Purpose/Objectives: To review the need for reading assessments for patients with cancer, review existing reading assessment tools, and make a case for a new tool specific to patients with cancer.

Data Sources: Published articles, experiences, and discussions with published authors in the field of literacy.

Data Synthesis: Valid and reliable tools that assess word recognition and comprehension exist for general use in health care. Word-recognition tests do not always predict comprehension, and a commonly used comprehension test has sections assessing only very low, second year of high school, and graduate-level skills.

Conclusions: A new tool, developed specifically for patients with cancer, may better capture reading ability and comprehension. It is being evaluated for use in a clinical setting.

Implications for Nursing: If nurses know their patients’ reading levels, they can plan more effectively for teaching self-care and discussing decision making. Outcomes related to health and satisfaction may improve if poor readers are given materials they can understand.

The Case for Development of a New Test of Health Literacy

Patricia Agre, RN, EdD, Ezra Stieglitz, PhD, and Glen Milstein, PhD

The American Medical Association (1999) defined health literacy as a “constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment” (p. 553). Healthy People 2010 said it is “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (U.S. Department of Health and Human Services, 2000). The National Adult Literacy Survey (NALS) of 1993 revealed that 90 million adults in the United States have low or inadequate reading skills, with 40 million–44 million being unable to locate information in a paragraph if inference was necessary (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993). Low health literacy is a significant problem associated with suboptimal use of medical screening (Davis et al., 1996, 2001; Dolan et al., 2004), poor health outcomes (Bennett et al., 1998; Williams, Baker, Parker, & Nurss, 1998), and high use of healthcare services (Berkman et al., 2004; Lindau, Tomori, McCrville, & Bennett, 2001; Marwick, 1997; Parker et al., 1999). Patients who cannot read well may not be able to decode directions on prescriptions, follow written directions for self-care activities, understand consent information, or learn about important health screening activities. As the extent of the problem has become clearer, research and discussion articles on the topic have increased.

People with low health literacy skills do not volunteer the information readily. Using literacy assessment tools to determine reading levels has become more common and more accepted, especially in hospitals serving at-risk populations, such as immigrants, people who fall below the poverty line, and those on Medicaid (Foltz & Sullivan, 1998; Gazmararian et al., 1999; Wilson, 1995). Unfortunately, even though the NALS report is cited frequently in medical literature, reading assessment is not standard in health care. Most practitioners spend time teaching one on one, but that may not be enough to ensure that patients receive, understand, and retain the information provided (Mayer & Villare, 2004; Schillinger, Bindman, Wang, Stewart, & Piette, 2004). Patients with low literacy skills often have less knowledge about their diseases (Gazmararian, Williams, Peel, & Baker, 2003; Mayer & Villaire; Williams et al., 1998), and they may not remember complex health messages.

Key Points . . .

➤ Inadequate health literacy is a significant problem.

➤ Using literacy assessment tools to determine reading levels is becoming more common and more accepted, especially in hospitals serving at-risk populations.

➤ Although valid and reliable reading assessment tests exist, a new, cancer-specific reading assessment tool, the Stieglitz Informal Reading Assessment of Cancer Text, may be more acceptable to patients because it can be linked directly to a patient’s need to understand self-care instructions and an institution’s obligation to provide such material.

➤ The discussion of the need for literacy assessments must move into the mainstream rather than being limiting to professionals interested in literacy issues and to institutions that serve predominantly minority, immigrant, or low socioeconomic patients.

Patricia Agre, RN, EdD, is the director of patient and family education at Memorial Sloan-Kettering Cancer Center in New York, NY; Ezra Stieglitz, PhD, is a professor of elementary education at Rhode Island College in Providence; and Glen Milstein, PhD, is an assistant professor of psychology at the City College of New York. Mention of specific products and opinions related to those products do not indicate or imply endorsement by the Oncology Nursing Forum or the Oncology Nursing Society. (Submitted April 2005. Accepted for publication May 24, 2005.)

Digital Object Identifier: 10.1188/06.ONF.283-289

283