There is much happening in the politics and financing of health care in general and dialysis services in particular. Your legislators are balancing the needs of many citizens while attempting to balance the budget.

Health care costs have almost tripled since 1990.

As more of us look to the Federal government for payment of our health care needs, the government is increasingly preoccupied with the task of ensuring that the taxpayers are getting the quality and safety that they deserve. Over the next 10 years, legislators want to reduce the ESRD budget by 1.2 billion dollars.

There has been much public comment that the quality and consistency of care in the United States is not commensurate with the cost. Congress and many private insurance companies are expecting physicians, hospitals, dialysis units, and other providers to health care to show that they are meeting quality standards.

The Government will expect dialysis units and the nephrologists on their staffs to report the results of their care. The Government and other payers will hold, reduce, or increase payment to providers depending on their results.

There are many unanswered questions about the process known as “pay for performance.” The most fundamental is what are the standards. For example, we expect every patient to have an adequate dialysis prescription from the physician and a correct delivery of that dialysis by the facility. We expect the patient to cooperate with his or her doctors recommended therapy.

If the facility’s income is reduced because a patient refuses to take the actions necessary to have an adequate dialysis (staying on, showing up, getting the right access, etc.), will the facility wish to discharge that patient? Many of the outcomes that a facility can be judged by depend on patient’s understanding and cooperating.

There will be an increasing need for patients and their facilities to act in concert to improve the quality of the treatment of all patients.

Facilities have to respect the choices that patients wish to make about their health. Patients need to understand when their actions are detrimental directly or indirectly to other patients or their facility. All need to improve the communication between patients and the patient care staff.

Peter DeOreo, MD,
Medical Review Board (MRB)
Chairperson
The Frequently Absent or Late Patient

Patients who frequently miss part or all of their scheduled dialysis treatment present a source of worry and frustration to dialysis unit staff. Many reasons account for this form of noncompliance and fall into the following broad categories:

1. conflicting life tasks such as child care and work needs
2. transportation issues
3. medical or psychiatric problems: intercurrent illness, substance abuse, depression and denial
4. unpleasant treatment experience such as feeling cold, cramps or nausea.

Noncompliance is detrimental to both the patient and the dialysis program. Patients who shorten their prescribed treatment times or skip treatments suffer increased mortality and hospitalization rates and a poorer quality of life.

The dialysis center faces financial consequences as a result of non adherence to schedule. The unused setup (supplies and technician time) is not reimbursed, thus raising overall cost per treatment.

The extent of non adherence to hemodialysis schedule is estimated to be far worse in the US than in Europe and Japan. About 10 percent of US in-center hemodialysis patients miss at least one treatment per month vs. less than 1% in Europe and Japan.

Patients who are ‘repeat offenders’ are typically referred to the social worker in an effort to better determine the identifiable reasons for the non compliance and attempt to alleviate the conflicts.

Unfortunately there still remains a handful of patients that do not respond to the initial interventions and continue to be severely noncompliant.

At The University of Chicago Medical Center Dialysis Program, we identified patients who continued to be non compliant despite initial measures, few were still often missing more than half of their scheduled hemodialysis treatments in a month’s time.

These patients were singled out for a more intensive intervention which consisted of receiving a letter that spelled out why they were singled out to receive the letter, our ongoing desire to provide excellent care, our expectations of the patient and consequences of not following the expectations.

The listed expectations included timely arrival for scheduled treatments and a four hour notice to staff if they were unable to attend a treatment.

In the event of not meeting expectations the patient would be required to communicate with the nurse manager and social worker before a treatment will be provided.

If the patient missed their scheduled treatment the dialysis staff would consider providing dialysis treatment at any available time within the current schedule, including another day and time or even at another University of Chicago Medical Center outpatient dialysis unit. The patient’s machine would not be set up until after the patient arrives.

Thus the patient may be required to wait in excess of an hour for the start of dialysis. Patients were lastly informed that because of the potential wait, if the treatment ends up running longer than the time the unit closes or another patient’s treatment is scheduled then their treatment would be shortened by the staff.

Patients who habitually skipped treatments were also placed in chairs that were typically on the
last/fourth shift.

A modified letter was provided to peritoneal dialysis patients who were repeatedly missing scheduled home dialysis clinic visits.

This letter again detailed the expectation that patients attend all scheduled clinic visits, call and reschedule in advance if unable to keep an appointment. Peritoneal patients were also provided with an advance six month clinic schedule.

For example, a patient who repeatedly ‘no showed’ was given a fixed appointment time of the first Wednesday of every month at 10:00am so transportation or child care can be arranged well in advance.

This simple intervention of providing a formal letter with spelled out expectations and consequences was met with mixed results. It was most successful in the peritoneal dialysis unit. In the outpatient hemodialysis units a couple of patients showed no improvement. The remaining four had a transient improvement in adherence to scheduled treatments, sustained for several months after receipt of the letter.

While no definitive conclusions can be drawn due to small sample size, our experience highlights the need to study the impact of interventions for attendance non-compliance in a formal quantifiable manner.

Karen Habercoss MSW and Orly Kohn MD, University of Chicago Dialysis Program

(Ms. Habercoss was a member of the Patient Leadership Committee (PLC) and Dr. Kohn is a member of the MRB)

(Continued from page 2)

Additional Resources for Adherence Solutions

For additional tools, visit The Renal Network’s Web site at http://www.therenalnetwork.org/services/non-adherence.php. There you will find booklets from different Networks providing an overview of adherence issues and suggested interventions. Articles created by Patient Leadership Committee members providing views on adherence from patient and staff perspectives and a poster on the need for adequate dialysis.

Dialysis Facility Compare (DFC) allows consumers to review and compare facility characteristics and quality information on all Medicare approved dialysis facilities in the United States. This information can help patients, that may be missing treatment due to work, child care, caregiver or other obligations to locate facilities that might better meet their time schedule or transportation needs. A link to Dialysis Facility Compare can be found on the Network main page, http://www.therenalnetwork.org.

Also of interest are the Tools for Assessing Functional Status found at http://www.therenalnetwork.org/services/functionstat.php. Links to Kidney Disease Quality of Life (KDQOL) and other assessment tools for depression and quality of life can be accessed on this page.
The Regularly Irregular Patient

“Where’s Bill?” He didn’t call or show today.” “Big surprise-NOT.”
Almost every unit has one or two or more patients like Bill who is regularly irregular in their attendance to treatment. They will attend two treatments and then miss one, two or more sessions. Then they will miss every other session. The staff, social worker, nurse manager, and even the nephrologist will meet with the patient (often with family members). They will present the concerns about the patient’s attendance, it’s effect on their heath, etc. and ask for suggestions on how the dialysis center can assist. The patient and family will suggest that the whole situation revolves around: transportation issues, family work schedules, children or other dependents schedules, etc. The staff will attempt to: provide schedule modifications, present behavioral and treatment contracts. And then, the patient will begin attending every scheduled session. You, and the rest of the treatment team, may even begin slapping each other on the back. “I think we did it. I think s/he now is vested in attending all the treatment s/he can get.”

Then the irregular attendance will return. This can have a very negative effect on the treatment schedule and the operation of the dialysis center. At times, when a dialysis unit is filled, an infrequently used treatment slot may be denied to a new patient needing that slot for life sustaining treatment.

Usually, in articles that are written about patient’s issues, a problem is presented, the staff engages in an innovative and highly effective intervention and, as the video fades out, we KNOW that the problem is now solved and gone. However, in my unit, the reality can some times not be as pretty. So, how do we handle these highly resistance patients? Why try?

The best reason for me is the same answer I learned in doing substance abuse and/or criminal behavior treatment with my private clients. You never know how many times it takes for someone to catch on to reality. It would be nice, if the first time we try to assist a patient, they would say, as in that V-8 commercial, “Wow, thanks, I needed that. Now I know what I need to do.” However, life does not follow neat and simple scripts. Change is usually a slow and difficult process. We assist our patients in discovering what will motivate them to make healthy choices. Unfortunately, I also know that some of our patients will never reach that point of change and they will have decreased health. They may die due to their choices.

We cannot force feed reality to our patients and make them make changes in behaviors and thinking. There are many things we can do to increase the odds that change will occur and to assist all during the process:

We can remember that it is written in the federal ESRD Conditions for Coverage “all patients are treated with consideration, respect, and full recognition of their individuality and personal needs…”

We can educate our staff that it is within a patient’s rights to refuse treatment. Being late to dialysis is not a reason to discharge a patient.

We can (of course after interventions and sufficient warnings of consequences) change the patient’s treatment time to a schedule that presents less negative effect on the unit or we can remove the privilege of a regularly scheduled treatment time.

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We can decide to not put ourselves in a judgmental role, dispensing negatives comments and dirty looks when the patient arrives late or after a period of absence. We can remember that we all make treatment choices based on what seems right to us. We can continue to listen to our patient and we then might better understand their choices. That understanding might lead to change.

We can show concern and understanding. We can use the skills presented in the toolbox on “Decreasing Dialysis Patient-Provider Conflict.”

We can, when we hear the frustration in fellow staff members’ voices or comments, remind them that this is not about them. In the end, it is about being there for our patients - even when we do not like the choices they make.

Hmmm. I believe that is what I hope I will receive from others - that they will see me and not just what I do. I hope that there is someone who accepts me for who I am - flawed as we all are – with warts and wrinkles.

Hmmm. Did I ask? Should we not give this gift of acceptance for who they are – not what they do - to our patients?

Craig Fisher, PhD, LCSW, Member of the MRB and PLC.

Frequently Asked Questions:

Q: How can we help patients know how much treatment time is lost when they sign off early?

1. Some patients will stay longer once they know the damage that shortened treatments may cause over the long run. You can gather statistics on the effects of missed treatments and calculate the treatments missed (by the patient’s treatment shortened) and present this information to the patient. This will make it more personalized and the fear of potential death may help the patient make the choice to stay for full treatments. You also can post information and encouragement to stay for their full treatment on the bulletin board.

2. Some patients will just need a little extra encouragement to stay for treatment. Other times, patients feel terrible during dialysis and just want to leave. They may start cramping, getting nauseous, cold, and feverish, etc. You can check their blood pressure, machines, flow levels, length of dialysis, medications, etc to check if there are other factors associated with dialysis that can be altered to make them more comfortable.

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<th>MEANS LOST TIME BY WEEK</th>
<th>AND LOST TIME BY MONTH</th>
<th>AND LOST TIME BY YEAR</th>
<th>IT ALL ADDS UP TO WEEKS LOST PER YEAR</th>
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<td>130 Minutes</td>
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Facility Best Practices: What Works to Improve Issues of Non-Adherence?

Network 11 compiled a list of interventions that dialysis units in their Network submitted as having increased adherence with their patients. The Renal Network, INC. (Network 9/10) has been given permission to share their suggestions.

Patient Initiatives

- Have one-on-one discussions with patient and trying to figure out why they don't want to come or stay their full treatment. Counseling to help the patient “discover” the problem and own the solution can be an effective intervention. Assisting them to feel less threatened and more accountable. Building a positive relationship with the patient is key. Have patient and family care conferences.
- Adjust the patient’s transportation schedule or change transportation companies.
- Have peer mentors.
- Inform patient each month of time missed or shortened.
- Put articles in facility patient newsletter about issues of compliance and feeling better.
- Encourage patients to shift priorities and adopt new beliefs about their need for dialysis.

Facility Staff Initiatives

- Greatest improvement has been with the schedule changes, when possible and realistic.
- Stick to their schedules and making them accountable and responsible for their own consequences has helped significantly.
- Call the patient when they miss a run.
- Give the patient information about being referred to transplant center and need for treatment adherence.
- Provide supportive problem solving during team/patient care plan meeting.
- Solve the root cause and consider individualization. Use motivational interviewing techniques and self-management program to explore reasons for skipped or shortened runs.
- Have the primary nurse be the main communicate or the patient and then reinforce through visits with dietitian and weekly visits with the nurse practitioner.
- Provide consistent and ongoing education and practice.
- Have a care team that is diligent and never gives up and that sets forth a positive, personable, cheerful climate in the unit. Provide consistent, quality care so that patients leave the unit feeling "good" about themselves and they therefore take better care of themselves.
- Give instructions for the day such as limit fluid intake the day of a snowstorm, then schedule patient in for the next day.
- Have contests (Kt/V, least missed treatments/shortened runs, etc.) to both improve compliance and to recognize those who don’t miss treatments.
- Help improve patient’s understanding of the problems that are created by non-adherence.
- Show patient their actual lab printout, then explain what this is doing to their health. An informed patient is able to make better decisions.
- Develop a written contract and include the patient’s input.
- Make sure all patients are properly educated on the importance of receiving their

(Continued on page 7)
entire treatment as prescribed by their nephrologists.

- Have Nephrologist provide intervention.
- Have daily or weekly meetings with patient while on the machine to encourage compliance.
- Have PRN Imodium available for patients experiencing diarrhea.
- A Continuous Quality Improvement Project at one dialysis unit showed that teamwork within the dialysis center promoted better communication with the patients and was key in improving treatment adherence. It appeared that the actions taken by various team members promoted increased adherence. Nursing staff was to set up machine when patient came in. Physicians were to encourage attendance on their rounds. Dieticians were to continue providing nutritional counseling, and Social Workers were to continue providing biopsychosocial interventions.
- Explain to patients the consequences of shortening a run. Our biggest issues are weight gains, high phosphorous and high potassium. So with the weight gains, I have started to use some visuals such as placing liter bottles filled with water up to the 6-cup line. I am also planning on setting 5-10 kilos on the counter, noting that it is 10 kilos or 22 pounds. We do have some patients that gain that much at times!
- Provide poster with pictures of the effects of underdialyzing.
- Consider alternative shift for the consistently non-adherent patient.
- Have multi-disciplinary monthly care plans reviewed with patients that include current problem area and past three months of data to show trends.
- Maintain comfortable room temperature and furnishings and decorative aspects are also considered to make the unit more comfortable.

Q: Does the atmosphere on the unit affect patients coming to treatment?

If motivation is a common issue among a number of patients in a particular facility, staff may wish to evaluate the atmosphere of the unit, i.e. interaction of staff and patient warmth, judgmental attitudes, etc. of staff toward patients. Sometimes, patient activities outside of the unit, such as support groups or luncheons can foster a sense of connectedness with the others and can motivate the patient to come to treatment and to stay for the entire treatment.

Q: Would a peer-mentoring program help with adherence issues?

You may find that fellow patients can say things in ways the staff cannot and have a different level of credibility since patients have had some of the same or similar experiences. You can develop a peer-mentoring program and train patients to offer support and motivation to other patients. They also can share what worked for them and how they felt when they learned they had to come to treatment on a regular basis. The Renal Support Network (RSN) also has a Hope Line (800-579-1970) that patients can call toll free for support and to ask questions.
Factors in Patient Adherence

Practical and logistic issues

- Affordability of care
- Access to transportation
- Scheduling conflicts

Social support

- Willingness of family, significant other, or caregiver to provide emotional and practical support

Patient's knowledge

- Educational background
- Willingness to learn about disease
- Staff's willingness to teach patient about kidney problems

Communication with healthcare provider

- Ability to speak the same language
- Willingness and ability to discuss options and difficulties
- Staff availability/approachability

Perception of health benefits

- Patient’s views of value of treatment
- Patient's willingness to modify lifestyle

Complexity of treatment regimen

- Treatment options
- Medications
- Side effects from treatment


(FAQ Continued from Page 7)

Q: What can staff do to motivate patients to stay their full treatment?

1. There are a number of different types of motivation and what motivates one person may not motivate another person. By interviewing patients, you may be able to learn more about their motivational level and what motivates them. Some people are motivated by internal cues and these people may be motivated by feeling better, knowing they are following their treatment regimen, and being in control of their health care plan. Others are more externally motivated and like the praise of the staff, the interactions with other patients, the movies they get to watch during dialysis, using a laptop computer during dialysis, playing games and receiving prizes.

2. When patients trust the staff and see true concern and motivation in those delivering the care, they may be more motivated to comply with their prescribed treatment time. Activities, books, and a calm environment can also be motivating factors.

3. Motivation hindrance issues should be evaluated by the social worker, as they may include emotions such as anger, fear, depression, etc., and they may warrant further intervention.