Health Literacy Research to Improve Kidney Disease Care

By Kerri Cavanaugh

Health literacy research over the past 2 decades has shaped its definition, determined how it is assessed, and provided us with an initial understanding about how this concept significantly contributes to the connections among patients, families, health care providers, and health systems. We all strive to apply the most rigorous and contemporary evidence in the care of patients, and this is no different for practices related to health literacy.

The US Department of Health and Human Services National Action Plan to Improve Health Literacy gives seven recommendations to act on now for better health. One recommendation calls for additional “basic research and the development, implementation, and evaluation of practices and interventions to improve health literacy” (1). Most reported health literacy research has been about people without kidney disease, but that is changing. Our team and others have shown that lower health literacy is common in individuals who require dialysis and may be as high as 50 percent. This estimate is somewhat lower for those who receive a kidney transplant, but it escalates to nearly 90 percent for patients with kidney disease who do not speak English as a first language. Individuals with kidney disease who require dialysis and have lower health literacy have been shown to have higher risks for hospitalization (2) and mortality (3).

A common misconception is that health literacy is defined primarily by a person’s reading skills. The Institute of Medicine asserts that the concept of literacy, not specific to health literacy, is broad and in addition to reading and writing includes speaking, listening, quantitative skills, knowledge, and the influence of culture on each of these components (4). Skills in health literacy affect how effectively patients obtain, process, and use health care information. Research leaders have identified health literacy as a key area to advance translational research and improved outcomes in kidney disease care (Figure 1).

Although several tools may be used to evaluate an individual’s health literacy skills (5), there are concerns that these assessments may not fully capture the broad range of activities and skills that health literacy defines. It is critical to recognize that health literacy is not exclusively “about them” but is in fact “about us”: our skills as health care providers in delivering information. Recognition and acceptance of the responsibility for clear communication is called organizational health literacy. A recent Institute of Medicine white paper provides an overview of existing measures that health systems may use to determine their current level of health literacy and identify specific areas where improvements can be made (6).

This growing recognition of the role of health literacy in kidney disease has contributed to its inclusion in interventions to improve kidney disease education. Efforts include promotion of patient-centered dialogue and shared decision-making in choosing renal replacement therapy options and in facilitating navigation of the transplantation evaluation process. Compliance with complex treatment plans requires an understanding of what is expected. The information burden for successful navigation of kidney disease is high. As care providers we must ensure that this information is delivered in a way that all people can receive and use effectively. This includes creating written educational materials that use formatting, use visual aids, and avoid complex text (7) and developing complementary programs for multidisciplinary teams of kidney care providers to deliver congruent information and instructions. Practices can incorporate health literacy strategies now into their existing quality improvement programs and contribute to our understanding of its impact. The Agency for Healthcare Research and Quality Health Literacy Universal Precautions Toolkit includes 21 brief, research-based tools with instructions for implementation (8).

Now is the time for commitment by the kidney community to address health literacy and improve care, promote kidney health, and potentially slow the progression or even prevent the development of kidney disease. Learn about health literacy, recognize its potential for positive impact, and align your actions with strategies to close any gaps in your own health literacy skills. The investment will be worth it.

References

Hope: An Essential Prerequisite for Health Literacy in Chronic Kidney Disease

By Dorri Schatell

Hope Abides

Hope abides; therefore I abide. Countless frustrations have not cowed me. I am still alive, vibrant with life. The black cloud will disappear, The morning sun will appear once again In all its supernal glory.

—by Sri Chinmoy Ghose

I have you ever sat in your examination room with a patient and the patient’s care partner and explained the progression of chronic kidney disease (CKD) and the ESRD treatment options for a second, third, or fourth visit in a row, watching your patient’s eyes glaze over when you say “diabetes,” while the partner’s eyes widen with fear? Does it feel as if your words aren’t getting through? You’re right. Your patients are shell-shocked: devastated by emotions, panicked, and feeling hopeless about their futures. We call it denial. Terrified patients can’t learn. Education researchers have noted, “Humans act emotionally before the conscious awareness of emotion can occur; we react before we know we are reacting.” A traumatized person in a state of alarm is less capable of concentrating, more anxious, and more attentive to nonverbal cues such as tone of voice, body posture, and facial expressions” (1).

The good news is that you can help your patients through their fears—by starting with hope.

The value of hope

The literature on hope offers some useful hints as to how we can help patients adapt, including setting and moving toward personal goals:

• A meta-analysis of studies of hope in family members of people with chronic illnesses (2) found that a key hope

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Figure 1. Health literacy as a key research component to improve kidney disease care


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