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 4: Cultural Considerations in Palliative Care

Faculty Outline

Slide 1

"Preservation of one's own culture does not require contempt or disrespect for other cultures."

Cesar Chavez

This module reviews dimensions of culture, which influence care in advanced disease. The assessment of culture is essential to understanding the person and patient-centered care. Cultural understanding is essential to adequate communication and in providing cultural and spiritual competent care to all Veterans and their families. Several factors exist:

- Culturally competent care includes recognition of multiple factors, i.e. ethnicity, gender, sexual orientation, and social class.
- Cultural factors significantly influence quality of life and communication with Veterans and families at the end of life.
- Culturally competent care is best provided through an interdisciplinary team approach.

- The 21st century brings heightened awareness of how beliefs, values, religion, language, and other cultural and socioeconomic factors influence health promotion and help-seeking behaviors. The significance of assessing cultural considerations in palliative care is vital.
  The nurse plays a key role in understanding and providing culturally competent palliative care to each individual patient.

- Culture influences palliative care in several ways:
  - Communication- how does the culture talk about illness/death? How open are people to talk about illness, dying and death? What about eye contact? Touch?
- How are decisions made about care? Does the patient make their own decisions or someone else in the family?
- Death rituals and bereavement practices are specific to culture and religion. How will the body be managed after death? Autopsy? Embalming? Cremation? Organ donation? Loud wailing or quiet stoicism at the death of their loved one? (Foley & Mazanec, 2011).

- The warrior culture, stoicism, and moral injury may impact the coping strategies, relationships, and response to serious illness (Grassman, 2015; Periyakoil, 2016).
Learning Objectives:

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

1. Identify three dimensions of military culture that may influence palliative care for Veterans across the life span.
2. List six shared military values of Veterans that may impact palliative care.
3. Discuss military stoicism as it relates to care at end of life.
4. Name four considerations of cultural communication.
Though the culture of the military may be unique, it has some common themes with non-military culture. For example:

- Culture is a system of shared symbols, serving as guides for our interactions with others (Mazanec & Panke, 2015).
- Cultural practices provide safety and security, integrity, and belonging.
- Culture is constantly evolving and changing in response to political, historical and other unique factors (Andrews & Boyle, 2012). Culture fundamentally shapes how an individual makes meaning out of illness, suffering and death. It therefore also influences how a person will interact with the health care system at the end of life (Mazanec & Panke, 2015). Culture is only meaningful when seen from the individual's perspective.
- Too often, our understanding of culture is limited sociodemographic characteristics such as race, ethnicity and religious affiliation. The tendency (also known as stereotyping) is then to assume a person holds particular beliefs and values and will behave in an expected way, and it is important not to rely solely on available cultural resources (i.e., handbooks, pamphlets) as a way to understand culture and individual needs of the person (Purnell, 2013).
Culture refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups.

*Cultural competence* implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities (US Dept HHS, Office of Minority Health, 2005 [adapted from Cross, 1989]).

- Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations.
- Cultural competence can also be defined as the attitudes, knowledge, and skills necessary for providing quality care to diverse populations (AACN 2008 & 2010; Douglas et al., 2014; Mazanec & Panke, 2015; Neubauer et al., 2016).

*Culturally competent nursing care* includes sensitivity to issues related to ethnicity, gender, sexual orientation, social class, economic factors, and other factors cited previously. Knowledge about other culturally diverse groups is essential within the context of cultural competence. Components of cultural competence (Campinha-Bacote, 2007 & 2011) include:

- Cultural awareness: Sensitivity to cultural diversity and self-assessment of biases.
- Cultural knowledge: Learning about beliefs and values of different cultural groups.
- Cultural skill: Applying cultural awareness and knowledge by completing assessments and planning interventions accordingly.
- Cultural encounters: Interactions with individuals from diverse cultures.
- Cultural desire: Motivation to become culturally knowledgeable, skillful, aware, and to seek cultural encounters.

An interdisciplinary team approach is vital to culturally competent care.
• **Race:** Many definitions exist and there appears to be no agreement on any scientific definition of race. In 2000, the Human Genome Project declared that there was no biologic or genetic basis for race (Hamilton, 2008). Race also may be significant due to physiologic differences in genetic makeup. These differences may be responsible for differing abilities to metabolize drugs, including certain analgesics such as codeine. Any discussion about culture and health care delivery needs to mention how racism impacts care. Power differentials emerge and can lead to institutional racism, affecting life opportunities, life styles, and quality of life.

• **Ethnicity:** Refers to complex interactions of dynamics involved in individual functioning and family/group behaviors, beliefs, and values. Ethnicity provides a sense of commonality with others. Individual ethnic meanings develop as a result of experiences and go beyond that of shared religion, nation of origin, geography or race (AACN 2008 & 2010; Andrews & Boyle, 2012). The 2010 Census revealed ethnic minorities make up 28% of the U.S. population (Humes et al., 2011). Trends suggest that by the year 2042, ethnic minorities will make up about 50% of the population (Vincent & Velkoft, 2010). Ethnic identity - based on rich cultural heritage, & social belief systems - reflecting in how we respond to life transitions; ways of communication, behavior, and illness beliefs, how major life decisions are made. Individuals may or may not be strongly connected with a particular group.

• **Gender:** Culture dictates male or female roles and activities within a culture (Douglas & Pacquiao, 2010). What roles do different genders play? What is acceptable/ unacceptable? Are families considered patrilineal/matrilineal in nature? Who should provide care to a sick relative? What communication patterns or behaviors are acceptable?

• **Age:** Subcultures based on age - there may be differing values, education, or attitudes within same family or community. Each age cohort group has its own identity and subculture (e.g.,
Baby Boomers, Millennium Generations). Respect for older adults is common in many cultures. Older adults may feel uncomfortable in collaborative relationships with health care professionals, having grown up with more paternal interactions with doctors or nurses.

