Seven Years and 50 Courses Later

End-of-Life Nursing Education Consortium Continues Commitment to Provide Excellent Palliative Care Education

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Over the past 7 years, more than 4500 nurses have attended a national ELNEC train-the-trainer course. These trainers have returned to their universities, clinics, acute care facilities, hospices, long-term care/skilled nursing facilities, and home care agencies and disseminated and implemented the ELNEC curriculum throughout their workplace, their community, and the world. They have been able to improve the quality of life and diminish the suffering of those who experience terminal illnesses. These trainers have developed care plans, algorithms, and interdisciplinary teams and have provided education to colleagues to improve the care of the dying and meet the needs of family members. On June 28, 2008, nurses from across the US came to Chicago, IL, to celebrate the 50th national ELNEC train-the-trainer course. This celebration will be the culmination of 7 years of developing six specific curricula to meet the unique educational and clinical needs of nurses in providing excellent palliative care for patients and their families. In addition, it will provide opportunities for nurses to receive an update on palliative care, network with other trainers, see how other nurses are implementing and disseminating ELNEC, and honor those who have made an exceptional contribution to palliative care.

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HOW THE END-OF-LIFE NURSING EDUCATION CONSORTIUM BEGAN

In 1998, nursing researchers and educators across the US were studying end-of-life (EOL) issues. This response came primarily from the findings of the Institute of Medicine’s (IOM) report on improving EOL care, which cited lack of education as a major barrier to nursing efforts in improving palliative care.\(^1\) In Washington, DC, the American Association of Colleges of Nursing (AACN) hosted a roundtable session to discuss the competencies that nurses needed in order to improve the care of the dying and develop curricular guidelines for faculty to incorporate into baccalaureate nursing education.\(^2\) The result of this collaboration produced a document entitled “A Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Care.” At the City of Hope (COH) in Duarte, CA, researchers were reviewing nursing textbooks for citations regarding care of the dying. Their study provided data that showed that less than 2% of content in 50 commonly used nursing textbooks had any information regarding EOL/palliative care.\(^3\) Further studies documented major deficiencies in the education on EOL care, not only in nursing textbooks but also among nursing faculty, who have insufficient knowledge to teach care of the dying to their students. In addition, numerous studies showed that limited time was devoted to EOL care in nursing school curricula.\(^4\) Nurses reported that they were conflicted about giving “the last dose” of pain medication to the dying and were confused about communicating with patients and families experiencing EOL issues. Nurses also stated that they experienced ethical issues related to withholding and/or withdrawing life-sustaining treatments.\(^5,6\)

In 1999, AACN and COH joined forces to develop a national education program on EOL care for registered nurses. Nursing faculty and clinical educators with extensive experience and research in EOL issues began to develop the End-of-Life Nursing Education Consortium (ELNEC) curriculum. The first curriculum, entitled ELNEC-Core, was based on the “Peaceful Death Document” and focused on nine EOL core areas (see Table 1). In February 2000, ELNEC-Core was funded by a major grant from the Robert Wood Johnson Foundation (RWJF), and the first course was held in January 2001 in Pasadena, CA.

SIX END-OF-LIFE NURSING EDUCATION CONSORTIUM CURRICULA DEVELOPED

To date, more than 4500 nurses, representing all 50 states, have attended a national ELNEC train-the-trainer program. These nurses are returning to their universities, clinics, hospices, acute care institutions, long-term care facilities/skilled nursing facilities (SNFs), and home care settings to provide training to their colleagues in excellent EOL/palliative care. These trainers are changing policies and practice standards, developing algorithms and care plans, forming interdisciplinary teams to meet the distinctive needs of terminally ill patients and their families, and adding EOL content to nursing curricula.

Since its inception in 2001, the ELNEC project has developed six curricula to meet the diverse specialty needs of the nursing workforce and the patients and families they serve. Every curriculum contains several common threads that are integrated throughout (Table 2). A brief description of each project is listed below, along with examples on how trainers have implemented and disseminated ELNEC throughout their institutions.

