or if the patient and the family will not come to a meeting to discuss the problem, proceed to the next step.

Step 5: Have a Team Member Develop a "Therapeutic Alliance"

One member of the treatment team can form a partnership or alliance to work together with the patient to resolve the problem. This team member is often the social worker or nurse, but it can be the dietitian or a patient care technician. It is important for the patient to know that he or she is not alone in addressing the problem, but that the team is working on the problem, too.

The chosen team member can meet with the patient once a week. If the patient only comes to dialysis sporadically, then the team member can meet with the patient every time he or she arrives for a dialysis treatment. During these meetings, the chosen team member should repeatedly mention, using simple terms, the benefits of dialysis.

It is important that various methods of patient education are attempted at this time. Conceivably, once patients understand fully what following the treatment plan means to their own best interests, health, and even life, they will follow it. Thus, not following the treatment plan can be either a problem of not understanding or not accepting the reality of renal failure. If it is a problem of not understanding, *every educational approach available to modern medical care should be attempted.*

This approach will take three to four weeks. If meeting weekly with the chosen team member does not produce the desired results, proceed to step six.

Step 6: Mobilize the Patient Mentor Program

Many clinics have established a patient-mentoring program specifically for situations such as noncompliance. Those that do not have a program and cannot start one probably have one or two patients who can serve as role models to other patients. A meeting between the role model and the patient with the problematic behavior can be attempted.

Before setting up a meeting, ask the mentor or role model if he or she is willing to help, and ask the noncompliant patient if he or she is willing to talk to the mentor. If either one refuses, the meeting should not be attempted. If both agree, the staff can facilitate the meeting and offer support and resources to the mentor. If possible, the two should meet in private either in one of the offices or in an examination room.

It is possible that the mentor may be able to say the right thing to the patient so that he or she will see the advantages of following the treatment plan. After the first meeting, both patients should be asked if the meeting went well. If it did not, a second meeting should not be attempted. If it did, the mentor can continue to meet with the patient as long as the two are willing.

To be carried out, this approach requires at least one to two weeks. If this step does not result in an improvement in compliance, proceed to step seven.

Step 7: The Behavior Contract

Many clinics use a behavior contract as a way of informing the patient that he or she must do specific things or he or she will be dismissed from care. However, if this is the approach to the behavior contract, it will be counterproductive. A well-written behavior contract can be a positive experience for the patient as well as the staff. (For instructions on writing a positive behavior contract, see "Contract of Care," April 2002, *NN&I.*)

A behavior contract is usually in effect for four to six weeks,

during which time the patient is monitored. If the behavior contract is not successful, proceed to the next step.

Step 8: The Letter of Concern

Writing an informal letter carries the weight of "putting it down in writing." The nurse or social worker can write an informal letter voicing concern that the patient's behavior is self-destructive and could have long-term effects. The tone of the letter should be one of concern. It needs to be non-threatening, informal, and easy to read. With the patient's permission, a copy of the letter should be sent to the patient's spouse, family members, or significant other. Those patients who are blind or cannot see or read English may require special assistance.

After the letter has been given to the patient, the nurse or social worker can again offer assistance with any problems that may interfere with faithful attendance for the entire treatment. The letter can also request that the patient drop by the office either before or after treatment to discuss the problem with the author of the letter. It would be helpful if the letter mentioned, "even if you can't think of anything" that could prevent the problem, "stop by anyway." This tone of an informal invitation for a chat may reach the patient.

When the patient visits the office, the tone should be of friendly concern. Many times showing concern and offering assistance is all it takes. A patient may think that no one cares whether he or she comes to dialysis, and this informal letter, along with the informal visit and chat, are intended to show the patient otherwise.

The staff needs to wait at least one week for the letter and chat to have an impact. If the letter does not improve the behavior, proceed to step nine.

Step 9: Treatment Team Review and Second, Formal Letter

As in any unusual intervention, it is best if the entire treatment team discusses the problem and agrees on the approach. When any one member of the treatment team says to the patient, "I don't know anything about that," the entire treatment team has failed.

The letter should be formal in tone and written by the attending physician or the medical director of the clinic. The letter needs to include a statement from the doctor, a paragraph in bold, capital letters that informs the patient of the adverse consequences of his or her choice. An example is:

"Continuation of this behavior could result in your being placed on another shift and you may have to wait until you actually show up at the clinic before we set up your machine. This wait could be as long as 30 minutes, and you will be taken off your machine when your shift is up."

With the patient's permission, a copy of the letter should be sent to the family. The letter should be followed up by a frank discussion with the doctor about the hazards of inadequate dialysis.

Step 10: Team Decision

If the previous steps do not result in any improvement in the patient's behavior, the treatment team must make a decision. Basically, the team must decide how the problematic behavior will affect the clinic. Is the problematic behavior affecting other patients, any staff, or the running of the clinic? Does it disrupt the orderly function of the clinic?

If the answer to these questions is "no," the patient's dialysis time can be changed to another shift (usually the last shift on Tuesday, Thursday, and Friday). Further, the clinic should not set up the patient's machine until he or she actually arrives at the clinic. The treatment should be discontinued when the shift is up, regardless of how much treatment time the patient has had. If this affects his or her health adversely, it was the patient's own choices that led to it. This plan can be continued until the behavior becomes too disruptive.

If the answer is "yes," or if the patient's behavior has become too disruptive, the patient's dialysis time should be changed and the clinic can contact the corporate renal provider's crisis management team or the ESRD Network in its area to ask for further suggestions.

Noncompliant patients are exercising their right to refuse treatment, or any part of a treatment. However, they are not free to choose the consequences of their choices. Deciding whether to stay for a complete treatment, or whether to show up for treatment is certainly the right of every patient. However, noncompliant patients do not have the right to complicate clinic schedules, delay the next patient's treatment, or cause staff to work overtime. ■