

## CARES:

### **Competencies And Recommendations for Educating Undergraduate Nursing Students *Preparing Nurses to Care for the Seriously Ill and their Families***

#### **Introduction**

Nurses play a key role in caring for seriously ill patients, as they assess and manage complicated diseases, monitor multiple technologies, and orchestrate respectful culturally-competent care with the interprofessional team. In today's complex health care delivery system, the needs of patients with serious illness and their families demand that nurses and their interprofessional team members be educated in palliative care.<sup>1</sup> Although there is evidence supporting the value of palliative care,<sup>2</sup> the number of health care professionals available to provide palliative care is inadequate to meet the needs of patients and families across the lifespan, the illness trajectory and health care settings.<sup>3</sup> Therefore, it is imperative that future nurses be prepared with the knowledge and skills to provide palliative care to the seriously ill. This document is a timely and essential statement grounded in the mandates for educating nurses in quality, safety and interprofessional team-based care.<sup>4</sup> Most importantly the document emphasizes the essential role of the nurse in providing compassionate, evidence-based palliative care at the highest level of the registered nurses' scope of practice.<sup>1, 4-6</sup>

#### **Historical Context**

In 1997, in recognition of the universal need for humane end-of-life care, the American Association of Colleges of Nursing (AACN), supported by the Robert Wood Johnson Foundation (RWJF), convened a roundtable of expert nurses and other health care professionals to stimulate scholarly dialogue on the care of patients at the end of life. This group of experts developed the End-of-Life Educational Competency Statements, to guide undergraduate nursing education in preparing future nurses to help patients attain "a peaceful death." The group also made recommendations concerning the content areas where these competencies could be addressed in undergraduate curricula.

Since its 1997 release by AACN, *Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care*<sup>7</sup> has served as a valuable resource to guide educators in preparing nurses to enter practice and competently care for patients at the end of life. The document has been an essential part of the foundation for the development of the End-of-Life Nursing Education Consortium (ELNEC)<sup>8</sup> train-the-trainer project, which to date, has been used to educate over 20,500 trainers from areas of nursing education, practice, and research. These trainers have trained over 550,000 professionals in all 50 states and 88 countries.<sup>8</sup>

## Status of Educational Needs Today in Undergraduate Nursing Education

More than 15 years after the release of the *Peaceful Death* document,<sup>7</sup> much work has been done to promote better care of the dying. Nurses are playing a vital role across a variety of clinical settings in the care of patients with serious illness and their families, collaborating with interprofessional partners and advocating for quality end-of-life (EOL) care. Today, the emphasis is on palliative care across the illness trajectory, moving conversations about goals of care to the time of diagnosis of a serious illness, discussing benefits versus burdens of various treatments, and attending to not only physical, but also psychological, social and spiritual/existential needs across the lifespan.

Support for the importance of preparing future nurses to deliver quality palliative care comes from multiple sources. For example, The 3<sup>rd</sup> Edition of the *National Consensus Project Guidelines for Quality Palliative Care*<sup>9</sup> identifies the nurse as a critical and important member of the team. The latest IOM Report, *Dying in America – Improving Quality and Honoring Individual Preferences near the End of Life*<sup>1</sup> reinforces the need to increase professional palliative care education to improve the quality of care and the importance of nursing leadership in this responsibility. Most importantly, *The Scope and Standards of Practice* document from the American Nurses Association (ANA) and the Hospice and Palliative Nurses Association (HPNA) emphasizes that a palliative approach to the care of patients with serious illness is integral to the practice of all nurses.<sup>5</sup> In addition, the HPNA Position Statement on *Palliative Nursing Leadership*<sup>10</sup> strongly encourages nurses to take leadership in clinical areas, administration/management, advocacy, education, and research.

In order to prepare future nurses to deliver quality palliative care, more education is needed in undergraduate nursing programs. In 1998, a review of 50 leading undergraduate nursing textbooks revealed that less than 2% of content was related to end-of-life care.<sup>11</sup> Seventeen years later, a review of ten leading undergraduate nursing textbooks published between 2013 and 2015 identified an increase in palliative care and end-of-life care content to 19%. However, much of the content was found to be inaccurate and outdated.<sup>12</sup> A 2015 survey of 71 nursing faculty from across the US revealed that students are not well prepared to deliver palliative care. The average score of faculty perception of student preparedness was 5.4 (on a scale of 1-10, with 10 being most prepared).<sup>12</sup>

In the fall of 2015, a roundtable of national nursing faculty, nursing administrators, and palliative care nursing experts convened to revise the original *Peaceful Death* document<sup>7</sup> to include care for patients with serious illness and their families from the time of diagnosis, across the illness trajectory and across the lifespan. The group discussed essential palliative nursing concepts, learning objectives and content that must be included in curricula in all nursing programs. Recommendations for innovative approaches to teaching palliative nursing concepts and content are reflected in the Appendices of this updated document. Nursing education must take the responsibility and opportunity to educate future nurses to be well-prepared to work with and lead interprofessional teams in improving care for seriously ill patients and their families.