- **Religion and spirituality** (Baird, 2015; Puchalski et al., 2009; Taylor, 2015): Religion is a system of faith and worship. “Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose feeling of the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant saved” (Puchalski et al., 2009). Some patients and families find comfort in the rituals associated with their beliefs. One example of a spiritual screening instrument is represented by the acronym FICA; Faith, Importance, Community, and Address in Care. While this acronym is widely used it should not be considered a comprehensive assessment instrument. In VA, only chaplains perform spiritual assessments, and only assessments approved by the Director of Chaplain Service may be used.

- **Gender identity or sexual orientation** (Douglas & Pacquiao, 2010; Mazanec & Panke, 2015): Gay, lesbian, and transgender individuals are often stigmatized. Though the military has a “Don’t ask, don’t tell” policy, this can have a significant impact on any conversations regarding sexual orientation. An inoffensive strategy when asking questions about sexual orientation is to state, “If you are sexual with others, are they men, women, or both?” End-of-life care may be a time for estranged children to attempt to reunite with parents (e.g., the son with HIV/AIDS who was disowned by his mother may attempt to re-establish the relationship). An important role of healthcare professionals is to assist in this process if the Veteran seeks support. These individuals may have experienced multiple losses, isolation, or different family systems that influence their present experience. Be aware that there may be some legal and ethical issues of domestic partnerships, as well as unresolved family issues and broken relationships.

- **Differing abilities**: People with differing abilities, physical or mental health variations, are often stigmatized or treated in an infantile manner. People with differing abilities and their families may feel alone and ostracized. “Differing abilities” has varied meanings across various cultures. In the U.S., legal efforts have been focused on ensuring that people with disabilities are entitled to the same rights as other individuals.

- **Financial status**: Minorities with an annual income below the poverty level have a significantly higher death rate when compared to those with average incomes. End-of-life care may financially deplete families with limited resources. Families may be reluctant to reveal their resources.

- **Place of residence**: refers to where people live and where they have come from.
  - Homeless individuals and those in prison often have co-morbid disorders of mental illness, substance abuse, and low socioeconomic status. Access to care is limited and they are often ostracized by society and the healthcare system.
  - It is estimated that 181,500 U.S. Veterans were incarcerated in 2011-2012, which was a lower rate than non-Veterans (BOJ, 2015).
• The U. S. Department of Justice Bureau of Justice Studies (BOJ, 2015) report that the number of veterans incarcerated in state and federal prison and local jail decreased from 203,000 in 2004 to 181,500 in 2011-12. The total incarceration rate in 2011-12 for veterans (855 per 100,000 veterans in the United States) was lower than the rate for nonveterans (968 per 100,000 U.S. residents). Non-Hispanic black and Hispanic inmates made up a significantly smaller proportion of incarcerated veterans (38% in prison and 44% in jail), compared to incarcerated non-Hispanic black and Hispanic nonveterans (63% in prison and 59% in jail). A greater percentage of veterans (64%) than nonveterans (48%) were sentenced for violent offenses. An estimated 43% of veterans and 55% of nonveterans in prison had four or more prior arrests. Mental health disorders were higher among Veterans (55%) versus non-Veterans and PSDT (31%) for Veterans versus non-Veterans (15%). It is unknown how many Veterans, had military discharge making them eligible for VA services or specifically what benefits they are eligible for while in prison (VA, 2015). Veterans in prison have special palliative and end of life special needs.

• Employment: Associated with socioeconomic status. Veterans may also derive self-identity and self-worth through their jobs/professions.

• Educational level: Related to socioeconomic status. Those with higher educational levels generally have greater resources. Education influences all aspects of life.

• Cause of death: Viewed by race and age reveal racial and social disparities (AACN 2008 & 2010). Minority populations have higher deaths due to injury, HIV infection, homicide and suicide. The protection of human rights is essential (TCN, n.d.).
This Slide illustrates some of the cultural demographics of Veterans.

Compared to other wars, almost 2 million Veterans from Iraq and Afghanistan are older and married (Reinberg, 2010).

Veterans have served, lived, and participated in a unique culture known as the military. Military service and its many experiences can define the way Veterans live and the way they choose to die (Hallerman & Kearns, 2008).
The military is unlike any other career and the demands of military life create a unique set of pressures on service members and their families.

For most people, their job is what they do; it does not so deeply define who they are. For families, military life offers a sense of community with clearly defined rules and expectations. Members of the military and their families share a unique bond, professional ethic, ethos, and value system. The military offers a sense of community and camaraderie unlike any other profession. But it also fosters a warrior ethos that rewards physical and emotional prowess and frowns upon weakness and timidity.

It is said that the military defends the Constitution; it does not emulate it. There are strict rules limiting freedom of speech and association. To maintain “good order and discipline” commanders at all levels are given widespread authority over the personal affairs of their subordinates and held personally responsible to resolve any issues that could potentially affect performance of duty.

Military culture is complex and impacts Veterans and their approach to health and wellness. The various wars and the threats to wellness that ensued have helped to define the subset of military culture that comes forward and is expressed by the Veteran.
The shared experience of serving in the military serves as a unifying means of connecting one to all. Connected through creed and values, there may also be distinguishers that can include whether they served as enlisted or commissioned officers and the branch and uniform they wore.

Basic training – all those who serve must go through basic training which serves to promote an intense sense of team work and dedication to achieving the team goal. For some, this may also be a very demoralizing experience.
• Be careful not to assume that because a Veteran is part of the military that pride and patriotism is a part of what they will naturally express. A good way to find out is to ask the Veteran to tell you how he feels about the service he provided as in the Army, Navy, etc.

