

Are Your Students Prepared to Provide Complex Care to Chronically Ill Patients?

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Are Your Students Prepared to Care for Those with Serious Illness



The Changing Demographics of Health Care

1 in 2 adults have a chronic disease (CDC, 2018)

90% of US \$3.3 trillion healthcare expenditures are for patients with chronic illness (including mental health issues)

Over 2.6 million people die/year in the US

Top 5 leading causes of death

- Heart disease
- Cancer
- Chronic lower respiratory disease
- Unintentional injuries
- Cerebrovascular diseases



<https://www.cdc.gov/chronicdisease/about/costs/index.htm>

Serious Illness in America: Its Impact on Care

- Patients & families wishes not elicited
- Exploding healthcare costs
- Poor understanding of prognosis
- Failure to treat pain and other symptoms
- Increased use of technology
- Gap in access to quality palliative care in many areas of the U.S.



CAPC, 2018; IOM, 2015

Barriers to Quality Care at the End of Life

- Unnecessary patient suffering
- Fragmented, burdensome care
- Medically inappropriate (futile) care
- Costly interventions
- Lengthy and repeated hospitalizations
- Overwhelmed caregivers



POOR Quality HIGH Cost



CAPC, 2018; IOM, 2015

Challenges Nursing Students Face Today Providing Increasingly Complex Care

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



Learning to provide primary palliative care
and advocate for specialty palliative care can help diminish these challenges

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, 2018)

Snapshot of Palliative Care in the US Today

- 94% of hospitals with 300 beds or more have palliative care teams
- 72% of hospitals with 50 or more beds have a palliative care program

Employers expect new nurses to know when to advocate for these services and to provide primary palliative care

- 90% of hospitals with palliative care are
 - located in urban areas
- 17% of hospitals in rural areas have
 - palliative care – telehealth is beginning to
 - address this gap!



CAPC, 2018

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

APRN ELNEC Curriculum, 2018

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 communication expertise, especially in advance care planning discussions and transitions of care
 - Emphasizes access to community resources and interdisciplinary team members

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



FOR IMMEDIATE RELEASE
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CONTACT: Rachel Farbman, 301-628-5062
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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, 2018

Celebrating 20 Years of Providing Palliative Care Education



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*

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>

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



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



What Topics Are Covered in the ELNEC-Undergraduate On-Line Curriculum?

- | | |
|---|--|
| #1: Introduction to Palliative Nursing Care | #4: Symptom Management in Palliative Nursing |
| #2: Communication in Palliative Nursing | #5: Loss, Grief, Bereavement |
| #3: Pain Management in Palliative Nursing | #6: Final Hours of Life |

*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>
- No need to seek support from school IT
- Cost is \$29/student/12 months access
- Schools of Nursing have the option to purchase the curriculum in bulk or to have students purchase it in their bookstores- and use financial aid package to pay!

Evaluation Data from 1/1/2017-10/1/2019

School Participation

- Over 350 schools of nursing enrolled or enrolling
- 48 of the 50 states plus DC
- of the 106 Hall of Fame programs, 90 % BSN/pre-licensure programs

Student Completions

- > 30,000 since launch in January 2017

Evaluation Data: Sample Responses to Quantitative Questions

% Strongly Agree/ Agree Responses to Module Evaluation Questions
October 2018-May 2019

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

Question 1: Content is relevant to my practice

Question 2: Technology is user friendly

What Students Are Telling Us

"Palliative care is such an essential component within comprehensive provision of care, and such an underutilized service. I agree that patients shy away from palliative care, which is often due to a lack of understanding around what that care entails or the mistaken belief that hospice and palliative care are synonymous entities. By having a more complete and accurate understanding of palliative care and the benefits patients derive from accessing those services, nurses can advocate for their patients and their families by providing education and clarity, which will promote a more optimal quality of life."



What Students are Telling Us (continued)

- *"This was a really great course, it gave me a lot of insight and understanding of how to handle these difficult conversations with patients and their families."* Communication- August 2019
- *"End-of-life nursing care is of the utmost importance. As nurses, we WILL see death, and it is something we need to know how to deal with."* Loss, Grief & Bereavement- February 2019
- *"I really found this course to be helpful. I was wondering how I was going to handle patients who were in the process of dying and their families, and I feel much more prepared in being part of the process now. Surely I have more to learn, but this was great insight into where to start. Thank you!"* Final Hours- March 2019

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

Online Programs are a Perfect Fit!

