

The Essence of Nursing: Providing Palliative Care Education to Better Serve the Seriously Ill

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Palliative Care: The Essence of Nursing

Palliative Care:

- Focuses on a holistic approach to the patient and family
- Addresses the physical, psychological, social and spiritual domains of quality of life
- Advocates for patient/family wishes and goals of care
- Is compassionate, culturally sensitive care



Introduction to Palliative Nursing

Dr. Betty Ferrell



(Move mouse over picture and hit play)

Why Do We Need Nurses to Be Prepared to Provide Palliative Care Now More than Ever?

- 1) Nurses must be able to fill the gap that exists in specialty palliative care services
- 2) Only nurses can give compassionate care
- 3) More people are dying now than ever before
- 4) We need more nurses to work in hospice care settings across the country

The Changing Demographics of Health Care

- 117 million adults have 1 or more chronic diseases
- 1 out of 4 adults have 2 or more chronic diseases
- Over 2.6 million people die/year in the US
- Top 5 leading causes of death
 - Heart disease (633,842)
 - Cancer (595,930)
 - Chronic lower respiratory disease (155,041)
 - Unintentional injuries (146,571)
 - Cerebrovascular diseases (140,323)



CDC, 2017

Serious Illness in America: Its Impact on Care

- Exploding healthcare costs
- Poor understanding of prognosis
- Failure to treat pain and other symptoms
- Increased use of technology
- Patients & families wishes not elicited



CHCF, 2017; Lui et al., 2014

Barriers to Quality Care at the End of Life



- Failure to acknowledge the limits of medicine
- Workforce that is too small to meet demands
- Lack of training for healthcare providers
- Hospice/palliative care services are poorly understood
- Lack of research
- Lack of payment models linked to quality measures
- Rules and regulations
- Denial of death

CAPC, 2015; NHPCO, 2015

What about Costs for Medicare and Medicaid Patients?

- The seriously ill constitute only 5-10% of patients (more than ½ of the nation's total healthcare costs)
- 10% of Medicare beneficiaries with 5 or more co-morbid illnesses (2/3 of total Medicare spending)
- The 4% of the sickest Medicaid beneficiaries (48% of total program spending)
- 76% of the national Medicaid budget goes to acute hospital services, the most expensive setting of care
- *Palliative care could decrease these expenditures*

CAPC, 2016



Challenges Nurses are Facing Today

- Workload stress
- Time pressures
- Recruitment and retention issues
- Rising moral distress
- Compassion fatigue & burnout

Quality Palliative Care

“Care that provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious advanced illness and their families. Palliative care may begin early in the course of treatment for a serious illness and may be delivered in a number of ways across the continuum of health care settings, including in the home, nursing homes, long-term acute care facilities, acute care hospitals, and outpatient clinics. Palliative care encompasses hospice and specialty palliative care, as well as basic palliative care”

NCP, 2013

Snapshot of Palliative Care in the US Today



- 67% of US hospitals have palliative care programs
- 90% of hospitals with 300 beds or more have palliative care teams
- 56% of hospitals with less than 300 beds have a palliative care program

National Palliative Care Registry™, 2017

Specialist Palliative Care

- An organized plan for a patient's serious illness in terms of proactive pain and symptom management, education, and use of resources appropriate to age and development
- Comprehensive pain and symptom management
- Expert communication skills for exploration of quality of life, informed decision making, goals of care discussions, and family meetings
- Psychosocial and emotional support for patient and family
- Attention to cultural, ethical and spiritual dimensions of care
- Planning for end-of-life in terms of setting and interventions consistent with patient goals

Primary Palliative Care

- Primary palliative care includes basic skills and knowledge about caring for individuals with chronic, serious and advanced illness, as well as dying patients:
 - Begins at diagnosis and is offered across the disease trajectory
 - Includes management of common pain and symptoms
 - Provides advance care planning discussions and support to complete advance directives
 - Emphasizes access community resources and interdisciplinary team members

Dahlin, 2015

ANA – HPNA: Call for Palliative Care in Every Setting

- Calls for Nursing to lead and promote palliative nursing in Administration, Education, Research, Policy, and Practice
- Many resources throughout and specifically in Appendix A



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American Nurses Association and Hospice & Palliative Nurses Association Call for Palliative Care in Every Setting

SILVER SPRING, MD – The [American Nurses Association \(ANA\)](#) and [Hospice & Palliative Nurses Association \(HPNA\)](#) have partnered to issue the *Call for Action: Nurses Lead and Transform Palliative Care*. This Call for Action supports the belief that seriously ill and injured patients, families, and communities should receive quality palliative care in all care settings.

