

ELNEC- For Veterans

END-OF-LIFE NURSING EDUCATION CONSORTIUM

Palliative Care For Veterans

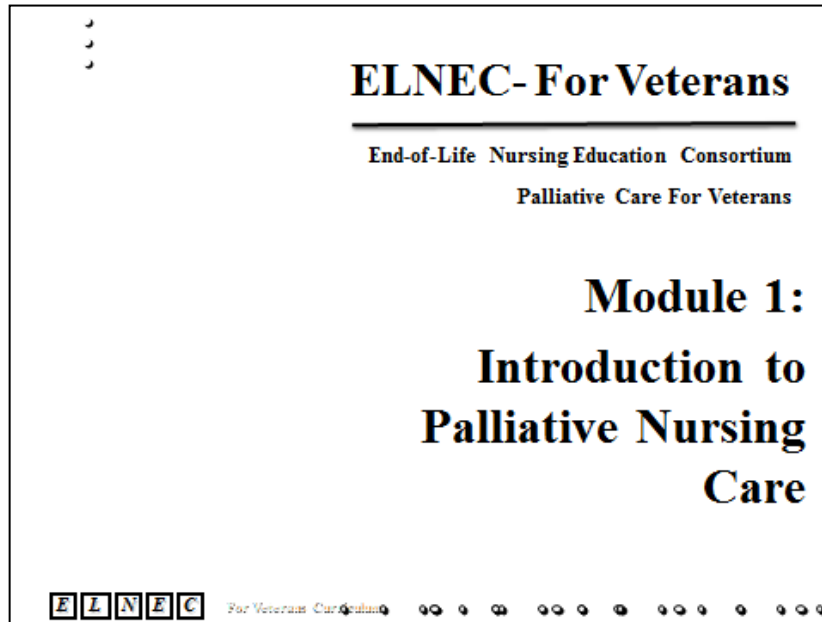
FACULTY GUIDE

Module 1 Introduction to Palliative Nursing Care

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 (Pam Malloy, MN, RN, FPCN, FAAN, Co-Investigator). Curriculum development and 6 national ELNEC-For Veterans train-the-trainer courses were generously funded by the US Department of Veterans Affairs (2009-2012).

Module 1: Introduction to Palliative Nursing Care Faculty Outline

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- This module creates the foundation for the *ELNEC-Palliative Care for Veterans* curriculum. It is an overview of palliative care for the Department of Veterans Affairs (VA).
- Defining the role of the nurse as a member of an interdisciplinary team in providing quality care to Veterans in a variety of clinical settings is essential. The National Consensus Project guidelines (NCP, 2013), National Quality Forum (NQF, 2006) report, and the Institute of Medicine (IOM) *Dying in America* (2014) and *Delivering High-Quality Cancer Care* (2013) reports provide insight and guidance for palliative nursing care which have important implications for working with Veterans and their families. For those working in healthcare, the commitment and responsibility to provide professional care is vital. Health system managers, payers, regulators and policy makers, likewise, have a responsibility to ensure that end-of-life care is compassionate, affordable, sustainable, and of the best quality possible.
 - The 2014 Institute of Medicine (IOM) report, entitled, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, reports that decisions made near the end of life are difficult and profound for patients and their families. Retrieved December 11, 2015 from: <http://www.nationalacademies.org/hmd/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>
 - The National Quality Forum, a leader in promoting quality healthcare, adopted the original NCP Guidelines and produced a document entitled: *A National Framework and Preferred Practices for Palliative and Hospice Care Quality*. Retrieved December 11, 2015 from <http://www.qualityforum.org/Projects/n->

[r/Palliative_and_Hospice_Care_Framework/Palliative_and_Hospice_Care_Framework_and_Practices.aspx](http://www.jointcommission.org/certification/palliative_care.aspx)

- Launched in September 2011, The Joint Commission's *Advanced Certification Program for Palliative Care* recognizes hospital inpatient programs that demonstrate exceptional patient- and family-centered care and optimize the quality of life for patients (both adult and pediatric) with serious illness. Last accessed December 11, 2015 from:
http://www.jointcommission.org/certification/palliative_care.aspx

This module, and those that follow, make the following key assumptions:

- The VA has made a commitment to improve and advance palliative care for all enrolled Veterans and their families.
- Veterans may experience unique end-of-life issues.
- There are opportunities for enhanced collaboration among interdisciplinary systems of care for Veterans and families at the end of life.
- Nursing has had a long history of caring for patients and families experiencing end-of-life/palliative care issues.
- Caring for the dying means not only “doing for” but also “being with.” Palliative nursing care combines caring, communication, knowledge & skill.

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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.
2. Identify the need for collaboration with interdisciplinary team members while implementing the nursing role in palliative care.
3. Recognize the unique demographics, health care economics, and service delivery for Veterans that necessitates improved professional preparation in palliative care.
4. Describe the philosophy and principles of palliative care and hospice palliative care that can be integrated across settings to affect quality care at the end of life for all patients.
5. Discuss aspects of assessing physiological, psychological, spiritual, and social domains of Veterans and families facing a life-threatening illness or event.
6. Explain various resources available to Veterans and their families.

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3. Recognize the unique demographics, health care economics, and service delivery for Veterans that necessitates improved professional preparation in palliative care.
4. Describe the philosophy and principles of hospice and palliative care that can be integrated across settings. Discuss aspects of assessing physiological, psychological, spiritual, and social domains of seriously ill Veterans and their families.
5. Explain various resources available to Veterans and their families.

Slide 3

Department of Veterans Affairs
Motto



“...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.”

President Abraham Lincoln
2nd Inaugural Address

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- The Department of Veterans Affairs (VA) is the largest integrated healthcare system in the United States. 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 also disability compensation and rehabilitation, education assistance, burial in a national cemetery, and many other benefits and services, including palliative care.
- 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 work with Veterans and their families, whether they are working in a VA or non-VA facility.

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**Department of Veterans Affairs
Hospice and Palliative Care
Program's Mission**

"To honor Veterans' preferences for care at end of life."

VHA, 2008b, p.1



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- The mission of the VA Hospice Palliative Care Program is to “honor Veterans’ preferences for care at end of life” (VHA, October 23, 2008b, p. 1). A summary includes the following:
 - Hospice is a covered benefit for ALL enrolled Veterans.
 - Palliative Care Consult Teams (PCCT) are present at every VA health care facility.
 - VA purchases Medicare certified hospice services from local agencies.
 - Care is provided in in-patient settings, clinics, in the home, and community.
- Nurses are the constant force in caring Veterans in a variety of settings.
- Nurses are privileged to have conversations with Veterans about their goals of care. Nurses clarify desires and expectations and provide instruction regarding palliative care. Nurses are valuable members of the healthcare team and they advocate for the patient.
- Nurses can honor Veterans by preventing suffering and by continuing impeccable assessment and management of symptoms. By doing this well, nurses have the opportunity to thank Veterans for their dedicated service to this country.

