Determinants of Quality of Life in Patients Near the End of Life: A Longitudinal Perspective

Carla P. Hermann, PhD, RN, and Stephen W. Looney, PhD

The primary objective of care for dying patients is to maintain or improve their quality of life (QOL) (Byock, 2000). However, major gaps exist in the knowledge regarding many problems related to end-of-life care, including how to enhance QOL for dying individuals (National Institutes of Health [NIH], 2004). When cure and prolongation of life are no longer possible, the individual’s QOL and response to dying must be emphasized. The promotion of comfort and the enhancement of QOL become primary goals of nursing care (American Association of Colleges of Nursing, 1998). Most studies with dying patients have focused on hospice patients, but the majority of people in the United States do not receive hospice care when they are near the end of life (National Hospice and Palliative Care Organization, 2010). In fact, many patients with terminal illness actively seek treatment to prolong life or palliate symptoms. A high number of uncontrolled symptoms and a great amount of physical and psychological distress have been reported for patients who are nearing the end of life.

Although the literature examining QOL in patients near the end of life is small, patients in palliative care have been found to experience problems that affect all areas of their lives (McMillan & Weitzner, 2000). Diminished QOL often is seen as inevitable in the last stages of life; however, the limited research on QOL at the end of life has presented conflicted findings. Early work found that patients experience a dramatic decline in their QOL as they approach the end of life (Morris, Suissa, Sherwood, Wright, & Greer, 1986); however, QOL was assessed primarily as functional status, which is a limited measurement. In their extensive work with hospice patients, McMillan (1996), McMillan and Weitzner (2000), and McMillan and Small (2002) found this population to have a generally high QOL. Viewing QOL multidimensionally, McMillan (1996) and McMillan and Weitzner (2000) reported that patients’ QOL decreased primarily because of problems in physical functioning, although patients maintained a relatively high level of social and spiritual aspects of QOL. In patients with cancer newly admitted to hospice home care, McMillan and Small (2002) found widely varying but, again, relatively high QOL scores.

Purpose/Objectives: To describe the quality of life (QOL) of patients near the end of life and to identify determinants of their QOL.

Design: Descriptive, longitudinal.

Setting: University-affiliated cancer center, two private oncologists’ offices, and patients’ homes.

Sample: 80 patients with either stage IIIb or IV lung cancer newly diagnosed in the previous month or recurrent lung cancer with distant disease.

Methods: Patients were interviewed for responses to instruments to assess demographic, physical, psychosocial, and spiritual characteristics. Baseline data were collected at the patients’ places of oncology care. Home visits were made for the two-month and four-month data collection points.

Main Research Variables: QOL; symptom frequency, severity, and distress; functional status; anxiety; depression.

Findings: Fifty percent of patients died within five months of their lung cancer diagnosis. Patients reported a relatively high QOL that did not change significantly as they approached the end of life. Symptom distress was the strongest determinant of QOL, followed by symptom severity, symptom frequency, and depression.

Conclusions: QOL was most affected by symptoms experienced in patients with advanced lung cancer, particularly distress associated with symptoms. Interventions for symptom management must be implemented at diagnosis because patients in this population may approach the end of life quickly.

Implications for Nursing: A routine and thorough symptom assessment is imperative for patients with advanced lung cancer. Attention to symptom distress is important because of its effect on QOL.