"Every nurse should have the knowledge and ability to facilitate healing and alleviate suffering through the delivery of safe, quality, and holistic person-centered primary palliative care," said ANA President Pamela F. Cipriano, PhD, RN, NEA-BC, FAAN. "Nurses within the palliative care specialty may practice in designated palliative and hospice teams – our call is for all nurses to take action to transform palliative care across all specialties and care settings."

Recommendations



1. Adopt the End of Life Nursing Education Consortium (ELNEC) curricula [Core, Geriatric, Critical Care, Pediatric, Advanced Practice Registered Nurse (APRN)] as the standard for primary palliative nursing education for pre-licensure, graduate, doctoral, and continuing education for practicing registered/vocational/practical nurses and advanced practice registered nurses.
2. Petition the National Council for State Boards of Nursing to increase palliative care content on the pre-licensure NCLEX-RN and NCLEX-PN.
3. Encourage state boards of nursing with continuing education re-licensure requirements to mandate inclusion of palliative care content.
4. Advocate the use of the National Consensus Project for Quality Palliative Care *Clinical Practice Guidelines for Quality Palliative Care* in the development, implementation, and evaluation of specialty, evidence-based palliative care services for all organizations...

NCP and NQF: 8 Domains of Palliative Care

Structure and processes of care

Physical aspects of care

Psychological and psychiatric aspects of care

Social aspects of care

Spiritual, religious, and existential aspects of care

Cultural aspects of care

Care of the patient at the end of life

Ethical and legal aspects of care

NCP, 2013

Why is Primary Palliative Nursing Education So Critical Now?

- Employers are expecting new graduates to have this content before being hired
- Specialty palliative care resources are limited; nurses must be able to provide primary palliative care in any setting & recognize the need for specialty palliative care when appropriate

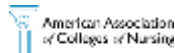


However.....

*NEW GRADUATE NURSES CAN
NOT PRACTICE WHAT THEY DO
NOT KNOW!*

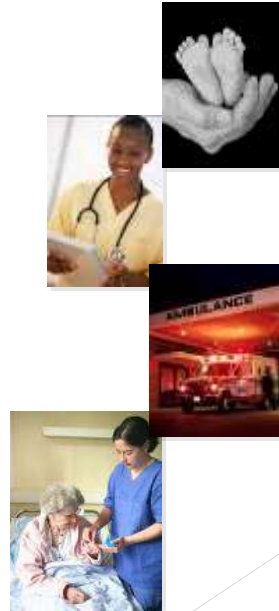


Celebrating 18 Years of Providing Palliative Care Education



ELNEC History

- 2000: Curriculum Developed
- 2001: 1st National ELNEC Course
- Currently 7 ELNEC Curricula:
 - ELNEC-Core
 - ELNEC-Geriatric
 - ELNEC-Pediatric Palliative Care
 - ELNEC-Critical Care
 - ELNEC-APRN
 - ELNEC-International
 - ELNEC-Undergraduate
 - ELNEC-APRN Oncology





Accomplishments Since ELNEC's Inception Jan 2001- July 2018

- **226** National ELNEC train-the-trainer courses have been held
- Training courses have been held across the US and internationally in **99** countries
- Translated into **8** languages
- Over **23,594** trainers
- Those trainers have gone back to their community and have educated over **707,820** healthcare professionals

The Space Between Video Kimbilio Hospice in Kenya

ELNEC Has its Roots in Nursing Education

- Dr. Betty Ferrell, the PI of the ELNEC Project, convened nursing experts to develop the *Peaceful Death Document: Recommendations & Curricular Guidelines for EOL Nursing Care* (AACN, 1997)
- Initial ELNEC-CORE course was developed for undergraduate and then graduate faculty
- In 2015, ELNEC team recognized the need to evaluate current palliative care education needs in undergraduate education and received generous funding from Cambia Health Foundation to: *Advance primary palliative nursing care for patients with serious illness and their families by educating nursing students during their undergraduate nursing program*

Are You Using the ELNEC- Undergraduate Curriculum in Your School of Nursing?



ELNEC-Undergraduate Project

- Cambia Health Foundation funded a 3 year project to
 - Evaluate the state of palliative nursing in undergraduate nursing education
 - Develop competencies that all students should meet by the time of graduation from their pre-licensure programs
 - Design and implement an innovative online curriculum to meet the recommendations of the new competencies
 - All programs in the four states of OR, WA, ID & UT were offered the curriculum for all their students, at no cost for one year of access



State of Undergraduate Palliative Nursing Education in the U.S. (2015)

- Despite an increasing demand for nurses to be prepared in primary palliative care, few nursing faculty members are prepared to teach this content
- Lack of available space in nursing schools' curricula is a barrier to adding this content into most nursing programs
- Many current textbooks are outdated and inaccurate

Ferrell, B., et al., (2016)

AACN CARES Document

- To address the gaps, palliative nursing experts and faculty from across the U.S. came together in Portland OR (2015) to write the American Association of Colleges of Nursing (AACN) Palliative CARES Document
- C ompetencies
- A nd
- R ecommendations for
- E ducating Nursing
- S tudents

