

Statewide Efforts to Improve Palliative Care in Critical Care Settings

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PRIME POINTS

- Lack of education in providing end-of-life care is an obstacle to nurses and other health care professionals as they strive to deliver palliative care.
- Education regarding pain and symptom management, communication strategies, care at the end of life, ethics, and other aspects of palliative care is urgently needed.
- This article describes implementation and evaluation of a comprehensive statewide effort to improve end-of-life care education for California nurses as an example of change at the state level.

In a 2004 study, researchers found that almost 20% of American deaths occur in a critical care setting or shortly after a critical care stay.¹ Historically, the focus of critical care has been primarily on curative therapies, and death has been viewed as failure. Now, awareness of the need to integrate palliative care in critical care settings has increased.² The challenges to providing quality end-of-life care include the hectic, fast-paced environment; different perceptions among team members regarding the patient's goals of care as far as aggressive treatment versus seeking limited or no treatment; communication barriers between health care professionals, patients, and patients' families; and a lack of research on improvements in the care of the dying in critical care settings.²⁻⁴ Often, because of these and other barriers, pain and other symptoms

are inadequately relieved and patients' goals of care are not addressed properly.⁵⁻⁸

Critical care nurses play an essential role in the care of intensive care patients by having the potential to improve the experience of dying for the patients they care for and the loved ones observing the death. Many critical care nurses have received little education or training in end-of-life care within their undergraduate or graduate nursing studies.⁹⁻¹⁶ Nurses cannot practice what they do not know. Therefore, providing palliative care education to student nurses is vital, so that they are prepared to assess and manage the complexities involved in the care of the dying once they graduate. To improve the care of the dying, critical care nurses must have the knowledge and tools to effectively provide care to persons with serious/life-threatening illnesses.^{2,4,17,18}

In an effort to improve the end-of-life experience, the Archstone Foundation in Long Beach, California

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(www.archstone.org), launched an End-of-Life Initiative in September 2006. The initiative seeks to change the culture of dying in California by building a strong palliative care base that will lead to improved patient care, management of symptoms, and better quality of life. The mission of the Archstone Foundation, a private grant-making organization, is to contribute to the preparation of society to meet the needs of an aging population. Since its inception in 1985, the Foundation has had an interest in elder care and end-of-life issues. One of the Archstone Foundation's priorities is to increase education and training of nurses, physicians, and social workers in palliative care.

In 2007, in order to address these educational needs and current curricular limitations, the Archstone Foundation made a commitment to support education of critical care nurses in California so that improved palliative care could be offered to persons who are dying in various critical care settings. The Archstone Foundation funded 4 End-of-Life Nursing Education Consortium-Critical Care (ELNEC-CC) training programs specifically for critical care resident nurses

in California. The first 2 courses (of the 4 funded courses) were held in 2007 and 2008, and the subsequent courses were held in 2009 and 2010. ELNEC-CC is a synthesis of research and knowledge in end-of-life care and is intended to help critical care nurses implement evidence-based care.

The ELNEC-CC curriculum, developed by critical care nurses, includes detailed teaching materials to integrate end-of-life content into continuing education courses and classroom resources for nursing students. The ELNEC-CC curriculum,¹⁹ developed from the ELNEC-Core curriculum and based on the American Association of Colleges of Nursing's "A Peaceful Death" document (1997) as a framework,²⁰ focuses on 8 end-of-life areas that are specific to critical care: overview of palliative nursing care as it relates to critical care; pain; symptom management; loss, grief, and bereavement; communication; ethical issues; final hours; and achieving quality palliative care. Universal themes abstracted from the Institute of Medicine report²¹ are woven throughout the ELNEC-CC curriculum, including the family as the unit of

care; the important role of the critical care nurse as advocate; importance of culture as an influence at the end of life; the critical need for attention to special populations such as children, the elderly, the poor, and the uninsured; the relevance of end-of-life issues in all systems of care across all settings; the influence of critical financial issues in end-of-life care; and necessity of interdisciplinary care for quality care at the end of life. Because end-of-life care is provided in a broad array of critical care settings, the curriculum was developed in 2005 and 2006 by expert critical care nurses from a variety of clinical settings to meet the needs of nurses working in intensive care units, coronary care units, burn units, emergency departments, and dialysis centers. The curriculum was developed with the use of evidence-based practices to support the content. To ensure ongoing validity of the content, participants assess the content of the curriculum through an evaluation form at the end of each training course.