• The era of service has its own unique culture, which can influence the outcome of a soldier’s experience. For example, WWII Veterans are more likely to have had areas of safe haven than Vietnam Veterans, who were often in immediate physical danger. This resulted in a higher incidence of stress-related disorders. Korean Veterans were often told not to discuss their military service and are sometimes overlooked in the discussion regarding the needs of Veterans. A significant number of Korean Veterans were POWs held by the Chinese, and subjected to torture and other mistreatment. So asking and understanding the military history of Veterans is important (NHPCO, n.d).

• Rituals such as pinnings or flag ceremonies are often so important in military life that they are codified. Pinnings ceremonies as promoted in We Honor Veterans accompanied by thanking and acknowledging Veterans for their service can be powerful ways of connecting with a Veteran.

• Military lifestyle, especially when deployment is a part of the picture, carries impact for families and their commitment that enabling their loved one to serve. [Link](https://www.youtube.com/watch?v=iDbI DPb6A7w) is a four minute overview about impact of stress and trauma on children and families after deployment.
A Veteran’s military experience has equipped him or her with a unique set of values and skills. These characteristics distinguish Veterans from their civilian counterparts and can make them valuable members of your team. Below are common traits associated with those who have served in the military.

- Highly structured and authoritarian way of life with a mission-focused, goal-oriented approach—both explicit and implied.
- Strict sense of discipline, tending to adhere to rules and regulations.
- Strong work ethic with high regard for physical and mental strength.
- Code of conduct and organizational culture that reflects well-defined and strongly supported moral and ethical principles.
- Decisive leadership that expects loyalty of subordinates and allies.
- Warrior Culture – Bravery, Duty, Honor and Courage.
- Loyal to Comrades- Leave no Man Behind!
- Protective of family and civilians, chivalrous.
- The Mission comes first above all else.
- All Volunteer Service (No Draft).

For more information:
https://bamaatwork.com/2014/08/29/understanding-military-culture/
Military culture promotes stoicism because it is highly effective at placing the mission and unit’s needs over those of the individual. Stoicism can interfere with the Veteran prioritizing their own healthcare needs. It is very possible that stoic veterans may not value bereavement groups as a healthy way to attend to their own grief needs. Instead, they might view support groups as forums for “cry babies;” (Grassman, D. L., 2009).

Normalizing the experience of grief may be helpful and providing alternative modalities for providing bereavement care such as community Veteran support groups may be helpful. “Routine” bereavement care for combat veterans may uncover much unresolved grief from deaths of comrades on the battlefield.

Showing fear or pain is considered weakness. For a good example of stoicism and its relationship.

It is not unusual for Veterans to have trust or guilt issues stemming from their military experience.

The high instance of substance abuse may stem from continually tamping down their own needs and at the expense of prioritizing the needs of the team.
Combat Veterans may have “cheated” death or been witness to those who have survived at all odds in highly stressful military situations. The idea that a chronic illness may have mortal consequences may be in direct conflict with how the Veteran has survived in previous life-threatening situations.

While stoicism is important to achieving strategic military goals such as teamwork and adherence to hierarchical authority; it can inflict psychological, emotional, social and spiritual suffering in civilian life. Stoicism may also directly interfere with the ability to feel and report pain. It is helpful to overcome this by normalizing the experience of military stoicism among Veterans, and suggesting ways that the Veteran can respond to pain that can help clinicians address underlying challenges to living well. For example: “Taking care of this pain may help us get you a bit closer to your goal of being able to return home and cherish the time you have left with your grandson.”

If stoicism is interfering with the Veterans experience of grieving or preparing for their dying, it may be more acceptable to provide individual counseling or private coaching. Placing Veterans with each other in regular activities may also provide an opportunity for normalizing of shared experiences. For example, witnessing Honor Rituals at the time of death, may help a Veteran recognize that even in death, a Veteran’s life is respected and honored.
The graph in this Slide shows the difference in the percentage of current Veterans race/ethnicity and period of service.

- **Note:** In April 2016, the Department of Veterans Affairs (VA) released Profile of Minority Veterans: 2014 which highlights data concerning the demographics, socioeconomic status, and health characteristics of Minority Veterans. It also compares major characteristics between Minority Veterans and Minority non-Veterans. For more information go to [http://www.va.gov/vetdata/docs/SpecialReports/Minority_Veterans_2014.pdf](http://www.va.gov/vetdata/docs/SpecialReports/Minority_Veterans_2014.pdf) (retrieved April, 2016).
The Veteran population is getting more and more diverse with the Post-911 and Pre-911 cohorts having the highest number of minorities.

### Veterans by Period of Service by Race and Ethnicity

<table>
<thead>
<tr>
<th></th>
<th>White</th>
<th>Black</th>
<th>AIAN</th>
<th>Asian</th>
<th>Some Other Race</th>
<th>Two or More Races</th>
<th>Hispanic</th>
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<tbody>
<tr>
<td><strong>Post-911</strong></td>
<td>65.5</td>
<td>15.4</td>
<td>0.7</td>
<td>3.0</td>
<td>0.2</td>
<td>2.7</td>
<td>12.4</td>
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<tr>
<td>(Sept 2001 to present)</td>
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<tr>
<td><strong>Pre-911</strong></td>
<td>69.5</td>
<td>16.8</td>
<td>0.8</td>
<td>1.9</td>
<td>0.2</td>
<td>2.0</td>
<td>8.7</td>
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<td>(Aug. 1990 to Aug. 2001)</td>
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<tr>
<td><strong>Vietnam Era Only</strong></td>
<td>82.7</td>
<td>9.2</td>
<td>0.7</td>
<td>1.2</td>
<td>0.1</td>
<td>1.2</td>
<td>5.0</td>
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<tr>
<td>(Aug. 1964 to April 1975)</td>
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<tr>
<td><strong>Korean Conflict Only</strong></td>
<td>88.5</td>
<td>5.4</td>
<td>0.4</td>
<td>1.1</td>
<td>0.1</td>
<td>0.5</td>
<td>4.1</td>
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<td>(July 1950 to Jan. 1955)</td>
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<td><strong>World War II Only</strong></td>
<td>91.9</td>
<td>3.8</td>
<td>0.2</td>
<td>1.1</td>
<td>0.0</td>
<td>0.6</td>
<td>2.4</td>
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<td>(Dec. 1941 to Dec. 1945)</td>
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<tr>
<td><strong>Peacetime Only</strong></td>
<td>78.8</td>
<td>12.2</td>
<td>0.7</td>
<td>1.4</td>
<td>0.1</td>
<td>1.2</td>
<td>5.7</td>
</tr>
</tbody>
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Note: Periods of military service shown here are coded with Veterans who have multiple periods of service being placed into their most recent period of service.
Women in the military today and as Veterans have played a prominent role in history and who in the past did not have access to services as they do today nor did they receive the same recognition as their male counterparts (CWI, n.d., DAV, 2014).
According to the VA (2014)
  o Total women Veterans is estimated to be over 2 M
  o The states with largest number of women Veterans: Texas, California, Florida, Virginia, Georgia

