Improving Health Literacy in Kidney Patients: Nephrology Social Workers as Leaders

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This article will discuss two research studies related to health literacy (HL) and nephrology: one conducted with dialysis patients at facilities in New York City on health information seeking behaviors, and one conducted with nephrology social workers on their use of health literacy knowledge, tools, and assessments. The results of both studies were presented at a roundtable event hosted by The Rogosin Institute in New York City to inform a discussion around improving health literacy of renal patients, their families, and care teams. The authors define health literacy, then discuss the methods and findings from both studies, and finally, drawing from both studies, make recommendations for nephrology social workers to improve health literacy among kidney disease patients and their care partners.

INTRODUCTION

Research suggests that nearly 9 in 10 adults in America have trouble understanding some or all of the health information they receive from their healthcare providers or from publically available materials (DHHS, 2010). This lack of understanding makes informed decision making impossible, and limits patient empowerment. Health literacy (HL) is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (DHHS, 2010). Low health literacy has been associated with higher rates of disease and poorer management of conditions (Dageford & Cavanaugh, 2013; Devraj et al., 2015). Recognizing the immense problem of low health literacy nationwide, in 2010, the U.S. Department of Health and Human Services released *The National Action Plan to Improve Health Literacy*, which is based on two key principles: 1) the universal right to accurate health information, and 2) the need for healthcare to be delivered in a way that benefits the patient's health and quality of life (DHHS, 2010).

Social workers play an essential role in ensuring patient understanding of a diagnosis, and have the potential to make a significant impact on improving HL nationwide. Social workers are in tune with the importance of communicating effectively with clients in many different ways. Nephrology social workers (NSWs) provide support and communication, ranging from a simple hug, fist-bump, or high-five, to an intense, emotional end-of-life discussion. These interactions may be one-on-one with a single patient or involve a few to many family members. NSWs act as advocates for patients, and insist that their patients' views be heard and respected, even if that voice conflicts with the opinions of the medical team, family members, or social norms.

In March 2015, The Rogosin Institute, a not-for-profit kidney care organization based in New York City, hosted a roundtable event that brought together experts in the fields of kidney disease and HL to discuss ways to better educate kidney patients and empower them to take charge of their healthcare. Hosted by Rogosin's Jack J. Dreyfus Center for Health Action and Policy (CHAP), the roundtable included individuals with kidney disease as well as nephrology representatives from medicine, nursing, social work, nutrition, health education, policy, and dialysis unit administration executives. Participants came to the roundtable from all over the United States to discuss the biggest challenges facing patients with chronic kidney disease (CKD) and end-stage renal disease (ESRD), and to brainstorm ways to address these challenges. The goal of the roundtable was twofold: 1) the development of actionable projects for pilot in New York City and/or other communities around the country, and 2) to publish and increase dissemination of information about HL and kidney disease. Two studies were presented at the roundtable: one related to patient experiences and barriers to learning about their kidney disease, and the other about NSWs' use of health literacy tools.

CKD and ESRD rates are growing in the U.S., and without adequate information and understanding about how to slow or halt progression, the number of patients with progressive kidney disease will continue. Kidney disease affects over 26 million people in the U.S., and over 600 million worldwide (Dageforde & Cavanaugh, 2013). Treating individuals with kidney disease is expensive; although they represent only 1.5% of Medicare patients, the treatment of people with ESRD takes 7.5% of the Medicare budget. When the treatment of people with CKD is added, the figure rises to nearly 17% of the Medicare budget (Saran et al., 2015). More attention must be paid to health education and disease prevention. HL tools and techniques need to be incorporated into the daily routines of all healthcare organizations and providers.

HEALTH LITERACY (HL)

Today we are bombarded with messaging—including health messaging—from media, healthcare providers, and other sources. Despite the abundance of information, too many people still struggle to understand their healthcare needs, properly take medication, or follow instructions from their clinicians. Koh and Rudd suggest that we are living in a troubling paradox where "people are awash in knowledge that they may be unable to use" (2015). Simply having information available is not enough; it must be easy to understand and use. While health literacy and general literacy are certainly related, health literacy requires understanding of complex health systems and a medical vocabulary, which can be difficult for even well-educated people, particularly given the rapid changes in healthcare. Social and cultural factors influence health literacy, as well; individual beliefs, value systems, and traditions have an impact on the way people perceive and receive health information (The Joint Commission, 2007).