"Western Governors University is excited to be a leader in incorporating the End-Of-Life-Nursing-Education Consortium (ELNEC) core modules into our pre-licensure BSN and RN to BSN nursing programs. The ELNEC core modules provide evidence-based content to deliver the knowledge and skills needed to guide practice to provide quality palliative care."

Mollie Nordgren, MSN, Ed, CNE
Academic Director, Undergraduate Nursing, WGU



- | | |
|--|--|
| <p>Alabama
Tuskegee University
University of Alabama
University of West Alabama</p> <p>California
Alameda County Community College District
California State University, Stanislaus
City of Hope
Hawaii Pacific University
Portland State University
San Francisco State University
West Coast University</p> <p>Connecticut
Southern Connecticut State University</p> <p>District of Columbia
Georgetown University</p> <p>Florida
University of Florida
University of Miami</p> <p>Georgia
Berry College</p> <p>Idaho
Boise State University
College of Eastern Idaho
Eastern Idaho Technical College</p> <p>Illinois
North Park University</p> <p>Indiana
Indiana University
Indiana University - Bloomington
Indiana University - Fort Wayne
University of Southern Indiana</p> <p>Iowa
Northwestern College
University of Iowa</p> <p>Kentucky
University of Louisville - Louisville</p> <p>Maine
University of Maine</p> <p>Massachusetts
Boston College
Curry College
Simmons College</p> <p>Michigan
University of Michigan - Ann Arbor
College of St. Scholastica
Concordia University - St. Paul
Minnesota State University
Michigan State University
Northern Michigan University
School of Nursing
Southern California College of Health Sciences</p> <p>Minnesota
Minnesota State University</p> <p>Mississippi
College Saver College</p> <p>New York
Columbia University
Philip Ruff and Mount Sinai Hospital
St. John Fisher College
SUNY Downstate Medical Center</p> <p>North Carolina
East Carolina University
Western Governors University</p> <p>Ohio
Case Western Reserve University
University of Central Ohio</p> <p>Oregon
Columbia Community College
Concordia University - Portland
Linn-Benton Community College
Lincoln Community College
Oregon Coast Community College
Oregon Health & Science University
Lincoln Community College
University of Portland</p> <p>Pennsylvania
Drexel University
Lehigh University
Lehigh Valley University
Lehigh University
University of Pittsburgh
Wilkes University</p> <p>Rhode Island
University of Rhode Island</p> <p>South Carolina
Medical University of South Carolina
Trident Technical College</p> <p>Tennessee
Middle Tennessee State University
University of Tennessee - Knoxville
University of Tennessee - Chattanooga
University of Tennessee - Martin
University of Tennessee - Murfreesboro
University of Tennessee - Sevier
University of Tennessee - Southeast
University of Tennessee - Van Dyke
University of Tennessee - West Tennessee
University of Tennessee - Yorkville</p> <p>Texas
Texas Woman's University
University of Texas - San Antonio</p> <p>Utah
Brigham Young University
Edgewood College
Utah Valley University
Utah State University
Utah State University - South Jordan Campus
Utah State University - Utah Valley
Utah State University - Northern Utah</p> <p>Virginia
Community College of Vermont
Norwich University
University of Vermont</p> <p>Washington
Benjamin Franklin College of Nursing
University of Washington
University of Washington - Tacoma
Western Washington University</p> <p>West Virginia
Blue Bell College
West Virginia University</p> <p>Wisconsin
Belmont College
Concordia University - Neosho
Concordia University - Portland
Concordia University - Wisconsin
University of Wisconsin - Stevens Point</p> <p>Wyoming
University of Wyoming</p> <p>International
Brazil Universidade Regional do Cariri</p> | <h2>Thank You for
Advocating for Primary
Palliative Care
Education in Your
Nursing Programs</h2> |
|--|--|



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AND ON BEHALF OF THE CEDARVILLE UNIVERSITY SCHOOL OF
NURSING

DR. CARRIE KEIB, DR. RACHEL PARRILL & DR. SHARON CHRISTMAN

Cedarville University

Cedarville, Ohio



*Our Hope:
To use excellent nursing practice
as a ministry for Christ*

NURSING 4020: Leadership and Management

“THE THIRD FLOOR OF THE HEALTH SCIENCES CENTER
TRANSFORMS INTO THE CEDARVILLE MEDICAL CENTER ON
THURSDAY AFTERNOONS.”

