Guest Editorial
End-of-Life Care: Nursing Leadership Remains Critical

In 1965, Glaser and Strauss wrote: Although doctors and nurses in training do have some experience with dying patients, the emphasis is on the necessary techniques of medicine or nursing, not on the fact of dying itself. As a result, sometimes they do not even know they are treating or caring for a dying patient. (p. 4)

So 35 years later, one has to ask whether nursing education, and equally important nursing practice, has evolved to ensure that all individuals who have chronic, debilitating, and life-limiting illnesses receive quality care across multiple settings. The answer to this question directly ties to the evolution of hospice and palliative care in the United States and to the important work of the End-of-Life Nursing Education Consortium (ELNEC).

The care that individuals and their loved ones receive has vastly improved, with 1.45 million patients receiving hospice care in 2008 (National Hospice and Palliative Care Organization, 2009) and the development of palliative care programs over the past decade. However, much remains to be done to improve care at the end of life. As noted by Tilden and Thompson (2009):

A significant issue impeding improvement in care for the dying is the mismatch between the dominate culture of recovery-focused medicine and the needs of an aging population. “Rescue medicine” is the default mode in American hospitals.... (p. 364)

In 2009, under the leadership of Betty Ferrell, PhD, RN, FAAN, the National Consensus Project for Quality Palliative Care disseminated the second edition of the Clinical Practice Guidelines for Quality Palliative Care. These guidelines set the standards for what constitutes high-quality palliative care, and they also inform nursing education. Nurses, as well as physicians and other health care providers, who care for individuals with chronic, debilitating, and life-threatening illnesses, as well as their loved ones, need to be deeply committed to ensuring that their knowledge and clinical skills keep pace with these standards. All direct care providers need to move beyond recovery-focused medicine if they are going to truly meet the needs of patients and their loved ones at the end of life. As noted by Shea (2010) in this issue of the Journal of Nursing Education, nurse educators in advanced practice palliative care nursing programs also must ensure that the curriculum addresses these competencies.

With funding from the Robert Wood Johnson Foundation (RWJF), the City of Hope partnered with the American Association of Colleges of Nursing in 2000 to form ELNEC (ELNEC, 2009). This education initiative was in response to the American Association of Colleges of Nursing’s 1998 publication Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care. ELNEC is based on a train-the-trainer model and was initially focused on nurses in the United States. More than 10,000 nurses and other health care professionals in the United States have participated in ELNEC. The educational offerings have been targeted at an array of specialty nurses, including critical care, geriatrics, oncology, and pediatrics, as well as nursing faculty (both undergraduate and graduate), staff development educators, and continuing education providers.

In recent years, ELNEC has also been offered in 63 international countries, on six of the seven continents, to an estimated 1,750 nurses and other health care providers. The ELNEC core content, which includes eight modules, and some of the specialty versions, has been translated into several other languages, including Japanese, Korean, Russian, and Spanish. The core modules include Nursing Care at the End of Life; Pain Management; symptom Management; ethical/legal issues; Cultural Considerations in End-of-Life Care; Communication; loss, Grief, Bereavement; and Preparation for and Care at the Time of Death.

The importance of this work, both within the United States and globally, is further evidenced by the array of funders who have contributed—RWJF, National Cancer Institute, Open Society Institute, Oncology Nursing Foundation, and the Aetna, Archstone, and California HealthCare Foundation. Given all that has been invested over the past decade in terms of financial support and human resources, the question is, what’s next?

Consistent with the unwavering commitment of the palliative care experts and staff who have contributed to ELNEC, the nearly 18,000 individuals who have completed ELNEC training need to actively lead efforts to ensure
that all individuals who have chronic, debilitating, and life-limiting illnesses receive quality care across multiple settings and throughout the world. These efforts require a number of Maxwell’s (1999) 21 indispensable qualities of a leader.

“Commitment: It Separates Doers from Dreamers” (Maxwell, 1999, p. 15)

ELNEC trainers have a responsibility to share what they have learned and to increase the number of nurses and other health care providers who have the prerequisite knowledge. These estimated 900 nurse educators in associate degree and baccalaureate degree programs and 400 graduate nursing faculty who have completed ELNEC training have a responsibility to ensure that the ELNEC content is integrated into curricula in meaningful ways and that the curricula changes are sustained.

“Courage: One Person with Courage is a Majority” (Maxwell, 1999, p. 37)

ELNEC trainers need to keep a watchful eye on the care that is being provided and to question when the care falls short of the standards for what constitutes high-quality palliative care. Nursing education needs to increase the pipeline of advanced practice nurses who have expertise in palliative care in order to meet the growing demand.

“Teachability: To Keep Leading, Keep Learning” (Maxwell, 1999, p. 141)

The ELNEC curriculum continues to be revised to reflect emerging knowledge about end-of-life care. With the ongoing support of the National Institutes of Health, current and future nurse scientists need to continue to generate the science that improves nursing care at the end-of-life. All ELNEC trainers need to keep abreast of best practices in palliative and end-of-life care.

Conclusion

With 10 years of experience and much to celebrate, the ELNEC faculty and staff should be commended for their efforts to improve palliative care. Nurses will need to continue to provide strong leadership to advance this important agenda and to move beyond “recovery medicine,” whether here in the United States or across the globe.

References


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The author has no financial or proprietary interest in the material presented herein.

doi:10.3928/01484834-20100323-01