

Module 1: Palliative Nursing Supplemental Teaching Materials/Training Session Activities Contents
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Module 1: Palliative Nursing Supplemental Teaching Materials/Training Session Activities

Module 1

Table 1: National Consensus Project (NCP) Domains and Corresponding National Quality Forum (NQF) Preferred Practices

NCP Domain	NQF Preferred Practice
<p>DOMAIN 1: STRUCTURE AND PROCESSES OF CARE</p> <p>Guideline 1.1 <i>Interdisciplinary Team:</i> Since palliative care is holistic in nature, it is provided by a team of physicians, advanced practice registered nurses, physician assistants, nurses, social workers, chaplains, and others based on need. The palliative care team works with other clinicians and community service providers supporting continuity of care throughout the illness trajectory and across all settings, especially during transitions of care. Depending on care setting and patient population, IDT members may be certified palliative care specialists in their discipline and/or have additional training in palliative care. Primary care and other clinicians work with interdisciplinary colleagues to integrate palliative care into routine practice.</p> <p>Guideline 1.2 <i>Comprehensive Palliative Care Assessment:</i> An interdisciplinary comprehensive assessment of the patient and family forms the basis for the development of an individualized patient and family palliative care plan.</p> <p>Guideline 1.3 <i>Palliative Care Plan:</i> In collaboration with the patient and family, the IDT develops, implements, and updates the care plan to anticipate, prevent, and treat physical, psychological, social, and spiritual needs.</p> <p>Guideline 1.4 <i>Continuity of Palliative Care:</i> The IDT has defined processes to ensure access, quality, and continuity of care, especially during transitions of care.</p> <p>Guideline 1.5 <i>Care Settings:</i> Palliative care is provided in any care setting, including private residences, assisted living facilities, rehabilitation, skilled and intermediate care facilities, acute and long-term care hospitals, clinics, hospice residences, correctional facilities, and homeless shelters.</p>	<p>PREFERRED PRACTICE 1 Provide palliative and hospice care by an interdisciplinary team of skilled palliative care professionals, including, for example, physicians, nurses, social workers, pharmacists, spiritual care counselors, and others who collaborate with primary healthcare professional(s).</p> <p>PREFERRED PRACTICE 2 Provide access to palliative and hospice care that is responsive to the patient and family 24 hours a day, 7 days a week.</p> <p>PREFERRED PRACTICE 3 Provide continuing education to all healthcare professionals on the domains of palliative care and hospice care.</p> <p>PREFERRED PRACTICE 4 Provide adequate training and clinical support to assure that professional staff is confident in their ability to provide palliative care for patients.</p> <p>PREFERRED PRACTICE 5 Hospice care and specialized palliative care professionals should be appropriately trained, credentialed, and/or certified in their area of expertise.</p> <p>PREFERRED PRACTICE 6 Formulate, utilize and regularly review a timely care plan based on a comprehensive interdisciplinary assessment of the values, preferences, goals, and needs of the patient and family and, to the extent that existing privacy laws permit, ensure that the plan is broadly disseminated, both internally and externally, to all professionals involved in the patient's care.</p> <p>PREFERRED PRACTICE 7 Ensure that upon transfer between healthcare settings, there is timely and thorough communication of the patient's goals, preferences, values and clinical information so that continuity of care and seamless follow-up are assured.</p>

<p>Guideline 1.6 <i>Interdisciplinary Team Education:</i> Education, training, and professional development are available to the IDT.</p> <p>Guideline 1.7 <i>Coordination of Care and Care Transitions:</i> Care is coordinated and characterized as the right care at the right time throughout the course of an individual’s disease(s) or condition. The IDT recognizes that transitions of care occur within care settings, between care settings, and between care providers. Care transitions are anticipated, planned, and coordinated to ensure patient goals are achieved.</p> <p>Guideline 1.8 <i>Emotional Support to the Interdisciplinary Team:</i> Providing palliative care to patients with a serious illness and their families has an emotional impact, therefore the IDT creates an environment of resilience, self-care, and mutual support.</p> <p>Guideline 1.9 <i>Continuous Quality Improvement:</i> In its commitment to continuous quality improvement (CQI), the IDT develops, implements, and maintains a data-driven process focused on patient- and family-centered outcomes using established quality improvement methodologies.</p> <p>Guideline 1.10 <i>Stability, Sustainability, and Growth:</i> Recognizing limitations in reimbursement for interdisciplinary palliative care, the IDT endeavors to secure funding for long-term sustainability and growth.</p>	<p>PREFERRED PRACTICE 8 Healthcare professionals should present hospice as an option to all patients and families when death within a year would not be surprising and should reintroduce the hospice option as the patient declines.</p> <p>PREFERRED PRACTICE 9 Patients and caregivers should be asked by palliative and hospice care programs to assess physicians’/healthcare professionals’ ability to discuss hospice as an option.</p> <p>PREFERRED PRACTICE 10 Enable patients to make informed decisions about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.</p> <p>PREFERRED PRACTICE 11 Provide education and support to families and unlicensed caregivers based on the patient’s individualized care plan to assure safe and appropriate care for the patients.</p>
<p>DOMAIN 2: PHYSICAL ASPECTS OF CARE</p> <p>Guideline 2.1 <i>Global:</i> The palliative care interdisciplinary team (IDT) endeavors to relieve suffering and improve quality of life, as defined by the patient and family, through the safe and timely reduction of the physical symptoms and functional impairment associated with serious illness.</p> <p>Guideline 2.2 <i>Screening and Assessment:</i> The IDT assesses physical symptoms and their impact on well-being, quality of life, and functional status.</p> <p>Guideline 2.3 <i>Treatment:</i> Interdisciplinary care plans to address physical symptoms, maximize functional status, and enhance quality of life are developed in the context of the patient’s goals of care, disease, prognosis, functional limitations, culture, and care setting. An essential component of palliative care is ongoing management of physical symptoms, anticipating changes in health status, and monitoring</p>	<p>PREFERRED PRACTICE 12 Measure and document pain, dyspnea, constipation, and other symptoms using available standardized scales.</p> <p>PREFERRED PRACTICE 13 Assess and manage symptoms and side effects in a timely, safe and effective manner to a level acceptable to the patient and family.</p>

