

IN EVERY ISSUE

Another Deafening Silence

BY BETTY FERRELL, PHD, RN

Patients should demand palliative care, no matter the stage of disease.

The field of oncology has known many silences that result in serious harm. The life-threatening nature of cancer—even in early stages and despite major treatment advances—is often met by denial and avoidance of the enormous physical, psychological, social, and spiritual consequences.

Over the past three decades, individuals with cancer have broken the silence to speak out on critical issues, such as the psychosocial consequences of surgery, the impact of treatment on sexuality, and the myriad of other serious quality-of-life concerns often ignored amidst a focus on treating the tumor and prolonging survival.

One of the latest oppressive silences has been in palliative care. In both professional and patient avoidance of the possibility of death, we have silenced important discussion about the needs of cancer patients across all phases of disease—diagnosis, treatment, remission, recurrence, long-term survivorship, or end-of-life care.

In part, the silence resulted from palliative care being limited only to hospice—care that focuses on the last weeks or months of life. Hospice was avoided, often until the final days of life, thus denying patients access to specialized care.

Fortunately, since the 1990s, palliative care has become an essential aspect of cancer care. Palliative care “upstreams” the great work of hospice and integrates excellent symptom control, psychosocial support, spiritual care, and other elements of whole-person care into the usual care of cancer, regardless of treatment or prognosis.

In 2004, national guidelines for palliative care were released by the National Consensus Project for Quality Palliative Care (www.nationalconsensusproject.org). The NCP guidelines emphasize that palliative care should begin at the time of diagnosis. The guidelines provide a clear framework of the elements of quality care, including processes, physical aspects, cultural aspects, and ethical and legal aspects, among others. Palliative care expands care to include the goals of enhancing quality of life—not only for patients, but also for family members—and helping with decision-making.

People with cancer and their families must break the silence surrounding palliative care. Not speaking of quality-of-life concerns doesn't make them go

away. In fact, silence intensifies the suffering associated with unmet needs. In the same way that breast cancer survivors broke their silence about needs following breast surgery, prostate cancer survivors spoke up about sexuality, and pediatric cancer survivors and parents voiced concerns about late effects of treatment, all people with cancer should demand and expect excellent palliative care.

The Center to Advance Palliative Care (www.capc.org, www.getpalliativecare.org) has led the charge for integration of palliative care in hospitals and cancer centers. Palliative care programs ensure access to expert symptom management, support for difficult decision-making, and interdisciplinary care demanded by the life-altering disease of cancer.

Speak up! Voice your symptoms and your concerns about quality of life. Ask your oncologist and your cancer treatment facility about palliative care. How does your care compare to the recommendations of the NCP guidelines for quality palliative care? Does your hospital have a palliative care program? Speak up for yourself and for others who may be too depleted and overwhelmed to speak for themselves.

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