Preassessment of Course Participants

Eighty-seven California nurses representing 19 of California's 58 counties (33%) attended the first Archstone-funded ELNEC-CC training program. Each participant had to send in an application, a letter of support from their director, goals for the next 12 months, and an institutional survey. The demographics of the nurses are shown in Table 1. Before attending, participants were asked to complete a preassessment survey that was focused on their perspectives on palliative care and how end-of-life/palliative care is provided

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Table 1 Demographics of 87 participants in the End-of-Life Nursing Education Consortium

Characteristic	%
Ethnicity	
White	61
Asian	21
Hispanic/Latino	9
African American	6
Other	3
Work setting^a	
Medical intensive care unit	51
Surgical intensive care unit	43
Cardiac care	30
Emergency department/trauma	9
Renal dialysis	3
Palliative care	3
Transplant	1
Pulmonary	1
Other (ie, hospices, schools of nursing, nursing organizations)	14
Sex	
Male	8
Female	92
Region	
Northern California	28
Southern California	72

^a Several nurses worked in more than 1 setting.

within their institution. In the pre-course surveys, the participants rated (on a scale of 0=not effective to 10=very effective) their teaching of end-of-life care content as moderately effective (mean score, 5.9) and perceived that their own nursing colleagues would be very receptive to more training about end-of-life care (mean score, 8.1). However, participants thought that their own institution was only moderately effective in teaching end-of-life care (mean score, 4.4) and that nurses within their community were also moderately effective in providing care for dying patients (mean score, 6.0). The participants were also asked to indicate if their institution has offered an end-of-life education program in the past 2 years and if so, what subjects had been presented. The end-of-life topics, which mirror

were lack of time; few financial resources or reimbursement issues; and minimum knowledge and education or few qualified educators. Other barriers cited included lack of resources or available hospices; minimum staff; “stigma” of death among staff and the community; misunderstanding, myths, and fears of “palliative care”; language and communication barriers; cultural differences; ethical dilemmas; and the advanced technology found in critical care settings, along with the notion of saving or curing.

the ELNEC-CC modules, that were identified most frequently were pain management (81%), communication (55%), and an overview of palliative nursing care in critical care (55%; Table 2).

Considerations of the greatest limitations/barriers to palliative care in their community or organization also were assessed. The most frequently cited barriers

ELNEC-CC Course Program

The 87 participants were California licensed registered nurses who had been selected for participation by their institution/agency to effect change in education (either as an educator, manager, or director) across various critical care settings (see Table 1). The ELNEC-CC curriculum¹⁹ was adapted from the original ELNEC-Core curriculum to reflect the specialized needs of critical care nurses to provide care to intensive care patients throughout the disease continuum and at the final hours of life. The 2½-day course started in the evening with an introduction to the training course and an “overview of palliative nursing” followed by a networking reception. The next 2 days entailed didactic lectures as well as discussions of specific critical care case studies, role playing, and use of video clips to demonstrate teaching strategies.^{19,22} Participants received a 1000-page syllabus with all contents on a CD, including PowerPoint slides, and a palliative care textbook in addition to other teaching tools/resources. At the conclusion, the participants rated the course overall as 4.89 on a scale of 1 (low) to 5 (high).