<p>of potential risk factors associated with the disease and side effects due to treatment regimens.</p> <p>Guideline 2.4 <i>Ongoing Care:</i> The palliative care team provides written and verbal recommendations for monitoring and managing physical symptoms.</p>	
<p>DOMAIN 3: PSYCHOLOGICAL AND PSYCHIATRIC ASPECTS OF CARE</p> <p>Guideline 3.1 <i>Global:</i> The IDT includes a social worker with the knowledge and skills to assess and support mental health issues, provide emotional support, and address emotional distress and quality of life for patients and families experiencing the expected responses to serious illness. The IDT has the training to assess and support those with mental health disorders, either directly, in consultation, or through referral to specialist level psychological and/or psychiatric care.</p> <p>Guideline 3.2 <i>Screening and Assessment:</i> The IDT screens for, assesses, and documents psychological and psychiatric aspects of care based upon the best available evidence to maximize patient and family coping and quality of life.</p> <p>Guideline 3.3 <i>Treatment:</i> The IDT manages and/or supports psychological and psychiatric aspects of patient and family care including emotional, psychosocial, or existential distress related to the experience of serious illness, as well as identified mental health disorders. Psychological and psychiatric services are provided either directly, in consultation, or through referral to other providers.</p> <p>Guideline 3.4 <i>Ongoing Care:</i> The IDT provides recommendations for monitoring and managing long-term and emerging psychological and psychiatric responses and mental health concerns.</p>	<p>PREFERRED PRACTICE 14 Measure and document anxiety, depression, delirium, behavioral disturbances and other common psychological symptoms using available standardized scales.</p> <p>PREFERRED PRACTICE 15 Manage anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms in a timely, safe, and effective manner to a level that is acceptable to the patient and family.</p> <p>PREFERRED PRACTICE 16 Assess and manage the psychological reactions of patients and families (including stress, anticipatory grief, and coping) in a regular, ongoing fashion in order to address emotional and functional impairment and loss.</p> <p>PREFERRED PRACTICE 17 Develop and offer a grief and bereavement care plan to provide services to patients and families prior to and for at least 13 months after the death of the patient.</p>
<p>DOMAIN 4: SOCIAL ASPECTS OF CARE</p> <p>Guideline 4.1 <i>Global:</i> The palliative care IDT has the skills and resources to identify and address, either directly or in collaboration with other service providers, the social factors that affect patient and family quality of life and well-being.</p> <p>Guideline 4.2 <i>Screening and Assessment:</i> The IDT screens for and assesses patient and family social supports, social relationships, resources, and care environment based on the best available evidence to maximize coping and quality of life.</p>	<p>PREFERRED PRACTICE 18 Conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, discuss goals of care, disease prognosis, and advance care planning, and to offer support.</p> <p>PREFERRED PRACTICE 19 Develop and implement a comprehensive social care plan that addresses the social, practical, and legal needs of the patients and caregivers, including but not limited to relationships, communication, existing social and cultural networks, decision-making, work and school settings,</p>

<p>Guideline 4.3 Treatment: In partnership with the patient, family, and other providers, the IDT develops a care plan for social services and supports in alignment with the patient’s condition, goals, social environment, culture, and setting to maximize patient and family coping and quality of life across all care settings.</p> <p>Guideline 4.4 Ongoing Care: A palliative care plan addresses the ongoing social aspects of patient and family care, in alignment with their goals and provides recommendations to all clinicians involved in ongoing care.</p>	<p>finances, sexuality/intimacy, caregiver availability/stress, and access to medicines and equipment.</p>
<p>DOMAIN 5: SPIRITUAL, RELIGIOUS, AND EXISTENTIAL ASPECTS OF CARE</p> <p>Guideline 5.1 Global: Patient and family spiritual beliefs and practices are assessed and respected. Palliative care professionals acknowledge their own spirituality as part of their professional role and are provided with education and support to address each patient’s and family’s spirituality.</p> <p>Guideline 5.2 Screening and Assessment: The spiritual assessment process has three distinct components – spiritual screening, spiritual history, and a full spiritual assessment. The spiritual screening is conducted with every patient and family to identify spiritual needs and/or distress. The history and assessment identify the spiritual background, preferences, and related beliefs, values, rituals, and practices of the patient and family. Symptoms, such as spiritual distress and spiritual strengths and resources, are identified and documented.</p> <p>Guideline 5.3 Treatment: The IDT addresses the spiritual needs of the patient and family.</p> <p>Guideline 5.4 Ongoing Care: Patient and family spiritual care needs can change as the goals of care change or patients move across settings of care.</p>	<p>PREFERRED PRACTICE 20 Develop and document a plan based on an assessment of religious, spiritual, and existential concerns using a structured instrument and integrate the information obtained from the assessment into the palliative care plan.</p> <p>PREFERRED PRACTICE 21 Provide information about the availability of spiritual care services and make spiritual care available either through organizational spiritual care counseling or through the patient’s own clergy relationships.</p> <p>PREFERRED PRACTICE 22 Specialized palliative and hospice care teams should include spiritual care professionals appropriately trained and certified in palliative care.</p> <p>PREFERRED PRACTICE 23 Specialized palliative and hospice spiritual care professional should build partnerships with community clergy and provide education and counseling related to end-of-life care.</p>
<p>DOMAIN 6: CULTURAL ASPECTS OF CARE</p> <p>Guideline 6.1 Global: The IDT delivers care that respects patient and family cultural beliefs, values, traditional practices, language, and communication preferences and builds upon the unique strengths of the patient and family. Members of the IDT works to increase awareness of their own biases and seeks opportunities to learn about the provision of culturally sensitive care. The care team ensures that its</p>	<p>PREFERRED PRACTICE 24 Incorporate cultural assessment as a component of comprehensive palliative and hospice care assessment, including but not limited to locus of decision-making, preferences regarding disclosure of information, truth-telling and decision-making, dietary preferences, language, family communicate, desire for support measures such as palliative therapies and complementary and alternative medicine, perspectives on death, suffering and grieving, and funeral/ burial rights.</p>

