

Are We Specializing in Neglect?

Whatever your specialty, palliation belongs in your practice.

Several years ago I was observing teaching rounds on a medical-surgical unit of a large hospital. We stopped outside the room of a 60-year-old man who had cancer, and the physicians and a nurse case manager began discussing the previous day's test findings, which showed extensive metastases. Acknowledging that the prognosis was now dire, the team focused on which chemotherapies would be warranted. I asked whether anyone had talked with the patient about hospice care. The physician administrator replied that such a conversation was premature and that at the appropriate time the patient's private physician should initiate that conversation. His response came despite recent discussions in this hospital regarding the fact that hospice referrals were being made too late for patients and families to benefit fully. The patient's wishes were not discussed, and the nurse case manager gave no indication that she saw herself as an advocate for a palliative approach.

Too often, we have abandoned a quintessential part of nursing—that of helping patients to manage their symptoms *even when their illnesses are incurable* and supporting them through a peaceful, dignified death. Over the last century the U.S. health care system has evolved in response to countless advances in biomedical science and new technologies aimed at diagnosing and treating disease. It has depended mostly on nurses to integrate these changes into patient care

successfully. But we have worked so hard at integrating cure-oriented advances that we've neglected the patient who cannot be cured. Consequently, too many people have suffered through excessive pain, dyspnea, agitation, and other symptoms that overwhelm any chance for a humane death. As writer Susan Sontag noted in 1977 in her book *Illness*



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as *Metaphor*, “death is now an offensively meaningless event,” a view that leaves the dying patient “robbed of all capacities of self-transcendence, humiliated by fear and agony.”

None of us wants a horrible death. As public demand for an alternative has grown, hospice services have proliferated. But hospice care usually pertains only to the last months of life. What happens to people with incurable illnesses who have longer than six months to live? In too many cases, physicians and nurses have neglected to provide adequate symptom management and support to these patients. That neglect has brought the need for palliative nursing care into sharp focus.

Other aspects of this neglect became apparent to me recently. A relative, diagnosed with aggressive, incurable lung cancer, decided that chemotherapy offered little benefit and too many side

effects. After a wonderful year with his family, he deteriorated quickly and died within weeks. His death was difficult, endured without benefit of palliation until the last 48 hours. His wife told me that her greatest burden was questioning whether her family had made the right decisions, after well-intentioned friends asked why her husband had “refused treatment.” But opting out of chemotherapy does not mean opting out of treatment. We cannot be so bound by the curative model of care that we fail to treat symptoms aggressively even when cure is not possible. We must reassure patients that they'll still receive treatment

to ensure a quality of life acceptable to them as well as a comfortable death. Relief from suffering, the opportunity to make the best of one's last days—these concerns are paramount to the dying.

The next time you have a patient with an incurable illness, will you be prepared to talk with that patient about treatment options for minimizing distress and obtaining humane end-of-life care?

This month's journal launches a bimonthly series on palliative nursing, supported in part by a grant from the Robert Wood Johnson Foundation. The series begins with an overview written by the series editors, Betty Ferrell, PhD, RN, FAAN, and Nessa Coyle, MSN, RN, FAAN, two of the leading experts in this important new specialty. Our goal is to ensure that compassionate approaches to incurable illness are no longer neglected. ▼