



Patient Leadership Committee, Special Projects Subcommittee
Project: Dialysis-Attendance Compliance

Physical and Psychosocial Issues Janet A. Welch, Ph.D.

Patient education is an essential part of all patient care. Knowledge is important for the dialysis patient to be able to deal with the complexities of renal disease and treatment. Knowledge, however, is not always enough for daily self-management. Often, a patient has to work around numerous problems. A positive dialysis environment is created and promoted when dialysis personnel work with individual patients to find solutions to their particular problems.

Skipping a dialysis treatment and shortening treatment time are often caused by similar types of problems. We conducted a brief informal survey of hemodialysis patients and staff to learn what physical or other problems lead to the decision to skip a dialysis treatment or shorten treatment time. The physical problems reported included nausea, vomiting, diarrhea before or on treatment, high or low blood pressure, itching, hunger, cramping, the need to use the bathroom after the treatment begins, and discomfort during venipuncture. Other factors reported included lack of transportation, boredom, personal time conflicts, and waiting time for treatment. In addition, some patients expressed just being tired of coming to dialysis or feeling the need for a day off.

Physical issues

When attempting to alleviate the physical problems, the nephrologist must be made aware of the symptoms that the patient is experiencing and be closely involved in daily patient-care management. The physician, staff, and patient may want to review the prescribed medications to see if altering the regimen would help relieve symptoms. The laboratory values and treatment settings also may be modified by the physician to reduce the physical symptoms experienced. Topical lidocaine may be used for persons who experience uncomfortable needle sticks. Encourage the patient to eat and to use the bathroom prior to the initiation of treatment.

In order to provide the safest and most comfortable treatment, all members of the health care team must include the patient when any decisions and/or changes are made in relation to therapy. Ongoing education is a must for the dialysis patient. Due to the ongoing physical symptoms of end-stage renal disease, patients must apply the information provided for them at various stages in their therapy. Constant review of the treatment plan may help our patients to have the best possible treatment available.

Psychosocial issues

Transportation. Transportation to and from the dialysis unit can be a major concern for some patients. If a family member or friend provides transportation for the patient to treatment, what happens when that person becomes unexpectedly ill and backup transportation is not available on that particular day? What happens to the patient if the designated driver has another appointment and the patient has to leave dialysis early or risk losing a ride home?

If a patient has a paid transportation service, what happens when the service does not show up, comes early, or comes on time and the patient has overslept? It may be possible for dialysis staff to work with a patient when considering transportation alternatives. Patients may feel more in control of their life if they have developed a plan listing several alternatives rather than reacting when an unplanned situation presents itself.

Boredom. To the dialysis patient, treatment sessions are long,

tedious, and boring. Televisions are provided in some units but not in others. If televisions are provided, watching the same programs day after day may make the treatment seem even longer. Some patients like to read, but report difficulty concentrating while receiving treatment. Other patients like to socialize during treatment, but may not be sitting in close proximity to other people who also like to socialize.

Keeping dialysis patients involved and active during treatment may have a positive effect on dialysis attendance or staying throughout the prescribed treatment. Dialysis staff, therefore, may want to consider ways to prevent or alleviate boredom in the dialysis unit.

Some units provide weekly bingo games, have annual parties, celebrate dialysis anniversaries, or have passive or active exercise programs. Other alternatives might include periodic, scheduled entertainment from local choirs, church groups, or Scout troops. Enlisting the help of volunteer clown groups may be an alternative in your area if the patients in your unit would not find this insulting. At your next staff meeting, generate a list of creative and fun activities that are realistic and can be routinely scheduled in your unit.

It may be even more important to find out how the patient would like to spend his or her time during dialysis treatment. Find out what the patient could contribute to alleviate the boredom and inactivity inherent in the procedure itself. Perhaps several patients with similar talents could provide entertainment during dialysis. Equally plausible may be efforts to organize patient-developed craft fairs or sales.

Personal conflicts. Dialysis patients have the same roles and responsibilities as other adults. They are spouses, parents, siblings, children, and friends and some have continuing job responsibilities. Some patients have civic responsibilities in their neighborhood, town, city, or state. How does your dialysis unit respond when a patient, for example, wants to attend a child's school play, a spouse's promotion celebration, the funeral of a very good friend, or a parent's birthday party? Can the dialysis schedule be changed for these very personal and valued activities? What kind of information do you provide patients for how they may reschedule a treatment during these times? Has a working patient

consulted with your unit about special needs related to their work schedule? Maintaining flexibility in the dialysis schedule may prevent a dilemma for patients who must choose between personal or work needs and a dialysis schedule?

Waiting time. Implied in a scheduled treatment time is the notion that the patient and staff will be ready at the scheduled time. Realistically, however, machines fail, accesses clot, patients have complications that slow their treatment, or prolonged bleeding may occur after needles are withdrawn, all of which interfere with treatment schedules. Further complicating treatment appointment times are the number of staff who call off work due to illness or personal crises on any given day. Although many of these events are uncontrollable in a dialysis unit, can we realistically expect patients to wait prolonged periods of time, thereby giving the message that we do not value their time?

Is it possible or realistic to reserve special back-up machines for unplanned events? Does your unit have supplemental or volunteer staff that may be available for staff call-ins?

Tired of coming/Need day off. How many times have you heard someone say, or maybe you've said yourself, "I'm too tired so I'm not going to work today" or "I need a mental health day?" Is it any surprise that our patients feel the same way? Can you imagine going to the doctor three times a week for the rest of your life? Yet this is what our patients must do to prevent serious consequences and even death. Stressing the short- and long-term benefits of regular dialysis treatments for the prescribed amount of time may help our patients in the decision-making process

Conclusion

There are many problems that may interfere with what we have labeled dialysis-attendance adherence. Although there are no interventions that have been tested by research, several approaches have been suggested and/or questions raised about how we might create an environment that promotes self-care decision-making to prevent skipping dialysis sessions or shortening treatment times. We hope that these suggestions will generate conversations in your individual units to create an environment that promotes positive working relationships between the patient and the healthcare team.