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 conflicting 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.