Comparisons Between Cancer Survivors and Family Members on Meaning of the Illness and Family Quality of Life

Suzanne Mellon, PhD, RN

Purpose/Objectives: To explore the meaning of the illness to the family and family quality of life (QOL) for survivors and family members and to describe similarities and differences between survivors’ and family members’ meaning of the illness and family QOL.

Research Approach: Descriptive, qualitative.

Setting: Homes of survivors and family members in an urban metropolitan area in the midwestern United States.

Participants: A sample of 123 Caucasian and African American cancer survivors, one to six years after treatment had ended, and their family members (N = 246). Four cancer diagnoses (i.e., breast, colon, prostate, and uterine) were represented.

Methodologic Approach: Two open-ended questions derived from a family model of survivorship. Content analysis was used to analyze the responses.

Main Research Variables: Meaning of the illness and family QOL.

Findings: The positive dimensions of survivorship in meaning of the illness and family QOL were seen for patients and family members, although long-term stressors also were reported. More similarities than differences in meaning and QOL were noted between survivors and family members.

Conclusions: Patients’ and family members’ perspectives of the meaning of the illness and family QOL are important to assess during survivorship to address both individual- and family-level perspectives in cancer care.

Implications for Nursing: Nurses should offer opportunities for patients and family members to search for positive meaning in the cancer illness, develop strategies to handle stressors that are present during survivorship, and enhance family strengths and resources to promote family QOL.

Key Points . . .

- Meaning of the illness and family quality of life identified by patients and family members show positive dimensions (e.g., increased valuing of life and family relationships, emphasis on health promotion, early detection) and ongoing concerns (e.g., having cancer in the family, fear of recurrence).
- Meaning of the illness has significance at both individual and family levels and is interrelated closely with family quality of life.
- Cancer survivors emphasized the importance of receiving support from others, whereas family members viewed support as enhancing quality of life.
- Further research on family survivorship is needed to explore the relationships between meaning and quality of life over time, family communication and coping strategies that promote quality of life, and the chronic stressors of survivorship.

Cancer survivorship, which begins at the time of diagnosis and continues throughout the remainder of life (Mullan, 1996), is critical to address as individuals continue to live years beyond their cancer diagnosis and treatment (Dow, Ferrell, Haberman, & Eaton, 1999; Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995; Ganz et al., 1996). Families experience the cancer illness with survivors, and strong support is evident in the literature for including family members when planning cancer treatment (Davis-Ali, Chesler, & Chesney, 1993; Lewis & Hammond, 1992; Morse & Fife, 1998; Northouse, Mood, Templin, Mellon, & George, 2000). However, a scarcity of research exists about family members during an extended survivor phase.

Major stressful events, such as a cancer illness, are influenced by the meaning that individuals and family members give to them. Although the meaning of the illness has been addressed with cancer survivors (Carter, 1993; Nelson, 1996; O’Connor, Wicker, & Germino, 1990; Taylor, 2000; Utley, 1999), few studies have examined the meaning of the illness to family members (Germino, Fife, & Funk, 1995; Hilton, 1996; Thorne, 1985; Wilson & Morse, 1991). In the past decade, quality of life (QOL) also has emerged as a critical outcome in cancer research (Aaronson et al., 1991; King et al., 1997). QOL is viewed as a subjective concept that is multidimensional and dynamic over time (Cella, 1994; King, 1998). Emphasis has been placed on individual QOL, but few studies have addressed the QOL of family members during the survivorship period.

Suzanne Mellon, PhD, RN, is dean of the College of Health Professions and McAuley School of Nursing, both at the University of Detroit Mercy in Michigan. This study was supported, in part, by the Surveillance, Epidemiology, and End Results National Cancer Institute contract #NO1-CN-65064 and the Helen Newberry Joy Foundation at Wayne State University in Detroit. (Submitted November 2000. Accepted for publication September 25, 2001.)