Limited HL is associated with poor health outcomes, including increased emergency room visits and hospitalizations, lower patient satisfaction, poor adherence to treatment plans, and death (Dageforde & Cavanaugh, 2013; Devraj et al., 2015; Liechty, 2011). Miscommunication or misunderstanding in healthcare can create an unsafe environment for patients (The Joint Commission, 2007). In the U.S., an estimated 90 million people have basic or below-basic HL skills. Only approximately 12% of U.S. adults have proficient HL (Dageforde & Cavanaugh, 2013; Koh & Rudd, 2015). Low HL disproportionately affects people who are older, have lower educational attainment, and come from lower socioeconomic status communities. These risk factors for low HL are among the same risk factors for kidney disease. Therefore, people at risk of developing kidney disease often have greater challenges in understanding, managing, and being engaged in their healthcare (Dageforde & Cavanaugh, 2013).

STUDY 1: PATIENT EXPERIENCE

The first study was presented at the roundtable event to ensure that patients' voices would be included in the discussion. Members of the Rogosin team conducted interviews with 41 patients at six dialysis units around New York City. The interviews, approved by the Weill Cornell Medical College Institutional Review Board, were conducted as part of a patient engagement study to reduce disparities in kidney disease. Participation was completely voluntary. Staff members at CHAP conducted the interviews during patients' dialysis treatment. Some interview participants were selected at random, while others were approached based on recommendations from unit social workers and administrators. Interview questions gathered respondent demographics, information-seeking behaviors, and the level of understanding about their health conditions. Respondents were varied in gender (54% female, 46% male), age (range from 24 to 88; average age 66), race (37.5% White, 40% Black, 12.5% Hispanic/Latino, 7.55% Asian), and language spoken at home. The majority of respondents spoke English at home (85%); however, others spoke Spanish, French, Chinese, or Arabic. Language was a limiting factor in this study, because the researchers did not have translation services available while conducting the interviews. One of the researchers was fluent in Spanish and conducted one interview in Spanish; however, the remaining interviews were conducted in English. Respondents had been on dialysis for as short as two months and as long as 15 years.

Interviews were recorded, and results were entered into the REDCap (Research Electronic Data Capture) system, coded, and analyzed for common themes. Respondents were asked if they wanted to learn more about their kidney health and disease, and how they liked to learn. More than half of respondents (58%) wished they knew more. The majority of respondents (65%) shared that they received most information about their kidney health from their doctor, nurse, social worker, dietitian, or dialysis technician. Others received information from pamphlets, the Internet, books, or other patients. Respondents were also asked if they felt that videos about kidney health, brochures, group classes, or more time with a doctor or nurse would be helpful. The vast majority (84%) expressed a wish for more videos to help them learn about their kidney health. Nearly two-thirds (64%) felt that more brochures and written materials would be helpful, and over half of respondents (55%) were interested in group classes to learn more. When asked if more time with their doctor or nurse would be helpful, only one-third (36%) of respondents felt this would be helpful, stating they had ample time to ask questions of their healthcare team during their dialysis treatments. Additionally, respondents were asked a series of questions about their difficulty understanding medical materials, including patient education materials, medical forms, and care plans. As seen in Table 1, responses were varied; some patients had no trouble with medical materials while others found it extremely challenging and needed additional assistance to understand and follow medical materials and recommended care plans.

Respondents were also asked about their comfort level with technology and their interest in using technology-based educational materials, including tablets to view videos and interactive programs. Approximately half (51%) of respondents had used the Internet to research their health condition, and 53% owned a smartphone or tablet. When asked if they would use tablets to view educational materials during their treatment if they were provided by the unit, nearly three-quarters (71%) said they would, and the vast majority (88%) said they would watch educational videos during treatment or at home if they were available on the Internet.