## **Competencies Necessary for Nurses to Provide High-Quality Care to Patients and Families facing Serious Illness:**

The following competencies build on the original work of the 1997 expert roundtable and emphasize the importance of nursing education to ensure quality palliative care across illness trajectories and settings. The use of these competencies, when embedded in the undergraduate curriculum, will empower future nurses to be leaders in advocating for access to quality palliative care and to compassionately promote and provide this essential care. Competencies new nurses need to have completed by the end of their undergraduate nursing education are:

1. Promote the need for palliative care for seriously ill patients and their families, from the time of diagnosis, as essential to quality care and an integral component of nursing care.
2. Identify the dynamic changes in population demographics, health care economics, service delivery, caregiving demands, and financial impact of serious illness on the patient and family that necessitate improved professional preparation for palliative care.
3. Recognize one's own ethical, cultural and spiritual values and beliefs about serious illness and death.
4. Demonstrate respect for cultural, spiritual and other forms of diversity for patients and their families in the provision of palliative care services.
5. Educate and communicate effectively and compassionately with the patient, family, health care team members, and the public about palliative care issues.
6. Collaborate with members of the interprofessional team to improve palliative care for patients with serious illness, to enhance the experience and outcomes from palliative care for patients and their families and to ensure coordinated and efficient palliative care for the benefit of communities.
7. Elicit and demonstrate respect for the patient and family values, preferences, goals of care, and shared decision-making during serious illness and at end of life.
8. Apply ethical principles in the care of patients with serious illness and their families.
9. Know, apply and effectively communicate current state and federal legal guidelines relevant to the care of patients with serious illness and their families.
10. Perform a comprehensive assessment of pain and symptoms common in serious illness, using valid, standardized assessment tools and strong interviewing and clinical examination skills.
11. Analyze and communicate with the interprofessional team in planning and intervening in pain and symptom management, using evidence-based pharmacologic and non-pharmacologic approaches.
12. Assess, plan, and treat patients' physical, psychological, social and spiritual needs to improve quality of life for patients with serious illness and their families.
13. Evaluate patient and family outcomes from palliative care within the context of patient goals of care, national quality standards, and value.
14. Provide competent, compassionate and culturally sensitive care for patients and their families at the time of diagnosis of a serious illness through the end of life.
15. Implement self-care strategies to support coping with suffering, loss, moral distress and compassion fatigue.

16. Assist the patient, family, informal caregivers and professional colleagues to cope with and build resilience for dealing with suffering, grief, loss, and bereavement associated with serious illness.
17. Recognize the need to seek consultation (i.e. from advanced practice nursing specialists, specialty palliative care teams, ethics consultants, etc.) for complex patient and family needs.

### **Addendum: Key Definitions**

**Family:** For purposes of this document, “the term “family” includes immediate relatives, by blood or marriage, same-sex partners, and any others designated by the patient as family.”<sup>13</sup>

**Hospice:** Hospice care consists of “a comprehensive set of services...identified and coordinated by the individual’s attending physician, medical director and by an interdisciplinary group to provide for the physical, psychosocial, spiritual and emotional needs of a terminally ill patient and family members, as delineated in a specific patient plan of care.”<sup>14</sup> “Hospice care is a benefit under the hospital insurance program. To be eligible to elect hospice care under Medicare, an individual must be entitled to Part A of Medicare and be certified as being terminally ill” (having a prognosis of a life expectancy that is 6 months or less if the illness runs its normal course).<sup>15</sup>

**Palliative Care:** Palliative care is “patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social and spiritual needs and to facilitate patient autonomy, access to information and choice.” (pg 12)<sup>9</sup>

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## Appendix I

### Content areas/Courses where competencies can be taught:

The purpose of the competency statements is to assist nurse educators in incorporating palliative care content into their existing curricula. Nursing schools use a variety of approaches to organize curriculum. There are common content areas, even though the particular courses may have different titles at different schools. Content areas or courses where various aspects of palliative care logically can be included are suggested below.

