

Graduate nursing education regarding end-of-life care

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Death from chronic illness continues to be associated with unrelieved symptoms, occurring in a hospital or other institution, with little discussion about advance directives. The role of nursing, particularly advanced practice nurses, is critical to improving care at the end of life. However, little attention is devoted to palliative care in most graduate nursing curricula, leaving advanced practice nurses poorly prepared to meet the needs of those approaching the end of their lives. The Graduate Educators program of the End-of-Life Nursing Education Consortium (ELNEC-Graduate) is one solution to this healthcare crisis. ELNEC-Graduate builds upon the existing ELNEC-Core program, yet focuses on the unique learning needs of advanced practice nurses. The purpose of the program is to provide nursing faculty with the knowledge and materials necessary to include palliative care throughout the graduate nursing curriculum, educating advanced practice nurses who will ultimately improve the care of those with life-threatening illness.

Despite recent attention to the need for improved palliative care, death from diseases such as cancer, cardiovascular disease, and other chronic illnesses continues to be associated with needless suffering. Pain and other symptoms are under-managed, and little consideration is given to the need for the difficult conversations necessary to determine the patient's goals of care. Nurses, particularly advanced practice nurses

(APNs), can significantly improve the care delivered to those with life-threatening illnesses. To provide this care, APNs must be educated regarding the specialty of palliative care. Unfortunately, little attention currently is paid to end-of-life (EOL) care in most graduate nursing curricula. The Graduate End-of-Life Nursing Education Consortium (ELNEC) is one solution to support nursing faculty in disseminating this content within graduate nursing curricula.

DEATH IN AMERICA

Death from diseases such as cancer, cardiovascular disease, and other chronic illnesses is often associated with needless suffering. For many, death is a time filled with pain, dyspnea, anxiety, and distress, with little choice regarding patient preferences for where and how they wish to die.¹⁻⁵ This lack of attention to EOL care affects all age groups, particularly children and the older adult, and includes a variety of settings, such as hospitals and long-term care facilities.^{6,7} Furthermore, studies demonstrate racial disparities in the provision of pain management to people with life-threatening illness and lack of availability of opioid medications, essential tools in the management of pain and other symptoms.⁸⁻¹¹ As a result of this lack of availability of appropriate palliative care, patients and their families are faced with choosing between therapies with curative intent or comfort

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Table 1. Survey of Master’s Level Nursing Curriculum

Curriculum Survey Master’s-Level Programs n = 131			
Advanced practice programs offered as major area of study (40 states responding)			
NP	82.2%		
CNS	53.5%		
Combined NP/CNS	17.8%		
Other	31.8%		
Assessment of the adequacy of specific EOL care content currently in overall program			
	% Offered	If Yes, Adequacy (1 = limited; 10 = extensive)	SD
		Mean	
a. Nursing Care at End-of-Life	68%	4.27	2.39
b. Pain Management	85%	5.76	2.34
c. Symptom Management	83%	6.05	2.37
d. Cultural Considerations	93%	6.04	2.27
e. Ethical/Legal Issues	93%	6.38	2.47
f. Communication	89%	6.40	2.22
g. Grief, Loss, Bereavement	76%	5.57	2.48
h. Preparation and Care for the Time of Death	52%	4.66	2.20
i. Achieving Quality of Life at the End of Life	66%	4.98	2.30
Types of materials currently used to teach EOL content			
Speakers, experts	61%		
Clinical experiences (ie, hospitals, hospices)	52%		
Textbooks	46%		
Case studies	37%		
Audiovisuals	34%		
Lecture guides/outlines on EOL topics	31%		
Internet Resources	18%		
Computer-assisted instruction	15%		
Standardized curriculum	5%		

care, despite the fact that both are needed to provide the best possible quality of life.

In response to this crisis in health care, several prestigious organizations have published documents calling for improvement in the care delivered to the dying. The Institute of Medicine (IOM) report *Approaching Death: Improving Care at the End of Life* asserted that people with advanced, potentially fatal illnesses should be able to receive competent, skillful care. The report identified gaps in knowledge about care of those at the end of life and recommended that educators should ensure that clinicians are prepared to provide appropriate care to the dying.¹² Other documents detailed the reasons for inadequate end-of-life care, including inadequate knowledge and education of health care professionals in symptom management and other palliative care skills.^{13–20} These reports emphasized the need for well-trained professionals, including nurses, to overcome the crisis in care of the dying that exists today. One specific strategy noted in these documents is the expansion of educational materials and curriculum development in palliative care.