ELNEC-Core

Eight ELNEC-Core courses, initially funded by RWJF, were designed to meet the needs of baccalaureate and

Table 1

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<th>ELNEC Modules</th>
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<td>Module 1: Palliative nursing care</td>
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<td>Module 2: Pain management</td>
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<td>Module 3: Symptom management</td>
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<td>Module 4: Ethical issues</td>
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<td>Module 5: Cultural considerations in palliative care</td>
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<td>Module 6: Communication</td>
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<td>Module 7: Loss, grief, and bereavement</td>
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<td>Module 8: Achieving quality palliative care</td>
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<td>Module 9: Preparation for and care at the time of death</td>
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associate degree nursing faculty members, continuing education (CE) providers, and clinical staff development educators. More than 1400 nurses from across the United States attended one of these eight courses. Five courses also were held in conjunction with the RWJF Last Acts regional conferences in collaboration with The Hospice of the Florida Suncoast. Faculty members who completed the ELNEC training returned to their colleges and universities and began disseminating ELNEC in pharmacology, ethics, medical-surgical nursing concept courses, and clinical rotations. Faculty members reported in their 12-month postcourse surveys that more than 19,000 students received EOL content through the ELNEC-Core curriculum.

In-services using the ELNEC curriculum were used by many staff development educators and CE providers in new employee orientations, annual competency reviews, and nursing internship and residency programs. Despite numerous responsibilities in their own institutions, 1 year after completing the ELNEC-Core course, 107 (49.3%) of these staff development educators/CE providers disseminated the curriculum to other nursing programs, clinical settings, and CE programs in their community.

Eileen Mann and Lisa Preston, two ELNEC trainers from Brigham & Woman’s Hospital in Boston, MA, go to work every day with the goal of making their patients’ lives better. Both Eileen and Lisa work primarily with patients with heart failure and their families and collaborate with other members of the interdisciplinary team to provide excellent specialized care through education received at ELNEC. Judy Conn, a palliative care coordinator, is committed to training all nurses in ELNEC at Our Lady of Bellefounte Hospital in Ashland, KY. The chief nursing officer at the hospital has made a commitment that all nurses must be ELNEC trained. Judy provides this training once a month on an ongoing basis. Armed with the belief that nurses cannot practice what they do not know, Judy is dedicated to educating all of her nursing colleagues at Our Lady of Bellefounte. Lastly, Sayaka Sakamoto attended an ELNEC-Core course 2 years ago while she was a graduate student in San Diego, CA. She has since moved back to her home in Japan and is working on furthering her education. She is also working with other scholars in palliative care to translate the ELNEC curriculum into Japanese.

On July 1, 2002, the ELNEC project received a grant from the National Cancer Institute (NCI) to train graduate nursing faculty. To date, 300 graduate nursing faculty, representing 278 of 438 (63%) graduate nursing programs in the US, attended one of the four NCI-funded ELNEC-Graduate training programs. In their 1-year postcourse data, the graduate nursing faculty reported improved effectiveness in their ability to provide EOL education and an increase of 18.4 hours of EOL content added to the graduate nursing curricula. The first cohort of 60 graduate faculty reported that 2139 graduate nursing students had attended at least one of their lectures using the ELNEC-Graduate curriculum.