<b>Course/ Content Area</b>	<b>Examples of Content</b>	<b>AACN Baccalaureate Essentials/ Competencies Addressed</b>
Fundamentals Course	<p>This foundational nursing course is usually taught in the first semester. Content should include:</p> <ul style="list-style-type: none"> <li>• Principles of hospice and palliative care</li> <li>• Self-care for the professional caregiver</li> <li>• Basic communication skills</li> <li>• Comfort, including management of pain and suffering</li> <li>• Cultural and spiritual considerations in serious illness</li> <li>• Care of the imminently dying patient and the family</li> </ul> <p>This introduction should lay the groundwork for further discussion of palliative care concepts in other courses</p>	<p><i>Essentials: I, II, III, V, VI, VIII, IX</i></p> <p>1, 2, 9 15 5, 6, 9, 11 10-12,14 3, 4, 7, 12 14, 16</p>
Communication Content	<p>Nurses are expected to provide the intervention of presence, advocate for patient's wishes, promote advance care planning discussions in line with the American Nurses Association position statements. Content should include</p> <ul style="list-style-type: none"> <li>• Listening skills</li> <li>• Techniques to elicit the patient's (or surrogate decision maker's) values, preferences, and beliefs related to serious illness</li> <li>• Techniques to communicate effectively with interprofessional colleagues</li> </ul> <p>Additional communication skills can be further developed in a range of courses, including Psych-Mental Health, Community/Population</p>	<p><i>Essentials: I, II, III, VI, VIII, IX</i></p> <p>5 7 6, 11</p>

	Health, and Ethics.	
Cultural Issues Content	<p>Cultural content related to serious illness should include</p> <ul style="list-style-type: none"> <li>• How to conduct a cultural and spiritual assessment</li> <li>• Cultural self-assessment for identifying how one's own values, practices and beliefs can influence care</li> <li>• Cultural and spiritual influences on attitudes and beliefs about serious illness, death and dying, and bereavement represented in the surrounding communities</li> </ul>	<p><i>Essentials: I, IV, V, VI, VIII, IX</i> 4, 7, 14</p> <p>3</p> <p>7, 8, 16</p>
Ethical/Legal Content	<p>Coursework should include content covering</p> <ul style="list-style-type: none"> <li>• Respect for others' attitudes and values, practices and beliefs particularly surrounding approaches to healthcare decision-making, death and dying, etc.</li> <li>• Relevant state and federal laws regarding informed consent, advance directives, portable (community based) do-not-resuscitate orders, such as MOLST &amp; POLST, aid-in-dying laws, medical marijuana, etc.</li> <li>• Common ethical dilemmas that arise in caring for the seriously ill (artificial nutrition and hydration, withholding and withdrawing life-sustaining treatment, and request for assistance with dying)</li> <li>• ANA Nursing Code of Ethics and professional nursing organization position statements relevant to providing care to the seriously ill patient and the family</li> </ul>	<p><i>Essentials: I -- IX</i> 3, 4, 7, 8</p> <p>9</p> <p>3, 8, 9</p> <p>8</p>
Health Assessment Course	<p>In a course on health assessment, students should be taught comprehensive assessment and clinical examination to assess for common problems experienced in serious illness. Content should include:</p> <ul style="list-style-type: none"> <li>• Standardized, valid tools to quantify and address all components of symptom assessment (beyond merely a numeric rating scale) for symptoms such as pain, fatigue, and dyspnea</li> <li>• Common symptoms experienced at the end of life, appropriateness of various</li> </ul>	<p><i>Essentials: I, II, III, IV, VI, VII, VIII, IX</i></p> <p>10</p> <p>14</p>

