CULTURAL CONSIDERATIONS IN END OF LIFE CARE
Developed by: Ellen Hoekstra, RN
Presented by: Russell Hilliard, PhD, LCSW, LCAT, MT-BC, CHRC
VP, Supportive Care & Patient Experience
VP, Quality Assurance & Performance Improvement

CRITERIA FOR SUCCESSFUL COMPLETION
- Be sure to sign the attendance sheet.
- Print your name and address clearly
- You must remain for the entire program in order to receive 1 contact hour credit for Nursing and Social Work CE.
- Complete and submit the evaluation form
- Participate in the post test discussion

DECLARATIONS
This program is provided to you by Seasons Hospice and Palliative Care.

There is no commercial support for this educational event.

The speaker declares that he is an employee of Seasons Hospice and Palliative Care, which provides the service described herein.

Approval by ANCC/CA- BRN/ASWB does not indicate endorsement of any products.
OBJECTIVES

- Learner will be able to state the definition of “cultural competence” as it relates to healthcare
- Identify at least five components of a cultural assessment
- Describe possible barriers to cultural competent care
- State three general considerations to keep in mind when working with all cultural groups
- Discuss specific cultural traits related to end of life care for various cultural groups

“CULTURE” DEFINED

Culture has been defined as an integrated pattern of learned beliefs and behaviors that can be shared among groups. It includes thoughts, styles of communicating, ways of interacting, views on roles and relationships, values, practices, and customs.

Source: Braun K, et al 2000

CULTURAL COMPETENCE

To be culturally competent the nurse needs to understand his/her own world views and those of the patient, while avoiding stereotyping and misapplication of scientific knowledge.

Cultural competence is obtaining cultural information and then applying that knowledge. This cultural awareness allows you to see the entire picture and improves the quality of care and health outcomes.
POSSIBLE BARRIERS TO CULTURALLY COMPETENT CARE

- Lack of diversity in health care’s leadership and workforce
- Systems of care poorly designed to meet the needs of diverse populations
- Poor communication between providers and patients of different racial, ethnic, or cultural backgrounds
- Our own backgrounds, culture, religious beliefs, and experiences

PERSONAL REFLECTION

- How do you identify yourself racially, ethnically, and culturally?
- When were you first aware of your own culture?
- What is the first memory you have of someone dying in your family?
- What were the rituals, practices or behaviors that your family observed at that time?
- What aspects of your cultural background do you feel strengthen your caring for dying patients and their families?

COMPONENTS OF CULTURAL ASSESSMENT*

- Birthplace
- Ethnic “identity” or community
- Decision making
- Language or communication
- Religion
- Food preferences or taboos
- Beliefs regarding death, dying, grief, pain
- Race
- Gender
- Age
- Sexual orientation
- Financial status
- Employment
- Education level
- Cause of disease/illness

*pertains to patient/family/community
**QUESTIONS FOR ASSESSMENT**

- Where do you go when you are sick?
- What do you take when you are sick?
- Do you feel you have religious beliefs that would influence your healthcare or treatment plan?

Example: What do you do when you have a headache?

---

**POPULATION FACTS**

<table>
<thead>
<tr>
<th>Quick Facts</th>
<th>Cook County</th>
<th>Illinois</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>5,294,664</td>
<td>12,901,563</td>
</tr>
<tr>
<td>Persons Under 18</td>
<td>24.8%</td>
<td>24.6%</td>
</tr>
<tr>
<td>Persons 65 and over</td>
<td>12.2%</td>
<td>12.2%</td>
</tr>
<tr>
<td>Females</td>
<td>51.2%</td>
<td>51.6%</td>
</tr>
<tr>
<td>White</td>
<td>66.8%</td>
<td>79.1%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>25.6%</td>
<td>14.9%</td>
</tr>
<tr>
<td>Asian</td>
<td>5.8%</td>
<td>4.3%</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>23.2%</td>
<td>15.2%</td>
</tr>
<tr>
<td>White/non Hispanic</td>
<td>44.8%</td>
<td>64%</td>
</tr>
<tr>
<td>Language other than English spoken at home</td>
<td>30.7%</td>
<td>19.2%</td>
</tr>
<tr>
<td>High School Graduates</td>
<td>77.7%</td>
<td>81.4%</td>
</tr>
<tr>
<td>Bachelor's degree/higher</td>
<td>28.0</td>
<td>26.1</td>
</tr>
<tr>
<td>Below poverty level</td>
<td>14.6</td>
<td>11.9</td>
</tr>
</tbody>
</table>

Source: US Census Bureau 2008 estimates
HOSPICE AND PALLIATIVE CARE IN A CULTURAL CONTEXT

- How will the patient/family manage the terminal diagnosis
- End of Life Planning/Advanced Directives
- What will the patients and family response to pain and management of that pain be
- What are their death and dying needs/wishes

ADVANCED DIRECTIVES
PATIENT SELF DETERMINATION ACT 1991

- This law makes it clear that you have the right to make decisions regarding your medical care including the right to accept or refuse treatment and the right to make an advance directive.