THE ROLE OF THE ADVANCED PRACTICE NURSE IN PALLIATIVE CARE

Advanced practice nurses are leaders in health care, serving in clinical, education, research, and administration roles. They are uniquely prepared to address the needs for improved care at the end of life, yet little information about care of the dying is currently included within graduate nursing curricula.^{13,21} Palliative care is absent from most nursing curricula and, when this coursework is offered, it is usually within the context of other courses or offered as an elective. This deficiency exists despite the publication of numerous consensus reports, standards and position statements from nursing organizations regarding the need for greater attention to EOL care in nursing curricula.^{22–25} These deficiencies are compounded by the lack of attention to palliative care in nursing textbooks, where only 2% of the content addresses EOL care.^{26–30} Additional studies by Ferrell and colleagues further demonstrate deficiencies in nursing education regarding EOL care.³¹

Table 2. Survey of Master's Level Nursing Curriculum: Importance and Efficacy of Existing Program

Curriculum Survey Master's-Level Programs n = 131		
	Mean (1 = not important/effective; 10 = very important/effective)	SD
How important is EOL care content to master's-level nursing education?	7.68	2.03
How effective do you believe a graduate of your program would be in caring for a dying patient?	6.38	2.19
How effective do you feel the master's-level faculty (overall) are in teaching EOL care content?	6.01	2.35
How receptive do you believe the master's-level faculty (overall) would be to increased EOL care education?	6.87	2.31
How effective do you believe your school's master's-level nursing program is in teaching end-of-life content?	5.66	2.32

Despite this lack of attention to EOL care in nursing education, the role of the APN in palliative care is critical. APNs are “nurses who have acquired the knowledge base and practice experience to prepare them for specialization, expansion, and advancement in selected practice roles.”³² Advanced practice nursing is distinguished from standard staff nursing roles based on the “complexity of decision-making, leadership, the capacity to negotiate complex organizations, expanded practice skills and knowledge.”³² Examples of advanced practice nursing roles include clinical specialists, nurse practitioners, nurse managers, nursing faculty, and researchers.^{33–35}

In a delineation study comparing the role of advanced practice oncology nurses with staff nurses, 5 domains were investigated: Direct Caregiver, Consultant, Administrator/Coordinator, Researcher, and Educator.³⁶ Respondents were asked to indicate the frequency with which they performed each behavior and the importance of each behavior to their practice. APNs indicated that they performed the behaviors on the Direct Caregiver and Educator subscales most frequently and believed these behaviors to be most important to their practice. Thus, an APN with expertise in EOL care has the potential to directly improve the care provided to patients, as well as educate fellow health-care professionals to deliver quality care.³³

THE ELNEC-GRADUATE PROGRAM

One strategy to overcome the lack of adequate attention to palliative care in nursing curricula has been the development of the End-of-Life Nursing Education Consortium (ELNEC). This program, which began in February 2000, was developed by nurse researchers at the City of Hope National Medical Center in collaboration with the American Association of Colleges of Nursing (AACN) to coordinate national nursing efforts

related to EOL care issues.^{37,38} The overall goal of the program has been to enhance nursing education in caring for patients in the last stages of life. The ELNEC project, originally funded by the Robert Wood Johnson Foundation, has developed a core curriculum to develop EOL expertise in faculty in undergraduate nursing programs, continuing education programs, and through the National Council of State Boards of Nursing, Inc. Based on the AACN “Peaceful Death” document, the curriculum focuses on 9 core areas in EOL care: overview of care at the EOL; pain management; symptom management; cultural considerations; ethical/legal issues; communication; loss, grief, and bereavement; preparation for and care at the time of death; and achieving quality care at the EOL.³⁹

Prior to adapting the ELNEC-Core curriculum to develop the graduate version, a survey of the 382 graduate nursing programs in the US was conducted to determine the existing state of palliative care content within these curricula. The findings represent 131 (34%) of graduate programs, supporting the need for improved EOL education (Tables 1 and 2). Although faculty noted that EOL care was very important to graduate nursing education, most perceived their own program to be only moderately effective, at best, in providing this information. All 9 areas of content were rated in the current curriculum as only moderately adequate with mean scores ranging from 4.27–6.40, using a 0–10 scale, where 10 indicated highest possible effectiveness.