Women who are active military (DoD, 2016):
  o 15% of DoD Active Duty Personnel are women
  o 161,415 female enlistees across all services

As of 2015, all military positions are open to women.

The Women’s Health Initiative (WHI) has been a research initiative funded by the VA to identify women’s health related needs and improve health care (See * below). The impact on quality of life and health is revealing new information about women Veterans including:
  o For older women from the Korean and Vietnam wars, the burden of chronic illness is high with 70% of women Veterans aged 65 years and older report three or more comorbid chronic conditions, including arthritis, hypertension, depression, chronic lung disease, osteoporosis, cancer, and posttraumatic stress disorder (Bastian et al., 2016).
  o Weitlauf (2016) and colleagues found that older women Veterans enrolled in the Women’s Health Initiative had a 13% higher all-cause mortality relative to non-Veteran women.

Exercise - Stop and Consider:
  • What type of diseases do you see most frequently with women Veterans?
  • How many are referred to palliative care services?
  • Are women Veterans cared for differently than male Veterans? If so, how?
  • Are wives of Veterans cared for differently than female Veterans?
  • Is there a history of sexual trauma? If so, is there a need for evaluation, counseling, treatment? How might this affect their palliative care plan of care?

Note:
  • Women’s Health Research initiative with the VA. Retrieved April 5, 2016 from http://www.research.va.gov/programs/womens_health/
  • For free access to The Gerontologist feature “Women Veterans in the Women's Health Initiative”, Volume 56 Suppl 1 February 2016, retrieved April 5, 2016 from http://gerontologist.oxfordjournals.org/content/56/Suppl_1.toc
World War (WW) II: 1941-1945
- Enthusiastically supported by Americans.
- Many soldiers lied about their age and joined the military service when they were 16 years old.
- Without television, Americans could be shielded from the war’s brutality, and hence it could be glamorized.
- Soldiers felt camaraderie and were in the war until it finished. Troops came home together after the war.
- They came home as heroes as the public was anxious to hear their wartime stories. But families generally only wanted to hear the “glories” of war and not about trauma and moral confusion (VA, 2009).

Korean Conflict: 1950-1953
- Not officially declared a war, but rather a “conflict.”
- Americans in the 1950’s were happy with post-World War II feats and they wanted to forget about war and configure ways of growing prosperously.
- Soldiers’ trauma had been minimized/neglected and their contributions have been largely forgotten (VA, 2009)

Cold War: “Atomic Veterans”
- Considered end of WWII in 1945 until the collapse of the Soviet Union in the 1990’s.
- Major fear was nuclear war.
- Approximately 200,000 US service personnel occupied Hiroshima and Nagasaki after the atomic bombing of Japan.
- Exposure to radiation has been associated with leukemia and other cancers (VA, 2009). For more information on radiation exposure and health go to http://www.publichealth.va.gov/exposures/radiation/sources/ (Retrieved April 5, 2016)
Vietnam War: 1964-1975
- There was a lot of television coverage.
- Soldiers shamed and dishonored for the most part.
- The draft forced many into the military; many who were opposed to the war.
- Many sons wanted the same “hero” status as their fathers who served in WW II.
- Soldiers were required to do only one-year tours.
- Anti-war protests in the US depleted their confidence in the war.
- Tragedy of war: toxic exposures
- Agent Orange exposure known to cause malignancies, birth defects, diabetes, peripheral neuropathies
- Their fighting and sufferings were futile (VA, 2009).

Many Vietnam Veterans were exposed to Agent Orange during their service, as over 19 million gallons of various herbicidal combinations were used between 1961 and 1971. Agent Orange was the most widely used of the herbicide combinations that were sprayed. VA has recognized that certain cancer and other diseases have been associated with exposure to Agent Orange. Other diseases include acute and subacute neuropathies, Parkinson's Disease, Hodgkin's Lymphoma, chronic B-cell leukemias, multiple myeloma, etc. For further information about Public Health and Diseases Associated with Agent Orange, go to [http://www.publichealth.va.gov/exposures/agentorange/diseases.asp](http://www.publichealth.va.gov/exposures/agentorange/diseases.asp) (Retrieved April 5, 2016).

Generational cultural clashes have occurred
- Some WW II vets had a difficult time comprehending that Vietnam was different.
- Some saw these soldiers as “wimps” who lost the war.
- The Veterans of Foreign Wars posts use to not allow Korean or Vietnam Veterans to join because neither of those wars were declared “wars”, but instead considered “conflicts.”
This is no longer the case (Grassman, 2009).

