

Infusing Culture Into Oncology Research on Quality of Life

Kimlin Ashing-Giwa, PhD, and Marjorie Kagawa-Singer, PhD, MN, RN

Purpose/Objectives: To review the literature relevant to understanding culturally informed oncology research, particularly as it relates to health-related quality of life.

Data Sources: Published articles and books.

Data Synthesis: A cultural perspective to the prevailing theory and research methods used in oncology research with respect to quality of life is imperative. A multidimensional and practical framework can be applied to increase cultural competence in research by addressing the purpose of the research, theoretical framework, and methodologic approaches.

Conclusions: Culturally competent, multicultural research will help the scientific community better comprehend disparities that exist in health-related quality of life so that benefits can be experienced by all patients.

Implications for Nursing: Nursing practice and research must continue its leadership role to infuse cultural competence and reduce disparities in the healthcare system.

Key Points . . .

- Nursing research has championed the inclusion of cultural competency within healthcare systems, and the Oncology Nursing Society embraces cultural competency as a strategy for reducing health disparities and promoting well-being among all communities.
- Ethnic minority populations will comprise the majority of the U.S. population by 2030 but currently are underrepresented in health-related quality-of-life studies and have poorer outcomes from cancer than European American populations.
- A theoretical and practical paradigm exists for blending cultural relevance and science for quality-of-life investigations.

Cancer is the second-leading cause of morbidity and mortality in the developed world as well as in some developing countries (World Health Organization, 2003). In 2005, more than 1.3 million people were diagnosed with cancer and approximately 9.8 million were living with a history of the disease in the United States (American Cancer Society, 2005). However, cancer outcomes are not equal across racial and ethnic groups. People of color bear an unequal burden of cancer (Hayes & Smedley, 1999), and although the most common cancer sites are the same for women (breast, colon, and lung) and men (prostate, colon, and lung) of all ethnic groups, the outcomes are not (American Cancer Society) (see Table 1). Cancer can be deadly, but it often is curable if diagnosed and treated in early stages. The five-year survival rates for all racial and ethnic groups for breast, prostate, and colon cancers are 88%, 99%, and 63%, respectively; however, the overall survival rates are lowest for African Americans, American Indians, and Latino Americans (American Cancer Society). Advances in treatment and increases in survival rates have generated significant research regarding the health-related quality of life (HRQOL) of cancer survivors, yet these studies only recently have begun to focus on the need for culturally competent research, with the Oncology Nursing Society (ONS) providing much of the leadership. This new direction is mandated by demography, disparity, and equity.

The demographic makeup of the United States is becoming increasingly diverse. In 2000, 35.3 million were Hispanics and Latinos, 211.5 million were European Americans, 34.7 million were African Americans, 11.2 million were Asian

Americans, 2.5 million were American Indian or Alaskan Natives, 1.2 million were of Arab or Middle Eastern descent, more than 874,000 were Pacific Islanders, and 6.8 million were multiracial or multiethnic (Grieco & Cassidy, 2001). Moreover, from 1990–2000, the population percent increase by ethnicity was Hispanic 58%, Asian 48%, Arab or Middle Eastern 38%, American Indian and Alaskan Native 26%, African American 16%, and European American 6% (Barnes & Bennett, 2002; de la Cruz & Brittingham, 2003; Grieco, 2001; Guzman, 2001; McKinnon, 2001; Ogunwole, 2002). The non-native U.S. population (of which Latin Americans and Asians comprise the largest groups) increased by 57% in that same time frame (Malone, Baluja, Costanzo, & Davis, 2003). Ethnic minority populations will comprise the majority of the U.S. population by 2030, will have poorer outcomes of cancer than European American populations, and currently are underrepresented in HRQOL studies. Research in HRQOL must consider diverse groups so that clinicians can fully understand survivorship outcomes and experiences.

Nursing research has championed the inclusion of cultural competency in healthcare systems, and ONS embraces cultural

Kimlin Ashing-Giwa, PhD, is a senior researcher at the Center for Culture and Health in the School of Medicine and Marjorie Kagawa-Singer, PhD, MN, RN, is an associate professor in the School of Public Health, both at the University of California, Los Angeles. (Submitted May 2005. Accepted for publication September 19, 2005.)

Digital Object Identifier: 10.1188/06.ONF.S1.31-36