The Nurse’s Role in Health Literacy of Patients With Cancer

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Patients with cancer are often faced with complex diagnoses that require decision making in a highly stressful environment. The role of the healthcare team is to ensure that patients have the information, tools, and resources needed to make informed decisions. However, low health literacy is a common and undervalued factor in the outcomes of patients, particularly those with cancer.

At a Glance
- An individual’s health literacy depends on various factors, such as education, culture, and complexity of the information.
- Oncology nurses are in a unique position to model and apply best practices for health literacy using evidence-based oral and written communication strategies with their patients.
- Implementing the fundamentals of universal precautions and the teach-back method are effective deterrents to the negative outcomes associated with low health literacy.

Numerous skills are needed for individuals to obtain health information and make decisions regarding their health care. Unfortunately, almost half of all American adults—90 million people—have limited health literacy (Kutner, Greenberg, Jin, & Paulsen, 2006; Nielsen-Bohlman, Panzer, & Kindig, 2004; Rudd, Anderson, Oppenheimer, & Nath, 2007). Defined as “the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Nielsen-Bohlman et al., 2004, p. 32), health literacy has many components beyond print literacy that influence a person’s ability to make healthcare decisions, including numeracy, oral literacy, and media literacy (Oldach & Katz, 2015). Health literacy is also a multifaceted concept that is often difficult for healthcare providers (HCPs) and researchers to completely grasp, measure, and understand.

A person’s health literacy depends on a number of factors, including education, culture, and complexity of the information at hand. Patients with cancer are expected to make difficult and often complex decisions regarding diagnosis and treatment at a time that is often physically and emotionally distressing (Dumenci et al., 2014). These circumstances will affect that person’s health literacy and, ultimately, his or her ability to access healthcare services, use preventive measures, make healthcare decisions, adopt healthy behaviors, follow healthcare advice, and communicate with HCPs (Agency for Health Care Research and Quality [AHRQ], 2010). Treatment options may not be fully understood; therefore, some patients with cancer may not receive the treatment that best meets their needs. Low health literacy also adversely affects cancer incidence, mortality, and quality of life. For example, information on cancer screening may be ineffective, and patients may, in turn, be diagnosed at a later stage (National Network of Libraries of Medicine, 2013).

Scope of the Problem

The U.S. Department of Education assesses health literacy using the National Assessment of Adult Literacy (NAAL) (National Center for Education Statistics, n.d.-c). Capturing a nationally representative assessment of English literacy among American adults aged 16 years or older, the NAAL project has been collecting data since 1992. In 2003, changes were made to the data collection to specifically measure health literacy. These changes allowed the data to demonstrate differences between the ability to read in general and the ability to read and apply health information. NAAL added three different health-related categories of tasks to help quantify health literacy: clinical, prevention, and navigation (National Center for Education Statistics, n.d.-b). Questions assess the participant’s ability to fill out a patient form or read a drug label (clinical tasks), understand the need for preventive health services (prevention), and...
determine health insurance benefits or eligibility (navigation) (National Center for Education Statistics, n.d.-b). Scores from those three categories, combined with the baseline literacy test, comprise the health literacy score (Kutner et al., 2006).

The 2003 NAAL grouped the more than 19,000 participants into four literacy levels based on the results: below basic (14%), basic (22%), intermediate (53%), and proficient (12%) (National Center for Education Statistics, n.d.-a). From below basic to proficient, the tasks that a person can complete with accuracy get progressively more complex (National Center for Education Statistics, n.d.-b). The findings indicate that only 12% of U.S. adults are considered proficient in health literacy and have the health literacy skills needed to navigate the complex medical system (AHRQ, 2010).

Management

Following health literacy universal precautions means acting in a manner that assumes all patients are at risk for having difficulty comprehending health information and accessing health services. Just as universal precautions are used by all HCPs to prevent exposure to and transmission of pathogens in the blood and other bodily fluids, the concept of health literacy is based on the assumption that every patient has low health literacy, every time, necessitating the need for providers to practice health literacy precautions. Studies have shown that all patients, regardless of health literacy level, appreciate straightforward communication tactics from their HCPs; they are not offended by and do not think poorly of the HCP who is practicing health literacy precautions (Garcia, Hahn, & Jacobs, 2010). Knowing the health literacy level of an individual patient is virtually impossible; in addition, that level may change over time because health literacy levels are not a static characteristic. Although many tools are available to screen patients, they are time-consuming and not well researched as part of the practice environment (Altin, Finke, Kautz-Freimuth, & Stock, 2014). Following health literacy universal precautions means using a variety of tools to ensure that written and oral communication is clear, concise, and easy to understand (National Institutes of Health [NIH], 2015). These tools guarantee that appropriate oral communication strategies are used in conjunction with suitable written communication strategies, and that both are always followed up with the teach-back method.

