Health Literacy: Enhancing Patient Engagement

By Barry H. Smith, Pamela Hoyt-Hudson, Jennifer Melendez, and Molly Phillips

Health literacy is all about communication and understanding among patients, families, and health care professionals, the fact that health literacy skills are also suboptimal among nephrologists, nephrology nurses, technicians, and other health care staff can only mean that the results of our treatment efforts are far less than they could be. This is simply unacceptable.

With the conviction that in this era of health care reform, the health literacy problem requires urgent attention focused on improving the quality of care we provide, the Rogosin Institute hosted a roundtable entitled Health Literacy and Renal Disease: Promoting Prevention and Quality, provided the keynote for this roundtable meeting.

In preparation for the roundtable, members of the Rogosin staff conducted interviews with 41 patients at seven different facilities (six dialysis facilities and one CKD clinic) to ensure that patients’ voices were incorporated into this discussion. The patients were asked about their understanding of their diagnosis, health care experiences, understanding of health-related communications of various types, and what tools they wish they had to help them understand their treatment and be better partners in their care. The participants ranged in age from 24 to 88, were split fairly evenly between men and women (54 percent men, 46 percent women), and had diverse racial and ethnic backgrounds. The ESRD interviewees had been receiving dialysis for as little as 2 months and as long as 15 years.

Key themes that emerged from the interviews included the need for more support from families, peers, caregivers, and the care team for the patients themselves and for their care partners; the importance of tailoring education to the specific needs of the individual patient; and the need for education materials of all types in different languages. The participants shared that simply receiving information about their health did not necessarily lead to behavior changes. When asked about how they would like to learn about their health care, 84 percent of the Rogosin patients interviewed stated that they considered videos to be valuable educational tools and wished that these were available to them.

With these data and the participants’ experience and expertise available in the room, discussion at the roundtable was spirited. The driving force of the discussion was the recognition of suboptimal health literacy skills among both kidney patients and the staff caring for them, and the urgent need to achieve better health and quality of life outcomes for patients with both CKD and ESRD. Throughout the discussion, common themes included the need to recognize the totality of the complex, difficult, and varied challenges facing CKD and ESRD patients; to promote a sense of hope among patients and their families; to address mental and emotional health issues; and to actively engage patients and staff in true care partnerships.

The group defined the following specific problems needing high-priority action:

- Fragmentation of the care of CKD and ESRD patients, most of whom have complex multiple comorbidities
- Lack of patient support systems
- Limited staff skills in health literacy techniques and tools
- Suboptimal appreciation of the importance of health literacy among patients and staff
- Limited distribution of already available educational and training information and tools to improve health literacy levels

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Universal Precautions for Health Literacy

By Cindy Brach

This month, KV Editorial Board member and special section editor Glenda Payne interviewed Cindy Brach, MPH, lead for health literacy at the Agency for Healthcare Research and Quality, about ways nephrology professionals can recognize issues in health literacy and more effectively bridge communication gaps.

Why the interest in health literacy, and why now? Current buzzwords such as “patient-centered,” “patient engagement,” and “improved experience of care” depend on clear communication. Miscommunication happens frequently, due to a mismatch in the health literacy of the members of the health care team (provider or patient). According to Richard Carmona, the former US Surgeon General, “Health literacy is the currency for success in everything we do in health, wellness, and prevention.” How can nephrology professionals recognize issues in health literacy and more effectively bridge communication gaps?

What is health literacy? How is this different from literacy or reading grade level?

Health literacy has traditionally been defined as an individual’s capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. A person’s health literacy depends on how complicated health information is, and how complex health-related tasks are. A national survey revealed that only 12% of adults in the United States are able to understand and use all the types of health information that are currently being distributed (1). Many people who read well have limited health literacy. They have difficulty understanding written medical instructions, finding information in complex documents, and extracting information from graphs and charts. Additionally, health literacy includes the ability to verbally communicate—both listening and speaking, the ability to understand and use numbers, and the ability to navigate the health care system.

How can patients or families with limited health literacy be identified?

There is no evidence that identifying patients and families with limited health literacy is effective (2). Health literacy is dynamic. At one visit an individual may be able to absorb and follow up on health information; at another time the same individual may be tired, scared, or feeling sick and not be able to understand or act on information as easily. Patients should, however, be asked about their literacy, and the health care team should be prepared to refer them to reading and math resources in the local community. The Agency for Healthcare Research and Quality (AHRQ) Health Literacy Universal Precautions Toolkit (Tool 20) describes the DIRECT approach to see whether patients would like to improve their reading skills (3). What is meant by “universal precautions” for health literacy, and why is this recommended?

Health literacy universal precautions structure the delivery system as though everyone may have limited health literacy. It’s just like blood safety: where everyone’s blood is treated as if it could be infected. When an organization has implemented health literacy universal precautions, it becomes easier for patients and families to understand what to do to take care of their health, and easier for them to navigate the health system. Health literacy universal precautions include a wide range of activities, such as making way-finding signage clear, offering help with forms, reviewing written materials together, confirming understanding at multiple points in every encounter, making referrals easy, and proactively following up.

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