<p>environment, policies, procedures, and practices are culturally respectful.</p> <p>Guideline 6.2 <i>Communication and Language:</i> The IDT ensures that patient and family preferred language and style of communication are supported and facilitated in all interactions.</p> <p>Guideline 6.3 <i>Screening and Assessment:</i> The IDT uses evidence-based practices when screening and assessing patient and family cultural preferences regarding health care practices, customs, beliefs and values, level of health literacy, and preferred language.</p> <p>Guideline 6.4 <i>Treatment:</i> A culturally sensitive plan of care is developed and discussed with the patient and/or family. This plan reflects the degree to which patients and families wish to be included as partners in decision-making regarding their care. When hosting meetings to discuss and develop the plan, the IDT ensures that patient and family linguistic needs are met.</p>	<p>PREFERRED PRACTICE 25 Provide professional interpreter services and culturally sensitive materials in the patient’s and family’s preferred language.</p>
<p>DOMAIN 7: CARE OF THE PATIENT NEARING THE END OF LIFE</p> <p>Guideline 7.1 <i>Interdisciplinary Team:</i> The IDT includes professionals with training in end-of-life care, including assessment and management of symptoms, communicating with patients and families about signs and symptoms of approaching death, transitions of care, and grief and bereavement. The IDT has established structures and processes to ensure appropriate care for patients and families when the end of life is imminent.</p> <p>Guideline 7.2 <i>Screening and Assessment:</i> The IDT assesses physical, psychological, social, and spiritual needs, as well as patient- and family preferences for setting of care, treatment decisions, and wishes during and immediately following death. Discussions with the family focus on honoring patient wishes and attending to family fears and concerns about the end of life. The IDT prepares and supports family caregivers throughout the dying process, taking into account the spiritual and cultural background and preferences of the patient and family.</p> <p>Guideline 7.3 <i>Treatment Prior to Death:</i> In collaboration with the patient and family and other clinicians, the IDT develops, implements, and updates (as needed) a care plan to anticipate, prevent, and treat physical, psychological, social, and spiritual symptoms. The care plan addresses the focus on end-</p>	<p>PREFERRED PRACTICE 26 Recognize and document the transition to the active dying phase and communicate to the patient, family, and staff the expectation of imminent death.</p> <p>PREFERRED PRACTICE 27 Educate the family on a timely basis regarding signs and symptoms of imminent death in an age-appropriate, developmentally appropriate, and culturally appropriate manner.</p> <p>PREFERRED PRACTICE 28 As part of the ongoing care planning process, routinely ascertain and document patient and family wishes about the care setting for site of death and fulfill patient and family preferences when possible.</p> <p>PREFERRED PRACTICE 29 Provide adequate dosage of analgesics and sedatives as appropriate to achieve patient comfort during the active dying phase and address concerns and fears about using narcotics and analgesics hastening death.</p> <p>PREFERRED PRACTICE 30 Treat the body after death with respect according to the cultural and religious practices of the family and in accordance with local law.</p> <p>PREFERRED PRACTICE 31 Facilitate effective grieving by implementing in a timely</p>

<p>of-life care and treatments to meet the physical, emotional, social, and spiritual needs of patients and families. All treatment is provided in a culturally and developmentally appropriate manner.</p> <p>Guideline 7.4 <i>Treatment During the Dying Process and Immediately After Death:</i> During the dying process, patient and family needs are respected and supported. Post-death care is delivered in a manner that honors patient and family cultural and spiritual beliefs, values, and practices.</p> <p>Guideline 7.5 <i>Bereavement:</i> Bereavement support is available to the family and care team, either directly or through referral. The IDT identifies or provides resources, including grief counseling, spiritual support, or peer support, specific to the assessed needs. Prepared in advance of the patient’s death, the bereavement care plan is activated after the death of the patient and addresses immediate and longer-term needs.</p>	<p>manner a bereavement care plan after the patient’s death, when the family remains the focus of care.</p>
<p>DOMAIN 8: ETHICAL AND LEGAL ASPECTS OF CARE</p> <p>Guideline 8.1 <i>Global:</i> The core ethical principles of autonomy, substituted judgment, beneficence, justice, and nonmaleficence underpin the provision of palliative care.</p> <p>Guideline 8.2 <i>Legal Considerations:</i> The provision of palliative care occurs in accordance with federal, state, and local regulations and laws, as well as current accepted standards of care and professional practice.</p> <p>Guideline 8.3 <i>Screening and Assessment:</i> The patient’s preferences and goals for medical care are elicited using core ethical principles and documented.</p> <p>Guideline 8.4 <i>Treatment and Ongoing Decision-Making:</i> Within the limits of applicable state and federal laws, current accepted standards of medical care, and professional standards of practice, person-centered goals form the basis for the plan of care and decisions related to providing, forgoing, and discontinuing treatments.</p>	<p>PREFERRED PRACTICE 32 Document the designated surrogate/decision-maker in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care.</p> <p>PREFERRED PRACTICE 33 Document the patient/surrogate preferences for goals of care, treatment options, and settings of care at first assessment and at frequent intervals, as conditions change.</p> <p>PREFERRED PRACTICE 34 Convert the patient treatment goals into medical orders, and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services, and hospital care through a program such as the Physician Orders for Life-Sustaining Treatments (POLST) Program.</p> <p>PREFERRED PRACTICE 35 Make advance directives and surrogacy designations available across care settings, while protecting patient privacy and adherence to Health Insurance Portability and Accountability Act (HIPPA) regulations (for example, using Internet-based registries or electronic personal health records).</p> <p>PREFERRED PRACTICE 36 Develop healthcare and community collaborations to promote advance care planning and completion of advance directives for all individuals (for example, the Respecting Choices and Community; Conversations on Compassionate Care programs).</p>

	<p>PREFERRED PRACTICE 37 Establish or have access to ethics committees or ethics consultation across care settings to address ethical conflicts at the end of life.</p> <p>PREFERRED PRACTICE 38 For minors with decision-making capacity, document the child’s views and preferences for medical care, including assent for treatment, and give appropriate weight in decision- making. Make appropriate professional staff members available to both the child and the adult decision-maker for consultation and intervention when the child’s wishes differ from those of the adult decision-maker.</p>
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Source:

National Consensus Project (NCP) for Quality Palliative Care (2018). *Clinical practice guidelines for quality palliative care*, 4th edition. Accessed February 16, 2021 from: <https://www.nationalcoalitionhpc.org/ncp/>

National Quality Forum. (2006). *A national framework and preferred practices for palliative and hospice care quality*. Washington DC: Author. Accessed February 16, 2021 from: http://www.qualityforum.org/publications/2006/12/A_National_Framework_and_PREFERRED_Practices_for_Palliative_and_Hospice_Care_Quality.aspx