<http://www.aacnnursing.org/Portals/42/ELNEC/PDF/New-Palliative-Care-Competencies.pdf>

Curriculum Development & Implementation

- *AACN CARES Document (Competencies and Recommendations for Educating Nursing Students)* Approved by AACN Board, Jan. 2016
- During 2016, ELNEC- Undergraduate Curriculum was developed
- In January, 2017 ELNEC- Undergraduate Curriculum- the first online, interactive curriculum for beginning nursing students was released through our learning management partner, Relias
- During the first 18 months, over 15,000 students have completed the curriculum and over 200 schools have enrolled or are enrolling



Key Features of ELNEC-Undergraduate Curriculum

- Each module contains:
 - Testimonials from nursing leaders in palliative care
 - Case studies requiring critical thinking
 - Brief video clips demonstrating palliative nursing skills
 - Application (NCLEX-style) quizzes at the end of each module- requiring mastery level of 80%
 - Pediatric and geriatric palliative care are woven throughout



6 MODULES

MODULE 1
INTRODUCTION TO PALLIATIVE NURSING

MODULE 2
COMMUNICATION IN PALLIATIVE CARE

MODULE 3
PAIN MANAGEMENT IN PALLIATIVE CARE

MODULE 4
SYMPTOM MANAGEMENT IN PALLIATIVE CARE

MODULE 5
LOSS, GRIEF & BEREAVEMENT

MODULE 6
FINAL HOURS OF LIFE

Topics Covered in the ELNEC- Undergraduate On-Line Curriculum

- Ethics & Culture content embedded across all 6 modules



Themes Throughout ELNEC-Undergraduate Curriculum

- Family as the unit of care
- Importance of honoring culture
- Vital role of the nurse as advocate



ELNEC-Undergraduate Themes (cont.)

- Palliative care is for all patients, across the life-span, with a serious illness & their families
- Palliative care should be provided across the disease trajectory and in *all clinical settings*
- *Interprofessional* care is essential for quality palliative care!



Ease of Access: Our Partnership with Relias

- Faculty can go online directly with Relias to request the curriculum:
<http://elnec.academy.reliaslearning.com>
- Cost is \$29/student for 12 months access
- Schools of Nursing have the option to purchase the curriculum in bulk
- Technology has been extremely smooth
- Schools of Nursing do not need to involve School IT

Successes! How Most Schools are Using ELNEC- Undergraduate

- Assign modules as part of course work: introductory sophomore level nursing courses, medical-surgical courses during third year, geriatric electives, and senior capstone courses
- Split modules among courses: Pain & Symptom Management in pharmacology; Communication and Loss, Grief, and Bereavement in psych-mental health; introduction to Palliative Care and Final Hours in Foundations course
- As an elective (although limits number of students getting education)
- In a flipped classroom format: assigning modules online, and following up with rich debriefing sessions in class

Evaluation Data from Jan 2017- July 2018

- School Participation
 - Over 220 schools of nursing enrolled or enrolling
 - 45 of the 50 states plus DC
 - % BSN/prelicensure programs
 - % ADN programs
- Student Enrollment
 - 10,906 users enrolled
 - 7,117 have completed the curriculum

Evaluation Data: Sample Responses to Quantitative Questions

% Strongly Agree/ Agree Responses to Module Evaluation Questions

Questions	Module 1: Introduction	Module 2: Communication	Module 3: Pain	Module 4: Symptoms	Module 5: Loss	Module 6: Final Hours
1	99%	98%	98%	98%	98%	98%
2	98%	98%	98%	98%	98%	98%
3	96%	97%	96%	96%	97%	98%

Question 1: Content is relevant to my practice

Question 2: Content is presented effectively

Question 3: As a result of completing this module, I will change my practice

What Students Are Telling Us



"I feel much more confident in my ability to navigate vulnerable and fragile situations with my future patients now that I understand and have practiced the skills that ELNEC has taught me."

"As a new nurse, the thought of caring for a dying patient was a terrifying thought before completing these modules. Now, I feel confident in offering a high quality of care and providing comfort to a patient nearing the end of their life."

What Students Are Telling Us (cont.)

"Before completing the ELNEC modules, I never really understood palliative care. The ELNEC modules opened my eyes to the benefit of palliative care and I now advocate that my patients understand the value of palliative care."

- Concordia University, St Paul, MN

"I have LOVED these courses! They have provided me with some knowledge and examples on how to deal with patients and families during these difficult times. The testimonials from the experts are so useful and relatable. These courses should be REQUIRED for all nursing students and nurses early into the program."

- Final Hours Module; Sept., 2017

"I liked learning some phrases to say when comforting patients and family because sometimes it is hard to know what to say."