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 enroll a Veteran by sending the Veteran’s *DD Form 214* (Separation Documents) to the VA eligibility office. For more information go to the National Archives Veterans Service Records, retrieved April 6, 2016 from <https://www.archives.gov/veterans/military-service-records/>


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Demographics of Veterans

Projected

- Total U.S. Veterans population: **21,681,000**
- Women Veterans population: **2,035,213**
- Surviving WWII Veterans: **697,806**
- Enrolled Veterans are older adults; multiple comorbidities
- Homeless Veterans

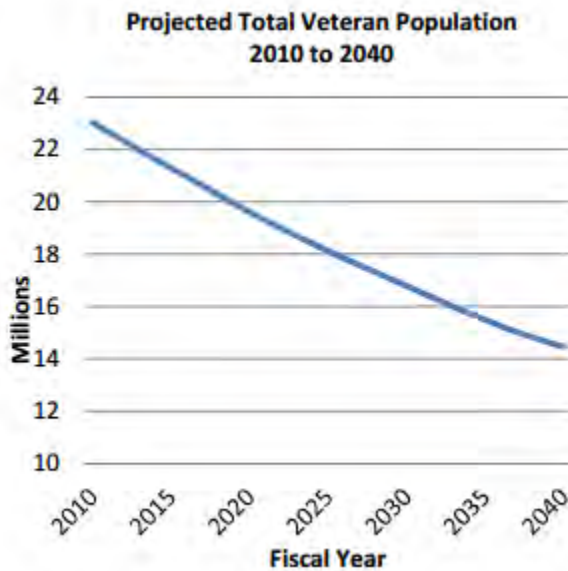
VA, 2015a; National Alliance to End Homelessness, 2015



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- The total U.S. Veteran population is estimated at 21,681,000 (VA, 2015a).
- The total women Veteran population is estimated to be 2,035,213 (VA, 2015a).
- Enrolled Veterans tend to be older in age with multiple comorbidities.
- The National Alliance to End Homelessness report in April 2015 identified 49,933 homeless veterans during point-in-time counts, which represents 8.6 percent of the total homeless population. This represents a substantial decrease (67.4 percent) in the number of homeless veterans counted only five years previously in 2009. Though veterans continue to remain overrepresented in the homeless population in the U.S., these recent decreases demonstrate the marked progress that has been made in ending veteran homelessness. (retrieved April 7, 2016 from <http://www.endhomelessness.org/library/entry/fact-sheet-veteran-homelessness>). Special attention must be paid to those Veterans who are without shelter and do not seek healthcare. If they are not in “the system” of receiving healthcare, then they will not be able to access hospice/palliative care services.
- Note: For more detail on homelessness, review the Culture Module and or <http://www.va.gov/homeless/>
- Additional information and graphs are below.

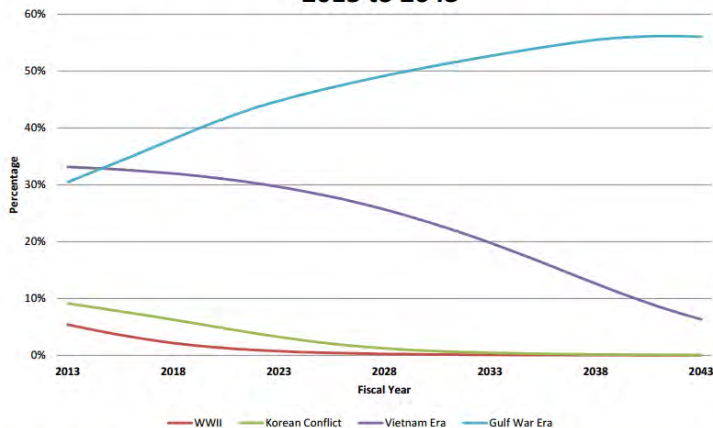
This is also interesting when examining projections of Veterans’



http://www.va.gov/vetdata/docs/QuickFacts/Population_quickfacts.pdf
 Not included specifically in references since numbers were not included.

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 April 18, 2016. For more information on TRICARE, a health program for uniformed service members and their families, National Guard/Reserve members and their families, survivors, former spouses, Medal of Honor recipients and their families and others, visit <http://tricare.mil/Plans/Eligibility.aspx> (retrieved April 18, 2016).

Projected Percent of Veteran Population by Period of Service 2013 to 2043



Source: Office of the Actuary, Veteran Population Projections Model (VetPop2014), Table 2L



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Characteristics of the Veterans Health Administration (VHA)

- **The largest integrated healthcare system in the U.S.**
- **Many layers and program services**
- **Nurses care for Veterans in VA and non-VA community settings**

Casarett et al., 2008a & 2008b; NHPCO, 2011


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- Generally speaking, there are unique challenges in providing excellent end-of-life care for Veterans.
- Some facts that provide nurses with distinctive opportunities to provide care to Veterans are:
 - The VHA system is large. Over 5 million Veterans/year are seen in VA facilities. Enrolled Veterans may have more co-morbidities (not just physical, but also psychological), so they may have many different specialty physicians caring for them (Casarett et al., 2008a).
 - The many layers of VA benefit system can cause much confusion and misunderstanding among Veterans and their families (Casarett et al., 2008b).
- Nurses who work in various VA institutions have a unique opportunity to plan, manage, and assess Veterans' healthcare, including their end-of-life care.
- The majority of Veterans do not receive their healthcare from the VA. Many receive care by community healthcare providers who may not understand that there may be unique end-of-life issues specific to some Veterans (i.e. military/combat history, etc.) (NHPCO, 2011).
- 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.

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Facts about Veteran Deaths and Palliative Care in the VA




- Less than 4% of Veterans die in VA facilities (NHPCO, n.d.a)
- 1 out of 4 dying Americans is a Veteran (NHPCO, n.d.b)
- WWII Veterans: 430 dying each day (National WWII Museum, 2016)
- 19,000 inpatient deaths per year in VA hospitals and Community Living Centers

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- Less than 4% of Veterans die in VA facilities (NHPCO, n.d.a)
- 1 out of 4 dying Americans is a Veteran. See *We Honor Veterans* program at the National Hospice and Palliative Care Organization (NHPCO, n.d.b) or visit <http://www.wehonorveterans.org>
- There are 430 WWII Veterans dying each day (National WWII Museum, 2016).
- In the VA inpatient setting (hospital and CLC), there are approximately 19,000 inpatient deaths per year (S. Shreve, personal communication, March 29, 2016). VA provides palliative care consultation services at each of its medical centers and inpatient hospice care in many of its nursing homes (known as *Community Living Centers (CLC)* the US (VHA, 2008a).
- When it is the Veteran's preference, VA contracts with community based hospice programs to enhance VA's ability to provide hospice care at home.

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Facts about Veteran Deaths and Palliative Care in the VA (continued)



- 40,000 palliative care consults per year
- 8,000 receive home hospice via contracts (VHA, 2008)
- Palliative Care Consult Teams at each VAMC (n=139)
- Hospice-Veteran Partnerships (NHPCO, n.d.a)

www.wehonorveterans.org

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- Depending on setting, approximately 40,000 Veterans receive an inpatient or outpatient palliative care consult per year, and 8,000 Veterans receive home hospice paid for by VA (there may be a small overlap of the two groups) (S. Shreve, personal communication, March 29, 2016).
- Every VHA Medical Center (n=139) has a palliative care team (S. Shreve, personal communication, March 29, 2016).
- To date, VA facilities and community hospice programs have established state-wide and regional partnerships in almost every state to promote/provide hospice services outside of VA. VA facilities and community hospice providers may face multiple administrative, logistical and communication challenges in working together to care for Veterans. *Hospice-Veteran Partnerships (HVPs)* have been established nationwide to address difficulties and increase access. Go to www.wehonorveterans.org/va-veteran-organizations/hospice-veteran-partnerships (retrieved April 12, 2016) for more information about Hospice-Veteran Partnerships.

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Exercise – Stop and Consider:

Video about Palliative Care



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.