The American Cancer Society and Oncology Nursing Society curriculum guide for advanced practice oncology nursing specialty education at the master's level was used as a foundation to the development of the ELNEC-Graduate curriculum. “The Master's Degree with a Specialty in Advanced Practice Oncology Nursing” includes core competencies for APNs.⁴⁰

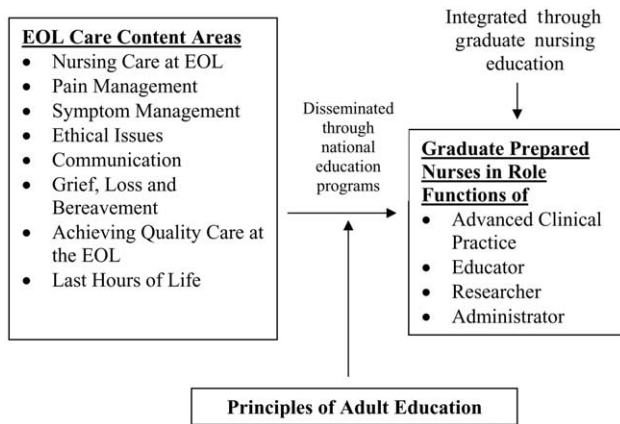


Figure 1. ELNEC-Graduate Education Framework.

Symptom management, palliative care, and care during the final stages of life are listed as critical content within the curriculum guide. The core competencies of this curriculum include: clinical practice, education, consultation, systems, role competency, research and outcomes evaluation, program development, and leadership. For clarity and brevity, these competencies are grouped under the following 4 role function areas: (1) Advanced Clinical Practice (clinical practice, consultation, role competency), (2) Educator, Researcher (research and outcomes evaluation), and (4) Manager/Administrator (systems, program development, leadership). These competencies provided a framework for the development of the ELNEC-Graduate curriculum (Figure 1).

Universal themes, also called “common threads,” were identified through review of existing consensus documents, published literature, and expert opinion. These include (1) the family is the unit of care, (2) the important role of the nurse as advocate, (3) the importance of culture as an influence at the end of life, (4) the critical need for attention to special populations such as children, the elderly, the poor, and the uninsured, (5) EOL issues impact all systems of care across all settings, (6) critical financial issues influence end-of-life care, (7) EOL care is essential across all life-threatening illnesses and in cases of sudden death, and (8) interdisciplinary care is essential for quality care at the end of life. These themes are woven throughout the ELNEC-Graduate curriculum. In addition to determining the core competencies and universal threads, an extensive review of the literature was conducted to attempt to ascertain unique learning needs of APNs in relationship to palliative care. In addition to symptom management concerns, several themes evolved, including issues related to reimbursement for services, prescriptive authority, utilizing research, ethical issues, communication and collaboration within a team, and facilitating care services.^{41–46} These issues were incorporated into the curriculum, which has been revised and

updated annually. For example, the recent Clinical Practice Guidelines for Quality Palliative Care, developed by the National Consensus Project for Quality Palliative Care, were distributed to participants in the most recent course and will be integrated throughout the next version of the curriculum.⁴⁷

The ELNEC-Graduate program is funded by a grant from the National Cancer Institute. Courses are held over a 3-day period, with 4 annual courses planned (2 have already been conducted and others are planned for 2005 and 2006). Workshop participants receive approximately 18 hours of didactic and experiential training, supported by extensive written resources and all handouts and slide materials on CD-ROM to facilitate teaching of EOL content. The project was originally funded for approximately 60 faculty to attend each course, with an eventual total of 240 participants representing 240 graduate nursing schools from all 50 states. However, the demand has been so significant that the investigators have been able to accommodate 153 attendees at the first 2 courses. Participants have come from 49 states.

The ELNEC-Graduate curriculum consists of 8 modules (Table 3). Along with didactic presentations, the sessions use techniques of discussion, video clips, case studies, role play, and other breakout sessions. Prior to the course, participants are asked to develop goals for implementing the ELNEC curriculum in their graduate programs. Time for and assistance with refinement of these goals is provided during the course. Panel presentations contrast 2 existing graduate programs that focus on palliative care, offering models for participants to replicate in their settings. This includes New York University, which offers a specialty program in palliative care, while the second, University of California-San Francisco, integrates palliative care throughout the graduate nursing curriculum.

