

Infusing Culture Into Oncology Research on Quality of Life

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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

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Table 1. U.S. Cancer Incidence, Mortality, and Survival Rates^a for 1997–2001 by Gender and Race or Ethnicity

Race or Ethnicity	Incidence Rate	Mortality Rate
Women		
African American	400.1	196.5
Non-Hispanic White	429.8	165.5
Asian or Pacific Islander	302.8	100.5
Hispanic or Latina	309.9	111.6
American Indian or Alaskan Native	222.5	113.4
Men		
African American	689.2	347.3
Non-Hispanic White	556.5	245.5
Asian or Pacific Islander	385.9	151.2
Hispanic or Latino	419.8	174.0
American Indian or Alaskan Native	263.2	167.0

^a Per 100,000, age-adjusted to the 2000 U.S. standard population

Note. From "SEER Cancer Statistics Review, 1975–2001," by L.A.G. Ries, M.P. Eisner, C.L. Kosary, B.F. Hankey, B.A. Miller, B.A., et al. (Eds.), 2004. Retrieved November 18, 2005, from http://seer.cancer.gov/csr/1975_2001. Reprinted with permission.

competency as a strategy for reducing health disparities and promoting well-being among all communities. Thus, the goal of eradicating health disparities lies in the provision of state-of-the-art health care and equitable access to quality care for all. ONS champions diversity and has adopted policies to foster culturally inclusive and responsive healthcare organizations, patient care, and research practices. The ONS (1999) guidelines for multicultural oncology nursing present strategies for achieving cultural competence in education, research, and practice.

The need for the inclusion of culture in the arena of HRQOL research is compelling. This article is informed by decades of behavioral health research with multiethnic populations, as well as the growing body of ethnomedical health disparities and HRQOL literature. A brief overview of culture and cancer is presented, as well as developments in theoretical and methodologic frameworks and paradigms to increase cultural relevance in cancer control studies.

Relationships Between Culture and Health-Related Quality of Life

HRQOL is demonstrably an excellent conceptual model with a good structural framework by which researchers can assess and understand the impact of cancer and its treatments on patients (Aziz & Rowland, 2002; Padilla, Grant, Ferrell, & Presant, 1996). But how can the variability in contexts such as culture, socioecologic status, and demographic characteristics be accommodated? Variations exist in the conceptualization of and methodologic approaches to studying HRQOL in culturally diverse populations.

Culture prescribes a way of life for a group of people to ensure their survival and well-being and provides the beliefs and values that give life meaning and purpose (Kagawa-Singer & Blackhall, 2001; Kagawa-Singer & Chung, 1994). Culture also provides consistency and predictability in everyday social interactions and inevitable stressful life events, such as cancer (Kagawa-Singer, 1993). Thus, because QOL is a subjective, multidimensional experience involving a summary evalua-

tion of positive and negative attributes that characterize an individual's life, such as health and illness (Padilla, Grant, & Ferrell, 1992), assessments necessarily are made within a cultural context.

Developments to Increase Cultural Competence in Oncology Research

Purpose of Research

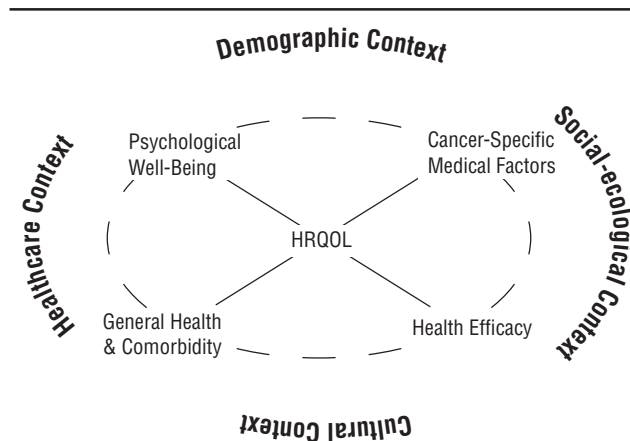
The purpose of research should include at least one deliverable community benefit that can be highlighted when a study is presented to the community. For example, Ashing-Giwa's (2005a) study on cervical cancer survivorship included a community forum to discuss the impact of cervical cancer on the lives of women and diverse communities in southern California.

A genuine concern for the community can facilitate studies that are conceptually and methodologically responsive to the population of interest. The expressed genuineness also promotes optimal community-research collaborative relationships (Ma, Toubbeh, Su, & Edwards, 2004; Tanjasiri, Kagawa-Singer, Nguyen, & Foo, 2002). Community-based participatory research is crucial to effectively examine and address health disparities. It demonstrates coleadership between traditional and community-based research partners in all components of the study, from development of research questions and methods to implementation, evaluation, and dissemination (Tanjasiri et al.). Community collaboration at all levels of the research process provides a better understanding of community needs, concerns, and capacities (Ma et al.) and improves validity, accuracy, and appropriateness of the research with ethnic minority communities (Kagawa-Singer, 2000). Therefore, a genuine interest in the target population forms the foundation on which the study builds and engenders cultural and socioecologic relevance (Ashing-Giwa, 2005a).