ADVANCED DIRECTIVES

<table>
<thead>
<tr>
<th>Knowledge of Advanced Directives</th>
<th>Percent having one respectively:</th>
</tr>
</thead>
<tbody>
<tr>
<td>69% European Americans</td>
<td>28%</td>
</tr>
<tr>
<td>47% Mexican Americans</td>
<td>10%</td>
</tr>
<tr>
<td>13% Korean Americans</td>
<td>2%</td>
</tr>
<tr>
<td>12% African Americans</td>
<td>0%</td>
</tr>
</tbody>
</table>

*Source: Caralis et al. 1993*
MYTHS REGARDING ADVANCED DIRECTIVES

- They are wills
- They require an attorney
- Care will be less attentive/aggressive
- They address burial arrangements

PERVASIVE THEMES

- Prayer to ease the passage of the soul
- Rituals or ceremonies to foster the passage to the “light” or into another “life”
- Involvement/support of family

GENERAL CONSIDERATIONS

- Consider how a patient wants to be addressed
- Observe the patient’s reaction to posturing and space
- Eye contact
- Touch
- Use of interpreters/communication
- May not be the patient’s decision
BELIEFS REGARDING DEATH AND DYING
- Hispanic/Latino Americans
- African Americans
- Native Americans
- Filipino Americans
- Vietnamese Americans
- Jewish Americans
- Chinese Americans
- Vietnamese Americans
- The Middle Eastern Community

*The following is based on "general" beliefs for broad cultural groups and may not apply to all members of that group.

2-13-15

HISPANIC/LATINO, 1 OF 1
- Primary language spoke is Spanish
- Predominant religion is Catholic
- When communicating, the patient may avoid eye contact as a sign of respect
- Feel end of life discussion may be "harmful" to patient
- The family, not the patient makes the decisions
- Patients do not complain of pain although, it is more culturally acceptable for women to do so
- Vocal expression of grief is acceptable and expected
- Relatives may help with care of the body
- After death, wakes may be prolonged with Novenas held the day after burial for 9 days thereafter
- Organ donation and autopsy are uncommon

AFRICAN AMERICAN, 1 OF 1
- The primary religions are Baptist, other protestant religions, and Muslim.
- Pain may be reported openly, but there is a fear of addiction
- Group most unlikely to have advanced directives in place
- Home remedies are frequently used for symptom management
- Elders are held in high regard, so discussing issues with the spouse or elder family member may be requested
- Open displays of emotion are acceptable and common
- A strong belief in the afterlife is held
- Families care for dying elders in the home, however some consider it "bad luck" to die in the home
- Some consider organ donation a taboo/may consider autopsy
- Family prefers the healthcare team to clean and prepare their loved one's body
NATIVE AMERICANS, 1 OF 1
- Do not openly express their religion due to fears of stigma or prosecution when using such items as eagle feathers or peyote
- Many different tribes with many different beliefs
- Family meetings are used to make decisions however some members may avoid discussing impending death
- Avoid eye contact and maintain a respectful distance
- Patients may not report pain as stoicism is valued
- May seek treatment from “Medicine Man”
- In some tribes, being in contact with the dying or dead is considered a reason for needing a cleansing, so some members will avoid contact if possible

FILIPINO AMERICANS, 1 OF 2
- Religion is predominately Catholic
- Trust treatment success is “God’s will” or part of “God’s ultimate plan”
- Patients do not report pain no matter how intense as they tend to close eyes and pray for relief
- May view pain as part of living an “honorable life”, in accepting pain it is an opportunity to atone for past sins
- Despite a poor prognosis or severity of illness, they remain optimistic for a cure
- High value placed on modesty, privacy, and confidentiality
- Non-confrontational, will not question authority figures such as doctors or nurses
- May feel uncomfortable in expressing emotions in a group setting

FILIPINO AMERICANS, 2 OF 2
- May feel uncomfortable in expressing emotions in a group setting
- Once death has occurred, death rituals revolve around their faith. The Novena is the most common prayer typically done for 9 days thereafter
- Organ donation/autopsy are unusual
There are four streams of American Jewish religious thought: Orthodox, Conservative, Reform, and Reconstructionist.

“Pikuah Nefesh” translates to “saving life.”

The shortening of life through suicide, assisted suicide, or euthanasia is categorically forbidden.