Module 1

Table 2: Nursing Actions to Foster Hope

Experiential processes

- Prevent and manage end-of-life symptoms
- Use lightheartedness and humor appropriately
- Encourage the patient and family to transcend their current situation
- Encourage aesthetic experiences
- Encourage engagement in creative and joyous endeavors
- Suggest literature, movies, and art that are uplifting and highlight the joy in life
- Encourage reminiscing
- Assist patient and family to focus on present and past joys
- Share positive, hope-inspiring stories
- Support patient and family in positive self-talk

Spiritual/transcendent processes

- Facilitate participation in religious rituals and spiritual practices
- Make necessary referrals to clergy and other spiritual support people
- Assist the patient and family in finding meaning in the current situation
- Assist the patient/family to keep a journal
- Suggest literature, movies, and art that explore the meaning of suffering

Relational processes

- Minimize patient and family isolation
- Establish and maintain an open relationship
- Affirm patients' and families' sense of self-worth
- Recognize and reinforce the reciprocal nature of hopefulness between patient and support system
- Provide time for relationships (especially important in institutional settings)
- Foster attachment ideation by assisting the patient to identify significant others and then to reflect on personal characteristics and experiences that endear the significant other to the patient
- Communicate one's own sense of hopefulness

Rational thought processes

- Assist patient and family to establish, obtain, and revise goals without imposing one's own agenda
- Assist in identifying available and needed resources to meet goals
- Assist in procuring needed resources; assist with breaking larger goals into smaller steps to increase feelings of success
- Provide accurate information regarding patient's condition and treatment in a skillful and sensitive manner
- Help patient and family identify past successes
- Increase patients' and families' sense of control when possible

Reference:

Cotter, V.T., & Foxwell, A.M. (2019). The meaning of hope in the dying. In: B.R. Ferrell, and J.A. Paice (Eds.) *Oxford textbook of palliative nursing*, 5th edition, (Chapter 30). New York, NY: Oxford University Press. Reprinted with permission.

Module 1

Table 3: Fast Facts and Concepts

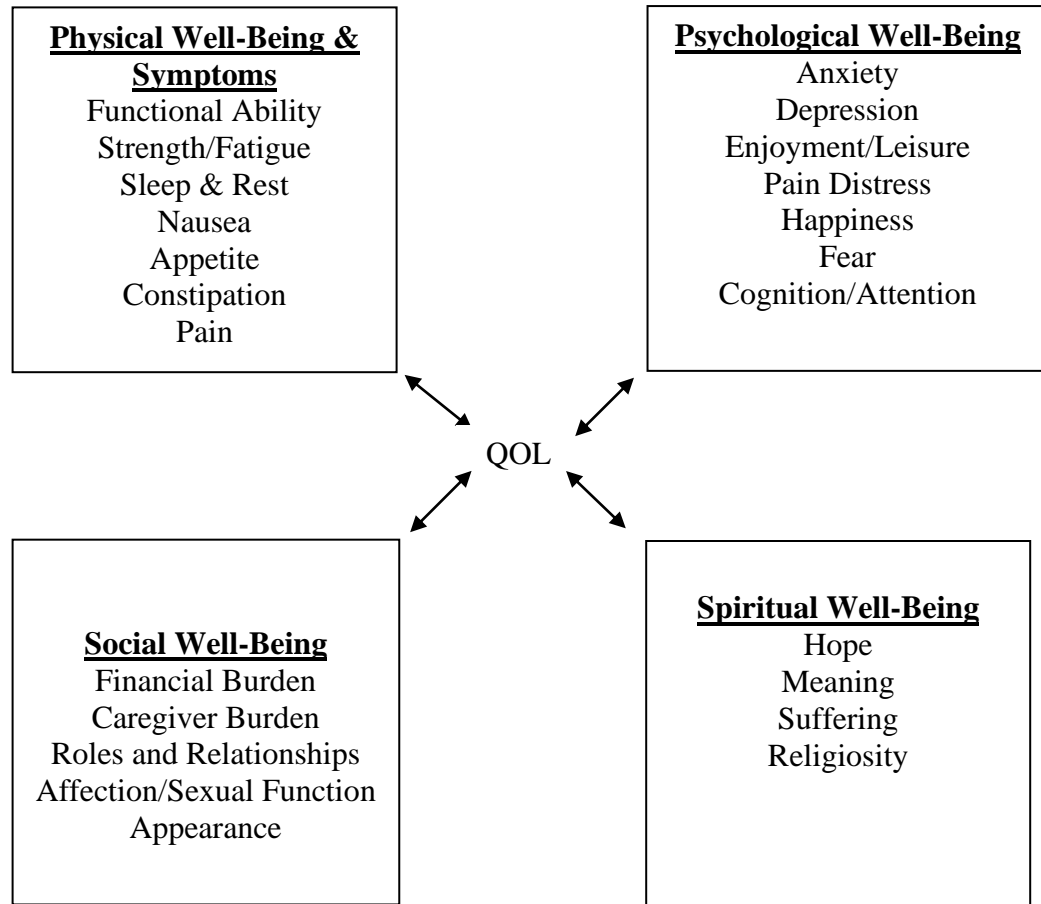
Fast Facts and Concepts provide concise, practical, reviewed and evidence-based summaries on key palliative care topics important to clinicians and trainees caring for patients facing serious illness. *Fast Facts and Concepts* are intended to be quick teaching tools that can be used for bedside rounds, as well as self-study material for health care trainees and clinicians.

Fast Facts and Concepts are published approximately once a month. They are also cross-published in the [*Journal of Palliative Medicine*](#). *Fast Facts and Concepts* are a free palliative care educational resource and can be reprinted, with proper attribution, for non-commercial educational purposes. They are published under a Creative Commons Attribution-NonCommercial-ShareAlike copyright.

For a listing of all *Fast Facts and Concepts*, go to the Palliative Care Network of Wisconsin (PCNOW) website <https://www.mypcnw.org/fast-facts/>

Module 1

Figure 1: Quality-of-Life Model



Source:

Ferrell, B.R., & Grant, M. (2000). *Quality-of-life model*. Duarte, CA: City of Hope National Medical Center. Reprinted with permission. Available online at www.cityofhope.org/NRE

Module 1

Figure 2: Achieving Quality of Life at the End of Life: Addressing Multiple Dimensions of Care

PURPOSE: To be a companion with Figure 1. These multiple dimensions of care will give the participants an opportunity to look at various ways of assessing and managing the patient's/family's physical, psychological, social, and spiritual well-being.

