

Primary Palliative Care Competencies for Undergraduate and Graduate Nursing Students (*CARES/G-CARES*, 2nd ed)

Introduction

Nurses are instrumental to the provision of holistic, culturally sensitive care for persons with serious illness or injuries and their families. Serious illnesses are those that, while potentially curable or manageable, are associated with a high one-year mortality, during which time the person's experience with the illness is burdensome and adversely impacts their quality of life and functional status.^{1,2} According to the Centers for Disease Control and Prevention (CDC), 6 in 10 adults in the United States have at least one chronic disease, while 4 in 10 have multiple comorbidities, with rates predicted to rise exponentially.³ Beneficial at any stage of a serious illness, palliative care is interdisciplinary* care designed to anticipate and respond to physical, psychological, social, and spiritual needs to optimize quality of life for patients, their families, and caregivers.⁴ Registered nurses and those at the advanced practice level are essential members of the interdisciplinary team, providing ongoing assessment and intervention, coordination of care, advocacy and education.^{4,5}

Access to and integration of palliative care for persons with serious illness and their families has been deemed a basic human right.⁶⁻⁸ The guiding principles of palliative care call on healthcare professionals to focus on what is important to the patient and family by assessing their goals of care, beliefs, values, and preferences and determining the best plan to achieve them.⁴ Although there is evidence supporting the value of specialty palliative care,⁴ the number of healthcare professionals available to provide specialty services is inadequate to meet the needs of this growing population.^{6,9} In today's complex healthcare delivery system, nurses and healthcare team members must be prepared to provide *primary palliative care* for patients with uncomplicated serious illness and their families.^{4,8} Therefore, **it is imperative that all nursing students- both entry- and advanced-level - receive quality education and clinical experience in primary palliative care to develop their competence prior to entering professional practice.**

Multiple sources support the importance of preparing future nurses in entry- and advanced-level programs to deliver quality primary palliative care. The 4th Edition of the *National Consensus Project Guidelines for Quality Palliative Care* identifies the nurse as a critical and important member of the team.⁴ *The Scope and Standards of Practice* 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.¹⁰ *Building the Workforce We Need for People with Serious Illness: Proceedings of a Workshop* recognized that the United States population living with multiple chronic conditions is rapidly increasing and consequently there is a dire need to educate the healthcare workforce, including nurses, to provide palliative care.¹¹ The consensus papers from Expert Panels of the American Academy of Nursing (AAN) call for nurses to be leaders in the delivery of palliative care, advocating for and improving access to palliative care for underserved communities and promoting social justice and equity.^{8,12} These landmark consensus documents strongly recommend a greater investment in palliative nursing care education nationally and globally.

* Within palliative care, the team is referred to as "interdisciplinary"; in nursing academia, it is "interprofessional"

The second edition of the *Competencies And Recommendations for Educating nursing Students (CARES)* emphasizes the essential role of nurses in providing compassionate, evidence-based primary palliative care at the highest level of their scopes of practice. The second edition also focuses on the nurses' role as advocates and leaders in advancing palliative care. Most importantly, this timely revision of the *CARES* document is in strong alignment with the new AACN *The Essentials: Core Competencies for Professional Nursing Education* (henceforth *Essentials*) that **recognizes hospice/palliative/and supportive care as one of the four critical spheres of care.**¹³

Historical Context for the Creation of Palliative Care Competencies

In 1997, in recognition of the universal need for humane end-of-life care, AACN, supported by the Robert Wood Johnson Foundation (RWJF), convened a roundtable of expert nurses and other health care professionals to create the document: *Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing*.¹⁴ In 2014, the Institute of Medicine report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, called for access to palliative care for all individuals living with serious illness.¹⁵ By 2015, societal and healthcare changes created the need to revise the *Peaceful Death* document to incorporate palliative care into the competencies and to expand nursing education into this important arena.

