

Understanding Health Literacy in Patients Receiving Hematopoietic Stem Cell Transplantation

Marlene Z. Cohen, PhD, RN, FAAN, Debra Jenkins, MSN, RN, Ezra C. Holston, PhD, RN, and Elizabeth D. Carlson, PhD, RN

Hematopoietic stem cell transplantation (HSCT) has become the standard of care for many patients with disorders of the hematopoietic system, such as hematologic malignancies (Gratwohl et al., 2010). Because this treatment has significant morbidity and mortality, understanding what it means for patients is important in shaping interventions to help them.

Patients with cancer typically report that they want to know all the available information about their type of cancer and its treatment, but they often are overwhelmed by the amount of information provided by clinicians, the mass media, and the Internet (Epstein & Street, 2007). Strategies to ensure that patients are informed are important. A systematic review by Husson, Mols, and van de Poll-Franse (2011) found that cancer survivors who had fulfilled information needs were satisfied, experienced fewer information barriers, and had less anxiety, depression, and better health-related quality of life. Another review found that low health literacy was associated with worse health outcomes (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011).

The Institute of Medicine (IOM, 2004) defined health literacy as “the degree to which individuals have the capacity to obtain, process, and understand the basic health information and services they need to make appropriate health decisions” (p. 32). This report also stated that health literacy includes the individual and depends on the skills, preferences, and expectations of health information from care providers, the media, and many other sources. Effective communication requires many skills, including both the patient and clinician understanding each other’s perspectives, the health condition, and the purpose of the interaction (Epstein & Street, 2007). Lack of health literacy in patients can be a major barrier to communication.

Low health literacy has been associated with several adverse health outcomes (Dewalt, Berkman, Sheridan, Lohr, & Pignone, 2004) and also may be important in explaining health disparities (Sentell & Halpin, 2006).

Purpose/Objectives: To describe the meaning of patients’ experiences with hematopoietic stem cell transplantation (HSCT), with a focus on health literacy.

Research Approach: A hermeneutic phenomenologic approach that combines descriptive and interpretive methods.

Setting: A National Cancer Institute-designated comprehensive cancer center in the southern United States.

Sample: 60 individuals who underwent HSCT; 20 Latino, 20 African American, and 20 Caucasian.

Methodologic Approach: In-depth interviews were conducted on five separate occasions. Interviews and analysis of verbatim transcripts used phenomenologic techniques.

Findings: The themes were as follows: they did not tell me, decision dilemmas, fears of dying, tough symptoms and side effects, and relying on others. These themes were found in all ethnic groups, both genders, and at all time points.

Conclusions: The themes from this study demonstrate that health literacy concerns are vital to patients’ understanding, decision making, and having active roles in their health care. Assessing patients’ understanding is important and requires a comprehensive approach because patients may not know what they need to ask and may not feel comfortable asking or raising objections because their fears, particularly that of dying, are barriers.

Interpretation: This article provides evidence that health literacy is not a simple function of age, ethnicity, race, or education. Health literacy and communication concerns require a more nuanced approach to provide optimal patient-centered outcomes.

Knowledge Translation: Understanding patients’ perspectives is vital to knowing what to communicate, how to communicate, and when to provide information. Providing information in a way patients can understand reduces risks for negative outcomes. A comprehensive assessment of patients’ understanding using improved education materials, clearer forms and communication techniques, teach-back methods, and reinforcement is needed to improve communication, particularly when illness and treatment evoke fears.

The purpose of the current study was to describe the meaning of patients’ experiences with HSCT over time. The authors selected participants from three ethnic