Physical Well-Being:

1. Multiple symptoms due to disease progression, debility, and organic and metabolic changes affect the physical well-being of the patient.
2. Pain is one of the primary concerns of terminally ill patients and their family members or caregivers.
3. Other distressing symptoms include dyspnea, GI disturbances, delirium, restlessness/agitation, fatigue/weakness, dysphagia and anorexia/cachexia.
4. Physical aspects also include functional ability, sleep and rest, and appetite.
5. Family members can develop or may have existing physical needs that impact their ability to care for the patient, as well as their ability to care for themselves. Physical symptoms can manifest during the bereavement period as well.

Psychological Well-Being:

1. Patients experience a wide range of emotions and psychological issues/concerns at the end of life.
2. Communication and support are important components of the psychological domain. Addressing and working through unresolved issues may greatly decrease suffering.
3. The meaning of illness along with physical and social attributes greatly impacts emotional responses. Meanings may change depending on individual circumstances (Borneman & Brown-Saltzman, 2019).
4. Depression must be differentiated from sadness (Salman et al., 2019) - sadness due to multiple losses (normal response) versus depression (psychiatric syndrome).
5. Erosion of the older adult's self-esteem.
 - a. "Ageist" approach by institutions and care givers
 - b. Loss of privacy and dignity
 - c. Lowered self-esteem can intensify feelings of psychological and physical pain, aloneness, and depletion of energy
 - d. May feel helpless and a burden to others.
6. Coping strategies - those that have been helpful in the past are explored along with the suggestions of new strategies. While denial is often viewed negatively, it can be a useful and appropriate means of coping with overwhelming loss.
7. The way an older adult will respond to his/her dying will be influenced by their background, past experiences, religions, philosophical orientation, and how involved he or she was in life prior to their illness (Touhy & Jett, 2018).
8. Cognitive assessment - includes decision-making capacity and competence, as well as assessing for the presence and causes of confusion, agitation, and delirium.
9. Psychological concerns - the emotional responses to illness and include: anxiety, sadness, fear, depression, loneliness, denial/acceptance, happiness,

distress associated with symptoms, grief/bereavement, hope/hopelessness, and guilt/anger.

10. Death anxiety scores on standard questionnaires suggest that older adults experience a decrease in death anxiety rather than an increase with advancing age.
 - a. Experience with cumulative losses and limitations (Kastenbaum, 1992).
 - b. Thought to be due to the elder's perception that they have been able to "live their life."

Social Well-Being:

1. The social structure and integrity of the family may be threatened. Relationships and roles are often disrupted and need to be redistributed, creating a certain amount of chaos.
2. Older adults have had many losses (family, friends, physical abilities, and independence), which contributes to social isolation.
3. Becoming a burden to one's family is often a concern to a patient. Family caregivers may be overwhelmed; the only caregiver might be an infirm elderly spouse.
4. Expressions of sexuality may change between partners, as illness progresses.
5. Children may manifest their emotional concerns by isolating themselves or by acting out in a classroom or at home.
6. Financial concerns may arise due to lost income from the patient and/or family members' missing work because of caregiver responsibilities.

Spiritual/Cultural Well-Being:

1. Religion and spirituality are complementary concepts (Highfield, 2000). Religion gives expression to a person's beliefs, values, and practices and provides answers to questions regarding suffering, illness, pain and death. Religion is the way in which a person relates to God.
2. A broader understanding of spirituality embraces a search for meaning in any given life experience (McClement, 2015).
3. The spiritual dimension involves the universal human capacity to transcend self and connect with others, surroundings, and powers outside of self, and exists independent of affiliation with an organized religion (Highfield, 2000).
4. A person's sense of spirituality is often the key to transcending losses and finding meaning in life. Allowing opportunities for meaning to unfold opens up the potential to move from the superficial to the profound (Borneman & Brown-Saltzman, 2019). Many search for the meaning of suffering, for forgiveness, or for acceptance.
5. The dying process can challenge and temporarily diminish hope, but it does not inevitably bring despair. Skillful attention to maintaining a person's unique meaning of hope can enhance quality of life and contribute to a process of dying that is meaningful to the patient and family (Cotter & Foxwell, 2019).
6. Religious and/or cultural rituals and activities are important means of support. Funeral rituals acknowledge the changed identity of the deceased from living to dead, as well as the changed identity of the bereaved. Rituals assist individuals to cope with multiple losses (Rando, 1984).

References:

- Borneman, T., & Brown-Saltzman, K. (2019). Meaning in illness. In: B.R. Ferrell and J.A. Paice (Eds.), *Oxford textbook of palliative nursing*, 5th edition (Chapter 36). New York, NY: Oxford University Press.
- Cotter, V., & Foxwell, A.M. (2019). The meaning of hope in the dying. In: B.R. Ferrell, and J.A. Paice. (Eds.), *Oxford textbook of palliative nursing*, 5th edition, (Chapter 23). New York, NY: Oxford University Press.
- Highfield, M.E.F. (2000). Providing spiritual care to patients with cancer. *Clinical Journal of Oncology Nursing*, 4(3), 115-120.
- Kastenbaum, R. (1992). Death, suicide and the older adult. *Suicide Life Threat Behavior*, 22(1), 1-14.
- McClement, S.E.. (2015). Spiritual issues in palliative medicine. In: N. Cherney, M. Fallon, S. Kaasa, R.K., Portenoy, & D.C. Currow (Eds.), *Oxford textbook of palliative medicine*, 5th edition (Chapter 17.1). Oxford, UK: Oxford University Press.
- Salman, J., Wolfe, E., & Patel, S.K. (2019). Anxiety and depression. In: B. R. Ferrell and J.A. Paice (Eds.), *Oxford textbook of palliative nursing*, 5th edition (Chapter 22). New York, NY: Oxford University Press.
- Rando, T.A. (1984). *Grief, dying and death: Clinical interventions for caregivers*. Champaign, IL: Research Press Co.
- Touhy, T. & Jett, K. (2018). *Ebersole and Hess' gerontological nursing and healthy aging*, 5th edition. St. Louis, MO: Mosby, Inc.