**Note:**


1. “VA assumes that certain diseases can be related to a Veteran's qualifying military service. We call these Presumptive diseases. VA has recognized certain cancers and other health problems as presumptive diseases associated with exposure to Agent Orange or other herbicides during military service. Veterans and their survivors may be eligible for benefits for these diseases,” Retrieved April 5, 2016 from [http://www.publichealth.va.gov/exposures/agentorange/conditions/index.asp#sthash.FyE9WtWB.dpuf](http://www.publichealth.va.gov/exposures/agentorange/conditions/index.asp#sthash.FyE9WtWB.dpuf).
• Gulf War Desert Shield/Desert Storm: 1990-1991 (or Desert Shield/Desert Storm or Persian War)

- “GULF WAR SICKNESS” Multi-symptom based medical/psychiatric conditions reported (i.e. fibromyalgia, chronic fatigue syndrome, memory loss, chemical sensitivity, PTSD, anxiety, depression). In addition, there was exacerbation of asthma, secondary to oil-well fire/smoke. Announcement from VA Secretary, Anthony Principi on December 10, 2001, confirmed that Gulf War Veterans were more than twice as likely as other Veterans to develop ALS (Horner et al., 2003).
- Unique health risks: Exposure to smoke, chemical or biological agents.
  - In June 1999, the Department of Veterans Affairs and U.S. Department of Defense requested that Centers for Disease Control and Prevention (CDC) assist in a study of amyotrophic lateral sclerosis (ALS) among Person Gulf War (GW) veterans. ALS is a fatal neurodegenerative disease that destroys the brain and spinal cord nerve cells. The CDC’s Environmental Health Laboratory conducted laboratory analyses of blood and urine specimens to look for signs of exposure to heavy metals. Initial results found military personnel who were deployed to the Gulf region during the 1991 GW experienced a greater post-war risk of ALS than those who were not deployed to the Gulf. Among approximately 2.5 million eligible military personnel, 107 confirmed cases of ALS were identified (an overall occurrence of 0.43 per 100,000 persons per year) (Horner et al., 2003). For further information, go to http://www.cdc.gov/nceh/veterans/default2i.htm (Retrieved March 10, 2016).
  - The VA continues to study US Veterans of the Persian Gulf War and the risk of death due to neurological diseases after GW service between 1990-1991 (see VA Public Health http://www.publichealth.va.gov/epidemiology/studies/postwar-mortality-neurologic-diseases-gulf-war.asp Retrieved March 10, 2016) and identify that death due to ALS, MS, Parkinson’s disease and brain cancer are not associated with the
GW in general. However, GW Veteran’s potentially exposed to nerve agents in Khamisiyah, Iraq, and to oil well fire smoke had and increased mortality due to brain cancer (Barth et al., 2009).

- **Operation Enduring Freedom/Operation Iraqi Freedom (OEF/OIF); effective September 2010, now referred to as Operation New Dawn (OND):** Military personnel were deployed in response to the September 11, 2001 terrorist attacks on the World Trade Center and the Pentagon. Since October, 2001, over 1.7 million US troops have been deployed for OEF/OIF/OND.
  - Long and multiple deployments to Afghanistan and Iraq have taken significant psychological tolls, evidenced by increasing incidence of suicide and suicide attempts.
  - Unique health risks include: Infectious diseases, cold injury, and high altitude illnesses.
  - Environmental hazards include: Exposure to sewage, agricultural and industrial contamination of water and food, air pollution, severe sand/dust storms.
  - Injuries include: Blast injuries (penetrating, blunt trauma, burns), traumatic brain and/or spinal cord injuries, vision loss, traumatic amputations, multi-drug resistant acinetobacter, leishmaniosis, and mental health issues (VA Advisory Council/NHPCO, 2009a, Grassman, 2009).
These sociologic challenges are not unique to Veterans, but military culture puts Veterans at risk for acquiring these conditions by virtue of the trauma of war.
The above statistics regarding homeless Veterans are tragic. It is a challenge to identify homeless Veterans who are terminally ill and bring them into the VA system early enough that they can benefit from hospice/palliative care. Nurses can play a strategic role in identifying terminally ill Veterans who are at high risk for being homeless and assuring that they are provided with compassionate and dignified care.

*Opening Doors*, the first-ever federal strategic plan to end Veteran homelessness, began in 2010. Since then, homelessness has decreased by nearly 50 percent, largely through the work of community partnerships. ([https://www.defense.gov/News/Article/Article/881729/veteran-homelessness-drops-nearly-50-percent-since-2010](https://www.defense.gov/News/Article/Article/881729/veteran-homelessness-drops-nearly-50-percent-since-2010)) Much remains to be done to address homelessness, especially as it impacts Veterans with serious illnesses.

Some of the biological and sociological causes of Veterans being homeless:
- A shortage of affordable housing
- Low salary
- Limited access to health care
- Mental Illnesses
- On-going effects of PTSD
- Substance abuse
- Lack of family/friend support

Some homeless Veterans are not comfortable in “facilities.” For some, they want to die as they lived-homeless. For these Veterans, it is important to connect them with community hospices that can provide care “under the bridge” or “on the street.”

**Note:** Homelessness Resources. Retrieved April 5, 2016.
For further information and resources on homelessness, see:

- Every VAMC has a homeless Veteran services coordinator who is responsible for providing outreach and services for homeless or at-risk Veterans (VA, 2016b). Do you know who this coordinator is in your facility?


- The National Center on Homelessness among Veterans (NCHV) (the Center) works to promote recovery-oriented care for Veterans who are homeless or at-risk for homelessness by developing and disseminating evidence-based policies, programs, and best practices. Established in 2009, the Center supports the implementation of the Department of Veterans Affairs (VA)'s Five Year Plan to End Homelessness among Veterans, put forth by the United States Interagency Council on Homelessness (USICH), in their 2010 Federal Strategic Plan to Prevent and End Homelessness, *Opening Doors*. Working collaboratively with community partners and university affiliates, the Center’s work is integrated and organized around four core activities.