Table 2 End-of-life content offered before the End-of-Life Nursing Education Consortium

End-of-life content	% of cases
Pain management	81
Overview of palliative nursing	55
Communication	55
Symptom management	53
Ethical/Legal issues	51
Grief, loss, bereavement	41
Cultural consideration	38
Achieving quality palliative care	33
Final hours	29

12-Month Evaluation After Course

As per previous ELNEC training programs, 12-month evaluation surveys were requested as follow-up to evaluate the training program.^{12,14,23,24} The data from the 12-month evaluation for the January 2007 Archstone-funded course had a response rate of 80.5% (n=70). These data demonstrated highly significant improvements from before to 12 months after the course in the ratings on the perceived effectiveness of the participant and the institution in providing end-of-life education (Table 3). When asked how helpful the ELNEC training program has been in improving end-of-life content in staff education, the mean response was 7.81 (on a scale of 0=not helpful to 10=very helpful). The participants reported that the greatest benefits of the ELNEC training were the enthusiasm and awareness that the trainers were able to share with other colleagues. In fact, 60% of the respondents stated that during the 12-month period after ELNEC training, they offered 205 classes across all 8 end-of-life content areas (modules) to 6566 nurses (Table 4).

Barriers cited by the other 40% for not yet having implemented courses since the training included lack of time, minimal financial support, staff time availability, and lack of administrative support; however, the barriers cited most often (approximately 30% response) were attitudes (misunderstandings) and lack of knowledge of palliative care on behalf of the entire interdisciplinary team.

In addition to extending the ELNEC education in their clinical

Table 3 Comparison of responses from before to 12 months after the course

Question	Score ^a		P
	Before	12 months after	
How effective do you believe you are in teaching palliative/end-of-life care content?	6.01	7.03	.001
How effective do you believe your work setting is in teaching palliative/end-of-life care content?	4.56	6.5	.001
Overall, how helpful has the ELNEC-Critical Care project been to you in improving end-of-life/palliative care education in your work setting?		7.81	

^a Based on a scale of 0=not to 10=very. Abbreviation: ELNEC, End-of-Life Nursing Education Consortium.

Table 4 Educational programs offered 12 months after the course

End-of-life topic/content	No. of classes offered	No. in attendance
Overview of palliative nursing	39	1074
Pain management	37	949
Symptom management	26	788
Ethical/Legal issues	24	795
Communication	23	1139
Grief, loss, bereavement	19	840
Final hours	20	523
Achieving quality palliative care	17	458
Total	205	6566

settings, participants were asked at 6 and 12 months after the course to report on the progress of the goals they had established in their initial application. Table 5 presents examples of the important activities implemented and disseminated after the course. For instance, regarding influencing system change, trainers are revising end-of-life order sets for intensive care patients, collaborating with administrators to improve the intensive care unit's waiting room, implementing palliative care rounds, negotiating and contracting for a 24-hour chaplaincy service, and more. Participants understand the importance of excellent bereavement care, and they attempt to connect

patients' family members with bereavement services through local hospices and other community organizations. Last, trainers are finding the ELNEC materials helpful in promoting professional education. Examples include using the curriculum to teach undergraduate nursing faculty and students about palliative care, organizing monthly teleconferences for the intensive care unit, reviewing palliative care articles at journal club, and many more. In addition, many critical care nurses belong to the American Association of Critical-Care Nurses, which provides further support through various resources related to end-of-life care (eg, self-assessment, e-learning,

Table 5 Examples of dissemination and implementation of ELNEC-Critical Care by course participants

Making systemwide changes for patient care

- Revising end-of-life order sets for patients in the ICU; in-service training of physicians, nurses, and respiratory therapists on new comfort care orders, symptom management, and terminal weaning
- Finalizing protocols so that family members can be present during cardiopulmonary resuscitation of their loved one
- Designing a sign to place on the outside door of a room where a patient is actively dying; this sign reminds the staff of the respect, dignity, and empathy that is to be given to the patient and the patient's family
- Discussing with medical director of critical care unit the addition of intravenous opiate infusions for pain management and for this to be added to the ventilator protocol order set
- Collaborating with administration to have the ICU waiting room painted and to have new furniture delivered
- Implementing palliative care rounds/increased use of palliative care consultation
- Using the "Getting to Know Me" form/poster for families of loved ones in the ICU to fill out so that staff has a better understanding of the patient, his/her family, his/her culture
- Negotiating/Contracting for a 24-hour pastoral care service
- Developing teaching materials for families on pain, ventilator withdrawal, and end-of-life care