- Communication module, Dec., 2017



What is the Number One Reason for Not Integrating ELNEC-Undergraduate into Curricula?

- Students don't have resources to do online assignments
- Schools cannot afford the cost of the curriculum
- Faculty are already teaching the content
- There is not room for this content in saturated curricula

We are Proud of our Champions' Successes and Grateful to our Champions who have Faced Challenges!

- Despite the curriculum being available totally online, many faculty have faced curriculum committees and other faculty members who are reluctant to include the curriculum in saturated nursing programs
 - "We don't have room for that in our courses."
 - "Don't we already teach this content somewhere?"
 - "Why do students need this education?"
 - "We need to focus on NCLEX pass rates, not palliative care."

What Schools of Nursing Are Telling Us

"Meeting the needs of individuals, families and communities to cope and adjust with life limiting illnesses is one of the most pressing needs of contemporary health care. Preparing nurses to provide palliative care across the life span is critically important, particularly at the pre-licensure stage. The End-of-Life Nursing Education Consortium in partnership with the American Association of Colleges of Nursing has created a wonderful Undergraduate Pre-Licensure Curriculum. These resources present both the science and art of palliative and supportive care within a comprehensive framework of knowledge, skills and competencies..."

Patricia Davidson, PhD, MEd, RN, FAAN
Dean, School of Nursing, Johns Hopkins University

Faculty Responses

"Students in both of our BSN tracks have consistently provided positive feedback after completing the ELNEC modules, including appreciating the interactive learning modality and the value of the content and applicability to practice".

"Even our experienced hospice nurses have shared how much they valued the ELNEC modules, with practical tips and information they were able to apply immediately to their practice every day".



Coming Soon: ELNEC-Graduate Online Curriculum



- Many ELNEC- Undergraduate faculty have asked for a comparable curriculum to teach graduate students primary palliative care
- Will utilize a similar process and first create competencies for graduate-level nursing students (MSN & DNP) who will be working in clinical, administrative, and educational settings
- Following approval of the competencies, a graduate online curriculum will be created

ELNEC-Graduate Online Curriculum



Curriculum will be
ready for release in
August 2019!

- Competencies under review by AACN
- When approved, ELNEC team will move forward with developing six one-hour online modules for curriculum:
 - Introduction to Palliative Care
 - Communication
 - Pain Assessment & Management
 - Common Symptoms: Assessment & Management
 - Care During Final Hours
 - Leadership in Primary Palliative Care

HALL OF FAME 2018
ELNEC- UNDERGRADUATE CURRICULUM
TOP SCHOOLS WITH THE GREATEST PARTICIPATION

Alabama: The University of Alabama, Tuskegee University

California: Santa Pacific University, City of Hope, Mount Carmel Mary's University

Connecticut: Fairfield University, Southern Connecticut State University, University of Connecticut

Florida: University of Florida, University of Miami

Georgia: Berry College

Idaho: Boise State University, College of Eastern Idaho

Illinois: North Park University

Indiana: Indiana University, Indiana University - Purdue University, University of Southern Indiana

Iowa: NorthWestern College, University of Iowa

Kentucky: University of Miami, John Hopkins University

Kansas: Kansas State University, Wichita State University

Kentucky: Eastern Kentucky University, University of Louisville

Maine: University of Maine

Maryland: Johns Hopkins University

Massachusetts: Simmons College

Michigan: College of St. John's, Central Michigan University, Eastern Michigan University, Michigan State University, Western Michigan University

Minnesota: College of St. John's, Central Michigan University, Eastern Michigan University, Michigan State University, Western Michigan University

Missouri: University of Missouri, University of Central Missouri

Montana: Montana State University

Nebraska: University of Nebraska, University of Central Missouri

Nevada: University of Nevada, University of Central Missouri

New Hampshire: University of New Hampshire

New Jersey: Rutgers University, University of Central Missouri

New Mexico: University of New Mexico

New York: State University of New York, University of Central Missouri

North Carolina: North Carolina State University, University of Central Missouri

North Dakota: North Dakota State University

Ohio: Ohio State University, University of Central Missouri

Oklahoma: Oklahoma State University

Oregon: Oregon State University

Pennsylvania: Pennsylvania State University, University of Central Missouri

Rhode Island: Brown University

South Carolina: University of South Carolina

South Dakota: South Dakota State University

Tennessee: University of Tennessee

Texas: Texas State University, University of Central Missouri

Utah: Utah State University

Vermont: University of Vermont

Virginia: Virginia Commonwealth University

Washington: Washington State University

West Virginia: West Virginia University

Wisconsin: University of Wisconsin

Wyoming: University of Wyoming

American Association of Colleges of Nursing | City of Hope

Thank You for
 Advocating for
 Primary Palliative
 Care Education in
 Your Nursing
 Programs

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