Expanding Conceptual Foundations for Multicultural and Health Disparities Research

A critical element of good research is the theoretical foundation. A well-organized theory provides a framework to (a) clarify the topic or area of interest, (b) govern the definition and conceptualization of the domains of interest, (c) generate hypotheses, (d) guide the measurement and instrumentation, and (e) ground the interpretation of the findings. One example of culturally contextualizing the theoretical foundation is the Contextual Model of HRQOL (Ashing-Giwa, 2005b) (see Figure 1). This framework explicitly incorporates the cultural and socioecologic domains to enhance the utility and validity of the HRQOL model for application to multicultural and health disparity studies.

The Contextual Model of HRQOL is informed by the traditional HRQOL Model, the Biopsychosocial Model (Committee on Population, 2004), more recent qualitative and quantitative studies with survivors from diverse ethnic backgrounds, the cancer and survivorship literature, and multicultural and psychological literature. The model includes socioecologic, cultural, demographic, and healthcare system contexts; general health and comorbidity; cancer-related medical factors; health efficacy; and psychological well-being. The domains may vary among and within ethnic groups and contain some generalizations about group membership. However, great cau-



HRQOL—health-related quality of life

Figure 1. The Contextual Model of Health-Related Quality of Life

Note. From “The Contextual Model of HRQOL: A Paradigm for Expanding the HRQOL Framework,” by K. Ashing-Giwa, 2005, *Quality of Life Research*, 14, p. 298. Copyright 2005 by Springer Science and Business Media. Reprinted with permission.

tion must be taken to avoid stereotyping. For example, ethnic minorities are overrepresented among lower socioeconomic standard (SES) groups in the United States. Although ethnic status unfortunately has been used as a proxy for SES, both dimensions should be disentangled and assessed. In this model, self-identified ethnic status and socioecologic and cultural contexts are distinguished.

Domains of the Contextual Model: The socioecologic context includes SES and life burden (e.g., neighborhood characteristics and resources, discrimination). SES is comprised of income, education, and employment status and history and, as with ethnicity, has been linked to survival prognosis: Lower SES predicts poorer survival rates (Freeman, 1991). Additionally, lower SES is a risk factor for poor QOL, including psychosocial distress (Adler et al., 1994; Ashing-Giwa, Ganz, & Petersen, 1999). Individuals from low SES groups have diminished access to timely and quality health care (Ashing-Giwa & Ganz, 1997; Elder et al., 1991; Freeman).

The cultural contexts should assess ethnicity (i.e., the integration of the geographic areas of ancestral origin and cultures [Ashing-Giwa, 2005b]), ethnic identity, acculturation, familial and community interconnectedness, attitudes and beliefs about illness and recovery, and spirituality. Culture influences health beliefs and practices, as well as overall well-being (Johnson, 1998; Kato, 1996; Sanders-Phillips, 1996). Culture can affect the meaning of cancer to the patient and family, care of the patient, and survivorship outcomes (Ashing, Padilla, Tejero, & Kagawa-Singer, 2003; Ashing-Giwa, Kawaga-Singer, et al., 2004; Ashing-Giwa, Padilla, Tejero, Kraemer, et al., 2004; Padilla & Kagawa-Singer, 1998; Ramirez, Suarez, Laufman, Barroso, & Chalela, 2000; Rodriguez, 1997).

An elemental cultural factor that may play an important role in cancer appraisal and HRQOL is spirituality (i.e., religious or spiritual faith, beliefs, and practices). Compared to European American cancer survivors, religious and spiritual beliefs and practices more often are endorsed by ethnic minority survivors as one of the most important coping resources

(Ramirez et al., 2000; Spencer et al., 1999). The results of several studies reveal a fair amount of spiritually infused optimism and hope despite tremendous cancer-related and socioecologic challenges, particularly among underserved ethnic minority survivors (Ashing-Giwa, Kagawa-Singer, et al., 2004; Ashing-Giwa, Padilla, Tejero, & Kim, 2004).

Additionally, healthcare systemic factors affect overall QOL, including access to cancer treatment and follow-up care, and quality of medical care (Freeman, 1991; Taylor et al., 2002). Historic and current disparities in the U.S. medical system (Hayes & Smedley, 1999; Smedley, Stith, & Nelson, 2003), such as the Tuskegee syphilis experiments, may be important factors dictating current health disparities.