Nursing 4020-Leadership and Management

- NSG 4020 is the last course before graduation (Spring semester) and provided concurrently with a **Senior** Preceptorship experience
- Content included, ethics committee, advance directives, family meeting principles, and care switching from curative to comfort care
- Didactic and Lab experiences
 - 6 labs (increasing to 7 next year) in groups of 8 nursing students rotating from week to week in a 4 hour timeframe
 - Topics include-Ethics & Palliative Care, Communication, Moderate Fidelity, High Fidelity, Root Cause Analysis, Leadership
- First 3 years, we used scenario of patient who had substance use disorder and alcoholic liver failure with complex family dynamics



Nursing 4020-Leadership and Management

- Our experience with this format
 - Emotional responses of current students in lab
 - Related to their experience with a dying person-personal or professional
 - Lack of clinical debriefing
 - Emotional and grateful emails from alumni once they completed the lab experience and entered into registered nursing practice
 - We wanted to add more content BUT in our current structure there was not enough lab time
 - We decided to gather some data regarding the effectiveness of what we were doing



Literature review UG education in EOL care

- A majority of UG nursing students have low levels of:
 - knowledge of pain and symptoms management^{1,2,4,9}
 - knowledge and comfort with psychosocial/spiritual care^{1,2,4}
 - comfort with patient and family communication^{4,9}
- Simulation is an effective means of increasing EOL knowledge^{3,4,8}
- EOL education should be integrated into undergraduate nursing education^{5,6,7,10}

Literature review then and now

- Another check of literature look in October 2019 of undergraduate nursing palliative care education
 - In China, Greece, Chile, & Brazil-similar contemplations are occurring
 - Knowledge can be low and attitudes negative toward providing palliative care
 - Lack of knowledge in palliative care, pain & symptom management, as well as, psychosocial and spiritual care
 - Difficulties facing care of the dying
 - Educational processes in palliative care are essential
 - United Kingdom 2019
 - “Active, experiential learning in the form of simulation teaching helps improve attitudes of undergraduate nursing and medical students towards end of life. In the absence of clinical exposure, simulation is a viable alternative to help prepare students for their professional role regarding end of life care.”
 - USA
 - Pediatric palliative care is particularly challenging and the use of simulation helps teach undergraduate nursing students in a safe environment for all participants

We should research our next steps...

- Ideas
 - Pre-test/post-test survey
 - Before and after education intervention
 - Education intervention will include
 - Pre-lab assignment
 - Didactic content delivery
 - High Fidelity Simulation experience
 - We should also survey students turned alumni one year after graduation
 - Begin the palliative care education-sooner within the undergraduate nursing curriculum!



The Details and The Discovery-Eureka!

- Looking for standards and Behold!
 - Palliative Care-CARES competencies of ELNEC (End of Life Nursing Education Consortium) endorsed by the AACN Board of Directors-Hooray!
 - 17 competencies for undergraduates
 - <https://www.aacnnursing.org/Portals/42/ELNEC/PDF/New-Palliative-Care-Competencies.pdf>
 - Even better content than we had contemplated
 - Reviewed ELNEC Undergraduate Education Learning Modules
 - Was attractive to us because
 - Expert, evidence-based content
 - Self-paced modules
 - Embedded quizzing
 - A certificate to be uploaded was already supplied
 - Faculty would not have to create content

SO...Two Major Plans

1. Apply for the Cedarville University Vice President for Academics Scholarship Grant Award
 - Awarded
 - 2018-2019
 - 2019-2020
2. Develop a formal palliative care content integration plan for the school of nursing curriculum committee
 - Approved in the 2018-2019 academic year for integration in the 2019-2020 academic year

The curriculum integration plan

- We aligned the curriculum outline of ELNEC alongside our undergraduate curriculum beginning at the sophomore year.
- We originally tried to match content in the way it made sense.
- Then our sophomore year professors were so excited about the plan they wanted to try to take on 4 of the 6 modules. They also wanted to develop mini-simulations within their class time.
- Which meant the other 2 modules would be delivered in the Junior year
- Time for review and simulation in the Senior year.



https://c2.staticflickr.com/4/3026/2626682758_209c385c05_z.jpg?zz=1

CU SON Faculty Response

- It's getting real
 - From the beginning, faculty were theoretically supportive as all had clinical experience understanding the need for palliative care education
 - Concerned about having to develop content
 - Appreciated one point of contact for the integration launch
 - Uncertainty about how it would all work together



https://www.google.com/search?q=rubber+meets+the+road+image&rlz=1C1GCEA_enUS765US765&tbm=isch&source=iu&ictx=1&fir=GBgq7WH5Wb0LsM%253A%252Cpfa04cYvKY3_tM%252C_&vet=1&usg=AI4_-kTJGN6nN2_dOGgV59CcgEI5pZPTlg&sa=X&ved=2ahUKEwj6-Gxwa7IAhXB6Z4KHxebDegQ9QEwC3oECAMQGg&biw=1338&bih=607#imgrc=c5225zsgOeL0M:&vet=1

How to measure?