Nurses cannot practice what they do not know. Many nursing schools were not preparing their students to provide quality palliative and end-of-life care.^{16,17} A national group of nursing faculty, administrators, and palliative care experts gathered in Portland, OR, with the support of the Cambia Foundation, to create the *CARES* document.^{18,19} These 17 competencies addressed the professional expectations of the nurse when providing primary palliative care for persons with serious illness and their families from the time of diagnosis, across the illness trajectory and throughout the lifespan. In 2016, the End-of-Life Nursing Education Consortium (ELNEC),²⁰ a partnership with AACN, recognized the need to develop an undergraduate curriculum to support faculty in schools of nursing to be able to meet the new *CARES*¹⁸ and prepare future nurses to care for persons with serious illness and their families. ELNEC Undergraduate²¹ was launched as an eight hour online interactive curriculum. Subsequently, ELNEC leadership recognized the need for similar education for entry-to-practice nurses. In 2019, the curriculum was updated to be inclusive of newly graduated nurses and reflect rapid changes in palliative care, resulting in the ELNEC Undergraduate/New Graduate curriculum.

In 2018, to respond to faculty requests, a panel was convened to develop competencies for nurses in graduate programs, *Graduate Competencies And Recommendations for Educating Nursing Students (G-CARES)*.²² These 13 competencies (eight for all graduate students and five for those providing direct patient care) defined the professional expectations of Masters and Doctor of Nursing Practice (DNP) students when providing primary palliative care. ELNEC also identified a need to develop a resource for graduate programs to assist faculty preparing students to meet the *G-CARES*.²² In 2019, the ELNEC Graduate²³ curriculum was released as a six hour online interactive curriculum specifically focused on education for advanced practice nurses (APNs).

Schools of nursing have been encouraged to adopt *CARES* and *G-CARES* and utilize ELNEC curricula in their academic programs. To date, the two curricula have been widely accessed²⁴ and numerous publications have highlighted their use.^{17,25}

Evolution of the Second Edition of *CARES* and *G-CARES*

A national group of nursing faculty and palliative care nursing experts updated the original *CARES* and *G-CARES*. The original competencies were separate documents and have been combined to reflect the format of the AACN *Essentials* (2021). *CARES* (2nd ed) consist of 15 competency statements for entry-level professional nursing students and *G-CARES* (2nd ed) consists of 12 competency statements for advanced-level nursing students.

Each revised *CARES* and *G-CARES* statement has been cross-walked with all concepts for nursing practice, domains, competencies, and sub-competency statements in the AACN *Essentials*. The team carefully considered the full nursing scope of practice for entry-level professional nurses and advanced-level nurses within primary palliative, hospice, and end-of-life care settings (AACN *Essentials* sphere of hospice/palliative/supportive care). In many instances, *CARES* (2nd ed) and *G-CARES* (2nd ed) competency statements aligned across multiple domains.

For a detailed description of *CARES* and *G-CARES* as aligned with AACN *Essentials* (2021) see Primary Palliative Care Competency (*CARES/G-CARES*): Alignment with the 2021 AACN *Essentials*.

***CARES* (2nd ed.) for Entry-level Professional Nursing**

Entry-level professional nurses should achieve the following by the end of their formal nursing education:

1. Advocate for and promote integration of palliative care for patients with serious illness or injury and their families across the disease trajectory as essential to quality care.
2. Consider the complex and evolving socio-economic factors that influence equitable palliative care delivery within health care systems.
3. Reflect on one's ethical, cultural, and spiritual values and their influence on relationships in palliative care.
4. Demonstrate respect for diversity, equity, and inclusion as essential for the delivery of culturally sensitive, quality palliative care.
5. Communicate effectively, respectfully, and compassionately with patients, families, interprofessional team members, and the public about palliative care.
6. Collaborate effectively within the interprofessional team to coordinate the delivery of high-quality palliative care across healthcare settings.
7. Demonstrate respect for person-centered care by aligning the plan of care with patient and family values, beliefs, preferences, and goals of care.
8. Apply ethical principles, social justice, and moral courage in the care of patients with serious illness, their families, and communities.
9. Comply with state and federal laws and institutional policies relevant to the care of patients with serious illness and their families.
10. Utilize evidence-based tools to perform a holistic health assessment of pain and other symptoms, considering physical, psychological, social, and spiritual needs.
11. Synthesize assessment data to develop and implement plans of care that address physical, psychological, social, and spiritual needs, utilizing holistic, evidence-based approaches.
12. Conduct ongoing reassessment and evaluation of patient outcomes, modifying the plan of care as needed to be consistent with goals of care.
13. Provide culturally sensitive care that is responsive to rapidly changing physical, psychological, social, and spiritual needs during the dying process and after death.
14. Support patients, families, and team members to cope with suffering, grief, loss, and bereavement.
15. Implement self-care behaviors to cope with the experience of caring for seriously ill and dying patients and their families.