Bereavement care

- Mailing condolence cards to family members whose loved ones died in a critical care setting (ie, ICU, critical care unit, emergency department), allowing continued communication with the family
- Connecting family members with bereavement services either at the acute care facility or through the local hospice (especially those whose family member died in the emergency department)

Professional nursing education

- Using the ELNEC-Critical Care curriculum to teach undergraduate nursing faculty and students about palliative care
- Using pain and symptom management modules from ELNEC for new employee orientation
- Reviewing supplemental teaching materials from the pain module during weekly in-service training sessions
- Using the materials from the communication module to teach Hispanic patients and care providers
- Organizing monthly ICU teleconferences, using ELNEC-Critical Care materials
- Implementing ELNEC as nursing continuing education or as interdisciplinary education
- Reviewing palliative care articles with journal club every 3 months

Abbreviations: ELNEC, End-of-Life Nursing Education Consortium; ICU, intensive care unit.

and numerous online documents) that are posted on their Web site (<http://www.aacn.org/WD/Palliative/Content/PalAndEOLInfo.pcms?menu=Practice>).

Conclusion

Critical care nurses are essential to advance palliative care for patients with serious or life-threatening illnesses, including those who are actively dying. Lack of knowledge is consistently identified as an obstacle

to health care professionals as they strive to improve palliative care.^{3,4,9-}

^{11,14,21} Education regarding pain and symptom management, communication strategies, care at the end of life, ethics, and other aspects of palliative care are urgently needed. Although efforts to increase the content related to end-of-life care in most undergraduate and graduate nursing curricula are ongoing, most practicing critical care nurses have not received formal training in palliative care.^{12,14,23} This issue was identified in the past, with studies conducted to examine critical care nursing textbooks, which often contained inadequate, if any, information on palliative care.^{25,26} More evaluation is needed in this area.

The ELNEC-CC program is an extremely successful educational effort that addresses the need for improved end-of-life care by adapting an existing curriculum to concentrate on the requirements of those nurses working in areas of critical care. The extensive support materials, including CD-ROM, binder, Web sites, newsletters, textbooks, case studies, and other supplemental items facilitates the ongoing learning by participants and the transfer of information to students and colleagues. Ongoing informal support from investigators, quarterly emailed newsletters (ELNEC Connections), and Web sites with numerous resources (eg, palliative care articles, national



To learn more about palliative care, read "Nurses' Perceptions of End-of-Life Care After Multiple Interventions for Improvement" by Hansen et al in the *American Journal of Critical Care*, 2009;18:263-271. Available at www.ajconline.org.

guidelines) provide additional support. In addition, the ELNEC Web site (www.aacn.nche.edu/ELNEC) provides a list of trainers by state, so new trainers can access names and e-mail addresses of trainers who live in their community. This list facilitates collaboration between trainers who may wish to teach ELNEC courses together and/or to work together to develop a city, county, or state palliative care coalition. The ultimate goal is to improve end-of-life care for patients in all critical care settings and enhance the experience of family members witnessing their loved ones dying.

To date (November 2006–October 2010), more than 850 critical care nurses have attended 1 of 9 national ELNEC-CC training programs; of these nurses, approximately 550 were from California. The ELNEC project team believes that a concentrated state effort made possible by a state-focused foundation can greatly affect the integration of palliative care. Critical and palliative care leaders should work closely with foundations to replicate the experience of the Archstone Foundation and ELNEC in California. The Archstone-ELNEC partnership continued through 2010 with a focus on the ELNEC-CC project. Through this continued support, ELNEC reached an additional 400 California critical care nurses. This effort will greatly enhance previous efforts,²⁷ with an ultimate aim of not only moving California to a model of excellence in palliative care, but also encouraging other states to follow. **CCN**

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