Responses to questions about what sort of information and support these patients felt were missing from their healthcare experience were varied. Many respondents shared that they wished they had more information at the time of diagnosis, possibly in the form of structured courses leading up to the start of dialysis. Some wished they had a better understanding of how the dialysis machines worked. Others wanted for more information was available about access and reasons for fistulas versus catheters. Many respondents wanted more information about the transplant process. Patients expressed a desire for educational materials in more languages to improve the understanding of non-native English speakers.

In addition to information, many respondents wanted more emotional support—for themselves, their families, and their care partners. They wished there were more ways to engage their families and care partners in their healthcare. This reflects the importance of the NSW's role in providing emotional support for adjustment to chronic illness, an important step toward patient engagement and empowerment for self-management of care.

Analysis of the interview responses revealed a number of key themes related to improving HL, including:

- The importance of tailoring patient information to the individual's experience and cultural background.
- The importance of addressing mental health challenges that patients face.
- Everyone needs more support as they cope with and navigate their diagnosis; even individuals with the best personal support systems need more support.
- Honest communication between providers and patients is essential.
- Patients can—and should—play a significant role as advocates in their communities to educate their peers about kidney disease prevention and to improve health outcomes for people at risk for kidney disease or those who have been diagnosed. When patients take a lead role in outreach and education, information can be delivered in a way that is relatable and accessible for diverse communities.

STUDY 2: NEPHROLOGY SOCIAL WORKER SURVEY

To learn more about the current status of HL in settings that serve kidney patients, an informal survey was developed, approved by the Council of Nephrology Social Workers' (CNSW) Executive Council, and then distributed to CNSW members in January 2015. The 10-item questionnaire was sent via the CNSW general listserv. Over the course of three weeks, 66 responses were received, representing approximately 10% of the CNSW membership. Eighty-six percent of those respondents were working in a dialysis setting and 14% in transplant.

This is a summary of the responses by CNSW members. No statistical analysis was conducted. Results can be seen in Table 2.

Based on the survey responses, NSWs view HL efforts as an important component in patient education and self-care management. However, few clinics currently measure the HL skills of patients. For a clinic to implement the use of HL techniques effectively with all staff, respondents believed there was a need for systematic implementation of HL education and skills training in the clinical setting. NSWs report being comfortable in the role of assessing HL, which is done by asking open-ended questions, usually during the psychosocial evaluation assessment. Common questions include:

- Can you tell me what your doctor has told you about your kidney problems?
- What do you know about why you need dialysis?
- What medications do you take, and what are they for?

More concrete questions that have an impact on HL concerns include:

- Who, if anyone, comes to doctor's appointments with you to listen and ask questions?
- Do you prefer to complete medical forms on your own, or do you want assistance?
- Do you have vision or hearing concerns?
- Which language do you prefer to use when speaking or reading about your healthcare needs?

Table 1. Patient Understanding

Question	Answer	Percentage
How often do you have someone (family member, friend, hospital/clinic staff, caregiver) help you read medical materials?	Always Often or sometimes Never	23 15 62
How often do you have problems learning about your medical conditions because of difficulty understanding written information?	Always Often or sometimes Never	3 31 66
How often are medical forms difficult to understand and fill out?	Always Often or sometimes Never	17 43 40
How often do you have difficulty understanding and following your annual care plan/planning information you receive?	Always Often or sometimes Never	29 27 44

Although NSWs feel fairly comfortable with HL, they mainly use open-ended questions, and only half use teach back techniques routinely; very few are aware of the validated tools to assess HL. This survey suggests that they would like more training to develop formal HL skills.

MOVING FORWARD

Based on the results of both studies, it is clear that patients want more information in a clear and informative manner, plus more support. NSWs are interested in more training to develop HL skills. Practical tools and techniques that NSWs and other healthcare providers can use include:

- *Using "universal precautions" for HL*: Providers have traditionally assumed that patients understood the information they presented unless questions were raised to suggest otherwise. Universal precautions take the opposite approach and assume that patients may have difficulty understanding healthcare information. The concept promotes the use of simple language, patient support services, and the creation of an easily navigated health system or office environment (AHRQ, 2015).
- *Using teach-back:* Asking patients to summarize what the clinician told them in their own words. This allows a provider to determine whether or not they were successful in providing the information clearly. Practitioners, including NSWs, can say to a patient "Help me see if I left anything out by telling me in your own words what you understood," which places the burden of communication and understanding on the provider instead of the patient (AHRQ, 2015).
- *Asking patients, "What questions do you have?"* instead of "Do you have any questions?" This technique encourages asking questions.
- *Using simple drawings and models* to help explain complex medical concepts.
- *Limiting information shared* to two or three points at a time, to prevent overwhelming a patient or their family.