Module 1

Figure 3: 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”.² 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 CARES¹⁸ 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).³ 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.⁴

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.⁵

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.⁶

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

References

1. Kelley AS. Defining “serious illness.” J Palliat Med. 2014;17(9):985. doi:10.1089/jpm.2014.0164
2. Kelley AS, Bollens-Lund E. Identifying the population with serious illness: The “denominator” challenge. J Palliat Med. 2018;21(S2):S7-S16. doi:10.1089/jpm.2017.0548
3. Centers for Disease Control and Prevention. Chronic Diseases in America. National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP). Published 2021. Accessed October 13, 2021. <https://www.cdc.gov/chronicdisease/resources/infographic/chronic-diseases.htm>
4. National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care. 4th ed. National Coalition for Hospice and Palliative Care; 2018. Accessed October 8, 2021. <https://www.nationalcoalitionhpc.org/ncp>
5. Kirkpatrick AJ, Cantrell MA, Smeltzer SC. A concept analysis of palliative care nursing: Advancing nursing theory. ANS Adv Nurs Sci. 2017;40(4):356-369. doi:10.1097/ANS.0000000000000187
6. World Palliative Care Alliance. Global Atlas of Palliative Care. World Palliative Care Alliance; 2020. <http://www.thewhpc.org/resources/global-atlas-on-end-of-life-care>
7. Rosa WE, Ferrell BR, Mason DJ. Integration of palliative care into all serious illness care as a human right. JAMA Health Forum. 2021;2(4):e211099. doi:10.1001/jamahealthforum.2021.1099
8. Rosa WE, Buck HG, Squires AP, et al. Nursing’s roles and responsibility to ensure universal palliative care access: A consensus paper of the American Academy of Nursing Expert Panels (Part 1- rationale and background). Nurs Outlook. Published online in press. Accessed October 13, 2021. <https://www.sciencedirect.com/science/article/pii/S0029655421001639>

9. Meier DE, Back AL, Berman A, Block S, Corrigan JM, Morrison RS. A national strategy for palliative care. *Health Aff (Millwood)*. 2017;36(7):1265-1273.
10. American Nurses Association, Hospice and Palliative Nurses Association. *Palliative Nursing: Scope and Standards of Practice — An Essential Resource for Hospice and Palliative Nurses*. (Dahlin CM, Sutermaster DJ, eds.). Nursingbooks.org; 2014. Accessed October 13, 2021.
https://www.hpna.org/HPNA_Item_Details.aspx?ItemNo=9781558105393
11. National Academies of Sciences, Engineering, and Medicine. *Building the Workforce We Need to Care for People with Serious Illness: Proceedings of a Workshop*. The National Academies Press; 2020. Accessed October 13, 2021.
<https://doi.org/10.17226/25789>
12. Rosa WE, Buck HG, Squires AP, et al. International consensus-based policy recommendations to advance universal palliative care access from the American Academy of Nursing Expert Panels. *Nurs Outlook*. Published online October 2021. Accessed October 13, 2021.
<https://www.sciencedirect.com/science/article/pii/S0029655421001639>
13. American Association of Colleges of Nursing. *The Essentials: Core Competencies for Professional Nursing Education*. American Association of Colleges of Nursing; 2021. Accessed June 1, 2021.
<https://www.aacnnursing.org/Portals/42/AcademicNursing/pdf/Essentials-2021.pdf>
14. Robert Wood Johnson Foundation, American Association of Colleges of Nursing. *Peaceful death: Recommended competencies and curricular guidelines for end-of-life nursing care*. Published 1998. Accessed October 13, 2021.
<http://www.aacn.nche.edu/el nec/publications/peaceful-death>
15. Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences near the End of Life*. The National Academies Press; 2014. Accessed November 23, 2014. /catalog/18748/dying-in-america-improving-quality-and-honoringindividual-preferences-near
16. Mazanec P, Ferrell B, Virani R, Alayu J, Ruel NH. Preparing new graduate RNs to provide primary palliative care. *J Contin Educ Nurs*. 2020;51(6):280-286. doi:10.3928/00220124-20200514-08
17. Ferrell B, Mazanec P, Malloy P, Virani R. An innovative end-of-life nursing education consortium curriculum that prepares nursing students to provide primary palliative care. *Nurse Educ*. 2018;43(5):242.
18. American Association of Colleges of Nursing. *CARES--Competencies And Recommendations for Educating Undergraduate Nursing Students: Preparing Nurses to Care for the Seriously Ill and Their Families*. American Association of Colleges of Nursing; 2016. Accessed October 21, 2021.
<https://www.aacnnursing.org/Portals/42/ELNEC/PDF/New-Palliative-CareCompetencies.pdf>
19. Ferrell B, Malloy P, Mazanec P, Virani R. CARES: AACN's new competencies and recommendations for educating undergraduate nursing students to improve palliative care. *J Prof Nurs*. 2016;47(6):252-256. doi:10.1016/j.profnurs.2016.07.002
20. American Association of Colleges of Nursing. *End-of-Life Nursing Education (ELNEC)*. Accessed October 13, 2021. <https://www.aacnnursing.org/ELNEC>

21. Relias LLC. About ELNEC Undergraduate/New Graduate. ELNEC. Accessed March 26, 2021. <https://elneec.academy.reliaslearning.com/about-elneec-undergraduate.aspx>
22. American Association of Colleges of Nursing. Preparing Graduate Nursing Students to Ensure Quality Palliative Care for the Seriously Ill & Their Families. American Association of Colleges of Nursing; 2019. <https://www.aacnnursing.org/Portals/42/ELNEC/PDF/Graduate-CARES.pdf>
23. Relias LLC. ELNEC-Graduate Curriculum. Published 2020. Accessed October 13, 2021. <https://elneec.academy.reliaslearning.com/ELNEC-Graduate-Curriculum.aspx>
24. American Association of Colleges of Nursing. ELNEC Fact Sheet. Accessed October 13, 2021. <https://www.aacnnursing.org/Portals/42/ELNEC/PDF/ELNEC-Fact-Sheet.pdf>
25. Davis A, Lippe M, Glover TL, McLeskey N, Shillam C, Mazanec P. Integrating the ELNEC undergraduate curriculum into nursing education: Lessons learned. *J Prof Nurs.* 2021;37(2):286-290. doi:10.1016/j.profnurs.2020.12.003
26. American Nurses Association. *Nursing: Scope and Standards of Practice*. 3rd ed. American Nurses Association; 2015.
27. American Nurses Association, Hospice and Palliative Nurses Association. Call for Action: Nurses Lead and Transform Palliative Care. Published online 2017. Accessed October 12, 2021. <https://www.nursingworld.org/~497158/globalassets/practiceandpolicy/healthpolicy/palliativecareprofessionalissuespanelcallforaction.pdf>
28. Lippe MP, Davis A. Development of a primary palliative nursing care competence model and assessment tool: A mixed methods study. Publication in progress.
29. National Quality Forum. *A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report*. National Quality Forum; 2006.
30. Centers for Medicare & Medicaid Services. *Hospice*. Published 2021. Accessed October 13, 2021. <https://www.cms.gov/Medicare/Medicare-Fee-for-ServicePayment/Hospice>