These participants have worked in a variety of ways to implement and disseminate ELNEC-Graduate. For example, Dr Barbara Edlund, associate professor at the Medical University of South Carolina College of Nursing, is the principal investigator of a 3-year grant by the Bureau of Health Professions/Health Resources Services Administration’s Division of Nursing to prepare adult nurse practitioners in primary care and palliative care. Using portions of the ELNEC-Graduate curriculum, this unique program allows adult nurse practitioners to meet the primary needs of patients, as well as manage their symptoms as the disease progresses. Dr Linda Strodtman, an assistant professor at the University of Michigan, along with her colleague and ELNEC trainer Maureen M. Goode Giacomazza, has produced a videotape entitled “Evan Mayday’s Good Death.” This documentary shows the importance

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**Table 2**

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<th>Common Threads Integrated Throughout ELNEC</th>
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<td>The family is the unit of care</td>
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<td>The important role of the nurse as an advocate</td>
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<td>The critical need for attention to special populations such as children, the elderly, the poor, and the uninsured EOL issues impact all systems of care across all settings</td>
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<td>Critical financial issues influence EOL care</td>
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<td>EOL care is not confined only to cancer or AIDS but rather is essential across all life-threatening illnesses and in cases of sudden death</td>
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<td>Interdisciplinary care is essential for quality care at end of life</td>
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**ELNEC-Graduate**

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of interdisciplinary care, especially when difficult EOL decisions need to be made. Because of not only the content but also the high quality of “Evan Mayday’s Good Death,” this video is shown at most ELNEC courses.

**ELNEC-Oncology**

In August 2003, the NCI also began funding the ELNEC-Oncology training program. This program trained 264 oncology nurses who were members of the Oncology Nursing Society (ONS). These nurses represented 141 of 222 (64%) ONS chapters in the United States. The goal was for these ELNEC-Oncology trainers to disseminate palliative care education through their local ONS chapters and improve care of cancer patients and their families. The last NCI-funded course was held in September 2006. Although the original intent of the ELNEC-Oncology training was for participant nurses to provide education to members of their ONS chapter, data from the first two cohorts (124 nurses representing 74 ONS chapters) revealed that 7593 nurses within their ONS chapters and 18,517 colleagues from their institution received ELNEC-Oncology training. Having opportunities to not only provide this education to ONS members but also disseminate ELNEC-Oncology so widely within clinical settings was an unexpected outcome.

Mary Pat Johnston and Lori Wendt from the Southeastern Wisconsin ONS Chapter held a 2-day ELNEC course for 56 members of their ONS chapter. Carma Erickson-Hurt, a member of the San Diego, CA, ONS Chapter, was instrumental in designing and organizing two palliative care comfort suites at the Balboa Naval Hospital. Besides offering numerous ELNEC courses, Carma also assisted in developing standard orders and pathways that have improved patient care and nurse advocacy for many patients. Teresa McLaughlin from the Southwest Connecticut ONS Chapter partnered with the American Cancer Society at a community health fair to provide education regarding palliative care awareness. In addition, Teresa presented an ELNEC module at the Leukemia/Lymphoma Society’s First Connection Program.

**ELNEC-Pediatric Palliative Care**

Since 2003, six national ELNEC-Pediatric Palliative Care (PPC) train-the-trainer courses have been conducted with more than 560 nurses in attendance. Adapted from the ELNEC-Core curriculum, the ELNEC-PPC curriculum was developed by 20 PPC experts and piloted in 2003. The Aetna Foundation partially funded the August 2005 and 2006 training courses. Much of the ELNEC-PPC curriculum was developed to answer the call for improved professional education to address the unique needs of children and their families at the end of life, as cited in the 2002 IOM report entitled “When Children Die: Improving Palliative and End of Life Care for Children and Their Families.” According to the IOM, 400,000 children in the US live with chronic, life-threatening conditions, and 53,000 of these children die annually. To address educational deficiencies among pediatric nurses in caring for these sick children and their families, ELNEC-PPC was developed.

The 12-month postcourse data from the first cohort revealed that more than half of the participants attended further education in palliative care (62%), became involved in a palliative care committee/task force (60%), subscribed to or read palliative/EOL care publications (53%), and/or collaborated with other organizations to implement ELNEC-PPC education (54%). It is also noteworthy that these nurses began to look at their own institution’s commitment to not only pediatric but also neonatal and perinatal palliative care.