Underserved, low SES individuals and ethnic minorities have limited access to health care because of high costs, lack of adequate health insurance, and reduced availability of adequate care facilities in many poor and rural communities. Language serves as an additional barrier, making navigating the healthcare system and patient-physician relationship even more problematic for ethnic and linguistically diverse minorities. Other practical problems, such the inability to take time off from work and lack of child care and transportation, may present competing demands and added stress during complex and lengthy cancer treatments (Asken & Florence, 1995; Hunt, de Voogd, Akana, & Browner, 1998). Additionally, ethnic minorities and underserved populations often do not have access to continuous, comprehensive, and state-of-the-art, quality medical care (Ashing-Giwa & Ganz, 1997; Padilla & Kagawa-Singer, 1998). Research demonstrates that ethnic minorities receive less and different care: African Americans are less likely to receive adjuvant treatments, and Asian Americans are more likely to receive mastectomies (Ashing-Giwa, Padilla, Tejero, Kraemer, et al., 2004; Hayes & Smedley, 1999). In addition to macrocontextual factors that impact HRQOL outcomes, other microcontextual and individual variables influence HRQOL, such as general health and comorbidity, health practice and utilization, cancer-specific medical characteristics, and psychological well-being (Ashing-Giwa, 2005b).

Methodologic Issues

In designing culturally responsive research, complex methodologic (procedural, protocol, instrumentation, dissemination) and structural (staffing) issues must be considered. Multiple methodologies as well as multiple methods of data collection also should be examined to increase the sample size and validity of the findings. Multiple methodologies may include combining qualitative and quantitative methods. Qualitative methods can provide necessary information about areas and populations about which little is known (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997; Strauss & Corbin, 1990; Waxler-Morrison, Doll, & Hislop, 1995), such as the influence of cultural and socioecologic contexts on health disparities in cancer survivorship. This information promotes a deeper understanding and the generation of new hypotheses (Ashing-Giwa, 2000; Waxler-Morrison et al.). Multiple data collection strategies may include key informants, focus group and in-depth individual interviews, medical chart reviews, mailed surveys, and telephone, face-to-face, or proxy interviews. Additionally, multiple sampling methods, including population-based, stratified, and snowball techniques, have been used to increase access to the available population of survivors and

to oversample African American, Asian American, and Latino participants who traditionally are underrepresented (Ashing-Giwa, Padilla, Tejero, & Kim, 2004).

The Research Team

Seven principles set the framework for a culturally responsive research protocol (Ashing-Giwa, 2005a): language competency, cultural competency, ethical conduct, mission or purpose, empathy, graciousness, and credibility. Language competency means that staff and research materials meet the linguistic and literacy need of the participants. To be ethically responsive and humanistic, a research team and all subject contact materials should be created to communicate effectively with the study participants. Language competency is essential for true informed consent and the validity of the study instruments. A culturally competent research staff possesses knowledge and sensitivity to participants' cultural origins, historic and current sociopolitical group status, and personal socioecologic and cultural context. In creating a research team, an investigator should assess for ethnic and cultural competency. Language and cultural competencies are probably the most important facilitators of research credibility and may prevent problematic ethical situations (Kagawa-Singer, 2000).

The research team should share the belief or mission that the study is purposeful and that the knowledge and understanding gained from the research can offer some benefit to participants or the target population, particularly those who are underserved (Ashing-Giwa, 2005a). The ability to genuinely experience and express compassion for the target population, as well as individual participants, is critical in gaining participants' trust. Additionally, empathy is essential for the facilitation of disclosure and thus the accuracy of the responses. Sincere gratitude (graciousness) is expressed to each participant who shares his or her cancer experience with the study. In addition, many studies provide some form of incentive or compensation for the participants' time. All members of the research team, including interviewers, should have basic knowledge about the illness, as well as resources available and accessible to participants.

Additional structural issues, such as appropriate staff training, may facilitate a respectful, culturally responsive research environment. The issue of staff training generally is overlooked in the research literature (Ashing-Giwa, 2000). An experienced, well-trained staff is one of the most valuable strengths of a research team. Staff trainings can be developed to increase competencies such as understanding basic cancer and QOL information, cultural and linguistic issues, ethical conduct, and informed consent. Ethical conduct involves (a) avoiding coercion and undue influence, (b) ensuring confidentiality within the limits outlined by the law (e.g., reporting requirements for child abuse, older adult abuse, and suicidality), (c) conducting appropriate closure or debriefing if necessary, and (d) providing appropriate referral to cancer-related community agencies and resources (e.g., American Cancer Society or National Cancer Institute's hotline or Web site if a participant requests more information on treatment and clinical trials). Staff training also should cover the research protocol and community-minded and patient-centered orientation (e.g., knowledge and information on the socioecologic contexts of the population of interest, active listening) (Ashing-Giwa, 2005a).