- Department of Veteran’s Affairs (VA) website: Ending Veteran’s Homelessness Retrieved April 5, 2016 from [http://www.va.gov/homeless/](http://www.va.gov/homeless/)

- For those working in non-VA facilities: Do you have Veterans who may be better served in a VA-facility? Many Veterans state that attempting to “get into the VA system” is confusing and a lengthy process.
  - Contact the Veterans of Foreign Wars (VFW) [http://www.vfw.org](http://www.vfw.org) or Disabled American Veterans (DAV) [http://www.dav.org](http://www.dav.org) as they have representatives who will help file all the forms (both websites retrieved April 5, 2016). These organizations can assist in navigating the VA system.
Ideally, all patients receiving palliative care would have stable housing. The poor and homeless live on the street and exist on very little. They can be seen as disenfranchised as many are mentally ill and have substance abuse problems. All of these factors can make providing excellent palliative care to this population very challenging.

It may take a long time to build trust with these patients.

No matter what they look like, what they smell like, what they say, or feelings that they may stir in us, it is important that we respect this person as a human being, deserving of care that we can provide.

Listen and appreciate their unique story as it may influence their response to being ill and dying.

Assess by recognizing and addressing maladaptive behaviors (Hughes, 2015).

Person-centered care is essential and understanding the effects of health disparities is at the heart of transcultural nursing (Clark, 2014).

**Exercise - Stop and Consider:**
- Do you care for homeless Veterans?
- How does your institution reach-out to homeless Veterans?
- What needs to be done to overcome barriers to reach homeless Veterans who have life-threatening illnesses and need palliative care?
- How does this culture of homelessness interfere with excellent palliative care?
- Every VAMC has a homeless Veteran services coordinator who is responsible for providing outreach and services for homeless or at-risk Veterans. Do you know who this coordinator is in your facility?

- Health Care for Homeless Veterans Program (HCHV) at http://www.va.gov/homeless/docs/HCHV_Sites_ByState.pdf
- Domiciliary Care for Homeless Veterans Program (DCHV) at http://www.va.gov/homeless/dchv.asp
• Demographics
  ➢ According to the VA (2016), more than 2 of 10 Veterans with PTSD also have Substance Use Disorder (SUD).
  ➢ War Veterans with PTSD and alcohol problems tend to be binge drinkers. Binges may be in response to bad memories of combat trauma.
  ➢ Almost 1 out of every 3 Veterans seeking treatment for SUD also has PTSD.
  ➢ The number of Veterans who smoke (nicotine) is almost double for those with PTSD (about 6 of 10) versus those without a PTSD diagnosis (3 of 10).
  ➢ In the wars in Iraq and Afghanistan, about 1 in 10 returning soldiers seen in VA have a problem with alcohol or other drugs.

  For more information about PTSD and Substance Abuse in Veterans, go to http://www.ptsd.va.gov/public/problems/ptsd_substance_abuse_veterans.asp

• It is important that nurses understand that many Veterans suffer from substance abuse, yet many times they are under-medicated for their pain due to their abuse history. This can cause complications in end-of-life care. Managing pain and other symptoms with opioids can be challenging during this time, but achievable with a thorough assessment and close management.

• Prevalence of heavy drinking and marijuana use is higher among Veterans compared to non-Veterans.

• Alcohol and other substance abuse issues are associated with serious medical issues and elevated mortality rates.

• Combat exposure is related to increased likelihood of recent drug use.
• Substance abuse is associated with a number of life-limiting conditions and at-risk behavior(s). In recent years, Vietnam Veterans have been experiencing many complicated medical problems and increasingly are receiving hospice care due to approaching end of life. We are at a stage where biological risk factors common to Vietnam Veterans (e.g., Hepatitis C, Agent Orange exposure) and psychosocial factors (social isolation, lack of support, substance abuse) are converging, resulting in poor health and elevated death rates. Hospices throughout the USA can expect to see more Veterans with liver disease related to prolonged alcohol abuse and/or Hepatitis C (often related to IV drug use).

• Open dialogue with the Veteran about the risks of overuse of pain medication, and any limits on prescribing will be an important part of the treatment plan.

• Interventions are focused on evidence-based psychotherapy or “talk therapy”, available at VAMCs and clinics with the following approaches:
  ➢ Cognitive Behavioral Therapy for Substance Use Disorder (CBT-SUD) which teaches patients to reduce their substance use and improve quality of life using helpful, balanced thoughts.
  ➢ Motivational Interviewing (MI) and Motivational Enhancement Therapy (MED) which helps the person focus on motivation for change. The MI approach is a conversation between the patient and medical providers about the reasons for change and benefits with reasons and benefits as the focal point. MET is a more targeted, structured version of MI that involves a brief assessment and helps Veterans to consider making changes regarding their alcohol and/or substance use.

• There may be emotional concerns related to substance abuse at end of life. Active substance users may have limited social support systems due to estrangement from families/friends. Thus, they may have special social/emotional support needs during end of life. Additionally, Veterans may feel guilt about their use or responsible for their illness if it is related to substance abuse (e.g., liver disease, heart disease).

**Note:** **Substance Abuse Resources** Retrieved March 10, 2016
- VA Mental Health, Substance Abuse at [http://www.mentalhealth.va.gov/substanceabuse.asp](http://www.mentalhealth.va.gov/substanceabuse.asp)
- Substance Abuse and Mental Health Services Administration (SAMHSA) at [http://www.samhsa.gov/](http://www.samhsa.gov/)
- Alcoholics Anonymous at [http://www.aa.org/?Media=PlayFlash](http://www.aa.org/?Media=PlayFlash)
- Narcotics Anonymous at [https://www.na.org/](https://www.na.org/)
• An important starting point in improving cultural assessment of Veterans and families is self-assessment. It is important to recognize our own culture and how that effects our interactions, decisions, language and behavior. Thus, a cultural self-assessment is a necessary prerequisite for providing culturally competent and appropriate palliative care.