G-CARES (2nd ed) for Advanced-Level Nursing

Advanced-level nurses should achieve the following by the end of their formal nursing education:

1. Articulate the value of palliative care to patients, families, interprofessional team members, and the public.
2. Facilitate access to palliative care as standard practice across the disease trajectory and healthcare settings for persons with serious illness and their families.
3. Respond to dynamic changes in population demographics, socio-economic factors, the healthcare system, and emerging technologies to improve outcomes for persons with serious illness and their families.
4. Demonstrate leadership guided by principles of ethics, social justice, equity, and moral courage in the advancement of quality palliative care.
5. Engage in strategic partnerships with interprofessional colleagues and community stakeholders to influence policies and quality improvement activities related to primary palliative care.
6. Contribute to the development and translation of evidence-based palliative care practice in clinical, administrative, and academic settings.
7. Utilize advanced palliative care communication skills with patients, families, and team members as appropriate to one's functional area of nursing practice and the professional context.
8. Promote delivery of care that supports holistic assessment and management of pain and symptoms common in serious illness at the full scope of practice.
9. Collaborate with healthcare team members to coordinate culturally sensitive, patient-centered, and family-focused palliative care across care settings.
10. Consult with specialty services for complex palliative care issues that exceed one's functional area of practice and educational preparation.
11. Advocate for environments of care that uphold the dignity of the patient and family during the dying process and after death through culturally sensitive and compassionate end-of-life care.
12. Contribute to an environment that fosters well-being for self, patients, families, and team members to cope with suffering, grief, loss, and bereavement.

Addendum A: Key Definitions

Family: “The diverse network of care-related persons, family of origin, family of choice, friends, volunteers, partners, and other designated people who journey with an individual through serious illness and death. Family is identified and determined by the individual with serious illness.”^{26–28}

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.”⁴ Palliative care is appropriate at any stage of illness, beneficial when provided in tandem with treatments of curative or life-prolonging intent, and based on needs rather than prognosis.²⁹ Given the focus and scope of palliative care, services can be offered in all care settings (in the community, acute care, clinics, cancer centers, dialysis units, homecare agencies, long-term care/skilled nursing facilities, hospices, telehealth, etc.).

Primary palliative care: (also known as generalist palliative care): “Palliative care that is delivered by health care professionals who are not palliative care specialists, such as primary care clinicians; physicians who are disease-oriented specialists (such as oncologists and cardiologists); and nurses, social workers, pharmacists, chaplains, and others who care for this population but are not certified in palliative care.”^{4(pii)}

Primary palliative nursing care: Holistic person- and family-centered care provided by generalist nurses to optimize quality of life by anticipating and intervening in the human response to serious illness.^{4,27,28}

Specialty Palliative Care: “Palliative care that is delivered by health care professionals who are palliative care specialists, such as physicians who are board certified in this specialty; palliative-certified nurses; and palliative care-certified social workers, pharmacists, and chaplains.”^{4(pii)}

Hospice: Hospice care “is a comprehensive, holistic program of care and support for terminally ill patients and their families. Hospice care changes the focus to comfort care (palliative care) for pain relief and symptom management instead of care to cure the patient’s illness.”³⁰

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Additional Helpful Resources:

Additional helpful resources regarding primary palliative nursing care education can be found on the End of Life Nursing Education Consortium (ELNEC) website Resources page:
<https://www.aacnnursing.org/ELNEC/Resources>

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