Communication Strategies

When considering health literacy universal precautions, the first rule in communication is to use plain language. Plain language is simple, everyday language that precludes medical jargon. The HCP should speak slowly, without rushing, and start with the main objectives. Encouraging patients to ask questions about the main objectives is a strategic approach that allows the patient to drive the depth of the discussion. Key messages should be repeated to help the patient retain important information (Brega et al., 2015).

In addition to using simple oral communication strategies, the HCP can supplement this exchange with written communication. The principles of written communication are similar to those of oral communication. Written plain language is operationalized as a reading level of fifth grade or below. Written materials should be limited to three main points with images that are relevant to the text. Plenty of white space should be left on the page because a crowded page may be overwhelming for patients (NIH, 2015). Perhaps most importantly, the HCP should remember to use written materials as a tool to help patients understand and retain information. HCPs should interact with their written materials by crossing out irrelevant or unimportant information and highlighting the information that is essential to knowledge.

Case Study

M.J. is a married 67-year-old retired pediatrician and mother of three grown children who was recently diagnosed with left breast invasive ductal carcinoma. She completed a lumpectomy and sentinel lymph node biopsy and is scheduled to begin adjuvant chemotherapy in one week for her T2N0 cancer. She has just received the first day of a highly emetogenic regimen and is going home with a complex antiemetic regimen of as-needed and scheduled medications, including dexamethasone (Decadron®) 8 mg once daily for three days, aprepitant (Emend®) 80 mg once daily for two days, and prochlorperazine (Compazine®) 10 mg every 6 hours as needed for breakthrough nausea. M.J.’s care team needs to be sure she has a clear understanding of how to take her antiemetic medications at home to prevent chemotherapy-induced nausea and vomiting. M.J.’s nurse prints some information regarding each medication from the Internet. She gives the papers to M.J. and tells her to take the aprepitant and dexamethasone once daily until the pills are gone and to use the prochlorperazine as needed. M.J. nods in understanding, and the nurse says, “These medications will help control potential emesis. Do you have any questions?”

Although M.J.’s nurse technically did her job instructing M.J. about her new medications, she missed several opportunities to use best practices and ensure the transfer of information. She assumed that M.J. had high health literacy because she was a pediatrician. She ignored the possibility that a pediatrician may have no experience with chemotherapy and complicated drug regimens, or that M.J. may be highly stressed and anxious, rendering her unable to focus on learning. The following is an example of how M.J.’s nurse could improve:

M.J.’s nurse consulted her patient education department for approved drug information materials. She crossed out the information that was not applicable to M.J., highlighted the three most important points about each medication, and made a simple chart showing M.J. when to take each medication. She sat down next to M.J. as she explained the regimen, stating, “You will take the aprepitant in the morning for the next two days and the dexamethasone in the morning for the next three days. You can take the prochlorperazine as often as every six hours as needed for nausea.” M.J. nods in understanding, and the nurse says, “I want to make sure I told you the right schedule. Can you tell me how you are going to take each medicine when you get home?”

In this example, the nurse spoke in plain language and avoided medical jargon. She ensured that printed materials met written communication best practices. The environment was respectful and shame free. M.J.’s nurse sat down, offered plenty of time for discussion, and asked open-ended questions. Although doing so may have taken the nurse longer to ensure that M.J. fully understood her medications, it also decreased the chances that M.J. would have to call the clinic with questions, need additional medication, or, worse yet, suffer from nausea and vomiting because of incorrect use of medications.
Teach-Back Method

Many patients are not simply auditory or visual learners; instead, they need a variety of communication strategies. The teach-back method is a way to ensure that the necessary, intended information has been transferred from the HCP to the patient (Brega et al., 2015). Similar to the nursing practice of having a patient perform a return demonstration with a skill needed for home care, the teach-back method requires the patient to explain back to the HCP what was taught. The HCP can then make any necessary clarifications until the patient has successfully “taught back” (Brega et al., 2015). If the patient has not fully grasped the information, the responsibility is on the HCP to tailor and clarify the information to the patient. In other words, the HCP must create a shame-free environment by indicating that any miscomprehension is because of the HCP’s miscommunication and not the patient’s inability to learn.

Implications for Nursing

Health literacy is an important mediator in all patient communication strategies. Patients cannot be expected to participate fully in their care or make appropriate health decisions without information that is sensitive to their health literacy needs. Oncology nurses are in a unique position to create a health literate environment by acting as role models for the entire healthcare team. Figure 1 provides a list of resources about health literacy for HCPs.

References


Conclusion

The inability to understand simple health information is a common, yet often overlooked, experience of patients. Health literacy is the term used to describe the capacity to which patients can comprehend and make decisions about their health care. Because health literacy is a difficult concept to measure in clinical practice, the practice of universal precautions for all patient interactions is the standard of care. In the context of health literacy, universal precautions involves the practice of plain language (written and oral) and the application of the teach-back method. The HCP is ultimately responsible for the success or failure of every patient interaction and transfer of knowledge. Using the universal precautions techniques and practices, HCPs can successfully and effectively give patients the information that is critical to their health and wellness.

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