

EDITORIAL

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A New Specialty in Cancer Care?

I was intrigued by a recent issue of *Cure*, 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 Excel-

lence 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 those 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 or other community-based settings? Are they receiving the palliative and hospice programs and services they need? Who is providing home care? What hap-

pens 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



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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

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Everyone has at least one great story. Now, *CJON* has a forum for poetry, artwork, anecdotes, or stories about the meaning of cancer and cancer nursing. This issue marks the debut of the Heart of Oncology Nursing (see p. 386). For more information or to submit your work, contact Associate Editor Barb Henry, APRN-BC, MSN, at pubCJON@ons.org.

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Hospice Organization, founded in 1978, also changed its name in 2000 to the National Hospice and Palliative Care Organization, and many hospice care programs added *palliative care* to their names to reflect the range of services they provide. For some reason, I was not really aware of those changes and the shift to provide palliative care services from the time of diagnosis throughout the cancer continuum. Am I the only one? It turns out that we have made a lot of progress since the late 1990s. According to the Center to Advance Palliative Care (2008), 31% of all U.S. hospitals provide palliative care programs, with the penetration highest in hospitals with more than 250 beds (77%).

A large part of cancer nursing has always been about symptom management, with a focus on quality of life throughout the illness continuum. Many Oncology Nursing Society members have participated in the End-of-Life Nursing Education Consortium program administered by City of Hope and the American Association of Colleges

of Nursing (www.aacn.nche.edu/ELNEC). Since 2000, more than 4,000 nurses across the United States have become trainers for improved end-of-life care—and their impact spreads to countless others. And yet, we know that patients still suffer from poorly managed pain and disease- and treatment-related problems. Ferrell (2008) noted the 2004 National Consensus Project for Quality Palliative Care guidelines (www.nationalconsensusproject.org) that promote the use of clinical practice guidelines for palliative care and the Center to Advance Palliative Care (www.cpc.org), which provides tools, training, and assistance to develop and provide palliative care programs. Are we using them?

Palliative care is an essential component of high-quality cancer care. As our collective gaze has shifted to many of the underaddressed survivorship issues, 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. If your practice setting does not offer or have access

to a palliative care program, advocate for one. If we don't, we can expect survivors and their families to speak up (Ferrell, 2008).

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