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Why Isn't All Care 'Palliative Care'?

Care that's based on need rather than prognosis.

“Those who learned to know death, rather than to fear and fight it,” said the recently deceased Elisabeth Kubler-Ross, “become our teachers about life.” By discussing death and dying frankly when it was deemed unseemly to do so, she helped many to think about how they wanted to live, particularly when confronted with serious illness. Those who participated in her workshops or read her writings over the years came to recognize the obscenity of leaving a dying patient alone in a room at the end of the hall.

But have nursing thought and practice changed sufficiently? In the January 2004 issue of the *Journal of the American Medical Association*, Teno and colleagues reported on a survey of family members and others who knew the circumstances surrounding the end-of-life experience of people who had died. The final place of care for 69% of the sample was a hospital or nursing home, despite the fact that the majority of people would prefer to die at home. Regardless of setting, staff were reported by respondents to have inadequately addressed several areas of care: pain (24%), dyspnea (22%), and emotional needs (50%).

A number of changes are required to remedy this situation:

- Providers, policymakers, and the public must discuss the need for a shift from a prolonging-life-at-any-cost approach to one that focuses on the patient's priorities, the quality of life, and the relief of suffering. Unfortunately, such conversation usually takes place only when a

provider realizes that cure is no longer possible. But palliative care is not an either-or proposition.

- Reimbursement policies should follow suit. Regular Medicare benefits cover only care that follows the curative approach, while coverage for care that follows the quality-of-life approach falls under the rubric of hospice care. On March 10 the *Wall Street Journal* reported that the Virginia Commonwealth University Medical Center actually cut its costs of caring for cancer patients by 57% when patients were on its 11-bed palliative care unit, compared with care provided on traditional units. And yet, fewer than 20% of community hospitals have palliative care services. At a time when health care costs are rising, Medicare and all insurers must pay for care that addresses patients' goals, whether curative or not.
- Providers must address the difficulties of talking with patients and families about their wishes *before* death is near. The first step is asking why this is so difficult. Providers must continue to talk about these issues in their institutions; patients and families must be assured that the end of curative treatment does not mean the end of all treatment.
- Nurses must anticipate the risk of dying by using the instruments Matzo discusses in “Palliative Care: Prognostication and the Chronically Ill” (September). The point isn't predicting the exact moment of death but rather talking about

dying and supporting patients and families as part of making informed treatment decisions.

- Family caregivers, who provide end-of-life care in the home, deserve more attention than they receive. To expect families to care for the dying without adequate training and support is harmful to all involved.

Teno and colleagues found that satisfaction with hospice care was higher than with care provided by hospitals, nursing homes, and home care providers. Undoubtedly, this is because in hospice care the patient and family define the goals of care and the care is truly interdisciplinary: all members of the health care team are valued participants. So why isn't all health care “palliative care”—that is, care that's based on need rather than prognosis?

Over the past 15 years, the Robert Wood Johnson Foundation has invested \$150 million in projects designed “to bring attention to the need for improvements in end-of-life care.” As a recipient of a grant under this initiative, *AJN* has published a series on palliative nursing care (available online at www.NursingCenter.com/AJNpalliative) over the past two and a half years, ending this month (see page 40).

We will continue to publish articles on this important topic and urge you to continue to teach yourself about best practices in palliative and end-of-life care. ▼



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