Because of the wide span of pediatric ages and needs (ie, neonates through adolescents), the opportunities that these pediatric trainers have had to improve care for children and their families have been remarkable. For example, Jill Clark lives in Austin, TX and works as a nurse case manager for the Central Texas Palliative Care Association. She has worked to develop a partnership between the Children’s Hospital of Austin and Esperanza, a long-term care facility for children, in the event that a child must be hospitalized. Jill also has created hospital transfer forms for Esperanza and developed a letter for parents whose children may need hospice and palliative care services. At the Hospice of Oklahoma County, Integris in Oklahoma City, OK, Anita Bell has worked in providing ELNEC-PPC education to three area institutions: a children’s chronic care facility, a home health agency, and an organization called Calm Waters. Anita and her colleagues have determined that it is mandatory for all hospice staff (ie, nurses, home health aides, chaplains, social workers, and volunteer coordinators) to complete the 2-day ELNEC-PPC training.
ELNEC-Critical Care

Also adapted from the ELNEC-Core curriculum, a critical care-specific course has been developed for nurses who work in intensive care, coronary care, burn, and dialysis units, emergency departments, and other clinical areas encompassing critical care. To date, over 430 nurses have attended one of the four ELNEC-Critical Care courses, which debuted in November 2006. The second ELNEC-Critical Care course was funded by the Archstone Foundation and was presented to California nurses only. Studies have revealed that one in five persons in the US will die in an intensive care unit within the last 3 days of life.13 As for cancer, heart disease, and other chronic diseases, critical care primarily has been focused on curative therapies, because death is considered a failure. However, many critical care interdisciplinary team members are becoming more aware and educated in the importance of integrating palliative care in this setting. Trainers for ELNEC-Critical Care have reported going back to their institutions and changing policies to enhance patient care in the critical care setting. For example, many ELNEC-Critical Care trainers returned to their institutions and began writing and adapting policies that would enhance the care of patients and their families in critical care settings. Examples of such changes include the following: family members would receive a family conference with the interdisciplinary team; visiting hours would be increased so that families have more frequent time with their loved ones; on-call chaplaincy service would be established in the emergency department; families would be encouraged to make a memory book of their loved ones and complete a “Know Me” poster so that staff have a better understanding of the patient’s culture, likes and dislikes, hobbies, and so forth; bereavement services for family members would be coordinated with the local hospice; and the staff would send a follow-up card to the families 6 and 12 months after the death.

Sometimes, critical care nurses have to make changes that do not involve care plans, implementation, algorithm development, or interdisciplinary team management. For example, Stephanie J. Craig is an intensive care nurse at the Veteran’s Administration Hospital in San Francisco, CA. Stephanie reported that the intensive care unit waiting room was not a pleasant place to send patients’ families. She felt badly that family members had to wait in a place of such disrepair to receive word about the status of their loved ones. So Stephanie pulled together a team and had the room painted and was able to purchase new furniture for the waiting room.

ELNEC-Geriatric

The latest specialty curriculum to be developed is the ELNEC-Geriatric training program. California HealthCare Foundation provided funding for the development of the ELNEC-Geriatric curriculum and a pilot course, which was held in February 2007 in Long Beach, CA for California nurses only. To date, 368 geriatric nurses have attended one of the four national ELNEC-Geriatric programs. The curriculum addresses the unique needs of geriatric nurses who work in long-term care facilities, SNFs, hospices, acute care facilities, clinics, home care agencies, and universities. Data show that approximately 50% to 60% of the elderly die in a hospital or long-term care facility.14 The ELNEC-Geriatric curriculum is unique from the other courses in that a portion is dedicated to training certified nursing assistants (CNAs) and other unlicensed personnel in EOL/palliative care. Reports from the 4-month postcourse updates of the first cohort (100% of the 84 participants sent in updates) show that, 157 and 117 palliative care education programs were presented to registered nurses and to other unlicensed personnel, respectively, using the ELNEC-Geriatric curriculum.15