Instrumentation

Most cancer-related measures were normed using middle to upper-middle class European-descended samples treated at major medical hospitals with university affiliation or cancer centers. Therefore, the cultural appropriateness and validity of instruments for multicultural samples are of concern (Kagawa-Singer, 2000; Russell & Champion, in press). The challenge of finding reliable and valid instruments is even more formidable when the study goals include multicultural and cross-cultural comparisons (Ashing-Giwa, Padilla, Tejero, & Kim, 2004). At least four steps in the instrumentation and translational process are particularly pertinent when conducting multicultural and healthcare disparities research: (a) **conceptualization** (the constructs to be examined must be relevant across ethnic groups), (b) **regulation** (the items that measure the constructs are equivalent across ethnic groups [reliability]), (c) **interpretation** (the items and instructions must connote the same message or meaning across ethnic and linguistic groups), and (d) **validation** (the items must measure the exact concepts across ethnic and linguistic groups) (Marin, Sabogal, Marin, Otero-Sabogal, & Perez-Stable, 1987). Qualitative strategies such as the key informant and focus group interviews, as well as the research literature from various disciplines (e.g., psychology, anthropology, ethnic studies), can significantly enhance the cultural appropriateness of the research instrument and interpretation of the findings.

Summating Culturally Informed Conclusions

Results must be interpreted in the context of appreciating all of the possible limits of the study (Kagawa-Singer, 2000). However, clinical significance and translational utility of study results rarely are discussed. These issues are particularly relevant to nurses and nursing research. Social scientists may find qualitative methods helpful in addressing contextual issues that can inform clinical or translational applicability of quantitative studies. One useful strategy is the focus group interview that is organized to assist an investigator in clarifying the findings. Thus, a focus group conducted at the beginning of a study may be used to generate new items during the instrumentation development phase. In addition, a focus group held at the end of the study is used to summarize the findings, generate new hypotheses, and create recommendations for application in the community during the clinical translational phase (Ashing-Giwa, 2005a).

Dissemination

Dissemination of the knowledge and lessons learned is essential to develop clinical and translational utility. Culturally informed, community participatory research transmits the findings to the scientific and medical community as well as to the community of interest. Therefore, sharing the findings, in clinically useful and summary statements, with advocacy and survivorship organizations and participants is a small deliverable, research benefit to the community (Ashing-Giwa, 2005a; Kagawa-Singer, 2000). Community reports can take many forms—from informal discussions at community agencies (e.g., staff and board meetings) to a communitywide, stakeholders conference. A research community advisory board can provide a valuable service in the preparation and dissemination of the results. For example, willing board members who are trained can present study findings to their constituents.

In multicultural studies, the dissemination of findings may be a central function of community advisory board members because of the language diversity of the study participants.

Discussion

Survivorship studies reporting on ethnically diverse communities have concluded that survivors often draw from their cultural context (i.e., their ethnicity, ethnic identity, family and community interconnectedness, and spirituality) to cope with cancer. Therefore, many survivors find strength, purpose, and comfort in their connectedness to God or a higher power, their family, and the resilience of their group (Ashing-Giwa, Kagawa-Singer, et al., 2004; Ashing-Giwa, Padilla, Tejero, Kraemer, et al., 2004; Bourjolly, 1998).

Overall, cancer research is an important part of the commitment to reduce cancer incidence, morbidity, and mortality and to improve HRQOL. Ethnic minorities are overrepresented in cancer burden yet underrepresented in research. Consequently, the body of knowledge concerning cancer control with ethnic minority and underserved patients (Ashing-Giwa, 1999) and in HRQOL research in particular is limited. Selection of treatment regimens, design of public policies, and programs for cancer care are based on evidence of efficacy

and effectiveness, including the comparative impact of treatments on QOL. As a result, the weight of scientific evidence that underscores the unequal burden of disease endured by ethnic minorities and socioeconomically poorer countries and populations mandates the demonstration of culturally informed investigations of health care and health outcomes, including HRQOL. Health disparities research demands the inclusion of traditionally excluded populations and attention to complex issues, such as sociopolitical context, cultural context, network and community context, and microlevel and personal dimensions.

In conducting culturally competent, multicultural research, the scientific community may begin to forge mutually beneficial relationships with underserved communities and further the healing and recovery process from the justified and well-documented distrust of research studies among ethnic minorities. Furthermore, if cultural competence can be achieved in the healthcare system, the quality of care for patients with cancer of all ethnic backgrounds can be advanced and cancer disparities in HRQOL for all patients can be eradicated.

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