• Each one of us has our own culture based on our heritage and life experience that influences our interests, emotions, biases -- how we view the world (Spector, 2013).

• Also, consider the cultural beliefs of co-workers. There is increasing cultural diversity amongst healthcare professionals and one should not assume that the team providing care at the end of life holds common beliefs.

• Understanding our own definition of culture then helps to uncover areas to assess in another. All health care providers should complete a cultural self-assessment including assessing his/her own view of other cultural groups before completing a patient or family assessment.
When conducting a cultural assessment, there are important considerations to include with regards to the patient, family and the community (AACN, 2008 & 2010; Mazanec & Panke, 2015):

- **Country of origin/current residence**: Where were the patient/family caregivers born? If an immigrant, how long has the person lived in this country? How old was he/she when they came to this country? What is the level of acculturation (Acculturation is the process of incorporating some of the cultural attributes of the larger society by diverse groups, individuals, or peoples) and contributing stress, adaptation and influence (Douglas & Pacquiao, 2010).

- **Culture/ethnicity the person identifies with**: What is the person’s ethnic affiliation and how strong is the ethnic identity? Do they live in an ethnic community? Is the community a source of support?

- **Community**: Major support people include family members, friends, spiritual leader/clergy/community.

- **Decision making**: How does the patient’s culture affect decisions regarding their medical treatment? Who makes decisions, the patient, the family, or a designated family member? Community, spiritual leaders/clergy involvement? (Blackford & Street, 2016).

- **Languages/communication**: Primary and secondary languages/dialects; speaking, reading ability and educational level; is it appropriate to share thoughts/feelings? Non-verbal: touch, eye contact, timing.
- Components of Cultural Assessment (continued):
  - **Religion/spirituality**: Religion, religious beliefs, rituals, importance of prayer, ritual ceremonies. Regular and continuous assessment of spiritual issues is vital (Puchalski et al., 2009). Partner with Chaplain, per the patient’s request (Handzo, 2016). It is important to consider that agnostics (people who believe that nothing is known or can be known of the existence or nature of God) and atheists (people who lack belief in the existence of God or gods) still may find significant value in ritual and ceremony – especially military rituals and ceremonies that can serve as a way of connecting them to the values of their time of service.
  - **Nutrition**: Meaning of food. Restrictions, religious observances
  - **Financial status or economic situation**: Impact on illness, services needed, availability of medications. Is the income adequate to meet the needs of the patient and family?
  - **Health and illness beliefs and practices**
    - What are the customs and beliefs around such transitions as birth, illness, and death?
    - What are their past experiences regarding death and bereavement?
    - How much does the patient and family wish to know about the disease and prognosis?
    - What are their beliefs about pain and suffering?
    - **Non-traditional therapies**: Folk remedies, herbal medications, other practitioners (i.e. massage therapist, healing touch, practitioners, etc.) sometimes used in combinations. May hesitate to inform health care providers for fear they will not be taken seriously; often mistakenly translated into “compliance” problem.
    - Care of the body after death
    - Organ donation -- For many, organ donation is not allowed or considered because of either personal or religious beliefs.
Caring for the spirit allows us to better care for the physical, psychological, and social needs of patients.
- When assessing the spiritual needs of a patient, it involves more than just asking what religion he or she is.

Spirituality can be quite valued for those who do not consider themselves “religious.”
- It is spirituality that gives life meaning and purpose.
- It provides a means to forgive and to ask for forgiveness, to love, to hope.
- This ethereal phenomenon allows for “transcendence”—to rise above whatever circumstance comes our way.

Religion is more “organized” and tends to be categorized as denominations (i.e., Catholic, Protestant, Jewish, Muslim, Buddhist, etc.) (Taylor, 2015).

Nurses must work closely with the chaplaincy service and make referrals as needed.

*The National Consensus Project for Quality Palliative Care*, Domain 5—Spiritual, religious, and existential aspects of care (NCP, 2013):
- Guideline 5.1: The interdisciplinary team assesses and addresses spiritual, religious, and existential dimensions of care.
- Guideline 5.2: A spiritual assessment process, including a spiritual screening, history questions, and a full spiritual assessment as indicated, is performed. This assessment identifies religious or spiritual/existential background, preferences, and related beliefs, rituals, and practices of the patient and family, as well as symptoms, such as spiritual distress and/or pain, guilt, resentment, despair, and hopelessness.
Guideline 5.3: The palliative care service facilitates religious, spiritual, and cultural rituals or practices as desired by patient and family, especially at and after the time of death.
• There are several examples of spiritual assessments, but this is simple and short and one that you can use in everyday conversations with your Veterans and their families (Puchalski, 2014).
  ➢ F = Faith: Does the patient have a faith belief? What gives his/her life meaning?
  ➢ I = Importance or Influence: How important is your faith to you? How does your faith influence your life?
  ➢ C = Community: Do you belong to a faith community? If yes, in what ways does this provide support to you?
  ➢ A = Address: How would you like for the team to integrate issues of spirituality into your care?

Stop & Consider: How do you start the conversation regarding spiritual aspects of your patients’ humanity? Evidence shows that patients must feel trust with their caregiver to share these existential-type experiences. How do you develop a trusting relationship with your patients, so they can feel comfortable sharing these types of thoughts/experiences?
• Examples of spiritual care interventions are (Baird, 2015):
  ➢ Providing presence.
  ➢ Deep listening.
  ➢ Bearing witness.
  ➢ Putting compassion into action.

• These interventions can assist in:
  ➢ Reconciliation.
  ➢ Self-worth.
  ➢ Resolving guilt.
  ➢ Forgiveness.
  ➢ Stronger relationship with God/Higher Being.

