and had somewhat limited English, felt that she was totally on her own and that no accommodation was made for her limitations, which included limited usefulness of audio teaching. Although almost all patients felt they had adequate information to modify their diet as needed, a review of their clinical records and conversations with their nutritionists found that many had significant nutrition issues (e.g., hyperphosphatemia, hypocalcemia, excessive fluid weight gain). Participants who had been closely followed up during their earlier stages of chronic kidney disease and had been educated by a practitioner were less likely to be overwhelmed by the complexity of the information provided at the initiation of dialysis.

Conclusion
If patients are to be successfully engaged as partners in their care, simple, repetitive health information must be provided in small segments and tailored to the individual. Validating that the information is received and understood by the patient and family, by the use of methods such as “teach-back,” which is discussed elsewhere in this issue, is an integral part of this process.

Linda McCann, RD, RCN, is associated with Satellite Dialysis in San Jose, CA, and is a member of the KN Editorial Board.

Table 1. Health literacy survey results

<table>
<thead>
<tr>
<th>Question/Statement</th>
<th>All Patients</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Had heard the term “health literacy”</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Understand/understand enough to answer questions from friends/family</td>
<td>16</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Understand/understand instructions on how to take medications</td>
<td>19</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Understand/understand dialysis as lifelong unless transplantation is possible</td>
<td>21</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Understand/understand dialysis options (hemodialysis, peritoneal dialysis, home, in-center)</td>
<td>17</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Understand/understand that blood work indicates progress/issues</td>
<td>17</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Received simple explanations of diet (eat/drink)</td>
<td>21</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Overwhelmed by language (potassium, dialysate, phosphorus)</td>
<td>15</td>
<td>7</td>
<td>5</td>
</tr>
</tbody>
</table>

Can We Talk ... about Health Literacy Strategies?

By Terri Ann Parnell

Chronic kidney disease (CKD) is a complex medical condition that requires multiple strategies including the ability to understand, implement, and maintain clinical recommendations and self-care treatment strategies (1). Heart disease, diabetes mellitus, and nephropathies are among the top 10 causes of death, with rankings of 1, 7, and 9, respectively (2). CKD affects approximately 26 million American adults in the United States, whereas millions of others are at increased risk (3). Understanding and managing CKD requires the ability to “obtain, process, understand, and communicate about health-related information needed to make informed health decisions” (4). Low health literacy is associated with poor management of chronic illness and has a negative impact on an individual’s ability to optimize his or her health outcomes (5). Although reports from national data in 2010 showed that in the United States, nearly nine out of 10 adults were below the proficient level in health literacy, and more than 75 million adults had basic or below basic health literacy (6), the health literacy burden should not be placed solely on the individual. Enhancing health literacy must be a collaborative partnership between the health care professional, who provides information and care, the individual receiving care and information, and the health care system.

Enhancing health literacy and person-centered care

Addressing health literacy is a cross-cutting priority that is vital to providing safe, effective, person-centered care. Each member of the health care team must participate in spearheading the implementation of health literacy strategies into practice, with the ultimate goal of advancing health through the delivery of safe, high-quality health care. In an effort to lessen the complex demands that are being placed on persons managing chronic disease, health literacy efforts require changes in both organizational and professional practices.

In 2012, the Institute of Medicine published 10 attributes that can assist organizations in creating an environment that enables and empowers all health care consumers to access and benefit from their health care services (7). The attributes of “health-literate organizations” begin with leadership setting the health literacy mission and vision, preparing the workforce to be health literate in an effort to meet the needs of all populations being served, and including members of the community in the planning and evaluating of health services. Health literacy strategies are integrated throughout all communications, including the assessment of patient understanding. Best practices are implemented and fully integrated throughout the organization to enhance culturally and linguistically appropriate communication and ultimately patient safety. To foster sustainability, organizations can develop patient education and health literacy committees that promote, sustain, and advance an environment that supports principles of equity, diversity, and health literacy (8). A health-literate organization creates a culture and expectation that requires all professionals to engage in the promotion of health-literate strategies and that ultimately prioritizes health literacy as a core organizational value (7).

Health care professionals have many responsibilities across an organization and therefore have a vital role in enhancing health literacy and the delivery of safe, effective, person-centered care. The culture of a health-literate organization fosters the use by all professionals of a “universal precautions approach” to health literacy rather than assuming an individual’s health literacy level. This approach will enable all persons to easily access, navigate, and use information and health care services.

Some specific strategies for enhancing health literacy

- Always ask at the initial point of contact about a patient’s preferred language to discuss health care, and obtain appropriate interpretation services when necessary.
- Begin where the patient is by asking what the patient already knows about his or her chronic disease. This approach may also help identify opportunities to enhance self-management skills.
- Learn about and always use “plain language” in each patient–provider interaction to promote clear communication.
- Incorporate the use of “teach-back” or “show-me” to ascertain understanding.
- The use of teach-back should not be a question-and-answer session or quiz for the patient, but rather an opportunity to assess how well the professional did in explaining information using everyday language.
- Teach-back also assists in identifying areas that require reinforcement or areas where barriers to learning may exist.
- Review and reinforce key action steps numerous times, possibly in several different ways, to foster learning.
- Summarize action steps, and end with “What questions do you have for me?” to provide a comfortable, shame-free environment. Phrasing the question in this fashion implies that you encourage and even expect questions and helps empower the patient to ask them when necessary.

Health literacy efforts must focus on enhancing communication and health maintenance skills so that patients can make informed health-related decisions and enhance adherence to their medical regimens (9). This is an important focus for patients managing chronic disease, where the aim is to improve overall adherence to medication and treatment regimens and ultimately enhance lifestyle behaviors. Health care professionals and health care organizations that prioritize health literacy as an essential component of care will provide person-centered care that will enhance patient safety, patient satisfaction, and ultimately patient outcomes.
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 those 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 3,100 patients with all stages of CKD in 26 locations. Our CKD program is our fastest growing program; a year ago, we treated only 1,570 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 provide 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 tells 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. Here 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 1,500 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 one 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


Terri Ann Parnell, MA, DNP, RN, is principal and founder of Health Literacy Partners, LLC.

Dorothy Johnson, MD, is vice chair of Dialysis Clinic, Inc.