A New Specialty in Cancer Care?

I was intrigued by a recent issue of Cancer, a magazine for patients with cancer. A cover headline boasted new insight into palliative medicine, and the issue included an article by Joanne Kenen (2008) and an editorial by Betty Ferrell (2008). Palliative care has been an important part of cancer care as far back as hospice and end-of-life care, so how is it new?

Hospice has been around for a long time, yet there are still too few referrals too late in the process for patients and families to benefit completely. When I worked with patients and families and encouraged hospice, I often heard concerns about focusing on dying, with death being imminent, rather than on living. I would respond that hospice is really about expert symptom management focusing on quality of life. However, the main focus on hospice has shifted to emphasize palliative care. In 1997, the Institute of Medicine identified that the goals of palliative care are “to prevent, relieve, reduce, or soothe the symptoms of disease or disorder without effecting a cure. Palliative care in this broad sense is not restricted to those who are dying or those enrolled in hospice programs” (Field & Cassel, 1997, p. 31). It should be integrated from diagnosis throughout the life of the survivor.

I recently participated in the Thought Leader Summit by the Alliance for Excellence in Hospice and Palliative Nurses. The interdisciplinary group, consisting of nurses and physicians from oncology, gerontology, pediatrics, critical care, emergency medicine, home care, and long-term care, convened to identify major trends and issues to be addressed by the Alliance and its member organizations. In preparation for the meeting, I interviewed eight palliative care and hospice nurses in a variety of settings and roles. What I learned surprised me.

- The ratio of patients with cancer to those with other diagnoses receiving palliative care and hospice services has shifted to be almost equal from one that was predominantly cancer-focused. One factor influencing the trend is improvements in survival of patients with cancer. But do patients with cancer in need still access these programs and services? If so, when do they do so in their illness continuum?
- The place of death is shifting away from the hospital. How many patients with cancer die in long-term care facilities and hospice programs and services they need? Who is providing home care? What happens if there is no caregiver at home? And what happens to the caregiver who lives at home?
- Most patients using these programs are Caucasian. Why? Are we providing culturally sensitive care? If so, why aren’t minority patients accessing these services? What can be done to deliver culturally sensitive palliative and end-of-life care?
- Reimbursement issues are becoming outdated as place and type of care have shifted. To be eligible for hospice, expected life expectancy should be six months, yet we want to offer palliative care services from the time of diagnosis. Another issue is related to how hospice and palliative care services are accessed in a long-term care facility. There are conflicting reimbursement issues—if only one is able to be reimbursed, who gets paid?

I now realize that palliative care is the term being used to move hospice-related expertise and services earlier in the cancer continuum. In fact, the Hospice Nurses Association, incorporated in 1987, added palliative care to its name in 1998 to become the Hospice and Palliative Care Nurses Association. The National Palliative care is an essential component of high-quality cancer care. Let us not forget to relieve the suffering and burden of this disease—no matter where our patients and families are on the cancer continuum.