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>¹⁰

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Module 1

Figure 4: Additional Teaching Strategies

1. Describe dying and death in the following time periods, based on media depiction, personal/family experience, or visionary expectations.
 - The early and mid-1900s
 - Early 2000s
 - Current time
 - In the future, such as in the year 2030, 2040, 2050

2. Discuss dying and death as presented in movies or plays such as:
 - *Coco*
 - *Up*
 - *Defining Hope*
 - *Philadelphia*
 - *Terms of Endearment*
 - *Wit*
 - *One True Thing*
 - *Fault of Our Stars*
 - *Homegoings*
 - *Extremis*
 - *Endgame*
 - *Being Mortal*
 - *Alternate Endings*

Address the following questions:

- What was the perception of serious illness and death?
 - What was the serious illness that a main character had?
 - Where did people die?
 - Who cared for the dying?
 - Who was present at the time of death?
 - How did the family members respond?
 - How did the community respond?
 - What expectations or beliefs were associated with dying and death?
 - How did people cope with loss?
3. Have participants create their personal loss inventory and discuss how it has influenced their personal and professional attitudes and behaviors.

 4. Have participants envision the following according to their personal and professional expectations including where, when, how, under what conditions or circumstances, etc.
 - Dying well
 - Dying badly

5. Ask participants how life priorities may change, if an individual were to learn that she/he would die within the next 12 months, 6 months, or 1-month. Discuss what the individual and family may need to do in those time periods?
6. Have participants interview an elderly member of the community or their family to identify changes in rituals related to dying and death that they have experienced over their life-time and seek suggestions for rituals that were a source of comfort and healing during the bereavement period.
7. Arrange for participants to attend an interprofessional palliative care team meeting. In class, post-conference or seminar, discuss the roles of various team members. Discuss the differences between interdisciplinary/interprofessional and multidisciplinary teams.
8. Discuss the merging of hospice nursing with palliative nursing; envision the type of care that will be offered.
9. Develop the character of a hospice/palliative nurse for a television movie. Include:
 - Personal and professional characteristics of the nurse.
 - Roles and responsibilities.
 - Care settings.
 - Ways of collaborating with other health professionals.
 - Situations in which the nurse would assume a leadership role.
10. Develop brief case studies of individuals with COVID-19, pulmonary conditions, cancer, HIV/AIDS, dementia, end-stage heart disease, end stage kidney disease, neurodegenerative disease, congenital conditions, for people of all ages. Ask participants to identify for each of the above patients, the:
 - Projected care setting
 - Support needed by caregiver
 - Potential resources available
 - Whether they would qualify for palliative care or hospice and why?
 - Further develop the case study to portray the multidimensional aspects of suffering; have participants discuss the threats to physical, emotional, social, cultural, or spiritual well-being of the patient and family caregiver presented.
11. Identify patient, healthcare provider, and healthcare system's barriers to palliative care, and identify a proactive strategy that may be taken by nurses to overcome each barrier.
12. Based on the spiritual and cultural perspectives of participants themselves, ask them to share their perspectives on living with life-threatening illness, family communication patterns, and attitudes toward dying and death.
13. Ask participants to anticipate quality of life issues for patients and family caregivers and identify interprofessional strategies/interventions needed at the following time points:
 - Time of diagnosis with serious illness
 - Living with life-threatening illness

- Active dying and death
- Bereavement period

Module 1

Figure 5: End-of-Life Nursing Education Questionnaire (ELNEQ)

Background: End-of-Life Nursing Education Consortium (ELNEC) train-the-trainer workshops prepare participants to teach ELNEC content to others. In 2010, researchers in Japan developed and validated the End-of-Life Nursing Education Questionnaire (ELNEQ) to measure the impact of ELNEC workshops on participants' readiness to teach the content. The study's objective was to evaluate the psychometric properties of the English version of the ELNEQ.

For each of the following, please indicate how much do you agree to the statement about end-of-life (EOL) nursing education. On a scale from 1 to 5, please circle only one answer that represents your level of agreement.

	Not at all	A little bit	somewhat	Quite a bit	Very much
【Confidence in Teaching】					
• I am satisfied with my ability to teach EOL care.	1	2	3	4	5
• I have sufficient ability to teach EOL care.	1	2	3	4	5
• It is not difficult for me to teach EOL care.	1	2	3	4	5
• I have no trouble teaching EOL care.	1	2	3	4	5
【Motivation for Teaching】					
• I am motivated to teach EOL care.	1	2	3	4	5
• I want to be actively involved in teaching EOL care.	1	2	3	4	5
• I want to spend more time teaching EOL care on patients' final hours.	1	2	3	4	5
• I want to spend more time teaching nurses' roles in EOL care.	1	2	3	4	5
【Preparation to Provide Teaching】					
• I am prepared to run group discussions in teaching EOL care.	1	2	3	4	5
• I am prepared to run case studies in teaching EOL care.	1	2	3	4	5
• I am prepared to run role-play sessions in teaching EOL care.	1	2	3	4	5
• I am prepared to give effective lectures on EOL care.	1	2	3	4	5
【Preparation to Lead Initiatives in EOL Care】					
• I am prepared to contribute to improve the quality of EOL care in my home institution or region.	1	2	3	4	5
• I know how to improve the quality of EOL care in my home institution or region.	1	2	3	4	5
• I am prepared to make plans to improve the quality of EOL care in my home institution or region.	1	2	3	4	5
• I have plans to improve the quality of EOL care in my home institution or region.	1	2	3	4	5
【Expected Influences on Participants】					
• Participants of my educational programs will improve quality of their EOL care.	1	2	3	4	5
• Participants of my educational programs will improve their ability of managing symptoms of patients with terminal illness.	1	2	3	4	5
• Participants of my educational programs will improve quality of their care for imminent patients.	1	2	3	4	5
• Participants of my educational programs will become more aware of their roles as patients' advocates.	1	2	3	4	5