Download and watch video at:
www.va.gov/GERIATRICAL/Guide/LongTermCare/Palliative_Care.asp#

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Exercise - Stop and Consider:

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Great video at: http://www.va.gov/GERIATRICAL/Guide/LongTermCare/Palliative_Care.asp#

Note:

- For more information about Veterans and ending homelessness go to *Ending Veteran Homelessness* website at www.va.gov/homeless/, retrieved April 12, 2016.
- For more information about health issues of concern for Veterans see *Military Health History Pocketcard for Clinicians* (VA, 2015b), retrieved April 12, 2016 from www.va.gov/oaa/pocketcard/issues.asp
- For further information on hospice and palliative care for rural and homeless Veterans: *Reaching out: quality hospice and palliative care for rural and homeless veterans* (NHPCO, 2011), retrieved April 12, 2016 from <http://www.wehonorveterans.org/sites/default/files/public/ExecutiveSummaryOptionYearTwo.pdf>

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Differences in Cause of Chronic Illness and Death by Wars

- World War II
- Korean War
- Vietnam
- Gulf War
- Operation Enduring Freedom/Operation Iraqi Freedom-now Operation New Dawn

VA Veterans Health Concerns
<http://www.va.gov/oaa/pocketcard/unique.asp>

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Many Veterans have conditions, diseases and illnesses associated with the particular war they fought in. Visit VA Veterans Health Concerns at <http://www.va.gov/oaa/pocketcard/unique.asp> .

- World War II (1939-1945): WW II Veterans today are all over the age of 80 years. These Veterans are subject to all diseases associated with aging (See *VA Military Health History Card* retrieved April 6, 2016 from Cardiovascular diseases, cancer, dementia (Alzheimer’s disease), PTSD (though called “Shell Shock” or “Battle Fatigue”)
- These Veterans benefited greatly from the invention of antibiotics (sulfa and penicillin) and blood transfusions, aeromedical evacuation, aggressive burn management/care, synthetic antimalarials and DDT. Preventive care was key too—immunizations (i.e., yellow fever, cholera, influenza, typhus, typhoid and tetanus).
- Korean War (1950-1953): These Veterans are subject to all diseases associated with aging (see above)
 - Cold injuries, such as frostbite and immersion (trench) foot were common. This could lead to peripheral neuropathy, skin cancer in frostbite scars (heels of feet and earlobes), arthritis in involved areas, chronic tinea pedis, nocturnal pain, cold sensation, PTSD.
- Vietnam (1964-1975): These Veterans are subject to all diseases associated with aging (see above)
 - Unique health problems are related to exposure to Agent Orange (pesticide/herbicide spraying). Examples of possible health risks/deaths include:
 - ◆ Malignant diseases
 - ◆ Lung cancer
 - ◆ Prostate cancer
 - ◆ Hodgkin’s and Non-Hodgkin’s lymphoma

- ◆ Sarcoma
- ◆ Multiple myeloma
- ◆ Chronic lymphocytic leukemia
- ◆ Hairy cell leukemia
- Non-malignant Diseases
 - ◆ Birth Defects: spina bifida
 - ◆ Type 2 diabetes
 - ◆ Peripheral neuropathy
 - ◆ Ischemic heart disease
 - ◆ Parkinson's disease
 - ◆ PTSD

- Gulf War (1990-1991) (called Desert Storm or Persian Gulf War). These Veterans are subject to all diseases associated with aging (see above) and other Gulf War illnesses, including PTSD Exposure to smoke and/or chemical/biological agents causing possible: fatigue, memory loss, confusion, inability to concentrate, mood swings, somnolence, gastrointestinal distress, muscle and joint pain, skin or mucous-membrane complaints.
- Exacerbation of asthma associated with oil-well fires.


- Operation Enduring Freedom/Operation Iraqi Freedom (2002-present) now called – Operation New Dawn (OND). These Veterans are subject to all diseases associated with aging (see above), including PTSD (Unique health risks include: Cold injuries, high altitude sickness, penetrating wounds, blunt trauma, chronic pain, burn/blast injuries, traumatic brain or spinal cord injury, traumatic amputation, multi-drug resistant acinetobacter, leishmaniasis (sandfly-transmitted infection of the skin), and mental health issues.

- In addition, amyotrophic lateral sclerosis (ALS) is a presumptive compensable illness for all Veterans with 90 days or more of continuously active service in the military.

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Various Experiences Can Affect a Veteran's Dying

- What branch of service?
- Enlisted? Drafted? Rank?
- Age?
- Combat and/or POW experience?
- PTSD (assess for social isolation, alcohol abuse, anxieties)?
- Stoicism



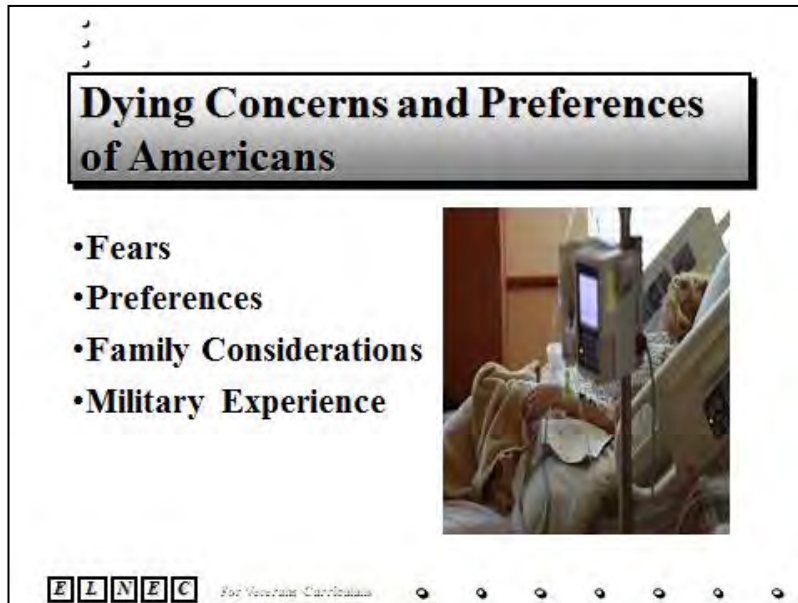
NHPCO, n.d.b & n.d.c.

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- Veterans may have a variety of influencing factors that can affect their dying process. It is important that nurses assess each of the following demographics and military history (NHPCO, n.d.b & n.d.c):
 - What branch of service that the Veteran served?
 - Conditions that the Veteran entered service (i.e. enlisted, drafted)
 - Rank of the Veteran during service
 - Age at the time of enlistment and upon discharge
 - Most Veterans were inducted between the ages of 18-25 years. Very important years as they are forming their young adult identity.
 - What gets indoctrinated during this time can have a life-lasting effect.
 - Length of service
 - The war or time period in which the Veteran served
 - Combat, Prisoner of War (POW) or other dangerous duty assignments


Note: Many Veterans may be stoic and this can interfere with communication of needs and wishes. It is also important to assess for Post-Traumatic Stress Disorder (PTSD), anxiety, alcohol use and more (see Module 3, Symptoms and Module 5, Cultural Considerations, for specific information). Accepting palliative care may be seen as giving up, surrendering, or being defeated. To learn more about the unique needs of Veterans at end of life, see the *Military History Checklist* at <http://www.wehonorveterans.org/get-practical-resources/resources-topic/intakeadmission> Retrieved January 26, 2016) (NHPCO, n.d.c)

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Dying Concerns and Preferences of Americans

- Fears
- Preferences
- Family Considerations
- Military Experience



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- Americans have many fears and concerns about the death and dying. These examples could include:
 - Fears:
 - They fear being in pain, as they may have witnessed the painful death of others.
 - Patients fear that they will be a physical and financial burden to their families. Many families may assume extreme debt in order to cover costs of care for terminally ill family members (Coyne, Smith & Lyckholm, 2015).
 - Many have come to fear the prospect of prolonged suffering and death characterized by over-treatment and the use of life-sustaining technology and invasive, debilitating treatments.
 - Patients and families worry that when "nothing more can be done," their health care providers will abandon them.
 - They fear that unrelieved symptoms may cause them to be more dependent on others.
 - Families may be uncertain about how to provide physical care and adjust to role changes (Steele & Davies, 2015)
 - Preferences:
 - Most adults prefer to be cared for at home if terminally ill.
 - The majority would be interested in a comprehensive program of end-of-life care, such as hospice.
 - Family considerations:
 - Older adult patients are often primarily cared for by their aged spouses who may have numerous chronic illnesses themselves.
 - 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).