For patients who are terminally ill, treatments that are not potentially curative may be refused, especially when harm may result.

Active treatment already started may not usually be withdrawn.

Where resuscitation would possibly result in the saving of a life, it is imperative that it is carried out—even if that life were to last only a few minutes before death.

Before death, a Jewish patient will want to see as many of their family and friends as possible.

The creation of a "living will" is a matter open to much debate among various Jewish groups.

Some groups of Jews may feel that discussing impending death with a patient is a “sinful activity.”

A dying patient might request the presence of a rabbi at any time to go through the ceremony of viddui and to pray.

Belief pain relief is meritorious but fine line between alleviating pain and hastening death.
Primary language spoken is Vietnamese
Predominant religions practiced are Buddhism, Confucianism, and Taoism.
According to Buddha, man was born into this world to suffer. The cause of suffering is the craving for wealth, fame, and power that brings about frustration and disappointment. This is the law of Karma, or cause and effect.
Vietnamese culture prefers non-verbal communication
Confucianism is more of a religious and social philosophy than a religion in the accepted meaning of the word.
Some believe the soul does not perish at death, but reincarnates in another existence and this goes on and on
There is little concern about death, the world beyond, and spiritual feelings in this religion
Taoists focus on finding harmony with natural order of things

Ancestor worship is a cornerstone of Vietnamese philosophy
The Vietnamese attach great importance to two traditional family obligations: to care for their parents in their old age and to mourn them in death
For Vietnamese elders, nodding of the head may show courtesy rather than understanding or consent
Most family members do not want the patient told of the terminal illness

Illness may be attributed to “catching bad wind" which is treated by “cupping” or coining
Some have an aversion to dying in the hospital because they believe that the souls of those who die outside the home wander with no place to rest
Will usually not consider a “DNR" removal of feeding tubes or ventilator
Resistant to organ donation
CHINESE AMERICANS, 1 OF 2
- Language spoken Sino-Tibetan family of languages with multiple dialects such as Mandarin, Wu, Cantonese, and Min. The standardized form is “standard mandarin”
- Predominant religion is Buddhism, Taoism, and Confucianism
- Belief in the Yin and Yang balance of body harmony
- First generation immigrants are reluctant to sign legal documents because of the honor culturally accorded to verbal agreements
- Family may prefer the patient not be told of the terminal illness or imminent death and may prefer to tell the patient themselves
- Some believe death in the home is bad luck
- Others believe that the patient’s spirit will get lost if death occurs in a hospital
- May use special amulets or cloths
- May practice “Cupping” or “coining”

CHINESE AMERICANS, 2 OF 2
- “Death” is a taboo subject because it is associated with evil or bad luck
- It is unacceptable within this culture to talk about their grief
- Complementary medical modalities may be used such as acupuncture or herbal medicine
- Fear blood draw or blood donation as it weakens the body
- Death of a child is not consistent with the natural order of things and may bring shame to the family
- Some prefer to bathe the body themselves
- They believe the body should be kept intact; organ donation or autopsy are unusual

THE MIDDLE EASTERN COMMUNITY, 1 OF 4
- The "Arab World" includes 22 countries in the Middle East and North Africa, population of 180 million
- Arabs speak various dialects of the Arabic language
- The majority of Arabs are Muslims but there are a large number of Arab Christians in Lebanon, Syria, Palestine, Iraq, and Egypt
- Some people wear amulets for protection against the evil eye or will burn incense to keep the evil eye away from the sick
- Muslims must observe prayer 5 times per day
THE MIDDLE EASTERN COMMUNITY, 2 OF 4
- Elders have a prestigious status in the Arab family because of their experience
- In the Arab Culture there is a strong sense of Paternalism what most Westerners call “Male Dominance”
- Men by culture give orders, but by the faith of Islam they are the “protectors” of their families
- They place a high value in modern Western medicine and have confidence in the medical profession

THE MIDDLE EASTERN COMMUNITY, 3 OF 4
- An Arab patient seeing a doctor expects relief from pain and to receive a medication on the first visit
- Nurses are perceived as helpers, not health care professionals, and their suggestions and advice are not taken seriously
- Arabs are not accustomed to the profession of social workers
- In Arab countries, patients are told only the good news about their disease

THE MIDDLE EASTERN COMMUNITY, 4 OF 4
- They consider death to be a destiny decided by God
- Diet may be an issue for Muslims
- Male nurses should not be assigned to female Muslim patients as female purity and modesty are major values
- Patients family members need to be with the body until it is ready to be removed from the hospital
- In Islam, violating the human body is normally forbidden, but it is permitted to save another person’s life
**CASE STUDY #1**

A 24 year old Korean man, visiting family in the United States, became ill and was hospitalized. With a diagnosis of renal and respiratory failure, was put on strict bed rest because exertion would be dangerous.

