Advancing the Psychosocial Care of Patients With Cancer at Life’s End: A Global Nursing Response

Betty Ferrell, PhD, MA, FAAN, FPCN, CHPN
2011 Mara Mogensen Flaherty Lectureship

Cancer remains a leading cause of death in both highly developed nations faced with an ever-aging population and in poor, developing nations that struggle with minimal healthcare resources for vast populations. In many nations, concurrent illnesses such as malaria, tuberculosis, and AIDS impact cancer care and the high mortality rates are accompanied by immense suffering due to factors such as lack of opioid availability and limited access to hospice or palliative care services.

In the United States, 570,000 people die of cancer annually and, worldwide, about 7.6 million people will die of cancer in 2011 (Jemal et al., 2011; Siegel, Ward, Brawley, & Jemal, 2011). For each of these people, the final chapter of their life can be not only a time of grief or suffering, but also an opportunity for profound healing, comfort, and growth. This opportunity is made possible by the expert psychosocial and physical care provided by compassionate and competent oncology nurses worldwide.

Elements of Nursing Care for Dying Patients

Palliative care has emerged worldwide based on the efforts of hospice to transform the culture of dying. The modern hospice movement from the 1970s to the present has advanced attention to physical, psychosocial, and spiritual care. Although there is tremendous diversity in nursing practice and resources worldwide, there are also many unifying elements that characterize nursing contributions to improve psychosocial care of patients with advanced disease and those who are dying.

The five elements I have observed over my 34 years in oncology nursing include

• Challenging the paradigm of care
• Creating expertise and knowledge in palliative care
• Fostering nursing presence
• Expert attention to the body and relief of symptoms
• A vision of the end of life as a spiritual experience.

I have identified these essential elements through observation of nurses throughout the world who we have come to know through our End-of-Life Nursing Education Consortium (ELNEC) project. ELNEC launched its first palliative care training program in 2001 and has since prepared over 12,500 nurses to serve as ELNEC trainers in all 50 U.S. states and now in 69 countries (American Association of Colleges of Nursing, 2011; Ferrell, Virani, Paice, Coyle, & Coyne, 2010; Malloy et al., 2011; Paice, Ferrell, Coyle, Coyne, & Callaway, 2007, Paice, Ferrell, Coyle, Coyne, & Smith, 2010). From Japan to Tajikistan, from Kenya to Russia, Romania to South Korea, nurses around the globe are improving the care of people with cancer at the end of life. Their work is a testament to our pioneers, such as Mara Mogensen Flaherty, and dedication to psychosocial care at this enormously important time of life.

Challenging the Paradigm of Care

Nurses have contributed greatly to psychosocial care by challenging existing paradigms of care. Oncology has evolved as a specialty with a focus on extending life or curing disease despite the reality of the high prevalence of advanced disease and deaths from cancer. Bringing attention to psychosocial needs requires challenging existing values, beliefs, and systems of care.

An excellent example of nurses challenging existing paradigms of care is within the Veterans Administration (VA) hospitals in the United States. The VA has made a major commitment to advancing palliative care and nurses have been at the forefront of these efforts. These VA nurses have challenged the practice of hospital deaths being hidden or silenced, with patients who die...