

ELNEC- For Veterans

END-OF-LIFE NURSING EDUCATION CONSORTIUM

Palliative Care For Veterans

FACULTY GUIDE

Module 1 Introduction to Palliative Nursing

The End-of-Life Nursing Education Consortium (ELNEC – For Veterans train-the-trainer program and curriculum was developed by the National ELNEC Project Team, a partnership between the City of Hope (Betty R. Ferrell, PhD, RN, MA, FPCN, FAAN, Principal Investigator) in collaboration with the American Association of Colleges of Nursing with updates undertaken by Carma Erickson-Hurt, DNP, LCDR, USN, RET. Curriculum development and national ELNEC-For Veterans train-the-trainer courses were generously funded by the US Department of Veterans Affairs (original courses and ongoing updates spanning 2009-2023).

Module 1: Introduction to Palliative Nursing Faculty Outline

Slide 1



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End-of-Life Nursing Education Consortium
Palliative Care For Veterans

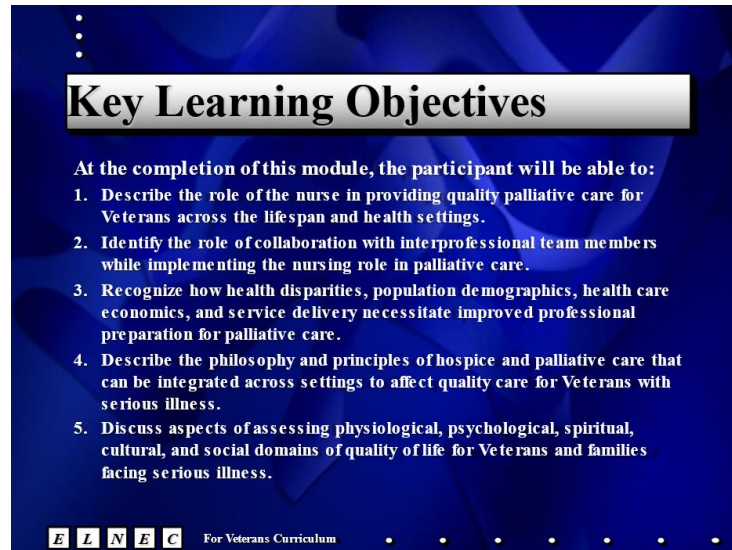
Module 1: Introduction to Palliative Nursing Care

“You matter because you are you. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but to live until you die”.

Dame Cicely Saunders
Founder of St. Christopher’s Hospice
London, England

- This module will be presented in 3 sections:
 - Section I: Overview of Dying in America (slides 1-11)
 - Section II: Defining Hospice and Palliative Care (slides 12-22)
 - Section III: Palliative Care for Veterans (slides 23-35)

Slide 2



Key Learning Objectives

At the completion of this module, the participant will be able to:

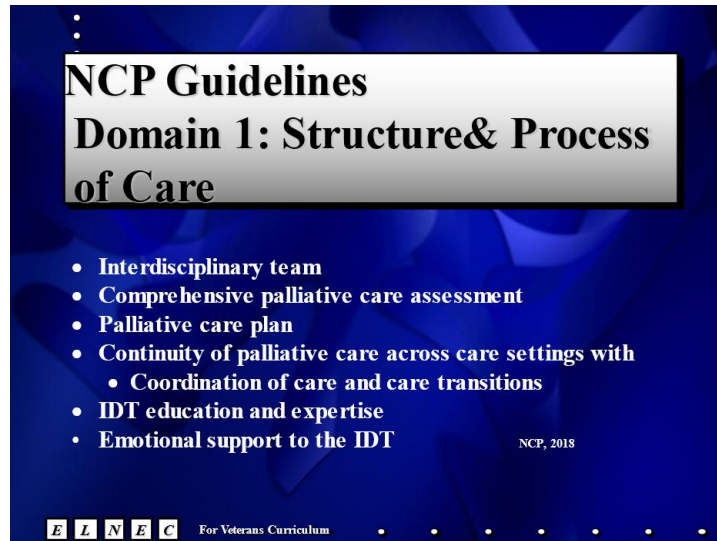
1. Describe the role of the nurse in providing quality palliative care for Veterans across the lifespan and health settings.
2. Identify the role of collaboration with interprofessional team members while implementing the nursing role in palliative care.
3. Recognize how health disparities, population demographics, health care economics, and service delivery necessitate improved professional preparation for palliative care.
4. Describe the philosophy and principles of hospice and palliative care that can be integrated across settings to affect quality care for Veterans with serious illness.
5. Discuss aspects of assessing physiological, psychological, spiritual, cultural, and social domains of quality of life for Veterans and families facing serious illness.

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Key Learning Objectives

1. Describe the role of the nurse in providing quality palliative care for Veterans across the lifespan and health settings
2. Identify the role of collaboration within interprofessional team members while implementing the nursing role in palliative care.
3. Recognize how health disparities, population demographics, healthcare economics, and service delivery necessitate improved professional preparation for palliative care.
4. Describe the philosophy and principles of hospice and palliative care that can be integrated across settings to affect quality care for Veterans with serious illness,
5. Discuss aspects of assessing physiological, psychological, spiritual, cultural, and social domains of quality of life for Veterans and families facing serious illness.

Slide 3



The slide features a dark blue background with a white box at the top containing the title. Below the title is a bulleted list of key components. At the bottom left is the ELNEC logo and 'For Veterans Curriculum', and at the bottom right is 'NCP, 2018'.

NCP Guidelines

Domain 1: Structure & Process of Care

- Interdisciplinary team
- Comprehensive palliative care assessment
- Palliative care plan
- Continuity of palliative care across care settings with
 - Coordination of care and care transitions
- IDT education and expertise
- Emotional support to the IDT

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NCP, 2018

National Consensus Project (NCP) Guidelines (NCP, 2018):

- Domain 1: Structure & Process of Care
 - *Interdisciplinary or Interprofessional Team:* 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.
 - *Comprehensive Palliative Care Assessment:* An interdisciplinary comprehensive assessment of the patient and family forms the basis for the development of an individualized patient and family palliative care plan
 - *Palliative Care Plan:* 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.
 - *Continuity of Palliative Care:* The IDT has defined processes to ensure access, quality, and continuity of care, especially during transitions of care.
 - *Care Settings:* 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.
 - *Interdisciplinary Team Education:* Education, training, and professional development are available to the IDT.
 - *Coordination of Care and Care Transitions:* 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.
 - *Emotional Support to the Interdisciplinary Team:* 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.

- *Continuous Quality Improvement*: 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.
- *Stability, Sustainability, and Growth*: Recognizing limitations in reimbursement for interdisciplinary palliative care, the IDT endeavors to secure funding for long-term sustainability and growth.

Slide 4

Let's meet Steve

- Steve is a 79 year old Vietnam Veteran with a history of diabetes, hypertension and renal failure
- He drives 25 miles one way every other day for dialysis
- His 40 year old physically disabled son who is unable to drive lives with him
- No other children, divorced
- Not religious but “spiritual”
- Four days ago he has a cerebrovascular accident (CVA) with left sided paralysis
- He will be discharged to rehab in the next few days
- He has no advanced directive and has always refused to sign a DNR/AND
- He has not used the VA for healthcare

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- Does this case sound familiar? Have you seen Veterans like Steve in your emergency department, medical unit, ICU, or in homecare?
- As his nurse, what are your most urgent concerns?
 - Would palliative care be appropriate for Steve? If so, what role could palliative care play in his care?
 - Could he qualify for hospice?
 - What interprofessional team members would you want to include in his care?
 - Besides his physical needs, what other needs may he have—psychologically, socially, spiritually?
 - What are some potential ethical issues you might envision in the future for Steve (prolonging life—burdens versus benefits, withholding/withdrawing medical interventions, medical futility, etc)?