	physiological measures for evaluating comfort, and the indicators of approaching death as part of an overall health assessment	
Pharmacology Course	<p>The introduction of appropriate pharmacologic management of pain and symptoms common in serious illness, such as dyspnea, nausea and vomiting, anxiety and depression, is an important part of the curriculum. Included in this content should be</p> <ul style="list-style-type: none"> <li>• Principles of equianalgesia</li> <li>• Discussion of the negative impact of myths &amp; misconceptions about use of analgesics</li> <li>• Discussion of current data related to safe opioid use and misuse across settings</li> <li>• Assessment and management of side effects of analgesics</li> </ul>	<p><i>Essentials: I, III, V, VI, VIII, IX</i></p> <p>11</p> <p>8</p> <p>9</p> <p>10, 11</p>
Nursing Management Courses ( <i>i.e. (medical-surgical nursing, pediatric nursing, maternal-child nursing)</i> )	<p>Nursing management courses usually include common illnesses and use of the nursing process to assist patients and their families across the lifespan in the management of problems across illness trajectories. Content should include:</p> <ul style="list-style-type: none"> <li>• Collaboration with interprofessional team members while implementing the nursing role in palliative care</li> <li>• Assessment and management of common symptoms that occur in persons with end-stage cardiac, pulmonary, liver and renal disease, cancer, dementia, immunosuppression, and other serious illnesses</li> <li>• Nursing actions to foster patient-centered, family-focused effective and safe transitions of care across the illness trajectory and sites of care.</li> <li>• Provision of care in the home, the roles of family caregivers, and the role of the nurse in supporting family caregivers</li> <li>• Implementation of palliative care with the appropriate use of technology as desired by patients and their families</li> <li>• Provision of end-of-life care for the patient who is dying and associated bereavement care and support for the family as an active, desirable, and important service</li> </ul>	<p><i>Essentials: I, II, III, VI, VIII, IX</i></p> <p>6, 11</p> <p>1, 12</p> <p>5, 12, 17</p> <p>12, 16</p> <p>4, 7</p> <p>7, 12, 14, 16</p>

	<ul style="list-style-type: none"> <li>Evaluation of the impact of nursing interventions on patient and family outcomes</li> </ul>	13
Psychiatric/ Mental Health Nursing Course	<p>Coursework that addresses mental health and psychiatric illness provides multiple opportunities to discuss key concepts in palliative care such as</p> <ul style="list-style-type: none"> <li>Recognizing one's own attitudes, feelings, and beliefs about end-of-life and death</li> <li>Recognizing one's own attitudes and biases about persons living with chronic mental illness</li> <li>Assessing and managing psychological and changes in cognitive status associated with serious illness (i.e. anxiety, depression, post-traumatic stress disorder, and delirium)</li> <li>Assisting the patient, family, colleagues, and oneself to cope with suffering, grief and loss, and crisis in the family</li> <li>Assessing the impact of diagnosis of serious illness for person living with chronic mental illness including medication incompatibilities, exacerbations of mental illness, etc.</li> </ul>	<p><i>Essentials: I, II, III, V, VI, VIII, IX</i></p> <p>3</p> <p>3</p> <p>10, 11, 12</p> <p>16</p> <p>2</p>
Community/ Population Health Course	<p>Community health provides an opportunity to address:</p> <ul style="list-style-type: none"> <li>Community and population level needs assessment to identify availability of palliative and hospice services, and the associated influences of access to, satisfaction with, and barriers to palliative care and hospice services</li> <li>Community and population level interventions, such as family caregiver support programs or church partnerships, to improve palliative and end-of-life care</li> <li>Evaluation of community and public health interventions designed to improve palliative and end-of-life care</li> </ul>	<p><i>Essentials: I, II, III, IV, V, VI, VIII, IX</i></p> <p>1, 2, 5</p> <p>12</p> <p>13</p>
Nursing Research	<p>Courses that address nursing research should include state of the science reports on care at the end of life by the National Institute of Nursing Research and the Institute of Medicine with examples of research done in</p>	<i>Essentials: I – IX</i>

	<p>palliative care settings and in settings where death is a frequent outcome. Areas of strong nursing research include:</p> <ul style="list-style-type: none"> <li>• Symptom assessment and management</li> <li>• Caregiving</li> <li>• Bereavement</li> <li>• Quality of life of the seriously ill patient</li> <li>• Culturally sensitive palliative care services</li> <li>• Access to end-of-life care</li> </ul>	2, 13
Nursing Leadership/ Capstone Course	<p>Because nurses are expected to play a critical role on the interprofessional team, educators must prepare them to take on this responsibility. Leadership content should include</p> <ul style="list-style-type: none"> <li>• History of nurse leaders in the field of palliative care</li> <li>• Palliative care's impact on service delivery, health care economics, and most importantly quality of life</li> <li>• Creating a supportive and patient-centered interprofessional team culture to ensure patient safety and quality and to address provider burnout and moral distress</li> </ul>	<p><i>Essentials: 1 – 9</i></p> <p>2</p> <p>1, 13</p> <p>6, 15</p>

## Appendix II

### **A Critical Resource for Undergraduate Nursing Faculty: Online Palliative Nursing Education Curriculum**

Although recommendations for teaching palliative care content have been suggested in Appendix I, it can be challenging to integrate additional content into an already crowded curriculum. Faculty who have not taught palliative care concepts before may feel unprepared to integrate the competencies and content into their courses. In order to meet the needs of both nursing faculty and students, we are developing a series of six online modules that address all components of palliative care as recommended by the *National Consensus Project Guidelines for Quality Palliative Care*<sup>6</sup> and will provide a mechanism to meet the competencies in this document. The End-of-Life Nursing Education Consortium (ELNEC) Core modules will be the foundation for this online curriculum.