Additional reinforcement and dissemination methods, including frequent newsletters and Web site access, and extensive evaluation provide a basis for the continuing education of these graduate nursing educators beyond the project period. To assist with networking, the Web site includes a list of ELNEC-Graduate faculty members who have completed the course (www.aacn.nche.edu/ELNEC/GraduateTrainers.htm). These graduate nursing educators are expected to incorporate EOL content into their curricula, impacting the vast majority of graduate nursing programs within the US. Participants have described the courses and the supplemental materials as extremely useful during the end-of-course evaluation.

The evaluation plan for ELNEC-Graduate is extensive. Participants provide a list of goals in their application to attend the program that is refined during the course. Participants provide evaluation of their goals at 6 and 12 months after the course. These evaluations include progress they have made towards these goals,

Table 3. ELNEC-Graduate Modules

Module	Title	Graduate Level Content
Module 1	Nursing Care at the End of Life	<ul style="list-style-type: none"> ● Delineation of the role of the APN in palliative care ● Reimbursement issues related to palliative care and APN practice
Module 2	Pain Management	<ul style="list-style-type: none"> ● Advanced physical assessment and differential diagnosis related to pain ● Prescriptive authority and practices ● Regulatory issues related to opioids ● Research related to novel therapies and routes of delivery for pain ● Evidence-based reviews of pain therapies used in palliative care
Module 3	Symptom Management	<ul style="list-style-type: none"> ● Advanced physical assessment and differential diagnosis related to symptoms ● Evidence-based reviews of therapies used to treat symptoms in palliative care ● Research issues in symptom control
Module 4	Communication	<ul style="list-style-type: none"> ● Conducting a family meeting ● Difficult communication and breaking bad news
Module 5	Ethical Issues in Advanced Practice Nursing	<ul style="list-style-type: none"> ● Address ethical, legal, and social issues for APNs related to palliative care
Module 6	Last Hours of Life	<ul style="list-style-type: none"> ● Making system changes to ensure control of symptoms during final hours of life (eg, policies to treat intractable symptoms, removal of life support)
Module 7	Loss, Grief, Bereavement	<ul style="list-style-type: none"> ● Identifying complicated grief in staff ● Interventions to address loss within professional colleagues
Module 8	Achieving Quality Care at the End of Life	<ul style="list-style-type: none"> ● Fostering policy development and system change to improve EOL care ● Review of sources for evidence-based practice related to palliative care

Note that each module is listed with content unique to the graduate level. The module on cultural issues developed for the ELNEC-Core is included on CD-ROM for participants as references, however, culture is integrated throughout all modules in ELNEC-Graduate.

obstacles or challenges they have met, as well as strategies they have learned to overcome any barriers. The outcomes of this project will be summarized following the final course in 2006.

CONCLUSION

Dying in America continues to be associated with needless suffering. Pain and other symptoms are poorly assessed and managed. Little attention is afforded to the existential distress that can occur at the end of life. Difficult communication regarding EOL care planning is not initiated, leaving patients little time to make decisions regarding how and where they wish to spend their final hours.

APNs can significantly contribute to this critically needed change in the way care to the dying is provided. To do so, these nurses must be educated regarding symptom management, communication strategies, and other aspects of palliative care. Little attention currently is paid to EOL care in most graduate nursing curricula,

however, and strategies are needed to facilitate overburdened faculty to integrate this content into existing curricula. The ELNEC-Graduate program provides a comprehensive curriculum aimed to provide information necessary for APNs. The extensive amount of support materials, including CD-ROM, binder, Web sites, newsletters, textbooks, and other supplemental items, reduces the burden on faculty to develop these resources. Participants rate the course and materials highly. In particular, participants valued the strong organization of the course, the clinical relevance of the material, the expertise of the highly qualified faculty, and the extensive resources provided in both writing and CD-ROM. Demonstrations on how to use and adapt the modules also were cited as extremely useful. Early efforts to integrate this content within their respective curricula are underway. These efforts will reach > 65% of graduate nursing programs throughout the US. At the end of this project, efforts to integrate this curriculum into graduate nursing programs will be underway in all

50 states. The end result of these efforts will be education of APNs to be able to deliver skillful and effective palliative care to a wide array of people with life-threatening illnesses, across the lifespan and in all settings where health care is delivered. The ultimate goal is to improve the quality of living and death, for both patients and their family.

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