With more training in the use of these validated tools and techniques to improve HL, both NSWs and patients can benefit, improve health outcomes, and increase active participation in care. NSWs can help patients navigate the healthcare system and direct them to high-quality information that is available and accessible.

The Institute of Medicine released a report in June 2012 listing 10 attributes of a health-literate organization, or organizations that actively work to improve patient experience and ease of navigation of healthcare systems and services. These attributes include:

1. Leadership that is actively engaged in HL;
2. Integration of HL into all aspects of organizational planning, evaluation, and quality improvement initiatives;
3. A well-prepared and trained workforce;
4. Inclusion of patients or population served in the design and development of materials and services;
5. Meeting the needs of population served while avoiding stigmatization;
6. Consistent use of HL tools and strategies in all levels of communication;
7. Readily available health navigation services and information;
8. Distribution of different forms of easily understood health information;
9. A focus on addressing the needs of high-risk patients and situations; and
10. Open communication about fees and health insurance coverage. (Brach et al., 2012).

Improving HL skills can help kidney care facilities improve health outcomes. To implement the needed systematic changes, support must come from the top down.

Social workers are trained to listen more than talk, to observe verbal and non-verbal cues, to interact in a culturally sensitive manner, and to rephrase questions. Medical social workers tend to do their most important work after the other healthcare team members leave the room; the often panic-stricken patient and family members turn to the social worker with fear in their eyes and questions. NSWs can clearly and calmly explain the complex medical terms and treatment options, plus encourage a shocked patient to consider what works best within the patient's lifestyle, wishes, resources, and support system. NSWs know to "begin where the patient is," and slowly and surely work toward the goals set by the patient and provider. This is done while encouraging any necessary behavioral change, suggesting referrals to resources, and helping the patient help themself.

These surveys indicate the interest in and need for validated health-literate communication for both patients and NSWs. Based on their relationships with patients and families, NSWs have an opportunity to play a leadership role in advancing HL and moving their organization towards health-literate status. Our survey found that NSWs are interested in improving HL within their clinics, enabling patients to truly understand their medical status become empowered to take control of their health. Informed patients are more likely to actively participate in self-care, leading to improved health outcomes. NSWs, together with patients, can implement systems, programs, and support that will increase HL among the communities served that will ultimately improve health outcomes and quality of life.

Table 2. NSW Survey Results

Question:	Answer	Percentage
Health Literacy is assessed at my clinic.	No Yes	70 30
If HL is assessed, which staff member does it?	Facility MSW Facility RN Nephrologist Dietitian CKD Educator Primary Care Provider CKD (pre-dialysis) MSW	36 20 17 15 5 4 3
Is HL assessed during the psychosocial evaluation?	Yes, all of the time None of the time Only when indicated (i.e., if low education level or non-English speaking) Most of the time Sometimes Rarely	32 26 20 12 7 3
A patient's education level is a good indication of HL.	No, but is commonly used No Yes	58 27 15
I am comfortable with my skills to provide good communication in a HL manner.	Yes Would like more guidance No response	73 24 3
I use techniques such as "teach back" or asking patients to repeat instructions in their own words to ensure that patients and families understand.	Most of the time Sometimes Rarely Never	44 39 11 6
HL is an important issue that: (Respondent could check multiple responses.)	Needs to be addressed Will require a systematic, interdisciplinary change within my clinic Not a focus at my clinic Needs to be addressed, but not a priority for me	70 47 27 9
What tool is used to assess HL?	Open-ended questions (no validated tool) Single Item Literacy Screener Short Assessment of HL (SAHL) Rapid Estimate of Adult Literacy in Medicine	96 2 1 1

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