After returning from ELNEC-Geriatric training, Pauline Jones and Linda Flumerfelt from the Hospice of the East Bay in Pleasant Hill, CA began networking with a local SNF. They developed a hospice newsletter for their SNF colleagues and referring physicians. They also provide white roses to the SNF to place on the door of a patient who is actively dying. Lynn Alice Briggs and Sr Clotilde Jardin from the Sisters of the Poor in San Pedro, CA have been collaborating with nursing faculty to have clinical students receive ELNEC training. Lynn Alice and Sister Clotilde are also providing monthly training to CNAs by using ELNEC role plays, writing a letter to "death," and remembering patients who have died.

**Providing End-of-Life Nursing Education Consortium Training Internationally**

The primary aim of ELNEC is to educate nurses to improve EOL care. Although our initial efforts were focused in the US, many ELNEC trainers have had opportunities to travel internationally and provide this
education to nurses and other healthcare providers throughout the world. For example, the Open Society Institute funded an ELNEC course in 2007 for 38 Eastern European nursing leaders in education and clinical practice at the first Salzburg Medical Seminar Series for Nurses in Palliative Care in Salzburg, Austria. These nurses represented 14 Eastern European countries. Because of the success of the first seminar, the ELNEC faculty was invited to hold a second ELNEC course in March 2008, with 39 participants from 17 various Eastern European countries in attendance. In addition, an ELNEC course was held in Tanzania in July 2007, supported by the Oncology Nursing Foundation. ELNEC trainers and faculty have traveled to six of the seven continents, representing 53 countries. Many trainers have provided ELNEC educational courses, whereas others have gone as consultants to work with educators, healthcare administrators, and community leaders to improve care of the dying in their countries. Some are working on translating ELNEC into other languages and adapting it to increase the relevance to other cultures. For more specific examples of disseminating ELNEC internationally, visit http://www.aacn.nche.edu/ELNEC/Global.htm.

WHAT IS NEXT FOR END-OF-LIFE NURSING EDUCATION CONSORTIUM?

In July 2007, the ELNEC-SuperCore curriculum was developed to meet the needs of hospice and oncology nurses and educators in clinical settings and universities. The first ELNEC-SuperCore course was held in Washington, DC, in October 2007, with more than 200 nurses in attendance—the largest national ELNEC course to date. Using the ELNEC-Core curriculum as a foundation, the ELNEC-Graduate and ELNEC-Oncology curricula were embedded and merged into the ELNEC-Core curriculum, which produced ELNEC-SuperCore. When attending an ELNEC-SuperCore course, separate breakout times are scheduled for case study review, role play, and other learning/networking opportunities, depending on the specific area where the nurse practices (ie, oncology, hospice, medical-surgical units, staff development, CE provider, undergraduate nursing faculty, and/or graduate nursing faculty).

CONCLUSION

Most Americans deny death and generally believe that medical science can cure any patient. In most incidence, death is seen as a failure of a healthcare system rather than as a natural aspect of life. Unfortunately, this belief affects all healthcare professionals, including nurses. Despite their excellent technical and interpersonal skills, nurses may not be completely comfortable with the specialized knowledge and skills needed to provide quality EOL/palliative care to patients and their families. No one spends more time at the bedside of a dying patient than the nurse. Nurses have the unique privilege of accepting the occasion to spend the last months, weeks, or hours with a patient and his or her family. This is a tremendous opportunity. However, with this opportunity comes the responsibility to be well educated and communicate the needs of the patient and family with the interdisciplinary team, practice with integrity, and advocate for relieving the suffering of patients who are experiencing the final months, days, or hours of life. The ELNEC project provides nurses with the knowledge and skills to provide this particular care to positively impact the lives of patients who are facing EOL and their families.

For more information about the ELNEC project, including upcoming training programs, visit www.aacn.nche.edu/ELNEC.

References


