Health Literacy: Critical for Success in Integrated Care

By Doug Johnson

During the past 3 years, we at Dialysis Clinic, Inc., have focused on providing care for all patients with kidney disease with the goal to reach out to them, wherever they are, and work with them to empower them to live the life they want to live, without allowing kidney disease to get in the way of their life dreams. For most patients with kidney disease, the best way to have optimal quality of life is to avoid dialysis. Therefore, our primary goal for treating patients with chronic kidney disease (CKD) is to avoid dialysis or delay its start.

Nationwide, there is a clear knowledge gap about CKD. Among individuals with stage 3 CKD, 93 percent do not know they have kidney disease. Even among those with stage 4 CKD, 47 percent are unaware that they have kidney disease (1).

We are learning that health literacy is much more than making handouts easier to read. To us, the key to determining health literacy, and improving health literacy skills, is to sit down with a patient one on one and spend whatever time is necessary to help the patient learn about kidney disease and, most important, about how to make it less likely that kidney disease will keep the patient from having the life she wants. As we talk with the patient, we can identify areas where our language is not clear and revise our discussion of these topics. We have modified our approach based on feedback from our patients, and we will continue to modify this program as our patients point out our gaps in communication and effective education.

We currently treat 3100 patients with all stages of CKD in 26 locations. Our CKD program is our fastest growing program; a year ago, we treated only 1570 patients. At the patient’s first visit, a care coordinator, a registered nurse, spends 1 to 1.5 hours talking with the patient. Unlike a 15-minute physician’s visit, this extended time allows the patient to express his or her life goals and the care coordinator to provide vital information about kidney disease and its treatment. Most important, this longer personal discussion allows the care coordinator to evaluate the patient’s understanding of kidney disease and to tailor the discussion to meet the needs of that specific patient.

In some of our locations, patients have the opportunity to choose “RoundingWell” patient check-ins.

These patients receive a RoundingWell text or e-mail several times each week. The messages, which are written at the 4th grade to 6th grade reading level, both evaluate a patient’s current knowledge about a topic and provide additional information to strengthen a patient’s health literacy skills. The care coordinator receives an electronic update on the patient’s response and is able to tailor future topics for discussion to best meet the needs of that patient.

One topic in which evaluation and strengthening of health literacy skills is critical is medical management without dialysis. Many patients, and their families, believe that dialysis will solve all of their health problems. It is critical to clearly explain that dialysis only treats kidney disease; the patient who also has a weak heart will still struggle from having a weak heart even after starting dialysis. Many patients, especially elderly patients with multiple comorbidities, will do just as well with medical management without dialysis and can thus avoid the stress and disruption of their lives that dialysis brings.

If a patient selects medical management without dialysis, the care coordinator meets with the patient’s family, evaluates their health literacy skills, and tailors the explanation to the family to facilitate their understanding that medical management without dialysis is a reasonable choice. This explanation emphasizes that we will continue close follow-up of the patient with the nephrologist or primary care physician and will add palliative care and hospice services when the patient is eligible if the patient requests it. We have found that this process has empowered many patients to choose medical management without dialysis. In Spartanburg, SC, site of our strongest program, more than 10 percent of patients have selected medical management without dialysis. Although each patient knows that this decision can be changed at any time, very few do so.

When a patient chooses dialysis, we evaluate the patient’s understanding of the benefits of dialyzing with a fistula and of dialyzing at home. We have found that once patients have the opportunity to fully learn about their choices in care, they are more likely to choose to dialyze at home, or dialyze in-center with a fistula. In our Spartanburg location, of patients who received CKD care coordination and started dialysis in 2014, 29 percent started dialysis at home (compared with a national average of less than 9 percent) (1), and 73 percent of patients who started dialysis in-center started with a fistula and never had a catheter (compared with a national average of 20 percent starting with a fistula) (1).

We are beginning to implement a more formal program for care coordination for patients using dialysis. We plan to treat about 1500 patients in this program. From our initial experience, we are learning that patients who have the opportunity to work with a care coordinator and receive RoundingWell check-ins become more engaged in their care. We anticipate that the outcomes for these patients will improve and that hospitalizations and costs of care will decrease. In a limited trial, we found that the number of in-hospital dialysis treatments decreased by 20 percent in 2014 in one hospital where we partnered with the hospital to educate and engage patients using dialysis who were likely to receive their hospital care at that location.

A key area in which we are working to improve health literacy is transplantation. We believe transplantation is the ideal treatment for a patient with kidney failure because those who undergo successful transplantation can more easily continue to work and do not need to have their lives interrupted with dialysis treatments. However, nationwide, only 2.6 percent of patients receive a preemptive transplant (1). We are seeing that as we more effectively educate patients about the option of transplantation and the steps they would need to take to receive a transplant, they have more hope of a possible future life without dialysis.

We have also learned that it is critical to educate patients about the possible benefits of palliative care and hospice to improve their quality of life and ease the transition to end of life. In Nashville, TN, our care coordinators approach patients when it seems that the burden of dialysis outweighs its benefits and talk with them about the potential benefits of palliative and hospice care. Of 60 patients approached, 13 selected hospice care and 31 selected palliative care, with 8 of those patients later transitioning to hospice.

As we work with patients to improve their lives, we are learning that it is essential to work on one to learn about and help them meet their own life goals. We find that by tailoring our work to the goals of each patient, we are able to evaluate their understanding of health issues, fill any educational gaps, improve their health literacy skills, and work with each patient to have the life they want to live, without allowing kidney disease to get in the way.

Reference

The data reported here have been supplied by the United States Renal Data System (USRDS). The interpretation and reporting of these data are the responsibility of the author(s) and in no way should be seen as an official policy or interpretation of the U.S. government.

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