The six modules can be used in face-to-face classroom education, online education, or a combination of both face-to-face and online, depending on faculty preference.

Topics that will be covered are:

- Introduction to Palliative Care
- Pain Assessment & Management
- Symptom Assessment & Management
- Communication
- Loss, Grief and Bereavement
- Care of the Imminently Dying Patient.

Ethical principles and cultural considerations will be woven throughout the six modules. Each module will include objectives, interactive slide content, video vignettes role modeling quality palliative care, case studies, supplemental materials and online resources, references, and NCLEX-style exam questions.

The curriculum and this consensus meeting to develop competencies and curricula guidelines for undergraduate nursing programs were funded by a generous grant from the Cambia Health Foundation. Because of the Foundation's historical support of healthcare initiatives in Oregon, Utah, Washington, and Idaho, these four northwestern states will receive the online curriculum through Relias Learning, beginning in January 2017, at no cost. The remaining states' will have access to this online nursing curriculum for a nominal fee. The goal is for 100% of undergraduate nursing programs to have access to the online ELNEC curriculum so that future nurses will be educated in palliative care.

## **Reviewers/Consultants**

Patricia Berry, PhD, RN, ACHPN, FPCN, FAAN: Oregon Health & Science University School of Nursing, Portland, OR

Dana Bjarnason, PhD, RN, MA, CNA: Vice President & Chief Nursing Officer for Oregon Health & Science University Healthcare, Portland, OR

Kirsti Boyd, MN, BA, RN: Everett Community College, Everett, WA

Susan Breakwell, DNP, RN: Marquette University, College of Nursing, Milwaukee, WI

Cathy Campbell, PhD, ANP-BC: University of Virginia School of Nursing, Charlottesville, VA

Connie Dahlin, MSN, ANP-BC, ACHPN, FPCN, FAAN: Hospice and Palliative Nurses Association, Pittsburgh, PA

Betty Ferrell, PhD, RN, MA, CHPN, FAAN, FPCN: City of Hope Medical Center, Duarte, CA

Alexandra Hanson, MSN, RN: Weber State University School of Nursing, Ogden, UT

Verna Hendricks-Ferguson, PhD, RN, CHPPN, FAAN: St. Louis University School of Nursing, St. Louis, MO

Deborah James, MSN, RN: University of Texas Health Science Center School of Nursing, San Antonio, TX

Tina Koch, MS, RN: College of Southern Idaho, Twin Falls, ID

Kathryn Lindstrom, PhD, FNP-BC, ACHPN, HSMI: Vanderbilt University School of Nursing, Nashville, TN

Pam Malloy, MN, RN, FPCN: American Association of Colleges of Nursing (AACN), Washington, DC

Kim Martz, PhD, RN: Boise State University, Boise, ID

Polly Mazanec, PhD, ACNP-BC, AOCN, ACHPN, FPCN: Case Western Reserve University, FPB School of Nursing, Cleveland, OH

Nanci McLeskey, DNP, MCG, MDiv, RN-BC, CHPN, FNGNA: University of Utah, College of Nursing, Salt Lake City, UT

Marie Nolan, PhD, MPh, RN, FAAN: John Hopkins University School of Nursing, Baltimore, MD

Elizabeth Palermo, DNP, RN, ACNP-BC, ANP-BC: University of Rochester School of Nursing/  
Strong Memorial Hospital, Rochester, NY

Sarah Shannon, PhD, RN, FAAN: University of Washington School of Nursing/ Northwest  
Hospital & Medical Center, Seattle, WA

Casey Shillam, PhD, RN-BC: University of Portland School of Nursing, Portland, OR

Vidette Todaro-Franceschi, PhD, RN, FT: Hunter-Bellevue School of Nursing, City University  
of New York (CUNY), New York, NY

Rose Virani, MHA, RNC, OCN, FPCN: City of Hope Medical Center, Duarte, CA

Sheree Walters, MSN, RN: Mt. Hood Community College, Gresham, OR

***\*These competencies were unanimously approved by the American Association of Colleges of  
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