• Understand and respect the Veteran’s culture.
There are specific cultural considerations in regards to communication.

- **Conversational style**: Assess whether the patient wishes to speak for him/herself or have a family member or other make decisions and serve as spokesperson. Ask Veterans how they would like to be greeted (e.g., first or last name? by rank, etc). Silence may denote respect or mean “no” (Neubauer et al., 2016). Demonstrate respect (Long, 2011).
- **Personal space**: How close is appropriate? Observe the patient’s reactions to posturing and space.
- **Eye contact**: Observe the patient’s reaction to eye contact. Avoiding eye contact in some cultures is seen as a sign of respect, not indifference.
- **Touch**: The acceptance of touch as a communication method is variable. Use empathy to determine the patient’s comfort with space and touch.
- **View of healthcare professionals**: Some cultures approach healthcare professionals with respect and may be afraid to question their physician or other healthcare professionals. Other cultures may respect the healthcare professionals, but are not afraid to be confrontational and question the team regarding various issues.
- **Auditory versus visual learning styles**: Supplement oral communication with visual teaching materials. Question Veterans/family members whether they would like materials in English or another language and whether they prefer written materials or audiotapes/videotapes. Narrative interviews – Listen to their stories and watch for cues regarding what is appropriate.
- **Military lingo**: Unless you have served, it is best to approach the use of military lingo with much respect – similar to how you wouldn’t try to recite something in a foreign language you are not familiar with. Saying “We have your back” can sometimes provide support for a Veteran.
• Various cultures have “rules” or “an understanding” that certain members of the family are to make decisions, certain members are to be in on discussions related to care, and certain members are responsible for determining whether full disclosure is appropriate.

• Some questions to think about include (Blackford & Street, 2016; Mazanec & Panke, 2015)
  ➢ Who makes decisions in the family? Who is the spokesperson? Is it the patient or a family member? Is it a family decision?
  ➢ Who should be included in discussions? This is also a matter of respecting confidentiality. Professionals may ask the family to select one person to serve as the key contact for information. Avoid HIPAA violations.
  ➢ Is full disclosure (e.g., telling the patient his/her diagnosis and/or prognosis) acceptable?
• Despite the influence of autonomy and other values on the U.S. health care system, many cultures embrace different values and ideas about health care, how decisions are made and the dying process itself (Mazanec & Panke, 2015).

• Patients and families from cultural backgrounds often rely on family, group or community decision-making models. Truth telling and disclosure may be appropriate in some scenarios, and avoided in others. Check this (Blackford & Street, 2016).

• Disclosure of diagnosis and/or prognosis: Certain diagnoses, for example cancer, as well as terminal prognosis, may not be told to the patient, as the belief is that the patient will give up hope, experience increased suffering. Conflict may arise when health care providers insist on full disclosure, particularly when the family is not included in this decision.

• If a patient is asked and chooses to designate a family member to make decisions and receive all information, then the patient's rights have been respected. Ascertaining patient’s desire for disclosure (Dahlin & Wittenberg, 2015):
  ➢ What do you want to know about your condition?
  ➢ Whom should we talk to about your treatments and outcomes?
  ➢ Whom do you want to know about your condition?
  ➢ Whom do you want to make health care decisions for you?
Recognize the language we use regarding certain treatment decisions and the impact it may have on those receiving the information. In addition, they are using that information to make decisions.

Most are framed using words with negative connotations, for example:
- Discontinuation of life-sustaining therapies
- Do not resuscitate (DNR)
- Withdrawing and withholding
- Organ donation

More and more, deaths in the U.S. are associated with decisions to forgo or discontinue treatment. We must be aware of how we are communicating with others, since the words we use may create barriers.

Attempt to rephrase and use language that includes a meaning of hope that matches the patient's and family's perspective. This will and should vary as you gain individual insights. Example: AND – “Allow Natural Death.”
• Despite best efforts, clashes will occur (Douglas & Pacquiao, 2010).

• The key is to continue attempts to understand each perspective, and take time to understand your own reactions and personal values. Failure to take the culture seriously means we choose to place our own values over those of differing backgrounds. Stereotyping, disregarding personal rights, etc. are examples of not respecting another’s culture.

• Suggestions to address cultural conflicts (Mazanec & Panke, 2015):
  - Assess your own reactions, potential bias. Be aware of your own ethical values.
  - Never deliberately lie to the patient or family.
  - Offer to make information available to the patient, but allow the patient to decline.
  - Use cultural guides to facilitate communication when indicated.

**Exercise - Stop and Consider:**
- In the past month, have you experienced a “culture clash?” If so, what caused it?
- What were ways that could have been considered to avoid the clash?
- Was the clash resolved? If so, how?
Culture is dynamic. It is important to recognize that culture influences all aspects of life, especially during illness, the dying process, death and bereavement (Andrews & Boyle, 2012; Mazanec & Panke, 2015).

There are many components related to culture and spirituality. It is critical to complete a cultural/heritage for the Veteran, family and community.

To understand cultural assessment for the Veteran, it is necessary to complete a self-assessment: How do your own values/beliefs influence your attitudes or behavior towards others? Nurses must become aware of their own cultural beliefs and values and how these influence their behaviors and attitudes about others.

Gain basic knowledge of the cultures common in your community. Get to know community and spiritual leaders and involve them in the care team when necessary. Increase your awareness and knowledge of culture and its impact in your care practices. Pursue critical reflection. Most importantly obtain information from individual assessments and complete assessments early!

Attributes that are essential to culturally competent nursing care include flexibility, empathy, a non-judgmental approach, language facility, and competence in approaches to sharing information about decision-making.

Gain skill in cross-cultural communication, cultural assessment, cultural interpretation, and intervention. Seek to understand; never assume.
• Interdisciplinary care is vital!

**Note:**

For more information is ways to improve culturally competent nursing care read:


