Module 1
Introduction to Palliative Nursing Care
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Slide 1

In this module, you will receive Veterans information regarding:

- The Department of Veterans Affairs (VA) Comprehensive End of Life Care Initiative (CELC)
- The Veterans served by VA
- Hospice and palliative care throughout VA healthcare system
- Assessment of Veterans for potential hospice/palliative care
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." This motto serves as a reminder that 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.

Nurses have a unique opportunity to work with Veterans and their families, whether they are working in a VA or non-VA facility. 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.
• VA is committed to provide hospice and palliative care to ALL Veterans that need these services (Department of Veterans Affairs, VA Health Administration & Office of Geriatrics and Extended Care, 2005). This is evidenced by:
  ➢ Hospice is a covered benefit for ALL enrolled Veterans.
  ➢ Hospice and palliative care consult teams are present at every VA health care facility.
  ➢ VA purchases Medicare certified hospice services from local agencies. Community partnerships need to be expanded.
  ➢ Care is provided in in-patient settings, in clinics, in the home, and community.

• Nurses are the constant force caring for these Veterans in a variety of settings.

• Nurses have the privilege 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.
• VA operates the largest unified health care system in the United States and provides care to over 5 million Veterans annually (Casarett et al., 2008a).

• 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.
The majority of Veterans do not receive their healthcare from the VA. Many receive care by community healthcare providers who may not understand the unique end-of-life issues specific to Veterans (i.e. military/combat history, Post Traumatic Stress Disorder (PTSD), etc) (NHPCO, 2010b).

Less than 4% of Veterans die in VA facilities.

Nurses in both VA and non-VA facilities need to be aware of the unique needs of Veterans (NHPCO, 2010b).
• Many Veterans live in rural settings and may have to travel long distances to receive care in a VA Medical Center (NHPCO, 2010b).

• 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.

• Nurses can orchestrate care in a variety of clinical and non-clinical settings.

• For more information about Veterans and homelessness go to: www.va.gov/homeless/

• For more information about health issues of concern for Veterans go to: 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, 2010b).
Nurses Caring for Veterans at the End of Life Must Understand the Culture

- Enrolled Veterans
  - Social isolation
  - Lack of family support
  - Low income

- Military camaraderie
- Culture of stoicism

Department of Veterans Affairs, VA Health Administration, 2005

• Nurses, as well as all healthcare providers who work with Veterans must understand their unique culture, so that excellent care can be provided (Department of Veterans Affairs, VA Health Administration & Office of Geriatrics and Extended Care, 2005).
  - Demographics from VA show that many enrolled Veterans have a limited support system (65% do not have a spouse) and many have low income. Average income = $10,000/yr. (US Congress Joint Economic Commission, 2009). Low income patients may find it difficult to have opportunities to discuss their values and goals with their health team (Lyckholm et al., 2010). Veterans are familiar with the military culture and respect and appreciate the camaraderie of their fellow soldiers.
  - Ask Veterans
    - If they want a volunteer who is also a Veteran
    - If they want a Veteran as a roommate if they are living in an inpatient facility
  - If staff are Veterans, they should introduce themselves as such.
  - Stoicism may prevent Veterans from admitting and/or asking for pain/symptom management. The value of stoicism, so earnestly and necessarily indoctrinated in young soldiers, may interfere with a peaceful death for all Veterans (Grassman, 2009).
• 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:
  ➢ VA system is large (over 5 million Veterans/year are seen in VA facilities).
  ➢ The many layers of VA benefit system can cause much confusion and misunderstanding among Veterans and their families (Casarett et al., 2008b).
  ➢ Enrolled Veterans tend to be older.
  ➢ An estimated 121,000 Veterans are homeless at some time during the year without shelter of healthcare, hence no access to hospice/palliative care. (For more information, review the Culture Module and or http://www.va.gov/homeless/)
  ➢ Enrolled Veterans may have more co-morbidities (not just physical, but also psychological), so they may have many different specialty physicians caring for them (Back et al., 2005; Casarett et al., 2008a; Finlay et al., 2008).
Various Experiences Can Affect A Veterans Dying

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

Department of Veterans Affairs, VA Health Administration & Office of Geriatrics and Extended Care, 2005

- Veterans may have a variety of influencing factors that can affect their dying process. It is important that nurses assess each of the issues:
  - What branch of service that the Veteran served?
  - What were the conditions that the Veteran entered service? Enlisted? Drafted?
  - Rank of the Veteran during service?
  - Age of enlistment? Age 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.
  - Many Veterans may be stoic and this can interfere with communication of needs and wishes.
  - Accepting palliative care may be seen as giving up, surrendering, or being defeated.
  - What is the length of service?
  - Which war or time period that the Veteran served?
  - Combat/POW experience other dangerous duty assignments
  - Assess for Post Traumatic Stress Disorder (PTSD)

- For more information see the Military History Checklist at www.wehonorveterans.org/i4a/pages/index.cfm?pageid=1 (Last retrieved February 23, 2012) (NHPCO, n.d)

**Module 1 Suggested Supplemental Teaching Materials:**

Figure 5: # 152- The Military History as a Vehicle for Exploring End-of-Life Care with Veterans.
• Americans have many fears and concerns about the “dying” and “death” process. These examples could include:
  ➢ Most adults prefer to be cared for at home if terminally ill.
  ➢ Majority would be interested in a comprehensive program of end-of-life care, such as hospice.
  ➢ 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 drain life savings in order to cover costs of care for terminally ill family members (Boni-Saenz et al., 2005).
  ➢ 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 (Egan-City & Labyak, 2010).
  ➢ 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).

**Note:** 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).
Hospice and Palliative Care

- **HOSPICE**
  - Most intense form of palliative care
  - Less than 6 months to live
  - Agrees to enroll in hospice
  - Chooses not to receive aggressive curative care

- **PALLIATIVE CARE**
  - Ideally begins at the time of diagnosis
  - Can be used to complement treatments

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 (Department of Veterans Affairs, VA Health Administration, (VHA) Directive 2008-041, 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 are their histories?
- What is the nurse’s role in hospice and palliative care?

Hospice

- Hospice supports the Veteran through the dying process and the surviving family through the dying and bereavement processes. 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. Provides care in the home, residential facilities, hospitals, and nursing facilities. In 1982, Congress created the Medicare Hospice Benefit (MHB).
- VHA Hospice Care: VHA Hospice Care is care 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, to be 6 months or less if the disease runs its normal course.
  - Accepts hospice care (Department of Veterans Affairs, Office of VA Health Administration & Office of Geriatrics and Extended Care, 2005).
• 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.

• 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” (World Health Organization, 2009). Palliative care is “both a philosophy of care and an organized highly structural system for delivering care” (NCP, 2009).

  • In addition, palliative care has as its goal 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, 2009). 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 (Department of Veteran Affairs, VA Health Administration, VHA Directive 2008-066, 2008b). Can be rendered along with life-prolonging treatment OR as the main focus of care. Medical care 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).

  • 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.
Hospice and Palliative Care cont.

- BOTH
  - Interdisciplinary care
  - Provide pain and symptom management
  - Physical, emotional, social and spiritual care

• Philosophy and principles of hospice and palliative care and service/support:
  - Patient/family are the unit of care
  - The use of interdisciplinary care and team
  - Provides pain and symptom management
  - Quality of life- addressing and providing physical, emotional, social and spiritual care.
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 Veterans and families across diverse life-threatening illnesses, 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, 2009).

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 MHB to the far right. For many Veterans, they are not eligible for the MHB.

**Module 1 Suggested Supplemental Teaching Materials:**
Table 1: National Consensus Project Domains and Corresponding National Quality Forum Preferred Practices
Death and Dying in America: Today

- Over 4700 hospice programs in the US
- Average length of stay in hospice is 69 days (median=21 days)
- In 2009: 1,560,000 patients received hospice services and 41.6% of all deaths in the US were under the care of a hospice program.
- Patients with chronic illnesses make up the majority of hospice patients (i.e. heart disease, dementia, etc)


• Death and dying have changed significantly over the past 40 years, as the hospice movement began in the US in the 1970’s (NHPCO, 2005 & 2010a).
  ➢ 4700+ hospice programs have been developed in the US.
  ➢ Average length of hospice service is 69 days. Median length of service was 21.1 days (meaning that 50% of hospice patients received care for less than 3 weeks and 50% received care for more than 3 weeks).
  ➢ The US hospice census:
    - In 2003: over 830,000 patients received hospice care.
    - In 2007: 1,400,000 patients received hospice care.
    - In 2009: 1,560,000 patients received hospice care.
  ➢ In 2009, almost 41.6% of all deaths in the US were under the care of a hospice program.
  ➢ 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 (i.e. heart disease, dementia, lung disease excluding cancers, etc) and only 41.3% of hospice patients have cancer.
  ➢ Routine home care accounted for 96% of patient care days.
  ➢ 69% of patients received care in the patient's home (i.e. private residence, nursing home, or residential facility).
  ➢ Race--80% are Caucasian, 9% Multiracial, 9% Black/African-American, 2% Asian, Hawaiian, Pacific Islanders, 0.2% American Indians (NHPCO 2010a).

Exercise- Stop and Consider:
Though much progress has been made in the past 40 years to improve care of the dying, 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, etc. to advocate for patients to receive palliative care at the time of the diagnosis of a life-threatening illness. This is a key role for nurses. They 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,” “needful to say ‘I
Love You’ and/or ‘I Forgive You,’” etc. Nurses’ contribution to advocating is monumental and their efforts pave the way for Veterans to die with dignity and honor.

- Did you take care of a Veteran last week that could benefit from hospice/palliative care? Describe your action for advocating for this Veteran.
- If you were unable to advocate for this Veteran, what barriers kept you from doing so? (see next slide for a list of barriers).
Barriers to Quality Care at End of Life

• Failure to acknowledge limits of medicine
• Lack of training for healthcare providers
• Hospice/palliative care services are misunderstood
• Many rules and regulations
• Denial of death

Glare et al., 2003

- It is important to be aware of the barriers to quality care at the end of life.

- Most often cited barriers include (Glare et al., 2003):
  - 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.

- VA facilities and community hospice providers may face multiple administrative, logistical and communication challenges in working together to care for Veterans. Hospice-Veteran Partnerships have been established nationwide to address difficulties and increase access. Go to www.nhpco.org/veterans for more information about Hospice-Veteran Partnerships.

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.

Module 1 Suggested Supplemental Teaching Materials:
Figure 1: Peaceful Death: Recommended Competencies and Curriculum Guidelines for End-of-Life Nursing Care
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.
- 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 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 are being 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, 2010b; Rosenfeld & Rasmussen, 2003).
• Further initiatives to improve care of Veterans through the VA can be found in the 2010 Department of Veterans Affairs Federal Benefits for Veterans Dependents and Survivors document. 

➢ The VA mandated that all VA facilities have a Palliative Care Consultative Team (PCCT) in place by May 2003 (amended in 2008). The directive made recommendations for 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 (Performance Reporting and Outcomes Measured to Improve the Standard of care at End 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. For more information, go to 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:
- Teaching ELNEC courses to VA staff community partners. Nurses and other members of the interdisciplinary team can not practice what they do not know.
- Developing pain and symptom algorithms and standard orders.
- Working with social workers and chaplains to develop bereavement services for families after the death of their loved ones.
- Orchestrating memorial services for Veterans who have died in the last 6-12 months.
- Providing grand rounds to surgeons on a palliative care case.
- Mentoring new nurses and physicians in palliative care.
- Expressing tangible gratitude for the Veterans services by presenting military certificates, pins or token of acknowledgment.
- Taking leadership in developing policies to honor the Veteran who had just died, by transporting bodies, covered with an American flag or flag quilts to the morgue or funeral home.
• 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 (Department of Veteran Affairs, VA Public Affairs, 2008).

• When it is the Veteran’s preference, VA contracts with community based hospice programs to enhance VA’s ability to provide hospice/palliative care to its Veterans.

• There has been an increase in the need for hospice and palliative care as the number of World War II and Korean era Veterans triple over the age of 85 from 2000 to 2010.

• By 2014, Vietnam Veterans over the age of 65 will comprise 60% of all Veterans in this age group.

• To date, VA facilities and community hospice programs have established state-wide and regional partnership in almost every state to promote/provide hospice services that are not provided by VA staff.

• Over 60 percent of Veterans who die in VA facilities receive palliative care services before their death.
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 outline the Veteran’s goals of care (Penrod et al., 2006). 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.
Differences in Cause of Chronic Illness and Death by Wars

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

Many Veterans have conditions, diseases and illnesses associated with the particular war they fought in (http://www.va.gov/oaa/pocketcard/).

- 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 (www.va.gov/oaa/pocketcard/worldwar.asp):
  - Cardiovascular diseases, cancer, dementia (Alzheimer’s), 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 (yellow fever, cholera, influenza, typhus, typhoid and tetanus.

- Korean War (1950-1953): These Veterans are subject to all diseases associated with aging (see above) (www.va.gov/oaa/pocketcard/korea.asp):
  - 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) (www.va.gov/oaa/pocketcard/vietnam.asp):
  - 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): These Veterans are subject to all diseases associated with aging (see above) and other Gulf War illnesses, including PTSD (www.va.gov/oaa/pocketcard/gulfwar.asp):
  - 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): These Veterans are subject to all diseases associated with aging (see above), including PTSD (www.va.gov/oaa/pocketcard/oefoif.asp):
  - Unique health risks include: Cold injuries, high altitude sickness, penetrating, 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), 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.
- VA is required to offer to purchase or provide hospice services, where indicated. This benefit is on par with all other medical services included in the Medical Benefits Package (Department of Veterans Affairs, Veterans Health Administration & Office of Geriatrics and Extended Care, 2005). Nurses must be aware of this benefit.

- VA offers to provide/purchase needed hospice and palliative care services for ALL enrolled Veterans, whether the services will be needed in an inpatient or home setting.

- 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 will retain their eligibility for VA care and benefits. NOTE: “Veterans need to be notified that VA has no authority to pay for any balances or co-payments that may be due after Medicare or any other non-VA source makes payment for hospice care” (Department of Veterans Affairs, Veterans Health Administration & Office of Geriatrics and Extended Care, 2005, page 2). Hospice services are part of the Medical Benefits Package.

- For nurses working in non-VA hospitals caring for Veterans, hospice care may be covered by VA, Medicare, Medicaid and most private insurers.

**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 the holistic care that should have been planned for months or years ago (Maudlin et al., 2006; Running et al., 2008).

- 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?
Providing Hospice Services to a Veteran who Becomes an Inpatient

- GENERALLY, VA provides needed inpatient hospice care at a VA facility (preferred option)
- VA may utilize Community Nursing Home (CNH) contracts
- VA may purchase inpatient hospice services from a community provider.

Note that VA will pay the hospice agency the per diem rate while the patient remains in a Community Nursing Home (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 with established hospice agency relationships can be used).

When a Veteran is placed by VA in a CNH, (i.e. Veteran lives far away form the VA inpatient hospice) a VA physician is to make the determination of need for hospice—life expectancy is less than 6 months. Every patient receiving care by a community hospice agency is required to have both a primary care physician as attending of record, AND a hospice medical director. [Refer to U. S. Department of Veterans Affairs, VA Health Administration & Office of Geriatrics and Extended Care, 2005. VHA Handbook 1140.5 for further information.]
Prognostication: May Be Used to Establish Goals of Care

- Performance status
  - ECOG and Karnofsky are poor indicators
- Multiple symptoms
- Biological markers
  - Albumin, etc.
- “Would I be surprised if this Veteran died within the next 6 months?”

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, 2005). For more information, go to [http://www.eperc.mcw.edu/EPERC/FastFactsIndex/ff_013.htm](http://www.eperc.mcw.edu/EPERC/FastFactsIndex/ff_013.htm)
- Instruments/tools (e.g. Karnofsky, ECOG) are poor measures for survival predictions in advanced disease (Glare et al., 2010; Lamont & Christakis, 2007).
- Biological markers (e.g. elevated platelet count, decrease in serum albumin, etc) can also be indicators of limited survival (Glare et al., 2010).

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, etc 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., 2000).
Two Palliative Care Frameworks for Assessing Patients

- **Making Promises Document:**
  - Begin by envisioning what a better care system would look like

- **Quality of Life Model:**
  - Identify physical, psychological, social, and spiritual aspects of care

Two frameworks that are helpful for nurses in conceptualizing patients experiencing end-of-life issues include:

- *Making Promises* document (Lynn et al., 2000)
- *Quality-of-Life Model* (Ferrell et al., 1991; Glass et al., 2010)

Slides 25 & 26 will give more information about how to use each of these frameworks.
• Systems of care must focus on the importance and value of excellent 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.
  ➢ 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 frightened, anxious. In a care system that works ideally what could you promise this Veteran? What would matter the most to this Veteran?

• Exercise- Encourage participants to share about a Veteran they have cared for this week.
  ➢ Could they make these “Promises” and keep them all?
  ➢ 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?

**Module 1 Suggested Supplemental Teaching Materials:**
Figure 2: Making Promises
• Quality of life at the end of life means addressing multiple dimensions of care (Ferrell et al., 1991; Glass et al., 2010).

• 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 56-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 care for her 2 teen-agers 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 children’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 22 years old. I had no business playing God.” (spiritual).

**Module 1 Suggested Supplemental Teaching Materials:**
Figure 3: Quality of Life Model
Figure 4: Achieving Quality of Life at the End of Life: Addressing Multiple Dimensions of Care
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" (Faas, 2004):
- We can not change the inevitability of death;
- We can not 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.
- Everyday, nurses are invited to be present at the last moments of a patient’s life; to care for him and his 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 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, 2010).

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 changing needs of the Veteran and family.
- Recognition that quality of life (QOL) is determined by the unique needs of the patient and family.

The nurse must remain focused on 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. Hopefully, others will accompany us when our time comes—and indeed it will (Vachon & Huggard, 2010).
Nurses have a unique opportunity to maintain patients’ and families’ hope by providing excellent physical, psychosocial, and spiritual palliative care (Ersek & Cotter, 2010).

Experiential processes include:
- Preventing and managing end-of-life symptoms.
- Encouraging patients and families to transcend their current situation.
- Encouraging reminiscing.

Spiritual/transcendent processes include:
- 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, 2009)].

Relational processes include:
- Minimizing patient and family isolation.
- Establishing and maintaining an open relationship.
- Communicating one’s own sense of hopefulness.

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.

Module 1 Suggested Supplemental Teaching Materials:
Table 2: Intervention to Foster Hope
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.
- 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, 2010).

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, 2010).

The role of the nurse in education: Competencies - Through education, the nurse masters competencies in excellent palliative care.

"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.
Final Thoughts

- Quality palliative care addresses quality of life for ALL patients
- Increased nursing knowledge is essential
- "Being with"
- Interdisciplinary care is vital

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.

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.

Palliative care is best provided by nurses functioning as part of an interdisciplinary team.

Exercise- Stop and Consider:

- What would you consider a good death? (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 were exhausted.
  - The patient died at home with dignity and surrounded by family and friends.
  - Attention was paid to 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 so that you are assured that each Veteran who dies has a good death?
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…?”

- 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.

**Module 1 Suggested Supplemental Teaching Materials:**
Table 3: Fast Facts- EPERC