Slide 5

Section 1: Overview of Dying in America

Nurses play a Major Role in Caring for Seriously Ill Veterans and Their Families

- Elicit goals of care
- Assess, manage, and coordinate care
- Listen to Veterans/family members
- Bear witness
- Communicate with all members of the interprofessional team
- Knowledgeable in evidence-based practice

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- Nurses' roles in caring for Veterans with serious illness and their families. They include:
 - Eliciting goals of care
 - Assessing, managing, and coordinating care
 - Listening to patients/family members
 - Bearing witness
 - Communicating with all members of the interprofessional team
 - Staying current with evidence-based practice
- As a member of the largest group of healthcare professionals in the United States, nurses must be educated to provide holistic, person-centered care, identify, respect, and advocate for patient choices, and access/provide palliative care. Thus, the American Nurses Association (ANA) and the Hospice and Palliative Nurses Association (HPNA) have concluded that “seriously ill and injured patients, families, and communities should receive quality palliative care in all care settings. This is achieved by the delivery of primary palliative nursing by every nurse, regardless of setting (ANA & HPNA, 2017).

Slide 6

The Facts About Dying in America Today

- **60 of American adults live with at least one chronic condition with 40 of these Americans having two or more chronic conditions**
- **Over 2.8 million people die/year in the US**
- **Top 5 leading causes of death in 2020**
 - Heart disease (696,962)
 - Cancer (602,350)
 - COVID-19 (350,831)
 - Accidents/unintentional injuries (200,955)
 - Stroke/cerebrovascular diseases (160,264). CDC: 2022

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- We live in society that views aging negatively and denies death .
 - According to the National Center for Chronic Disease Prevention & Health Promotion (NCCDPHP), 60% of American adults live with at least one chronic condition and 40% of these live with two or more chronic conditions (NCCDPHP, 2021).
 - Over 2.8 million people die/year in the US (Murphy et al., 2021)
- Many Americans die from chronic illnesses, although the COVID-19 pandemic altered these statistics for 2020. (Ahmad & Anderson, 2021) The top five leading causes of death in America in 2020:
 - Heart disease (696,962)
 - Cancer (602,350)
 - COVID-19 (350,831)
 - Accidents/unintentional injuries (200,955)
 - Stroke/cerebrovascular diseases (160,264). CDC: 2022 (accessed July 17,2022 <https://www.cdc.gov/nchs/fastats/leading-causes-of-death.htm>)

Slide 7



Serious Illness in America: Its Impact on Care

- **Exploding healthcare costs**
- **Misdiagnosis(es)**
- **Failure to treat pain and other symptoms**
- **Increased use of technology**

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- Serious illness is defined as “a health condition that carries a high risk of mortality AND either negatively impacts a person’s daily function OR quality of life OR excessively strains their caregiver” (Kelley & Bollens-Lund, 2018).
- Healthcare spending in the United States hit \$3.8 trillion in 2019 (CMS, 2020).
- 90% of healthcare spending goes to treating chronic and mental health illness (CDC, 2021).
- Medicare spending will increase with the number of baby boomers coming into the system.
- Misdiagnoses can complicate the development of a plan of care for seriously ill patients and increase their financial burden. At one of the nation’s leading medical institutions, more than 20 percent of patients who sought a second opinion were misdiagnosed by their primary care providers (Van Such et al., 2017).
- Failure to treat pain and symptoms remain a major issue in healthcare due to lack of education in pain and symptom management.
- Technology is more refined than ever before. Though it is widely used to prolong life, it may not always restore life.
- Ethical issues include inadequate communication and preparation, leading to situations where patients do not have their wishes honored.

Slide 8

Impact of Chronic Illness on Patients and Families

- **Prolonging life but promoting suffering?**
- **Burdens vs Benefits**

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- Due to the numerous side effects associated with a complex disease and treatment(s), many Veterans with chronic illness are frequently seen in emergency rooms and many times, admitted to the ICU, or medical/surgical/oncology units.
- At what point do you ask about these interventions?
 - Are they prolonging this Veteran's life?
 - Are they non-beneficial?
 - Are the burdens of treatment outweighing the benefits of treatment?
 - Are treatments promoting suffering for the patient and their loved ones?
 - Are treatments increasing the risk of depression and anxiety?
 - Are treatments promoting complicated bereavement for the family members/caregivers?
 - Are treatments ethically and respectfully considering financial burdens of any non-beneficial treatments?
 - If chemotherapy or other life-sustaining treatments are continued, does this prevent/delay palliative or hospice services?

Slide 9

A blue-themed slide with a white title box at the top. The title is "What Constitutes Quality Care at the End-of-Life?". Below the title, there are two bullet points. At the bottom left, there is a logo for "ELNEC For Veterans Curriculum" and a series of small white dots on the right side.

What Constitutes Quality Care at the End-of-Life?

- **For Healthcare Teams: providing symptom management and discussing the emotional aspects of the disease**
- **For Patients: achieving a sense of control, attaining spiritual peace, succeeding in having finances in order, strengthening relationships with loved ones, and believing that their life has meaning**

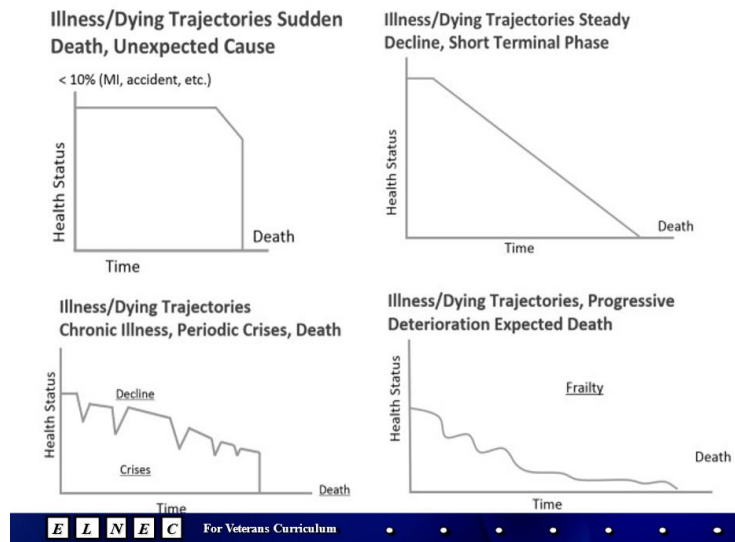
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- Palliative care consult teams [in acute care settings, clinic settings, long term care settings and home settings] found that symptom management was foremost of patient concerns. Patients also were open to discuss emotional aspects of their disease. By ensuring clear patient and family communications to provide psychosocial support tend to relieve pain, dyspnea, nausea and any other distress (Fogelman & Gerringer, 2016).
- It has also been noted that patients want to achieve a sense of control for as long as they can attain spiritual peace, to succeed in having their finances in order, to strengthen relationships with their loved ones, and to believe that their life has had meaning (Thomson et al., 2017).

STOP & CONSIDER: In your current practice:

- Do you concentrate on symptom assessment and management?
- Do you have frequent discussions with Veterans about the emotional toll their disease has on their everyday life?
- If not, how can you overcome the barriers that prevent these important areas of practice?

Slide 10



- **Sudden/Unexpected Death:** Disease and dying trajectories illustrate differences in the dying experience by examining the duration of the dying process and the course of the disease or injury. A sudden death, unexpected cause (e.g., MI, car accident, act of hate/terrorism, etc.) (Field & Cassel, 1997).
- **Steady Decline, Short Terminal Phase:** Steady decline, short terminal phase (e.g., pancreatic cancer) (Field & Cassel, 1997).
- **Chronic Illness, Periodic Crises, Death:** Chronic illness with periodic crises, and death (e.g., congestive heart failure, COPD, end-stage liver disease, AIDS, etc) (Field & Cassel, 1997). Periodic acute exacerbation. High symptom burden. Prognostication is challenging (Quill et al., 2019).
- **Progressive Deterioration/Expected Death:** Lingering expected death (e.g., frailty, such as an older adult who is declining but no specific acute cause of death) (Lunney et al., 2003). Prolonged and gradual physical and cognitive decline with increased fatigue, weight loss, food/fluid intake, multiple co-morbidities. Caregiver support is critical. Prognostication is difficult (Quill et al., 2019).