Conflict arose when the family would get him out of bed to squat over the bedpan on the floor. The nurse tried to explain that the bedpan was to be used in bed, but they spoke little English and became very upset.

**CASE STUDY #1, DISCUSSION**

In most Asian countries, traditional toilets are holes in the ground. To eliminate from the bowels, one squats over the hole. There is no other way to do it. Elimination is considered unclean and certainly should not be done in bed. The patient was trying to maintain standards of cleanliness and decency. He was using the bedpan in the only way he knew how.

After a co-worker explained the patients behavior, the nurse called the doctor and had him rewrite the orders from strict bed rest to bathroom privileges as needed with assistance. The patient and family were much happier and more cooperative as a result.

**CASE EXAMPLE #2**

When the nurse entered the room of her Iranian patient, she found the patient huddled on the floor, mumbling. At first she thought the patient had fallen out of bed, but when she tried to help her up the patient became visibly upset. She spoke no English and the nurse had no idea what the problem was.
CASE EXAMPLE #2, DISCUSSION

The patient had been praying. She was practicing her religion in the traditional manner. Since she was scheduled for surgery the next day, she thought it was especially important to pray.

Devout Muslims believe they must pray to Mecca, the Holy Land, five times a day. Traditionally, they pray on a prayer rug placed on the floor. If the nursing staff had some understanding of Muslim customs, they could have arranged to provide the patient some privacy during certain times of the day so she could pray.

SUMMARY OR CONCLUSION

There are many dimensions of culture: ethnic identity, gender, age, differing abilities, sexual orientation, and religion and spirituality.

As culture influences all aspects of life, especially how one deals with illness, end-of-life care, and grieving, healthcare providers must know how to interact with people of various cultural backgrounds and identities.

Culturally sensitive care is best provided through an interdisciplinary approach, using the gifts that all members of the health care team can offer.

POST TEST, 1 OF 3

1. True or False: Cultural competence in healthcare takes into account the person’s cultural background, cultural beliefs, and their values and incorporates it into the way health care is delivered to that individual.

2. Four components of a cultural assessment include the following:
   a) Height, weight, race, language
   b) Religion, birthplace, language, and sexual orientation
   c) Age, weight, address, language
   d) Height, language, parent’s address, language

3. True or False: A possible barrier to cultural competent care may be our own backgrounds, culture, religious beliefs, and experiences.
POST TEST CONTINUED, 2 OF 3

4. True or False: Two general considerations to keep in mind across all cultural groups are eye contact and touch

5. True or False: When communicating with Hispanic patients, the patient may avoid eye contact as a sign of respect

6. African Americans are the group most likely to have advanced directives in place

7. Which cultural group believes being in contact with the dying or dead is considered a reason for needing a cleansing, so some members will avoid contact if possible?

POST TEST CONTINUED, 3 OF 3

8. Which cultural group may view pain as part of living an “honorable life”, in accepting pain it is an opportunity to atone for past sins?

9. True or False: Chinese Americans believe strongly in organ donation and autopsy

10. True or False: The ritual of “cupping” or coining practiced by some Asian groups may be mistaken for elder or child abuse.

ANSWERS

1. True
2. B
3. True
4. True
5. True
6. False
7. Native Americans
8. Filipino Americans
9. False
REFERENCES

- US Census Bureau 2008 estimates
- ANA Georgia Nurses Association

REFERENCES CONTINUED

- Cultural Competence Journal of Hospice and Palliative Care Nursing: May/June 2008
- Chinese cultural dimensions of death, dying, and bereavement: focus group findings Journal of Cultural Diversity, Summer, 2002 by A. Yick and R. Gupta
- Culturally Diverse Communities and End-of-Life Care American psychological Association Sharon Valente, PhD, R.N. & Bill Haley, PhD with (Drs. Anderson, Kobilos, Neimeyer, Stillion, and Werth)
- Caring for Women From Culturally Diverse Backgrounds Jane Cioffi, RN, PhD, Medscape Nurses

REFERENCES CONTINUED

- Nursing Implications for Treating “Kanser” in Filipino Patients Journal of Hospice and Palliative Nursing Kathryn Schmit, RN, BSN 12/22/2005
- Cultural Considerations at the End of Life AAACN Viewpoint, Mar/Apr 2005 by Russell, Sally S
- End-of-Life Needs of Patients Who Practice Tibetan Buddhism From Journal of Hospice and Palliative Nursing Marilyn Smith-Stoner, PhD, RN 07/29/2005
- Resource: thinkculturalhealth.com