Teaching self-management: New Conditions emphasize patient participation in care

By Paula Sec Alt, MS, and Dorian Schatell, MS

The new Conditions for Coverage \(^1\) clearly establish the importance of patients directing and participating in their own dialysis care. First, the Conditions mandate the establishment of an interdisciplinary team (IDT) with the “patient, or the patient’s designee” as a participating member. (§ 494.80). Next, the Conditions place responsibility for patient assessment (§ 494.80) and patient care planning (§ 494.90) squarely on the shoulders of that team.

This strong emphasis on the patient’s role as a member of the IDT, and as an active participant in care, can be found throughout the new Conditions. It reflects CMS’ stated intention in revising the Conditions to move toward “a more patient-centered, outcome-oriented approach…” (pg. 20371). “One of the fundamental principles that guided us,” the Conditions writers note, was to “stress patient satisfaction and ongoing patient involvement in the development of the care plan and treatment” (pg. 20371).

The Interpretive Guidance (IG) \(^2\) goes a step further by requiring facilities to promote patient participation. Not only do “patients have the right to know about and participate in their care and treatment to the extent that they desire,” (V456) the “facility must encourage patient participation in care planning” (V456).

Research rationale

Strong community support (cited in the preamble to the Conditions), as well as solid research, provide a compelling rationale for involving patients in their care. Dialysis patients who self-manage are likely to know more about their disease, its symptoms, and dialysis treatments—and enjoy better outcomes—than those who do not participate.\(^3\) Educational interventions with an emphasis on empowerment have been shown to improve depression,\(^4\) medication adherence,\(^5\) treatment attendance,\(^6\) and choice of vascular access.\(^7\)

It just makes sense that patients who participate in care planning are more likely to follow the plan. And, encouraging patient participation is also likely to improve patients’ self-esteem and sense of self-worth.\(^8\) Research has shown that patients who take the lead in choosing their treatment modality, or work together with their medical team, are much more likely to choose home dialysis modalities—and more likely to survive and to get a transplant.\(^9,10\)

A culture of participation

Encouraging patients to participate in their care takes a conscious effort on the part of every staff person who interacts with patients. “Your staff absolutely has to be on board,” says Edward Jones, MD, medical director of the Mt. Airy self-care dialysis facility in Philadelphia.\(^11\)

For some staff members, this emphasis on patient participation will mean a change in how they approach patient care and patient communication. Training sessions that help staff understand and empathize with the patient experience can provide the motivation to change behavior (see featured program in sidebar). Explaining the reasons why it is important to encourage patient participation in care, including improved outcomes, better patient and staff morale, as well as the need to comply with the new Conditions, will also help. One good resource for helping clinic staff learn why and how to encourage self-management is the Core Curriculum for the Dialysis Technician, 4th edition.\(^12\) This comprehensive training manual includes helpful information about communicating with patients, helping patients cope, providing patient education, and the importance of self-management. Another resource is Building Quality of Life: A Practical Guide to Renal Rehabilitation at www.lifeoptions.org under “free materials.” This manual devotes an

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entire chapter on ways to encouraging patient participation in care, goal setting, helping patients reach their goals, and evaluating outcomes.

The clinic social worker is another excellent resource. He or she is trained to assess patients' abilities and psychosocial needs, and might be willing to conduct staff sessions on how to build communication skills. Beth Witten, MSW, ACSW, LSCSW, offers these tips for promoting active patient participation:

- Provide information in a way patients can understand
- Offer choices
- Use motivational interviewing techniques. For example:
  - Use reflective listening (to help understand a patient’s point of view)
  - Be accepting and nonjudgmental
  - Reinforce motivational statements
  - Affirm patient’s freedom of choice and self-direction
- Monitor patient’s readiness to learn

Witten also suggests some practical communication techniques, including:

- Sit at the patient’s eye level
- Listen carefully and speak slowly
- Avoid jargon and use simple explanations
- Use pictures and diagrams whenever possible
- Focus on topics that patients want to know about
- Provide handouts if possible
- Use “teach back” to confirm that patients understand
- Encourage questions (Ask-Me-3)
- What is my main problem?
- What do I need to do (about the problem)?
- Why is it important for me to do this?

Plan of care

According to the Conditions, the patient’s plan of care must “be signed by team members, including the patient or the patient’s designee; or, if the patient chooses not to sign the plan of care, this choice must be documented on the plan of care, along with the reason the signature was not provided” (§ 494.90). Just getting a signature is no longer enough; the signature is important as a way to demonstrate patient participation in self-management. And, CMS surveyors’ tools include interview questions for patients about whether they truly participate in, and comprehend, the care plans they are signing.

Getting patient participation in interdisciplinary team meetings can be a scheduling problem, but the Interpretive Guidance suggests alternatives like “offering the patient the option to participate in IDT care planning or to attend a planning meeting in-person or by telephone from home” (V456). According to Witten, some clinics now post the schedule of care plan meeting times to boost patient attendance; others offer to call patients at home during the meetings to get their input. “Many staff members are surprised at the willingness of patients to get involved,” said Witten. Finally, the IG allows for “chair-side” review of the care plan (V456) if the patient agrees and privacy can be provided.

Tools for patient self-management

DaVita’s Diet Helper

By Sara Carlson RD, CDE and Debbie Benner, MA, RD, CSR

Variety is the spice of life—and being on a special diet does not mean the end of variety and tasty meals for CKD patients. However, in the past, resources to help patients manage their day-to-day lives with this complex diet were limited. To respond to the need, DaVita launched DaVita Diet Helper, an online meal planner for late-stage CKD diets. Since its initial launch, use of the site has continued to grow.

The Diet Helper enables patients to design kidney friendly meals, which include recipes for main dishes, beverages, condiments, side dishes and snacks. There are a number of meal plans to meet six selected protein levels. This tool can also be individualized for diabetic and non-diabetic options, and provides flexibility with varied potassium level options, for patients on liberal or restricted potassium diets. Since most diets for Stages 4-5 CKD and dialysis patients emphasize lower sodium and lower phosphorus intake, all of the meals are low in these two elements. DaVita Diet Helper is a great resource for patients in later stages 4 and 5 CKD, and many in stage 3 are finding it helps them learn more about the components of a kidney diet.

Some of the special features of the tool include:

- Two weeks of meals and snacks
- Recipe and diet tips
- Food choices and carbohydrate choices
- A nutrition log that allows patients to track their nutrient intake each day
- A shopping list generated from the meals selected
- A food analyzer to quickly look up foods to view nutrients of importance
- Information on food labels and packages

DaVita Diet Helper can be found at www.davita.com/diethelper

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Specific self-management topics

In addition to generally encouraging patient participation in all aspects of care, the Conditions require that clinics provide education in specific topic areas as a means of encouraging higher levels of self-management. These areas include:

- Treatment options. The new Conditions require that patients be informed about all treatment modalities. This is a first, since previous regulations required that clinics inform patients only about modalities offered at their clinic. Now, “documentation in patient records must demonstrate that facility staff provide unbiased education to patients/designees about transplantation and all dialysis treatment options (modalities and settings) offered for kidney failure, whether or not those options are offered at the current dialysis facility” (V458).

- Patient-driven options

Tools for patient self-management

Fresenius program helps patients build self-management skills

By Gilda Gussin, MEd

Fresenius Medical Care’s UltraCare program has a new component, Thrive! with UltraCare (Thrive!). It is a three-phase program with a strong focus on helping patients build self-management skills. The rationale for Thrive! grew out of research showing that patients who self-manage are more adherent and have better outcomes, including quality of life. Towards these ends, Thrive! has two complementary program goals:

- To build patient skills in self-management and
- To build staff skills in partnering with patients to solve problems that lead to non-adherence with treatments.

The new Conditions for Coverage requirements for patient education and counseling on adherence to treatment plans, participation in care planning, and decision-making, have since added additional reasons to pursue the Thrive! education agenda.

Three phases

Our first step in promoting patient self-management—and the focus of Phase I of the Thrive! program—involves building staff empathy for patient experiences, including role-playing, watching candid video interviews with patients, and other exercises. As a result, staff attitudes about the importance of wellness or self-management skills increased, as did their understanding about the necessity to talk with each patient about what he or she needs to act in healthier ways.

The focus of Phase II involved gathering baseline data about adherence. Phase III builds on these foundations, and includes patient wellness education programs about specific topics and practical, skill-building exercises. It also includes further staff education on how to find and understand the root causes behind patients’ actions, and how to motivate healthier actions. Full implementation of Phase III is scheduled to be completed by 2010. FMCNA has already begun deployment of the program with “train the trainer” sessions throughout the country to ensure that Fresenius staff knows how and why to offer these wellness tools to their patients.

Patient-driven options

The Thrive! program lets patients choose topic(s) they are interested in—a key principle of adult learning. A menu lets patients review their choices, including seven video programs, and/or audio and booklets about topics like depression, fluid management, handling emotions, treatment goals, and more.

The materials feature patients sharing their stories and self-management techniques that worked for them. A series of “Try It” exercises at the end of each program are designed to help patients practice the featured skills and reflect on key components of behavior change, such as:

- What’s important to me?
- What choices do I have?
- What is getting in the way of reaching my goals?
- What might help me overcome the obstacles I face?

“Try It” exercises can be done in group sessions or alone—whatever patients feel best suits their style. Thoughtful participation can help patients gain a better understanding of the vital role they play in improving their own dialysis outcomes.

Practical skills are also needed for successful self-management. Thrive! provides practical tips with a series of take-home “Manage It” cards that reinforce education and offer real-life strategies for living with dialysis, curbing thirst, controlling fluid intake, managing treatments, and more.

Thrive! is designed to include all of the elements of a successful self-management program:

- Trained, supportive clinic staff
- Patient-driven choice of topics
- Factual education combined with self-awareness exercises
- Practical, skill-building tips from other patients
- Reinforcement in the form of take-home information and practice exercises

For more information about Fresenius Medical Care’s Ultracare, visit them at www.ultracare-dialysis.com.
developing a resource packet on their own, or by directing patients to an existing resource, such as Medicare’s Dialysis Facility Compare (at www.medicare.gov/dialysis). Because home dialysis (in all its forms) represents the highest level of self-management, the Conditions also require that clinics document the reason(s) a patient is determined to be unsuitable for, or refuses, home dialysis (V512).

Vascular access and care. “Patients must be informed and educated about the benefits, risks, and hazards of each type of vascular access” (V550). And, “patient education should address self-monitoring the vascular access."

Comprehensive hemodialysis access resources can be found at www.fistulafirst.org.

Dietary and fluid management. The IG mentions the need to provide education about diet and fluid management is a number of places (V562, V545, and V546). “Patients must be educated to understand their role in managing the prescribed diet, medications, and bone health” (V546). Dietitians play the central role in this area and have developed a wide range of tools to assist them.

Other topics. Facilities must also work to provide their patients with education about the dialysis experience, dialysis management, infection prevention, quality of life, rehabilitation, and how to cope. In addition, the “patient’s medical record must demonstrate the provision of patient education and training in all of the listed subject areas” (V562). According to the IG, “there may be a single form or section of the medical record for information on patient education, or it may be located in various parts of the record.”

Assessing team performance

The Conditions require that each dialysis facility must “develop, implement, maintain, and evaluate an effective, data-driven, quality assessment and performance improvement (QAPI) program...” The performance measures required in the QAPI focus on health outcomes and the reduction of medical errors, but the quality assessment process could also be applied to the evaluation of efforts to provide patient education and self-management support.

A useful tool, developed for use in diabetes, but valid and reliable across chronic illnesses, is the “Assessment of Primary Care Resources and Supports for Chronic Disease Self-Management Tool.” It can be found at www.diabetesinitiative.org/lessons/documents/PCRSandBackgroundUserGuideRev.12.08.FINAL.pdf.

This tool can help IDTs identify where they are doing well and where there are gaps in their self-management education. It can help to track progress over time, and promote planning and discussion by the IDT. It might also be a useful addition to the QAPI process.

A new era

The new Conditions for Coverage, the IG, and the accompanying Measures Assessment Tool (MAT) have everyone scrambling to adjust practices and procedures. Insofar as these new regulations usher in a new era of dialysis care that includes more patient involvement, higher levels of patient self-management and self-care, and increased patient awareness of treatment options (including home hemodialysis PD, and transplant), the results will be worth the effort.

References

2. Centers for Medicare Medicaid Services. ESRD Program Interpretive Guidance Update: (Ref S&G-09-01), October 2008