- Military experience: Combat Veterans' last experience with death may have been filled with fear, horror and helplessness on the battlefield. These experiences can influence perceptions of a "peaceful" death, complicating their end-of-life experience (Grassman, 2009).

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Barriers to Quality Care at End of Life

- Failure to acknowledge limits of medicine
- Lack of training
- Hospice/palliative care misunderstood
- Rules and regulations
- Death-denying society
- U.S. Grade of “B” in palliative care

CAPC, 2015, Coyle, 2015

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- It is important to be aware of the barriers to quality care at the end of life.
- Most often cited barriers include (Coyle 2015):
 - Failure to acknowledge limits of medicine.
 - Lack of training for healthcare providers.
 - Hospice/palliative care services are poorly misunderstood.
 - Many rules and regulations.
 - Denial of death that is prevalent in our society
- As a nation, we still score a “B” in terms of overall access to palliative care (CAPC, 2015). More can be done to enhance palliative care across the United States.

Exercise - Stop and Consider:

- Which of these barriers are most common in your institution?
- Ask participants to offer suggestions for breaking down barriers and to share from their own examples/experiences.

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Hospice and Palliative Care

Palliative Care:	Hospice:
<ul style="list-style-type: none">• Ideally begins at the time of diagnosis• Can be used to complement medical treatments• Occurs across all settings	<ul style="list-style-type: none">• Most intense form of palliative care• Prognosis: < 6 months to live• Patient agrees to enroll in hospice and chooses not to receive non-beneficial care

NCP, 2013

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- Hospice and Palliative Care (HPC) collectively represents a continuum of comfort-oriented and supportive services provided in the home, community, outpatient, or inpatient settings for persons with advanced life limiting disease (VHA, 2008a).
- With an understanding of the unique aspects of caring for Veterans experiencing end-of-life issues, let’s talk about hospice and palliative care and how these services can make a difference in a Veteran’s life:
 - What is hospice?
 - What is palliative care?
 - What is the nurse’s role in hospice and palliative care?
- Hospice
History of hospice: In the late 1960’s, 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 way-stations 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 those near the end of life’s journey need support in order to complete their passage well. In 1982, Congress created the Medicare Hospice Benefit (MHB).
- Hospice provides comprehensive medical and supportive services across a variety of settings and is based on the idea that dying is a part of the normal life cycle. Hospice care can be provided in the home, residential facilities, hospitals, and nursing facilities. Hospice supports the Veteran and family during the dying process and through bereavement with grief support for the surviving family.
- VHA Hospice Care: VHA Hospice Care is offered to be provided or purchased for a Veteran meeting all of the following criteria:
 - Is diagnosed with a life-limiting illness.

- Has treatment goals focused on comfort rather than cure.
 - Has a life expectancy, deemed by a VA physician, of 6 months or less if the disease runs its normal course.
 - The Veteran agrees to and accepts hospice care (VHA, 2005 & 2008a).
- Because hospice takes care of the terminally ill, it quickly becomes associated with death. Our culture does not deal well with death. Coming under the care of a hospice program has been seen as a “death sentence,” leading many patients/families to resist admission to hospice. For this reason some of those involved in end-of-life care began advocating for the use of another concept--palliative care.
- Palliative care
 - Palliative care is defined as, "an approach that improves the quality of life of patients and their families, facing the problems associated with life-threatening illness, through the prevention and relief from suffering, by means of early identification, impeccable assessment, treatment of pain and other problems physical, psychosocial, and spiritual" (WHO, 2009). Palliative care is “both a philosophy of care and an organized highly structural system for delivering care” (NCP, 2013).
 - In addition, the goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies (NCP, 2013).
 - History of palliative care: Palliative care today is no longer limited to hospice care; however palliative care began in the hospice movement. The first United States hospital-based palliative care programs began in the late 1980s at only a handful of institutions such as the Cleveland Clinic and Medical College of Wisconsin.
 - Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patients and family members, helping with decision-making, and providing opportunities for personal growth (VHA, 2008b).
 - Can be rendered along with life-prolonging treatment OR as the main focus of care. Medical care is provided by an interdisciplinary team. Identifies physical, psychological, spiritual, and practical burdens of illness. Is integral to all health care delivery system settings (e.g. ED, nursing home, home care, assisted living facilities, outpatient and non-traditional settings).

How can the nurse explain palliative and hospice care to patients and families in a clear, simple and reassuring way?

“Palliative care is a special kind of care that helps you and your family with the stress of serious illness. We come in alongside your other doctors and help with pain or other uncomfortable symptoms caused by your illness or your treatments.”

“Hospice is a special kind of care that helps you stay comfortable at home. It includes offering emotional and spiritual support for you and your family.”

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Both Hospice and Palliative Care

- **Interdisciplinary care**
- **Pain and symptom management**
- **Physical, psychological, social and spiritual care**
- **Role of the nurse: empathy, unconditional positive regard, genuineness, attention to detail (Berry & Griffie, 2015)**



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- The philosophy and principles of hospice and palliative care include the following:
 - The patient and the family are the unit of care
 - The use of interdisciplinary care and team is an integral component of palliative care
 - Provides pain and symptom management
 - Quality of life: addressing and providing physical, emotional, social and spiritual care.
 - Berry and Griffie (2015) identify 4 characteristics of the nurse in achieving quality of life in palliative care and at the end of life: empathy, unconditional positive regard, genuineness and attention to detail.

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Hospice Care in America 2014

- 6,100 hospice programs
- 1.6 to 1.7m patients received hospice care
- Ethnicity: 92.9% Non-Hispanic/Latino origin
- Location of hospice patients at death: 58.9% in patient's place of residence, 31.8% hospice inpatient, 9.3% acute care
- Age: 83.9% of patients age 65 and older
- Days on hospice care: median 17.4 days, mean 71.3
- Diagnosis: 36.6% cancer, 63.4%, non cancer

NHPCO, 2015

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- End of life care has changed significantly over the past 40 years, as the hospice movement began in the US in the 1970's (NHPCO, 2014a & 2015).
 - 6,100 hospice programs have been developed in the US.
 - 1.6 to 1.7 million patients accessed hospice care in 2014
 - Ethnicity: 92.9% Non-Hispanic/Latino origin and 76% White/Caucasian which means penetration of palliative/hospice care into minority populations is necessary.
 - Location of hospice patients at death: 58.9% in patient's place of residence, 31.8% hospice inpatient, 9.3% acute care
 - Most patients are older adults (83.9% for patients age 65 and older)
 - The median (50th percentile) length of hospice service in 2014 was 17.4 days, meaning that about half of the patients served received care fewer than 17 days and half received care more than 17 days. The average length of service was 71.3 days.
 - When the hospice movement began in the US in the 1970's, most patients receiving hospice care had cancer. Today, the majority of hospice patients have chronic illness (63.4%) and only 36.6 % of hospice patients have cancer.
- The interdisciplinary team is vital in delivering quality care to patients at end of life regardless of where they live.

The figure below comes from
http://www.nhpc.org/sites/default/files/public/Statistics_Research/2015_Facts_Figures.pdf
Facts and Figures 2015, page 3.



Figure 1. Interdisciplinary team

Exercise- Stop and Consider:

Though much progress has been made in the past 40 years to improve care of the seriously ill, nurses play a key role in attempting to enroll patients earlier into hospice care. Nurses play a vital role in communicating with physicians, social workers, and other team members to advocate for patients to receive palliative care at the time of the diagnosis of serious illness. This is a key role for nurses. Nurses have those late night conversations with patients who state they are “fearful of being connected to tubes,” “dreading suffering,” “concerned about unfinished business with family members,” and are “needful to say ‘I Love You’ and/or ‘I Forgive You,’” and more. The nurse as advocate is a significant role and their efforts pave the way for Veterans to die with dignity and honor.