- Currently, no available measurement tool for the palliative care CARES competencies
- Created one based on ELNEC competencies
 - Likert scale
 - Adapting the language of the competencies into a survey
 - Electronic Survey
 - Co-Investigator & PhD partner, who is not providing the education intervention, came to class to explain study and discussed consent with the students
 - Study participation would in no way effect a student's grade

We did the first pilot research Spring 2018-2019

- First week, tested our theoretical process to actual experience
 - Each week the faculty providing the educational intervention would tell the co-investigator the group member student names
 - Had some failures due to our communication
 - Lack of seeing one another face to face
 - SO, we decided to provide all of the group student names for the rest of the semester and set a reminder to launch the survey. Eventually dated the survey to launch automatically
- Here is what we found

Data gathered in Spring 2019 n = 37, a 39% response rate

Question	Pretest disagree	Posttest disagree	p
When a patient asks, "Am I dying?", I think it is best to change the subject to something cheerful	45%	73%	.005
I would feel like running away when the person actually died	65%	73%	.125
As a patient nears death, the nurse should withdraw from his/her involvement with the patient	50%	70%	.002

Question	Pretest agree	Posttest agree	p
Families should maintain as normal an environment as possible for their dying member.	32%	68%	.01
Caregivers should permit dying persons to have flexible visiting schedules.	66%	92%	.01
I am able to demonstrate respect for cultural, spiritual and other forms of diversity for patients and their families in the provision of palliative care services	24%	52%	.004
I am able to educate and communicate effectively with the patient, family, health care team members, and the public about palliative care issues.	8%	30%	.000
I am able to assess, plan, and treat patients' physical, needs to improve quality of life for patients with serious illness and their families.	30%	58%	.006
I am able to assist the patient, family, and informal caregivers to cope with and build resilience for dealing with suffering, grief, loss, and bereavement associated with serious illness.	11%	33%	.003
I am able to assess, plan, and treat patients' psychological and social needs to improve quality of life for patients with serious illness and their families	19%	36%	.008

Our plan

● Strengths

- Supportive CU SO Leadership
- Willing faculty
- Agreement the education was important
- Innovative, student centered thinking shared by all who were involved
- If faculty completed the modules they also received CEU's

● Weaknesses

- First role out of the first module was scheduled to be due on a Sunday-BAD PLAN ALL AROUND
- We did not have students perform initial log in to the system in class. Despite creating a "how to" video, some students did have difficulty with initial log in.
- No matter how much you plan ahead there are always unexpected challenges

Current study protocol for Spring 2019-2020

- Keep the same pilot
 - Pre & Post Test education intervention with CARES Qualtrics survey
 - Keep same pre-lab assignment
 - Same simulation scenario
 - Moved ethics committee content into another Junior level class
- Add
 - Sending the Qualtrics CARES survey again to alumni from last May
- If things go to plan, students should have completed all of the ELNEC modules by the time they come to the Ethics/Palliative Care lab time. Therefore, the previous didactic material should be able to be moved thru more quickly and lend to more time for simulated experience

Next steps

- Finish the pilot study article for publication-80% complete
- The ELNEC Self-Paced Learning Module integration is well underway
 - Current Juniors and Seniors are in a transition plan to complete all modules before they graduate
 - Current Sophomores will begin with our desired future curriculum plan
 - We also just initiated the ELNEC Graduate Curriculum with 12 graduate Family Nurse Practitioner Students the first week in October.
- Initial verbal feedback from all groups was positive once launch occurred
- Write second article and publish including new nurse information

Three parting thoughts

- Another finding in the literature and one we observed at CU SON was the need for additional debriefing. Time after the entire clinical day was complete.
 - We are going to trial a monthly “parlor style” clinical debriefing in early evening
- Yet, another literature finding was the purposeful protection of our preceptors to shield patients/significant others/family members from students during the dying process. It is understandable, but does not provide opportunities for even observation.
 - We are going to dialogue with our adjunct clinical faculty and our main clinical partners to appropriately look for experiences for students.

And Finally

- The CU SON faculty recognized our desire to train our nursing students to provide competent holistic palliative care. Assuring our students knew how to provide and understand the importance of spiritual care was a part of our mission. The integration of the ELNEC modules should help us achieve this goal.
- AND, we are beginning to develop a faith-based overlay as to how to train undergraduate nursing students with the addition of this perspective. Our desire would be to use this with future students or other schools if they were interested.

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Questions

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