Slide 11

Overview of Caregivers: Their Commitment and The Cost

- **Most Adults prefer to die at home, generally requiring family to provide support**
- **Family members provide ~80% of the care**
- **Caregiving can increase risk of premature death for the caregiver**
- **VA Caregiver resources**

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- In surveys, most adults prefer to die at home, surrounded by family and friends. This means in many cases, patients depend upon family members to provide their care. However, demographics have changed over 40 years in that most often, all caregivers must work.
 - Today there are approximately 41 million unpaid caregivers in the US (Reinhard et al., 2019). It is estimated that family members provide 80% of their loved one's care (Stajduhar & Dionne-Odom, 2019)
 - Families receive little training about care provision and are often uncertain and scared about providing physical care.
 - Older adult patients are often primarily cared for by their aged spouses who may have numerous chronic illnesses themselves. Studies of older adult couples found hospitalization of the spouse was associated with increased risk of death for the caregiver (NIH, 2019).
 - 18-35% of caregivers experience some form of psychiatric morbidity and many suffer physical and financial hardships, as well as social isolation and spiritual angst (Stajduhar & Dionne-Odom, 2019).
 - Older children, with chronic or acute illness, may be caring for their aged parents (e.g., 70-year-old daughter who is going through chemotherapy for colon cancer is caring for her 91-year-old father with dementia and heart disease) (Stajduhar & Dionne-Odom, 2019).
 - Fewer children and a more mobile society provide fewer available family members to provide care for their seriously ill loved one
- Factors that could predict a caregiver's poor adjustment up to a year after treatment include (NIH, 2019):
 - Strain in the relationship between the patient and caregiver
 - Negative communication
 - Poor social support
 - Role overload

The Department of Veteran Affairs (VA) Caregiver Support Program (CSP) offers clinical services to caregivers of eligible and covered Veterans enrolled in the VA health care system. The program's mission is to promote the health and well-being of family caregivers who care for our Nation's Veterans, through education, resources, support, and services. (VA 2022, <https://www.caregiver.va.gov/>) Some of the service offered are: Skills training, mobile support, one-on-one coaching, group support and coaching, self-care, peer support mentoring, telephone support, online programs. Some Veteran caregivers may also be eligible for a financial stipend.

Suggested Video: Supporting Caregivers:

https://www.youtube.com/watch?v=rOcsaIAovvI&ab_channel=VeteransHealthAdministration

STOP & CONSIDER: It is difficult for caregivers to express their personal needs, and they may be too overwhelmed to prioritize and articulate their concerns. Nurses must assess the stress and burden of caregivers, assess the complexities of the care they are providing, acknowledge the difficult and exhausting work of caregiving, support and reinforce education.

- ***This Concludes Section I**

Module 1: Introduction to Palliative Nursing Faculty Outline

Slide 12

Section II: Defining the Characteristics of Hospice and Palliative Care

What is Hospice?

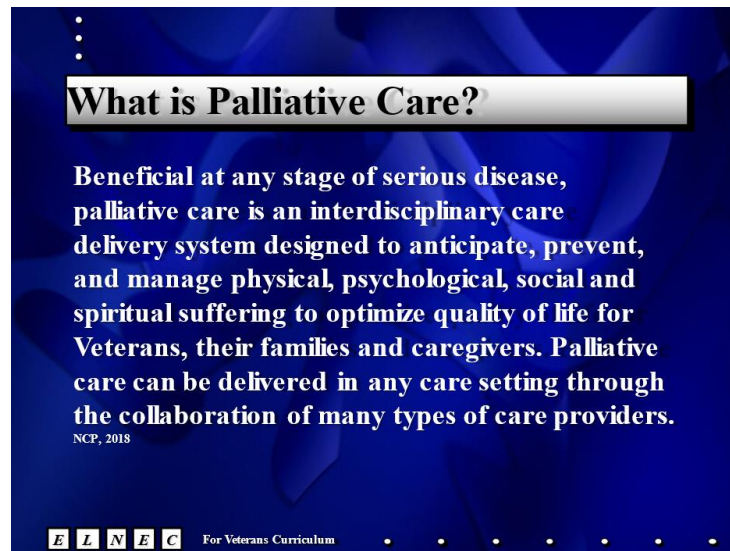
- Definition
- History
- Hospice services

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- Hospice is a specific type of palliative care provided to individuals with a life expectancy measured in months – 6 months or less. Hospice teams provide patients and families with expert health care, emotional, psychological and spiritual support, focusing on maintaining quality of life while dying (NCP, 2018).
- History of hospice: In the late 1960s, modern programs to care for the dying were organized (St. Christopher’s in London was the most notable, founded by Dame Cicely Saunders). The word “hospice,” borrowed from the Middle Ages, was used to designate waystations for pilgrims on their way to the Holy Land. Dame Saunders viewed life as a journey, and just as pilgrims needed a place of support to be able to finish a journey, so patients near the end of life’s journey need support to complete their passage well.
- Because hospice cares for individuals with a terminal illness (prognosis of six months or less), it is associated with death. Hospice may be seen as “death sentence,” leading many patients/families to decline admission to hospice.

NOTE: Hospice benefits and Medicare/Medicaid. The Centers for Medicare and Medicaid services (CMS) provide updates frequently. Check these sites for continuing updates <https://www.medicare.gov/coverage/hospice-care> [Accessed July 5, 2022]

Slide 13



- The definition of palliative care in the United States described by the National Consensus Project (NCP, 2018) states:
 - “Beneficial at any stage of a serious illness, palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families and caregivers. Palliative care can be delivered in any care setting through the collaboration of many types of care providers” (NCP, 2018).
- Palliative care is:
 - *“Appropriate at any stage in a serious illness, and it beneficial when provided along with treatments of curative or life-prolonging intent.*
 - *Provided over time* to patients based on their needs and not their prognosis
 - *Offered in all care settings* and by various organizations, such as physician practices, health systems, cancer centers, dialysis units, home health agencies, hospices, and long-term care providers.
 - *Focused on what is most important to the patient, family, and caregiver(s)*, assessing their goals and preferences and determining how best to achieve them” (NCP, 2018).
- VA palliative care: The VA defines Community Outpatient Palliative Care as comfort care that focuses on relieving suffering and controlling symptoms, so Veterans may continue to do what is most important to them (VHA, 2022). Palliative care in the VA aims to improve the quality of life and can be combined with treatments aimed at curing or controlling disease processes. It can be started at the time of diagnosis and continue throughout the course of the illness. A VA medical facility that offers VA outpatient palliative care does not preclude a Veteran from also using community outpatient palliative care (e.g., distance may prohibit the Veteran from traveling to a VA medical facility) (VHA, 2022)

Primary versus Specialty Palliative Care (PC)

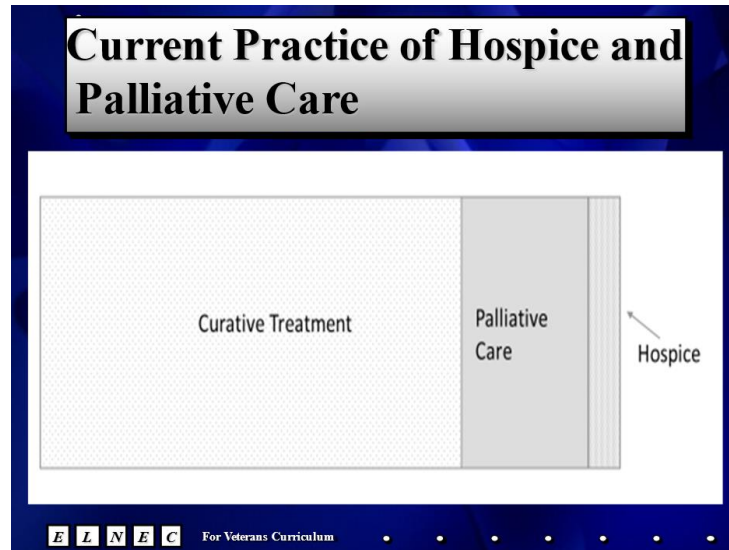
- **Primary palliative care**
 - **Delivered by HCPs who are not PC specialists**
 - **HCPs have a responsibility to acquire core skills and knowledge in PC for basic needs; and refer to specialist when indicated**
- **Specialty palliative care**
 - **Delivered by IDT who are specialists in PC**

IOM, 2015, NCP, 2018

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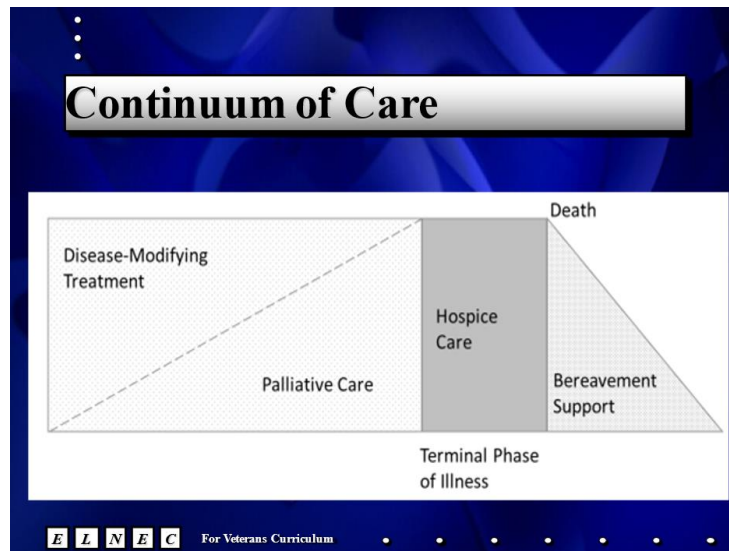
- Primary palliative care (also known as generalist palliative care) (NASEM, 2015)NCP, 2018, ANA and HPNA 2017):
 - Delivered by health care professionals who are not palliative care specialists.
 - All clinicians have a responsibility to acquire core skills and knowledge in palliative care for basic needs and to refer to specialist when indicated.
- Specialty palliative care:
 - Delivered by an interprofessional team of health care professionals with specialist education and training in palliative care
- An example of the difference between primary and specialty care is the primary care clinician who can manage uncomplicated hypertension, yet more complex cases would be referred to a cardiologist.

Slide 15



- Today, patients with serious illness have a long trajectory of cure-focused treatments, followed by palliative care, with short interval of hospice use.

Slide 16



- This diagram delineates the continuum for palliative and hospice care as the disease progresses and the patient enters into the terminal phase of illness (NQF, 2006). Palliative care is integrated from the time of diagnosis of a serious illness and continues throughout active treatment and bereavement (NCP, 2018).

Slide 17

Snapshot of Palliative Care in the US Today

- **72% of US hospitals with 50 or more beds have palliative care programs**
- **94% of hospitals with 300 beds or more have palliative care teams**

(CAPC, NPCRC, 2019)

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- Access to palliative care remains inadequate for millions of Americans living with serious illness despite continuing growth in the number of U.S. hospitals reporting palliative care programs. Key points of this report are (CAPC & NPCRC, 2019):
 - 72% of US hospitals with 50 or more beds have palliative care programs.
 - 94% hospitals with 300 beds or more have palliative care teams.
 - 86% of the 56 freestanding children hospitals with 50 or more beds report having a pediatric palliative care program.
 - Regionally, hospitals in New England, the Pacific, and mid-Atlantic regions have the highest palliative care prevalence. The Central West and East South-Central regions have the lowest access to palliative care.
 - Nursing recognized hospice and palliative nursing as a specialty in 1987. Medicine recognized palliative care as a medical subspecialty in 2008. The field has grown to include 7500 board-certified palliative care physicians, and more than 18,000 palliative care–certified nurses (APRNs, RNs, LV/PNs in adult and pediatric care). The Social Work Hospice & Palliative Care Network (SWHPN) released a palliative care certification examination in 2018, and specialty training and certification opportunities now exist for chaplains, physician assistants, and pharmacists.

Slide 18

Characteristics of Palliative Care Philosophy and Delivery

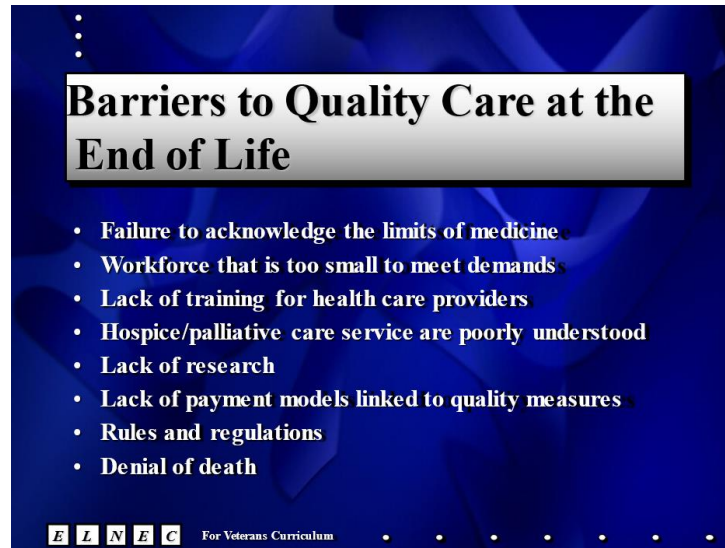
- Interprofessional care
- Collaboration and communication between Veterans, families, health care providers
- Services provided concurrently with or independent of curative/life prolonging care
- Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death
- Services provided in acute care settings, clinics, and throughout the community

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- The palliative care philosophy and delivery can be characterized as (NCP, 2018):
 - Care is provided, and services are coordinated by an interprofessional team.
 - Patients, families, palliative and non-palliative health care providers collaborate and communicate about care needs.
 - Services provided concurrently with or independent of curative or life-prolonging care.
 - Patient and family hope for peace and dignity are supported throughout the course of illness, during the dying process, and after death.
 - Services provided in acute care settings, clinics, and throughout the community.

Suggested Video: *Palliative Care: One Couple's Story of Living While Dying*

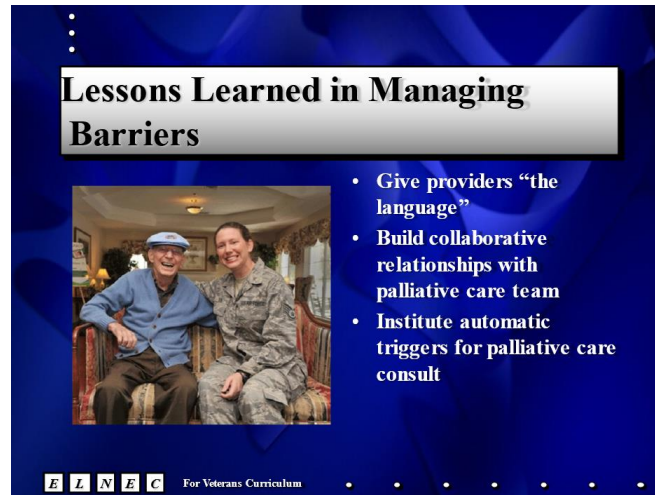
<https://www.youtube.com/watch?v=0VpDW0qy4oE> (2 minutes, 19 seconds) [Accessed July 21, 2022]



- There are many barriers to quality care for individuals with serious illness. Some of the most common barriers include:
 - Failure to acknowledge the limits of medicine may lead to non-beneficial care and the use of aggressive curative treatments that can prolong the dying process and contribute to physical and emotional suffering.
 - Workforce shortages in palliative care specialists within all the health disciplines.
 - There is a great need for additional research to provide evidence for optimal care for those with serious illness. Many current practices have not undergone rigorous testing, in part due to lack of funding for symptom research in this population.
 - Lack of adequate education and training of professionals especially in controlling pain and other symptoms:
 - Addressing only the physical aspects of care, and not assessing the psychological, social, and spiritual needs.
 - Many healthcare professionals are uncomfortable communicating bad news and prognosis.
 - Lack of role models in palliative care for not only current staff, but for students who are preparing for various roles in healthcare.
 - Hospice/palliative care services are poorly understood (Hawley, 2017; NHPCO, 2021)
 - Delayed access to hospice and palliative care services occurs because those services are not well understood, and there remains confusion over when it is appropriate to consult or transfer care to palliative care.
 - Because of this delay, patients and families do not reap the full benefits of hospice and palliative care services.
 - Rules and regulations often impede good end-of-life care (e.g., restrictive visiting hours and inadequate policies for pain and symptom management):

- Regulation of controlled substances has led to fear of prosecution for prescribing and administering medications to relieve pain and other symptoms.
 - Issues regarding access to care, insurance coverage.
- Lack of understanding and culturally insensitive care prevents many from accessing palliative care.
- A lack of payment models that link to quality measures are few. Congressional legislation is pending that would facilitate research, professional development and public education in palliative care.

Slide 20



Lessons Learned in Managing Barriers


- Give providers “the language”
- Build collaborative relationships with palliative care team
- Institute automatic triggers for palliative care consult

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- Though barriers exist in providing and promoting palliative care, there are lessons learned in managing these barriers.
- Many times, providers fear that if they talk about palliative care, their patients will assume they are “giving up” on them. A simple way to introduce palliative care: “We have been managing your heart failure for some time now, and I want to make sure we are doing everything possible to help you do as well as you can. The palliative care team can make sure your symptoms are well controlled and that you and your family are getting an extra layer of support.”
- Joint clinical visits between palliative care and other specialists can be helpful in building collaborative relationships. This increases knowledge about the components of palliative care. In these joint visits, palliative care providers can learn more about newer approaches to care (i.e. new chemotherapy medications, left ventricular assist devices, etc.). These joint visits also are beneficial for the patient who can see that the clinicians are part of a team and that palliative care does not mean that he or she is being abandoned by his/her admitting/primary physician.
- Triggered referrals have the benefit of helping providers more objectively identify patients who may benefit from consultation, facilitate palliative care as part of routine care for patients, and set the stage for outcomes-based research. For example, patients with advanced heart failure and comorbidities, such as renal failure, oxygen-dependent chronic obstructive pulmonary disease, dementia, and metastatic cancer, are triggered for automatic palliative care consultation. Once the patient is identified, the specialist or primary care physician is contacted to ensure that the patient is appropriate for a palliative care consultation.

Prognostication is Difficult: Can Cause Confusion as to when to Initiate Palliative Care

- **Four Principles of survival prediction**
 - It is a process
 - Evolves over the disease trajectory
 - Accuracy varies by definition, population and time
 - Exact time of death cannot be predicted accurately
- **Performance status**
 - Karnofsky- ECOG poor predictors, multiple symptoms, biological markers (e.g. albumin)
 - “would I be surprised if this Veteran died in the next 6 months?” Hui, 2015, Lynn et al, 2007



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- Prognostication is difficult (Hui, 2015):
 - It is a process.
 - It evolves, depending on the diagnosis, co-morbidities, age, etc.
 - It is not a science and its accuracy vary by definition, population, and time.
 - The exact time of death cannot be accurately predicted, irrespective of medical/nursing specialty.
- Survival predictors include:
 - Patient performance status (energy and activity levels) can be used to predict survival in cancer patients.
 - Instruments/tools (e.g., Karnofsky, ECOG) are poor measure for survival predictions in advanced disease.
 - Patient clinical signs and multiple symptoms (dyspnea, dysphagia, weight loss, xerostomia, anorexia, and cognitive impairment) are associated with limited survival time in cancer patients.
 - Biological markers (e.g., elevated platelet count, decrease in serum albumin, etc.) can also be indicators of limited survival.
 - Clinician predictions: While studies have indicated that clinicians tend to overestimate survival, a useful method is to ask yourself, “Would I be surprised if this patient were to die in the next six months?” This helps the clinician determine when further discussions are needed, revisiting goals of care, and for whom appropriate palliative and end-of-life services including advance care planning, comfort care, and increasing psychological, social and spiritual support might be beneficial (Lynn et al., 2007).

Slide 22

Exercise – Stop and Consider:

Which of the following Veterans could benefit from palliative care?

- A. 64 year old Gulf War Veteran with congestive heart failure, hypertension and diabetes
- B. 32 year old Marine with acute myelogenous leukemia
- C. 57 year old Navy Veteran with amyotrophic lateral sclerosis
- D. 79 year old Vietnam Veteran with Parkinson's disease

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Correct answer: All would benefit from palliative care.

- For Clinicians: Do you see patients with all these diseases?
 - If so, are they seeing anyone from the palliative care team?
 - If not, what system changes need to take place for this to happen?
 - What is your role in helping this change to occur?

***This Concludes Section II**

**Module 1: Introduction to Palliative Nursing
Faculty Outline**

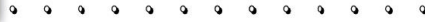
Slide 23



ELNEC- For Veterans

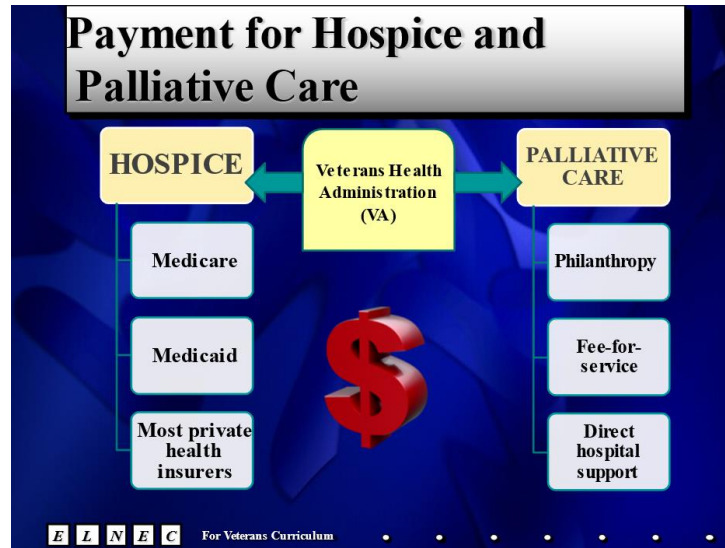
End-of-Life Nursing Education Consortium
Palliative Care For Veterans

**Module 1:
Introduction to
Palliative Nursing
Part III**



This section will discuss palliative hospice care for the Veteran population.

Slide 24



- **Hospice:** Under the Medicare Hospice Benefit (MHB), a patient signs off his/her Medicare Part A (hospital payment), once he or she chooses to receive hospice care rather than curative treatments and enrolls in the MHB with direct care provided by a Medicare-certified hospice agency. Similar hospice benefits are offered by Medicaid and most private health insurers.
- **Palliative Care:** Palliative care services in the United States are paid by philanthropy, fee-for-service, or from direct hospital support. Practitioners working in palliative care may bill Medicare, as well as other payers for their care, but reimbursement is low, since most services are nonprocedural. This has resulted in a recent growth in hospital-based palliative care services being reimbursed through hospital operating budgets. Hospitals will absorb these palliative care costs because in the long run, they save money by delivering this care to their sickest and most vulnerable patients. This prevents these patients from extended hospital and ICU stays and interventions that may be non-beneficial.
- Veterans who are enrolled in the Veterans Administration (VA) can use the VA palliative care and hospice services. The challenge for many is understanding how the VA system works and how to access VA benefits. VA Hospice Care: Home Palliative and Hospice Care (PHC) is comfort-oriented care for Veterans with life-limiting illness provided in the Veteran's home. VA-purchased routine and continuous hospice care covers hospice diagnosis related home visits, medications, supplies, biologicals, durable medical equipment and ancillary services (VHA, 2022) Hospice Care is part of the VHA Standard Medical Benefits Package, so all enrolled Veterans are eligible IF they meet the clinical need for the service. There are NO COPAYS for Hospice Care, whether it is provided by the VA or an organization with a VA contract.

Concurrent care hospice (concurrent care) is an important aspect of care at the VA as patients with incurable disease are able to receive disease-directed therapy (e.g., immunotherapy, chemotherapy,

radiation, IV furosemide), while paying for hospice at the same time. The VA made a conscious decision in 2009 to avoid having veterans make “the terrible choice”, between continuing disease-directed therapy and allowing strong interdisciplinary support from hospice at home (Broderick, 2020). Importantly, under the VA hospice program, veterans are able to receive concurrent medical and hospice care without the cessation of disease-modifying therapies—a unique feature that is not currently available in the Medicare Hospice Benefit (VHA, 2022)

Slide 25

The image shows a screenshot of a 'MILITARY HISTORY CHECKLIST' form. The form is divided into several sections: 'PATIENT DATA', 'VETERAN STATUS INFORMATION', 'MILITARY BACKGROUND', and 'VA BENEFITS INFORMATION'. Each section contains various questions and checkboxes for completion. At the bottom of the form, there is a footer that reads 'ELNEC For Veterans Curriculum'.

What is a Veteran?

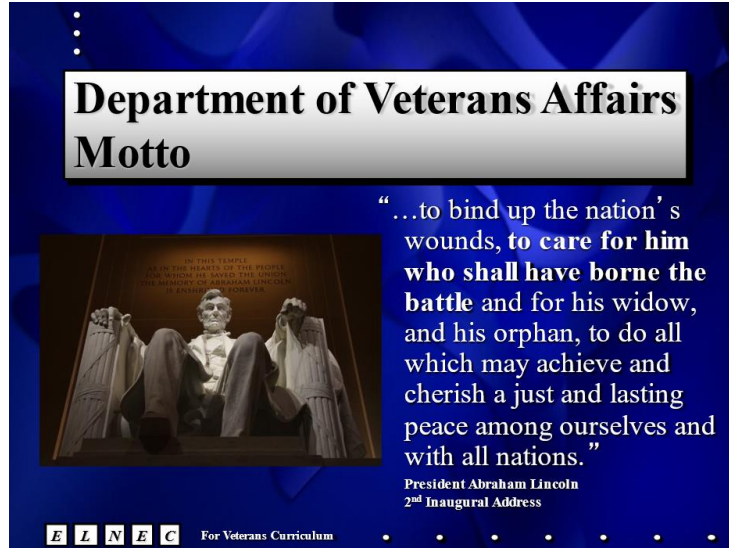
- This course is specifically designed with a focus on Veterans. A basic understanding of Veterans is essential to providing Veteran-centric care.
- A Veteran is a person who served in the active military, naval, or air service, and who was discharged or released therefrom under conditions other than dishonorable
 - The term “active duty” means— (A) full-time duty in the Armed Forces, other than active duty for training; (B) full-time duty (other than for training purposes) as a commissioned officer of the Regular or Reserve Corps of the Public Health Service (C) full-time duty as a commissioned officer of the National Oceanic and Atmospheric Administration (NOAA)
 - The term “Reserve” means a member of a reserve component of one of the Armed Forces. — (A) the Army Reserve; (B) the Navy Reserve; (C) the Marine Corps Reserve; (D) the Air Force Reserve; (E) the Coast Guard Reserve; (F) the Army National Guard of the United States; and (G) the Air National Guard of the United States.
- The term “Armed Forces” means the United States Army, Navy, Marine Corps, Air Force, and Coast Guard, including the reserve components thereof (veterans assistance brief 2019)
- Veterans may have experiences from their military service that present unique needs at the end of life. Because the unique needs, Veterans may require specific interventions. The first step to addressing these issues is to identify them as Veterans (WHV, 2022). The Military History Checklist is available to identify who is a Veteran, evaluate the impact of the experience and determine if there are benefits to which the Veteran and surviving dependents may be entitled.

The military history checklist can be downloaded at: https://www.wehonorveterans.org/wp-content/uploads/2020/02/Veterans_Military_History_Checklist.pdf

A guide to support the checklist can be downloaded at:

https://cdn.ymaws.com/www.hospicefed.org/resource/resmgr/hpcf_m_pdf_doc/military_history_checklist_g.pdf

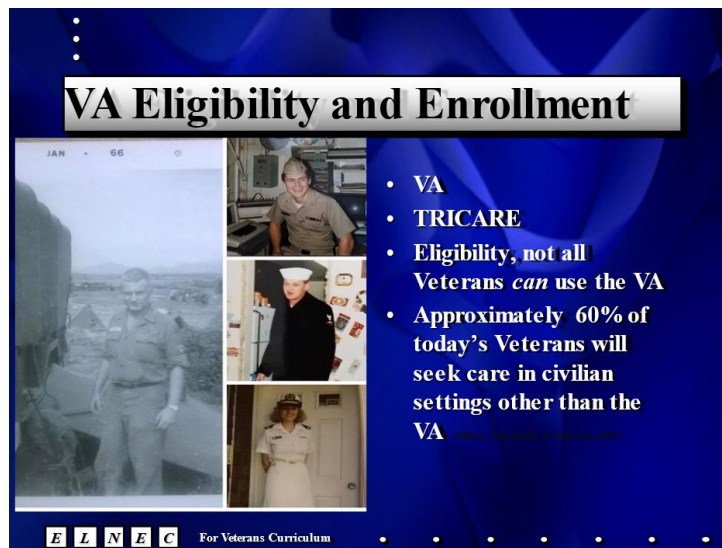
Additional resources for assessing Veterans can be found at: <https://www.haveyoueverserved.com/>



The slide features a dark blue background with a subtle American flag pattern. At the top, a white box with a black border contains the text "Department of Veterans Affairs" in a bold, serif font, with "Motto" centered below it in a larger, bold, serif font. In the center, there is a photograph of a bronze statue of Abraham Lincoln seated between two standing figures, with a plaque above the statue containing the motto. To the right of the photograph, the motto is written in white, serif font: "...to bind up the nation's wounds, to care for him who shall have borne the battle and for his widow, and his orphan, to do all which may achieve and cherish a just and lasting peace among ourselves and with all nations." Below the quote, it is attributed to "President Abraham Lincoln 2nd Inaugural Address". At the bottom left of the slide, the acronym "ELNEC" is displayed in white, with "For Veterans Curriculum" written below it. A series of small white dots is visible along the top and bottom edges of the slide.

- It has as its motto, on a pair of metal plaques found at the entrance to the Washington, DC headquarters, this quote: “...to care for him who shall have borne the battle and for his widow, and his orphan.” (President Abraham Lincoln, 1865). This motto serves as a reminder that the VA, a federal agency, is responsible for serving the needs of Veterans. This is accomplished by providing not only health care, but disability compensation and rehabilitation, education assistance, burial in a national cemetery, and many other benefits and services, including hospice and palliative care. The Veterans Health Administration (VHA) is the United States’ largest integrated health care delivery system, serving over 9 million enrollees at nearly 1300 health care facilities.
- When referring to Veteran healthcare, the correct terminology is to use the term Veteran Health Administration or “VHA,” but many Veterans simply use the term “VA” when referring to any type of Veteran benefits.
- Enrollment in the VA has increased, in part because of enrollment of Veterans from the wars in Afghanistan and Iraq, and economic factors. (Panangala & Sussman, 2019).
- The VA system consists of inpatient hospitals, long-term-care facilities, called Community Living Centers (CLCs), and Community Based Outpatient Clinics (CBOCs).

Slide 27



The slide features a dark blue background with a white title box at the top center containing the text "VA Eligibility and Enrollment". Below the title, there are three small images: a large photo of a soldier in a desert environment, a smaller photo of a man in a military uniform, and another smaller photo of a woman in a military uniform. To the right of these images is a bulleted list. At the bottom of the slide, there is a white box with the letters "E L N E C" and the text "For Veterans Curriculum".

VA Eligibility and Enrollment

- VA
- TRICARE
- Eligibility, not all Veterans *can* use the VA
- Approximately 60% of today's Veterans will seek care in civilian settings other than the VA

E L N E C For Veterans Curriculum

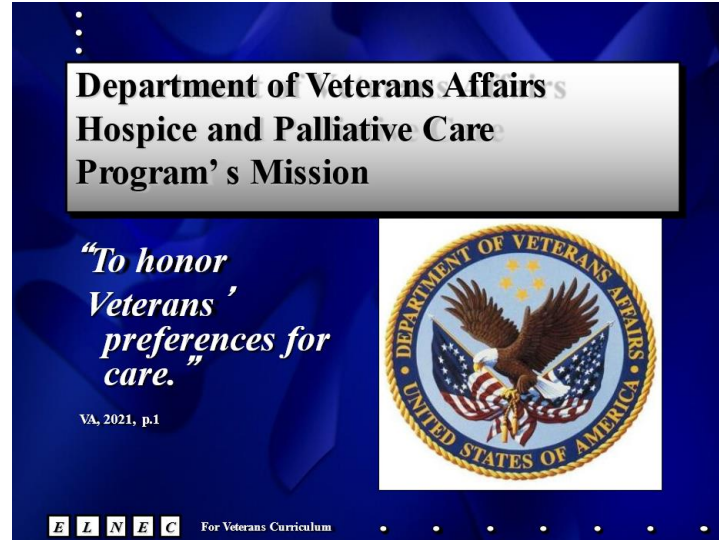
- It is a common misperception that all Veterans can use the VA system for healthcare (Erickson-Hurt, McGuirk & Long, 2017). Although many Veterans do use the VA, most do not. The reasons that Veterans do not use the VA vary and may include, but are not limited to, having another source of healthcare, Veterans' lack of awareness of healthcare benefits, and a belief that they are not eligible. Another possibility is Veterans may have applied for benefits in the past and were denied. (Erickson-Hurt, McGuirk & Long, 2017). Military retirees (those who have served at least 20 years), Active Duty and eligible family members are able to use the military health care system and insurance known as TRICARE.
- If Veterans are not enrolled in the VA, they cannot access any healthcare benefits. Veterans will need a copy of their "Certificate of Release or Discharge from Active Duty" most commonly known as the "DD 214" to begin the enrollment application process.
- Each Veteran's unique eligibility status can determine services and the VA evaluates every Veteran for eligibility for enrollment and assigns them a category based on a scale of 0% to 100% disability linked to military service. Approximately 60% of today's Veterans will seek care in civilian settings other than the VA (Elliott, Chargualaf & Patterson, 2021).

Note: Understanding benefits for Veterans can be complex. The *Veterans Benefits Administration* has numerous Benefit Brochures for Veterans with the following health related and other topics: Disability Compensation Brochure, VA and DoD Benefits Online, and the Summary of VA Benefits and more from http://www.benefits.va.gov/BENEFITS/Benefits_Summary_Materials.asp (retrieved May 19, 2022). For more information on TRICARE, visit <http://tricare.mil/Plans/Eligibility.aspx> (retrieved May 19, 2022).

Note: Many Veterans may not have previously used the VA. They may not know that they are now entitled to hospice care provided by or paid by the VA. Community hospices may not realize that they can assist to enroll a Veteran by communicating with the local VA. The process begins with the Veteran's *DD Form 214* which is taken to the VA eligibility office. Most Veterans will have their DD 214, but if they do not it may be found at the National Archives Veterans Service Records, <https://www.archives.gov/veterans/military-service-records/> (retrieved May 20, 2022).

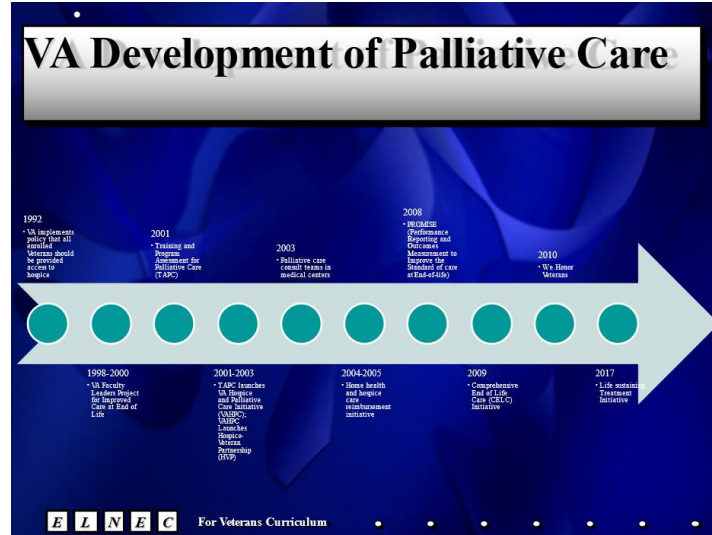
- No other healthcare provider spends more time at the bedside, planning, assessing, managing, and communicating with patients, their families and the interdisciplinary team than the nurse. As such, nurses have a unique opportunity to support Veterans and their families, whether they are working in a VA or non-VA facility.

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- VA is committed to provide hospice and palliative care to ALL Veterans that need these services. The mission of the VA Palliative Hospice Care (PHC) program is to honor Veterans' preferences for care (VA, 2021). A summary includes the following:
 - Hospice is a covered benefit for ALL enrolled Veterans.
 - VA medical facilities are required to identify Veterans who may be appropriate for PHC and determine their specific preferences for care.
 - PHC are covered services, on equal priority with other medical care authorized, to be appropriately provided in authorized inpatient, outpatient, or home care settings.
 - VA programs emphasize the comprehensive management of the physical, psychological, emotional, social, and spiritual needs of the Veteran.
 - Palliative Care Consult Teams have been required by policy since 2003 at every VA health care facility
 - Veterans with serious chronic illness often require both VHA and community-based services, VA has a responsibility to promote efficient transitioning of Veterans to and from these community-based services
 - Veterans receiving hospice care provided or purchased by VA (e.g. outpatient, contract nursing home or in a VA medical facility) are exempt from first-party medical copays.
 - Dually eligible Veterans (e.g., for both VA care and Medicare) choose the payer of their choice. Veterans who choose the Medicare hospice benefit or other non-VA payer retain their eligibility for full VA care and benefits (VA, 2021).

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VA has a substantial history of embracing palliative care.

- (1992) VA implemented a new policy indicating that all enrolled Veterans should be provided access to a hospice program, either within VA or through referral to a community hospice agency.
- (1998-2000) VA Faculty Leaders Project for Improved Care at the End of Life intended to educate faculty and expand palliative care information contained in the curriculum
- (2001) The Training and Program Assessment for Palliative Care (TAPC) Project to identify and describe hospice and palliative care programs within the VA and create resources to facilitate the development of hospice and palliative care programs was initiated.
- (2001-2003) TAPC launched the VA Hospice and Palliative Care Initiative (VAHPCI). This two-year project was funded in part by generous grants from the NHPCO, the Center for Advanced Illness Coordinated Care and Rallying Points, a Robert Wood Johnson funded project. It focused on improving Veterans' access to hospice and palliative care services within the VA and in the community and included efforts to improve end-of-life care education and facilitate the development of local VA/hospice partnerships.
- (2003) The VA mandated that all VA facilities have a Palliative Care Consultative Team (PCCT) in place. This directive made recommendations for the involvement of nursing, medicine, social work, chaplain, and psychological/mental health services.
- (2004-2005) Home Health and Hospice Care Reimbursement Initiative expanded availability and reimbursement of home health and hospice services by partnering with an expanded network of community programs and service providers, including services offered in home settings.
- (2008) The PROMISE (**P**erformance **R**eporting and **O**utcomes **M**easurement to **I**mprove the **S**tandard of care at **E**nd-of-life) was developed as part of a collaborative quality improvement effort. As part of this initiative surveys were conducted on all families of Veterans who died as inpatients in VA facilities.
- (2009) VA's Comprehensive End of Life Care (CELC) Initiative was a large-scale initiative to increase access to high-quality hospices and palliative care among Veterans. The program focused on ensuring that hospice and palliative care services are reliably accessible at all VA facilities and infrastructure development for long-term sustainability. It also established funding

for interprofessional palliative care team members (pharmacists, psychologists, etc.) at each medical center

- (2010) The We Honor Veterans campaign was initiated. The collaboration between the National Hospice and Palliative Care Organization (NHPCO) and the VA provides educational tools and resources. Partners enrolled in the program can earn levels from one to five based on their commitment to veteran centric care.

More information can be found at: <https://www.wehonorveterans.org/>

- (2017) VA initiated the Life Sustaining Treatment Decision Initiative, focused on educating clinicians on conducting goals-of-care discussions ensuring patients' goals, values, and preferences are elicited and documented in the electronic medical record using standardized tools across the continuum of care (Sullivan et al, 2022).

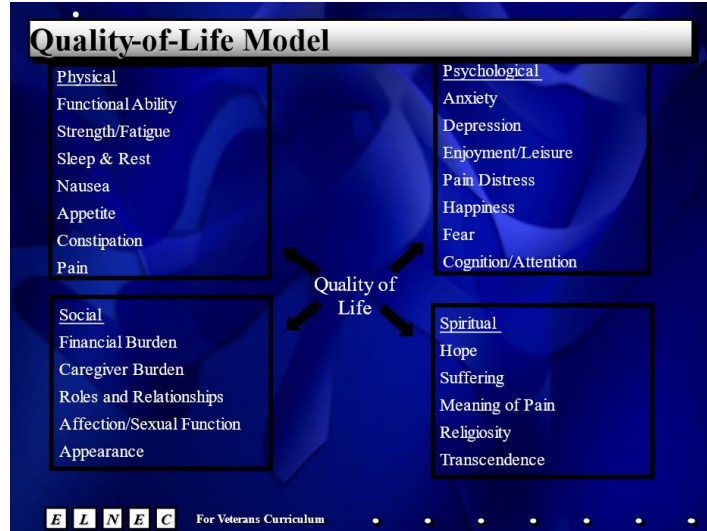
Note: Though each of the initiatives and projects listed are outstanding, there is still work to do to provide excellent palliative care to each Veteran and his/her family

Slide 30

The slide has a dark blue background with a pattern of overlapping translucent shapes. At the top, a white banner with a black border contains the text "Exercise – Stop and Consider:". Below this is a video player interface. The video player has a title "Video about Palliative Care" and a description: "Palliative care helps Veterans and their families manage illness with plans of care. Watch this video to listen to Veterans and doctors talk about how VA palliative care helps patients live their lives." The video player shows a still image of two people talking. Below the video player, the text "Download and watch video at:" is followed by the URL "www.va.gov/GERIATRICS/Guide/LongTermCare/Palliative_Care.asp#". At the bottom left of the slide, the logo "ELNEC" is displayed, with each letter in a separate box, followed by the text "For Veterans Curriculum".

- Watch the VA video on palliative care in the VA system and what it means to Veterans


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- The primary purpose that every healthcare facility should provide palliative care is because it is not only the right thing to do, but also has been deemed as a basic human right for all (Open Society Foundation, 2016).
- Providing palliative care in an effort to improve quality of life at the end of life means addressing multiple dimensions of care
- Address each of the four dimensions of care listed above, giving examples from your own practice. Talk about a recent patient that many of the participants may have taken care of. Point out that people can experience major problems within each of these dimensions. For example: *A 42-year-old woman Veteran was diagnosed 3 months ago with pancreatic cancer.*
 - She is unable to take care of her home, cook, and care for her two teenagers due to chronic fatigue, pain, and nausea (physical).
 - She is anxious and fearful about her condition and distraught that she cannot obtain pain relief (psychological).
 - She is sad that she is unable to participate in her children's activities and continue with her community responsibilities. She has alopecia and has lost 20 pounds since becoming ill. Her clothes no longer fit, and she does not have the energy to shop for new ones. "My husband says he is frustrated with me" (social).
 - She feels hopeless, because she knows she only has a few months to live. She believes that her suffering is due to God punishing her for past sins. She wants to make the last days/weeks/months of her life as positive as possible, but she cannot find peace among all the pain and suffering (spiritual).

Slide 32

Role of the Nurse: Improving Palliative Care for All Patients



- Some things cannot be “fixed”
- Use of therapeutic presence
- Maintaining a realistic perspective

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- Nurses play an important role in improving palliative care. Remember that some things cannot be “fixed” (Martinez & Berry, 2015):
 - We cannot change the inevitability of death.
 - We cannot erase the anguish felt when someone we love dies.
 - We all must face the fact that we, too, will die.
 - No matter how hard we try, the perfect words or gestures to relieve Veteran and family distress rarely, if ever, exist—that is why presence is so important.
- The use of “presence” as a way of expressing compassionate caring:
 - Every day, nurses are invited to be present at the last moments of a Veteran’s life; to care for that Veteran and their family at the time of death; to care for the bereaving family.
 - Nurses can use therapeutic presence as a means of communicating care for the Veteran struggling with emotional/spiritual elements of suffering associated with multiple losses.
 - “Presence may in fact be our greatest gift to these patients and their families” (Borneman & Brown-Saltzman, 2019).
- Maintaining a realistic perspective
 - There is no right way to die, no cookbook approach.
 - Crises and difficulties arise along with unexpected and profound joys.
 - A flexible approach is essential to meet the changing needs of the Veteran and family.
 - Recognition that quality of life (QOL) is determined by the unique needs of the Veteran and family assists the nurse in remaining focused on goals of care.
- Nurses who work in various VA institutions have a unique opportunity to plan, manage, and assess Veterans’ healthcare, including their end-of-life care.
- Nurses who work in the community are also caring for Veterans, some of whom are enrolled in VA and most of whom are not part of the VA healthcare system.
- Nurses in both VA and non-VA facilities need to be aware of the unique needs of Veterans.

**Extending Palliative Care
Across Settings**

- Nurses as the constant
- Expanding the concept of healing
- Becoming educated
- Joint Commission Advanced Certification in Palliative Care

E L N E C For Veterans Curriculum


The slide features a dark blue background with a white title box at the top. Below the title is a small photograph of a nurse in a white uniform attending to a patient in a hospital bed. To the right of the photo is a list of four bullet points. At the bottom left, the acronym 'E L N E C' is displayed in white boxes, followed by the text 'For Veterans Curriculum'. A series of small white dots is visible along the bottom edge of the slide.

- Nurses are the healthcare providers who spend more time with patients and their families than any other member of the healthcare team. Nurses can impact quality end-of-life closure by identifying persons with any life-threatening illness or condition. This can take place in a variety of settings, such as:
 - Acute care
 - Emergency departments
 - Rehabilitation centers
 - Long-term care/skilled nursing facilities
 - Infusion and dialysis clinics
 - Home
- Early identification means that palliative care can be started sooner, allowing Veterans and families to set and achieve goals.
- Expanding the concept of healing:
 - Ensuring quality end-of-life closure: At the end of life, nursing care shifts from a focus of wellness/recovery to an understanding of “healing” (Coyle, 2015).
- The role of the nurse in education:
 - Competencies - Through education, the nurse masters competencies in excellent palliative care (AACN, 2016 & 2019; HPNA, 2021; Malloy& Davis, 2019).

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Final Thoughts

- Quality palliative care addresses quality of life concerns
- Increasing nursing knowledge is essential
- “Being with”
- Importance of Interprofessional care
- Resources and support are available (We Honor Veterans)



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- Quality palliative care encompasses physical, psychological, social, and spiritual aspects and includes the family as the unit of care. These are not only defining features of the nursing role, but also support the philosophy and principles of palliative care as well as reflect the dimensions within the Quality-of-Life model.
- Some final thoughts:
 - Since nurses cannot practice what they do not know, increased knowledge is essential to improve patient care via undergraduate/graduate nursing education and professional development.
 - Palliative nursing is not only “doing for,” but is also largely “being with” patients and families.
 - Palliative care is best provided by nurses functioning as part of an interprofessional team.
- Some final questions: What would you consider a quality palliative and hospice care? (let participants share their thoughts—below are some answers you may receive)
 - The Veteran was free from pain and other distressing symptoms.
 - Adequate time was spent addressing important Veteran/family ethical concerns to achieve quality closure.
 - The Veteran and family’s culture, traditions, and rituals were respected.
 - All possible treatments aimed at curing the illness were exhausted.
 - The Veteran died at home with dignity and surrounded by family and friends.
 - The Veteran was able to live long enough to finish unfinished business.
 - The Veteran lived long enough to witness a particular event (e.g., a birth, graduation).
 - The Veteran had their unique service respected and acknowledged
- Generally speaking, there are unique challenges in providing excellent end-of-life care for Veterans. The VA provides a full range of benefits to all enrolled Veterans. The system is complex and healthcare providers are not expected to achieve the same expertise as those whose job it is to enroll Veterans (NHPCO, 2022).

- Hospices and other healthcare providers are encouraged to have a general understanding about the basic benefits. Most importantly, it is very important to know where to turn for expert advice and guidance (NHPCO, 2022)

Consider...



What steps do you need to take to improve palliative care at your institution so that you and other members of the team are prepared to “care for him who shall have borne the battle...?”