Permission has been given by the principal author, Barbara A. Head to use this tool. Proper attribution should be provided by citing the article Head, B.A., Schapmire, T., & Faul, A.C. (2013). Evaluation of the English version of the End-of-Life Nursing Education questionnaire. *Journal of Palliative Medicine*, 16(11), 1375-1381. doi: 10.1089/jpm.2012.0596

Module 1

Figure 6: Tools and Resources for Palliative Care: Important Resources to Help You in Providing Excellent Palliative Care

1. ELNEC Curricula

Once you have completed an ELNEC train-the-trainer course, you have all the resources needed to teach others. PowerPoint slides, talking points, case studies, up-to-date references, supplemental teaching materials—all will give you the vital information you need to share with other colleagues. Remember to purchase a new ELNEC curriculum every 3 years. For more information, go to www.aacnnursing.org/ELNEC/About/ELNEC-Curricula



2. ELNEC Resources

There are many resources available on the ELNEC Resources webpage, including newsletters, videos, reference cards, infographics and other tools to assist educators and clinicians. <https://www.aacnnursing.org/ELNEC/Resources>

3. ELNEC Online through Relias™

Relias Learning offers online training to senior care, health and human services, public safety, and intellectual and developmental disabilities organizations. Their mission is to help clients achieve the highest quality practice and accreditation standards with online learning and compliance programs. The following ELNEC curricula are online via Relias: Core, Critical Care, Geriatric, and Pediatric Palliative Care. To learn more, go to <https://www.relias.com/product/elnecc-training>.



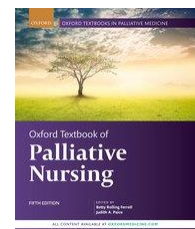
4. The National Consensus Project for Quality Palliative Care: *Clinical Practice Guidelines for Quality Palliative Care*

Endorsed by more than 80 national organizations, the new national palliative care clinical practice guidelines seek to ensure the millions of people living with serious illness have access to vital care that can help meet their needs. The guidelines promote improved access to palliative care, which is focused on giving patients and their caregivers relief from the symptoms and stress of serious illness, is based on need, not prognosis, and can be provided along with disease-focused treatment. The guidelines call for a seismic shift in the delivery of this specialized care by urging all health care professionals and organizations to integrate it into the services they provide to people living with serious illness. The guidelines also include tools, resources and practice examples to help with implementation. The guidelines can be downloaded for free at <https://www.nationalcoalitionhpc.org/ncp/>



5. 2019 Edition of the *Oxford Textbook of Palliative Nursing*

This textbook is written by some of the world's foremost experts in palliative care. While written primarily by nurses, many other members of the interprofessional team have also contributed to this work. This 5th edition is edited by Drs. Betty Ferrell and Judith Paice. This textbook can be purchased in hardcopy and as e-book. <https://global.oup.com/academic/product/oxford-textbook-of-palliative-nursing-9780190862374?q=ferrell&lang=en&cc=us>



6. 2022 Edition of *Advanced Practice Palliative Nursing*

Advanced Practice Palliative Nursing is the first text devoted to advanced practice nursing care of the seriously ill and dying; addressing all aspects of palliative care including physical, psychological, social, and spiritual needs. Chapters include: leadership, the role of the palliative APRN across settings, common conditions, common symptoms in serious illness, pediatric palliative care, communication, and special populations such as care of individuals with serious mental illness, individuals experiencing homelessness, Veteran's and caring for individuals of the LGBTQ+ community. The text is written by palliative APRNs in the field and includes authors who have pioneered the role of the advanced practice nurse in palliative care. This volume offers advanced practice content and practical resources for clinical practice across all settings of care and encompassing all ages, from pediatrics to geriatrics.

7. 2021 HPNA Palliative Nursing: Scope and Standards of Practice 6th edition— (both APN & RN)

This publication addresses what is expected of all palliative nurses by specifying the who, what, where, when, why, and how of their practice. It reflects the concepts of social determinants of health and health equity. Endorsed by the American Nurses Association, there is detailed discussion of that scope of practice gives the context—the underlying assumptions, characteristics, environments and settings, education and training requirements, key issues and trends, and ethical and conceptual bases of the specialty—needed to understand and use the palliative nursing standards of practice.

8. Hospice and Palliative Nurses Association (HPNA) Resources

Position Statements: <http://advancingexpertcare.org/position-statements/>



9. City of Hope (COH) Nursing Research & Education (NRE)

City of Hope Nursing Research & Education Division organizes its research around three major themes: quality of life, symptom management, and communication. Studies range from diagnosis and treatment to survivorship and end-of-life care, and each investigation provides valuable insights concerning cancer control and population. Available on the COH-NRE website are pain assessment tools, patient education materials, quality assurance materials, end-of-life resources, research instruments and other resources. For more information, go to www.cityofhope.org/NRE.



10. Fast Facts and Concepts

Fast Facts and Concepts provide concise, practical, peer-reviewed, and evidence-based summaries on key topics important to clinicians and trainees caring for patients facing life-limiting illnesses. These FREE educational resources can be reprinted, with proper attribution, for non-commercial educational purposes. www.mypcnow.org/fast-facts/



11. Defining Hope – A documentary of nursing in America.

This video offers a view of the breadth of nursing across America for individuals with serious illness. It provides the underlying humanity of nursing in a variety of settings – rural, community, urban settings across populations. For more information – <https://www.hope.film>. Other documentaries include *American Nurse* <https://www.americannurseproject.com> and *In Case of Emergency*. <https://www.incaseofemergency.film>

12. *The Space Between: Documentary of Palliative Care at Kimbilio Hospice, KipKaren, Kenya*

This video, *The Space Between*, exemplifies nursing leadership. It is a human story about hope and perseverance that examines the impact of



health care poverty in an international through the scope of dying with dignity. For more information, go to thespacebetween.doc.com/

13. Community Education Slides Regarding Palliative Care

Many ELNEC trainers are asked to provide information about hospice/palliative care throughout their community (i.e. Rotary Clubs, VFWs, women's meetings, churches, etc). These slides can be altered and customized to your particular community. These slides can be downloaded from www.aacnnursing.org/ELNEC/Resources