- Did you take care of a Veteran last week who could benefit from hospice/palliative care?
- Describe your actions advocating for this Veteran.
- If you were unable to advocate for this Veteran, what barriers kept you from doing so?

Slide 18

Eligibility for VA Hospice Benefit

- **Included in the Medical Benefits Package (both inpatient or home settings)**
- **Eligible for both VA and Medicare may elect to have hospice paid for by either benefit**

VHA, 2005

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- VA offers to provide/purchase needed hospice and palliative care services for ALL enrolled Veterans, whether the services are provided in an inpatient or home setting. This benefit is on par with all other medical services included in the Medical Benefits Package (VHA, 2005).
- A Veteran who is dually eligible for both VA and Medicare may choose to have hospice services paid for under the Medicare Hospice Benefit. Veterans who choose Medicare retain their eligibility for VA care and benefits.
- For nurses caring for Veterans in non-VA hospitals, hospice care may be covered by VA, Medicare, Medicaid and most private insurers.
- A recent study indicated that Veteran hospice users were older than non-veterans but did not differ from other demographics with cancer being the primary diagnosis and most receiving care at home (Wachterman et al., 2014).

Exercise- Stop and Consider:


Having hospice benefits does not always convey an understanding and use of them. Being unaware or misinformed about this benefit will prevent Veterans from receiving this holistic care.

- How many Veterans that you cared for last week are aware of the VA Hospice Benefit?
- Can you identify those Veterans who would benefit from hospice services today?
- If the Veteran is not enrolled in VA, do you know how to expedite enrollment?

Slide 19

Hospice Care for Veterans

- Hospice care provided at home
- Inpatient care provided (VHA, 2005)
- VA contracts with Community Nursing Homes (CNH)
- VA may purchase inpatient hospice care from a community provider
- Concurrent palliative and hospice care among Veterans with cancer beneficial (Mor et al., 2016)
- Growing need for hospice care within VA (Frahm, Barnett & Brown, 2011)



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- If inpatient level hospice care is needed, VA provides it at a VA facility hospice unit, or in a local Contract Nursing Home (CNH)
- VA will pay the hospice agency the per diem rate while the patient is in a *CNH*, if the hospice agency provides consultative services as well as hospice diagnosis-related medications, biologicals, and durable medical equipment. (Note: Only *CNH*'s that have a valid contract with VA and have established hospice agency relationships can be used).
- A VA physician is to make the determination of need for hospice (e.g. life expectancy is less than 6 months). Every patient receiving care by a community hospice agency is required to have both a VA primary care physician as attending of record, AND a hospice medical director (VHA, 2005).
- A 2016 study of the VA's provision of concurrent care (hospice care *and* chemotherapy or radiation) showed that while concurrent care increased among Veterans dying with cancer, from 16.2% to 24.5%, so did the receipt of hospice care, from 55-68% (Mor et al., 2016).

Slide 20

Prognostication

- May be used to establish goals of care
- Survival predictors
 - Palliative Performance Scale
 - Tools (e.g., Karnofsky, ECOG) are poor predictors of survival
 - Biological markers
- Clinician predictors
- Estimating Prognosis (VHA, 2005)

Lynn, 2008; Quill, 2014; Weissman, 2015

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- Prognostication is the estimation of the future course of a disease and survival and can be used to assist Veterans and their families to establish goals of care.
- Survival predictors include:
 - Patient performance status (energy and activity levels). Can be used to predict survival in cancer patients. For example, patients with solid tumors typically lose approximately 70% of their functional status the last three months of life (Weissman, 2015). For more information, go to <http://www.mypcnw.org/#!/blank/hh45g>
 - Prognostication can be challenging (Quill, 2014). Instruments/tools [(e.g. Karnofsky Performance Status Scale (KPSS), Eastern Cooperative Oncology Group (ECOG))] are poor measures for survival predictions in advanced disease. Excellent communication skills are necessary (Dahlin & Wittenberg, 2015).
 - Palliative Performance Scale. The PPS is a reliable and valid tool and correlates well with actual survival and median survival time for cancer patients in outpatient and ambulatory settings. It has been found useful for purposes of identifying and tracking potential care needs of palliative care patients, particularly as these needs change with disease progression (Weissman, 2015). For more information, go to <http://www.mypcnw.org/blank-irr0h>
 - 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 for nurses to have conversations with physicians, social workers, chaplains, and other palliative care professionals around this question: “Would I be surprised if this patient were to die in the next six months or so?” This helps the healthcare team 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). Additional information on estimating prognoses in non-cancer diseases if available (VHA, 2005).

Slide 21

Palliative Care

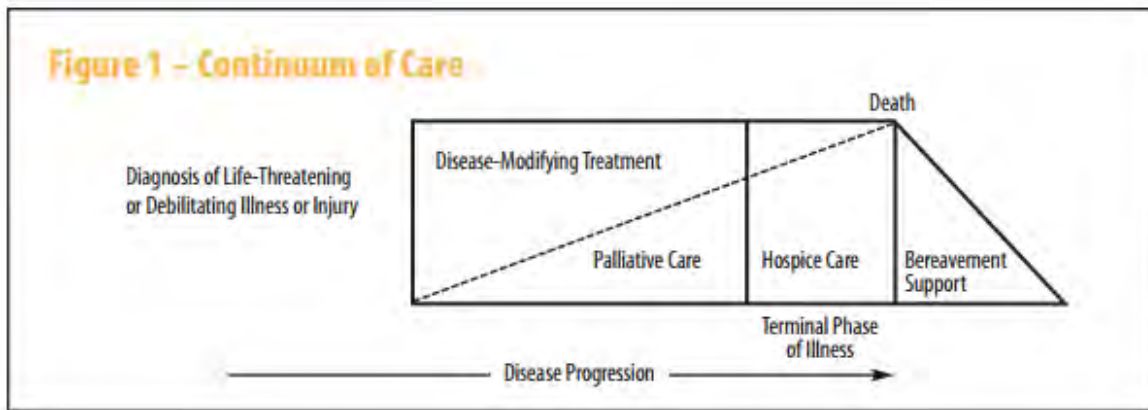
Figure 1 - Continuum of Care

The diagram illustrates the continuum of care for a patient with a life-threatening or debilitating illness. It starts with a 'Diagnosis of Life-Threatening or Debilitating Illness or Injury'. The care continuum is represented by a horizontal line that rises to a peak at 'Death' and then descends. The rising part is divided into 'Disease-Modifying Treatment' and 'Palliative Care'. The peak is labeled 'Death'. The descending part is divided into 'Hospice Care' and 'Bereavement Support'. A horizontal arrow below the diagram is labeled 'Disease Progression' and points to the right. A vertical line marks the start of the 'Terminal Phase of Illness', which begins with Hospice Care and ends at Death.

⁹ Defined by the Centers for Medicare and Medicaid Services in its proposed Hospice Conditions of Participation and as adapted from the World Health Organization.¹³

NQF, 2006

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⁹ Defined by the Centers for Medicare and Medicaid Services in its proposed Hospice Conditions of Participation and as adapted from the World Health Organization.¹³

This figure came from NQF 2006. NCP 2013 does not have a diagram.

http://www.qualityforum.org/Publications/2006/12/A_National_Framework_and_PREFERRED_Practices_for_Palliative_and_Hospice_Care_Quality.aspx

Also, see page 5 of the Textbook.


- In this diagram, palliative care receives the same focus as curative care, while patients receive attention to the prevention and relief of suffering by means of early identification and impeccable assessment.

- This diagram delineates the continuum for palliative and hospice care as the disease progresses and the patient enters into the terminal phase of illness. This care extends to all enrolled seriously ill Veterans and families, including bereavement support.
- Palliative Care can assist patients and their families in two major ways:
 - Delineates goals of care so quality of life can be achieved for both the patients and their family.
 - Effectively manage symptoms to maximizing patients comfort (Fischberg & Morris, 2011; NCP, 2013).
- Since Palliative Care is part of the VHA Standard Medical Benefits Package, all *enrolled Veterans* are eligible IF they meet the clinical need for the service. Copays may be charged for Palliative Care.
- It is important that nurses understand this concept and continuum of care and that they articulate this to not only the patient and their family, but also to other members of the interdisciplinary team. Knowing the patient’s “goals of care” will assist in knowing when palliative care should be initiated.

Note: The diagram above shows the MHB to the far right and applies to Veterans who are enrolled as beneficiaries in the Medicare program (e.g., age of 65, disabled, ESRD) making them eligible for the MHB.

Slide 22

Two Palliative Care Frameworks for Guiding Care



- **Making and Keeping Promises:**
 - Begin by envisioning what a better care system would look like (Lynn, 2000)
- **Quality of Life Model:**
 - Identify physical, psychological, social, and spiritual aspects of care (Ferrell et al., 1991)

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- Two frameworks that are helpful for nurses in assessing patients and guiding quality end-of-life care include:
 - “Making and keeping promises” in *Improving care for the end of life: A sourcebook for health care managers and clinicians* (Lynn et al., 2000)
 - *Quality-of-Life Model* (Ferrell et al., 1991; Chovan et al., 2015)

The next two slides provide more information about how to use each of these frameworks.

**Making and Keeping Promises:
Changing Systems of Care**

1. Good Medical Treatment
2. Never Overwhelmed by Symptoms
3. Continuity, Coordination, & Comprehensiveness
4. Well Prepared, No Surprises
5. Customized Care, Reflecting Your Preferences
6. Consideration for Patient and Family Resources
7. Make the Best of Every Day

Lynn et al., 2000

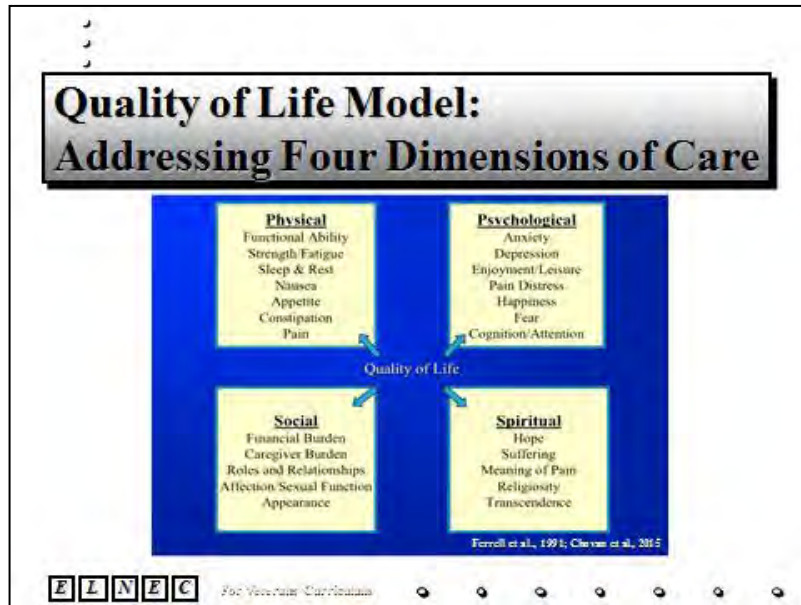
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- Systems of care must focus on the importance and value of excellent person-centered and person-directed palliative care. Administration and managers must commit to educating staff in palliative care and change those systems that inhibit or prevent this care from occurring.
- In *Improving care for the end of life: A sourcebook for health care managers and clinicians* (Lynn et al., 2000) emphasizes good medical treatment, coordinated and comprehensive care; continuity of care across care settings, patients well-prepared with no surprises, customized care that is inclusive of preferences, the consideration of patient and family resources and patients never overwhelmed by symptoms. It is about making promises and keeping them. Making the best of each and every day becomes a pivotal overall goal.

Exercise - Stop and Consider:

1. Think of a Veteran you have cared for in the past week who has no chance for a cure and his/her advanced stage of illness will not permit restoration of health. This Veteran is likely frightened, anxious. In a care system that works ideally what could you promise this Veteran? How could you find out what would matter the most to this Veteran?
2. Encourage participants to share about a Veteran they have cared for this week.
 - Could they make these “Promises” and keep them all?
 - In which areas are they confident they could keep the promise(s)?
 - Which areas need more attention?
 - What can YOU do to begin keeping all *Making Promises*?
 - What systems of care need to be improved?
 - How would you respond given the unique needs that relate to their specific military experience?

Slide 24



- Quality of life at the end of life means addressing multiple dimensions of care (Ferrell et al., 1991; Chovan et al., 2015). Retrieved April 6, 2016 from <http://prc.coh.org>

Exercise-Stop and Consider: Address each of the four dimensions of care listed above, giving examples of how you could assess the patient in the following case study: A 66-year-old female Veteran Army nurse was diagnosed 20 months ago with ovarian cancer.

- She is unable to take care of her home, cook, and help care for her 2 grandchildren due to chronic fatigue, pain, and nausea (physical).
- She is anxious and fearful about her condition and distraught that she can not obtain pain relief (psychological).
- She is sad that she is unable to participate in her grandchildren’s activities and to 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 can not find peace among all the pain and suffering. She feels guilty for how she triaged some soldiers when she was a nurse in Vietnam. She knows that some of her decisions about who got treated and who didn’t caused some soldiers to die. “I was playing God. I was 21 years old. I had no business playing God.” (spiritual).

Slide 25

History of Palliative Care in VA

- **1992: Policy - “All Veterans should be provided access to a hospice program...”**
- **1998-2000: VA Faculty Leaders Project for Improved Care at End of Life**
- **2001: Training and Program Assessment for Palliative Care (TAPC)**
- **2001-2003: TAPC launches VA Hospice and Palliative Care Initiative (VAHPC); VAHPC Launches Hospice-Veteran Partnership (HVP)**

NHPCO, 2011

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VA has a substantial history of embracing palliative care.

- In 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.
- *VA Faculty Leaders Project for Improved Care at the End of Life* (1998-2000), intended to educate faculty and expand palliative care information contained in the curriculum for general internal medicine residencies.
- The *Training and Program Assessment for Palliative Care (TAPC)* Project conducted in 2001 was to identify and describe hospice and palliative care programs within the VA, create resources to facilitate the development of hospice and palliative care programs, and explore the viability of initiating palliative care fellowship programs.
- Results of TAPC lead to the development of the *TAPC Toolkit* and implementation of the VA Interprofessional Palliative Care Fellowship program at six VAMC sites.
- TAPC also launched the *VA Hospice and Palliative Care Initiative (VAHPC)* in November 2001. This two-year project was funded in part by generous grants from the National Hospice and Palliative Care Organization 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.
- In local communities, partnerships continue to be developed between VA professionals and community hospices. A *Hospice-Veteran Partnership (HVP)* is a partnership of people and community organizations working together to ensure excellent care at the end of life that is available for Veterans and their families. The mission of HVPs is to establish enduring networks of hospice and VA professionals, Veterans, volunteers, and other interested organizations working together to

provide quality services through the end of life for all Veterans (i.e. State Veterans Homes, Veteran Service Organizations). The National HVP Program is an initiative by The Department of Veterans Affairs (VA) Hospice and Palliative Care program office in collaboration with the National Hospice and Palliative Care Organization (NHPCO). Individual HVPs have been developed in almost all states across the country (NHPCO, 2011).

Slide 26

**History of Palliative Care in VA
(continued)**

- **2003-Present: Palliative Care Consultative Team (PCCT); Accelerated Administration & Clinical Training (AACT)**
- **2009- Comprehensive End of Life Care Initiative (CELC):**
 - GEC Veteran Experience Center
 - GEC Implementation Center
 - GEC Quality Improvement Resource Center

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- Further initiatives to improve care of Veterans through the VA can be found in the *2014 Department of Veterans Affairs Federal Benefits for Veterans Dependents and Survivors* document, retrieved April 13, 2016 from http://www1.va.gov/opa/publications/benefits_book.asp
 - The VA mandated that all VA facilities have a Palliative Care Consultative Team (PCCT) in place by May 2003 (amended in 2008). This directive made recommendations for the involvement of nursing, medicine, social work, chaplain and psychological/mental health services and requires facilities to submit an annual report to VA Central Office regarding their activities.
 - Launched in 2008, *VA's Comprehensive End of Life Care (CELC) Initiative* is a large scale effort to increase Veterans access to high-quality hospices and palliative care among Veterans.
- VA's Comprehensive End of Life Care (CELC) Initiative is a multi-pronged three-year initiative to ensure that hospice and palliative care services are reliably accessible at all VA facilities and to build an infrastructure for long-term sustainability of quality end-of-life care.
- The PROMISE (**P**erformance **R**eporting and **O**utcomes **M**easurement to **I**mprove the **S**tandard of care at **E**nd-of-life) center is part of the CELC initiative and is a collaborative quality improvement effort. The PROMISE center (also referred to as the Center for Health Equity Research and Promoting: CHERP) conducted surveys on all families of Veterans who die as inpatients in VA facilities, retrieved April 7, 2016 from <http://www.cherp.research.va.gov/PROMISE.asp>

Note: Though each of the initiatives and projects listed on slides 16 & 17 are outstanding, there is still work to do in order to provide excellent palliative care to each Veteran and his family.

Nurses have a unique opportunity to make a difference! Examples of what other nurses are doing to improve palliative care include:

- Nurses and other members of the interdisciplinary team cannot practice what they do not know. Teaching ELNEC courses to VA staff and community partners can bridge that gap.
- Developing pain and symptom algorithms and collaborating with prescribers to create standard orders.
- Working with social workers and chaplains to develop bereavement services for families after the death of their loved ones.
- Arranging memorial services for Veterans who have died in the last 6-12 months.
- Mentoring new nurses in palliative care.
- Expressing tangible gratitude for the Veterans services by presenting military certificates, pins or a token acknowledgment.
- Taking leadership in developing policies to honor Veterans at time of death, i.e., Dignified Departure or Final Salute Ceremonies to transport bodies draped with an American flag or flag quilt to the morgue or funeral home.

Exercise -Stop and Consider:

- How is your institution doing providing quality end-of-life care?
- The GEC Veteran Experience Center (formerly known as PROMISE Center) is a center supported by the VA's Comprehensive End-of-Life Care Initiative, whose goals are:
 - To identify and reduce unwanted variation in the quality of end-of-life care throughout the VA. They work closely with the VA Center for Implementation Practice and Research Support (CIPRS) to support quality improvement efforts in end of life care across the VA.
 - To define and disseminate processes of care ("Best Practices") that contribute to improved outcomes for Veterans near the end of life and their families. The principal activities of the GEC Veteran Experience Center include collecting and tracking data about structures of care; processes of care (via medical record reviews) and outcomes of care (via the Bereaved Family Survey). All next of kin of record for Veterans who have died as inpatients in VA facilities are encouraged to complete the survey. For more information about this project, go to <http://www.cherp.research.va.gov/PROMISE.asp> , retrieved February 25, 2016.

Slide 27

Palliative Care Progress at VA


- **No Veteran Dies Alone Program** (Chicago Tribune, 2016)
- **Reduction in cost with improved satisfaction** (Penrod et al., 2010)
- **Shared Decision-Making and Advance Care Planning Worksheets**
- **VA Goals of Care Conversation Training**
- **Supportive care of families** (Williams et al., 2011 & 2012-2013)
- **Improvement in nurse work environment and staffing contributes to quality of care**
- **Partnership with National Hospice and Palliative Care Organization - *We Honor Veterans***

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- The VA instituted the program “No Veteran Dies Alone” (February 15, 2016; Chicago Tribune) and it is active in 1/3 of the Veterans facilities across the U.S. The VA Center for Health Equity and Research (CHERP) promotes this program that features a VA-wide hospice and palliative care team who have a comprehensive tool kit, orientation guide, and other educational materials, for hospice volunteers who contribute their time to the “No Veteran Dies Alone” program” <http://www.cherp.research.va.gov/promise/newsbriefs/noveterandiesalonevolunteerresource.asp> for additional details. Many VA employees serve as NVDA volunteers. The manual can be downloaded at http://www.wehonorveterans.org/sites/default/files/public/No_Veteran_Dies_Alone.pdf
- A study was done in two urban VA facilities, outlining the benefits of hospital-based *Palliative Care Consultation Teams (PCCT)*. The results of the study showed that communication between the Veteran and the PCCT was vital in order to document the Veteran’s goals of care (Penrod et al., 2010). In-patient costs were decreased as evidenced by:
 - Veterans less likely to be admitted to ICU.
 - Fewer laboratory and technological tests performed.
 - Communication throughout the hospital stay with the PCCT and Veteran allowed goals to be refined as needed, and to have the goals honored by the PCCT.
- The VA Geriatrics and Extended Care features resources and tools in advance care planning that includes a *Values Worksheet* and *Shared Decision Making Worksheet* for Veterans and modules/training videos for care staff that includes the *For Caregivers Self-Assessment Worksheet*, helpful for family/other caregivers role and responsibilities retrieved April 1, 2016 from <http://www.va.gov/GERIATRICS/index.asp>

- Additional resources include an array of training materials under *the National Center for Ethics in Health Care, Caring for Patients with Serious Illness: Building Clinicians' Communication Skills* website. The *Goals of Care Conversations Training* includes four interactive modules and videos useful for practitioners to improve their skills in caring for patients with serious illness across all VA settings, retrieved April 13, 2016 from <http://www.ethics.va.gov/goalsofcaretraining.asp>
- Researchers continue to explore factors that promote quality of life at the end of life with greater understanding of family presence in hospital settings (Williams, Bailey & Woodby, 2012-2013) and staff behaviors that provide supportive care, such as information-sharing, the need for privacy and intimacy, physical comfort and emotional reassurance (Williams et al., 2012).
- Additional studies have been conducted to ascertain quality of life as it relates to the organization of nursing care and nurse staff with results indicating that improvement in the work environment contributes to quality of care received by Veterans at the end of life (Kutney-Lee et al., 2015); the potential differences across VA settings, such as Community Living Centers (CLCs) compared to other VA settings where Veterans die (Ersek et al., 2015); and gender differences with female Veterans receiving comparable or in some areas better (satisfaction of care) care than their male counterparts as evaluated by family members (Ersek et al., 2013).

Role of the Nurse: Improving Palliative Care for All Patients



- **Nurses spend more time at the bedside than other healthcare providers**
- **Some things cannot be “fixed”**
- **Therapeutic presence and “being with”**
- **First and foremost: Patient/family goals of care**

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- Nurses play an important role in improving palliative care for patients. No other healthcare provider spends more time at the bedside than the nurse in assessing, managing, communicating with patients, their families, and the interdisciplinary team.
- Remember that some things cannot be "fixed" (Vachon et al., 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 patient 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 patient’s life; to care for him/her and the family at the time of death; to care for the grieving family.
 - Nurses can use therapeutic presence as a means of communicating care for the patient 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, 2015).
- Maintaining a realistic perspective, as 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 evolving needs of the Veteran and family.
 - Recognition that quality of life (QOL) is uniquely defined by each patient and family.
- The nurse must remain focused on Veteran/family goals of care. As the team meets to discuss the Veteran, the nurse must keep the team focused on the Veteran’s goals of care (Grassman, 2007).

- Though the body may not be healed, the mind, soul, and spirit can be healed.


Note: In order to continue this difficult work of “not being able to fix things,” nurses must grieve the loss of their patients and be grateful for the privilege to make this journey with them.

Slide 29

Maintaining Hope in the Face of Death

- **Unique Opportunity**
 - Excellent physical, spiritual care
 - Maintain hope
- **Processes**
 - Experiential
 - Spiritual
 - Relational
- **Special consideration for Veterans**

Cotter & Foxwell, 2015 ; Grassman, 2015



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- Nurses have a unique opportunity to help patients and families maintain hope by providing excellent physical, psychosocial, and spiritual palliative care. (Cotter and Foxwell, 2015).
- *Experiential* processes include:
 - Preventing and relieving end-of-life discomforts.
 - Helping Veterans and families facing end of life to create new possibilities by mapping out how they want it to go in goals of care conversations.
 - Collaborating with the IDT to create a care/treatment plan that aligns with the Veteran/family's map.
- *Spiritual/transcendent* processes include:
 - Encouraging life review.
 - Facilitating participation in religious rituals/spiritual practices.
 - Making necessary referrals to clergy and other spiritual support people.


[**Note:** For those working with Veterans, there may be a forgiveness issues including acts they may have seen or committed in combat (Grassman, 2015)].
- *Relational* processes include:
 - Being sensitive to patient and family isolation.
 - Establishing and maintaining an open relationship.
 - Shifting the context of hopefulness from hope for cure to hope for finding comfort, dignity, and meaning during the dying process.
- *Rational thought* processes include:
 - Assisting patient/family to establish, obtain, and revise goals without imposing one's own agenda.
 - Assisting in identifying available and needed resources to meet goals.

Increasing patients'/families' sense of control when possible by eliciting and honoring their wishes. The unique needs of people approaching end of life generally fall into three categories: comfort, dignity, and meaning. Here are some examples of how nurses can meet these needs:

- Comfort: supporting holistic pain and symptom management through meticulous assessment, and advocacy.
- Dignity: giving Veterans and families choices about as much as possible in the face of progressive loss.
- Meaning: helping Veterans and families find meaning in the Veteran's living and dying through goals of care conversations, life review, positive regard, and presence.

Slide 30

Extending Palliative Care Across the Continuum of Care



- **Nurses are the constant caregivers across settings**
- **Expand the concept of healing**
- **Become well-educated**
- **Be willing to be a “change agent”**

Coyle, 2015; Malloy, 2015

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- Nurses are the health care providers who spend more time with Veterans and their families than any other member of the health care 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/ Community Living Centers (CLCs)
 - Outpatient Clinics.
 - Home Based Primary Care.
- Early identification means that palliative care can be started sooner, allowing patients and families to set and achieve goals (Coyle, 2015).
- Expanding the concept of healing: Ensure 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).
- Through education, the nurse masters competencies in excellent palliative care (Malloy, 2015).
- Become a *change agent*. Systems of care continually need to be reevaluated and updated. What prevents you from giving excellent care to your Veterans? Miscommunication among team members? Long admitting protocols that prevent the Veteran from getting on the unit and receiving immediate care? Poor documentation records? Lack of protocols/care plans/algorithms that prevent or prompt pain and symptom management?
- Seeing examples of these problems prompts us to think about what WE can do, as nurses, to improve palliative care to Veterans, no matter what setting they are in.
- Special note regarding the role of the nursing assistant in end of life care: Nursing Assistants are the unsung heroes of end of life care. They spend the most time at the bedside. The nature of their

care is frequent and intimate. They are the experts on the patient's skin and observe responses during personal care that help us recognize pain, dyspnea and other discomforts that may be hidden by stoic patients or may have gone unnoticed when patients are unable to give report. Patients and families may reveal concerns to NA's that they do not discuss with other busy members of the care team. Be sure to get and give report to NA partners.

Slide 31

Summary

- Quality palliative care addresses quality of life
- Palliative care and hospice models of care support the patient and family
- Role of the nurse
- Collaborative interdisciplinary care is essential
- Many valuable resources for Veterans (NHPCO, n.d.d.; www.WeHonorVeterans.org)



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- Quality palliative care addresses quality of life for all patients. 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.
- Palliative care and hospice support quality of life at the end of life for all patients.
- The role of the nurse is special and unique in palliative care. Since nurses cannot practice what they do not know, increased knowledge is essential to improved 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.
- Collaborative interdisciplinary teamwork is essential for quality palliative care.
- Various resources for hospice professionals and staff are available on the We Honor Veterans website (NHPCO, n.d.d). www.wehonorveterans.org
- Attention to the needs of Veterans and their families is both an honor and a privilege. Become familiar with opportunities to make a difference at your facility and secure ideas for implementation of palliative care that supports quality of life at the end of life for Veterans (Gabriel et al., 2015).

Exercise- Stop and Consider:

- What would you consider a good end of life outcome? (let participants share their thoughts—below are some answers you may receive)
 - The patient was free from pain and other distressing symptoms.

- Adequate time was spent addressing important patient/family concerns in order to achieve quality end-of-life closure.
 - All possible treatments aimed at curing the illness and desired by patient were exhausted.
 - The patient died peacefully at home surrounded by family and friends, if/as desired.
 - Attention was paid to patient/family suffering and relieving it.
 - The patient was able to live long enough to complete unfinished business.
 - The patient lived long enough to witness a particular event (e.g., a birth, graduation).
- Is there anything you can change in your institution to assure these good outcomes?

Slide 32



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 meet the needs of seriously ill Veterans and their families?

ELNEC For Veterans Curriculum

- Encourage participants to think about this question throughout the next few hours as they go through the *ELNEC- for Veterans* training.
- The goal of this training is to increase palliative care knowledge so that nurses are better equipped to improve palliative care for ALL Veterans in ALL settings.

Note:

- Continuing your education regarding palliative care beyond ELNEC training is important. There are many resources available for you to obtain and reinforce what you have learned at ELNEC- For Veterans. Examples:
 - Stanford Cancer Palliative Education Network (CancerPEN) is a cyber palliative care learning community with the specific aim of creating and disseminating course material about palliating cancer. A series of standalone courses aimed at immersing the learner into the principles and practice of cancer palliation that are self-paced. Available for internet use free of charge to clinicians of the US Department of Veterans Affairs. For further information and/or to begin this education, go to: <http://ecampus.stanford.edu/>, retrieved February 26, 2016.
 - Hospice Palliative Nursing Association and Journal of Hospice Palliative Nursing offer low-cost and no-cost continuing education programs. Your local HPNA chapter may sponsor educational conferences open to members and non-members alike.
 - VA Talent Management System (TMS) offers a multitude of free continuing education offerings to all VA employees
 - Collaborate with your facility's Palliative Care Consultation Team (PCCT) to design/participate in lunch and learn presentations to focus more in-depth on specific aspects of end of life care: pick a symptom per month to learn about both pharm and non-pharm interventions that nurses may provide.

- Partner with your facility's PCCT to recruit volunteer Palliative Care Champions in all venues of your medical center to get additional training from the PCCT to serve as go to PC resources in acute care, critical care, and the ED at night, on weekends, and on holidays.
- Implementing ELNEC for Veterans education at your facility? Read the following paper: Gabriel, M.S., Malloy, P., Wilson, L.R., Virani, R., Jones, D.H., Luhrs, C.A., & Shreve, S.T. (2015). End-of-Life Nursing Education Consortium (ELNEC) - For Veterans: an educational project to improve care for all veterans with serious, complex illness. *Journal of Hospice and Palliative Nursing*, 17(1), 40-47. doi:10.1097/NJH.0000000000000121