Cultural and Religious Aspects of End of Life Care

NYSNA Continuing Education

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This course has been awarded 2 contact hours.

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NYSNA has been granted provider status by the Florida State Board of Nursing as a provider of continuing education in nursing (Provider number 50-1437).

Note: This course does not satisfy Florida State Mandatory End of Life Care continuing education requirements. Visit the online course catalog for the following online courses that **DO** meet the Florida State requirements.

- Advance Directives: Patient Self Determination
- End of Life Care

How to Take This Course

Please take a look at the steps below; these will help you to progress through the course material, complete the course examination and receive your certificate of completion.

1. **REVIEW THE OBJECTIVES**

   The objectives provide an overview of the entire course and identify what information will be focused on. Objectives are stated in terms of what you, the learner, will know or be able to do upon successful completion of the course. They let you know what you should expect to learn by taking a particular course and can help focus your study.

2. **STUDY EACH SECTION IN ORDER**

   Keep your learning "programmed" by reviewing the materials in order. This will help you understand the sections that follow.

3. **COMPLETE THE COURSE EXAM**

   After studying the course, click on the "Course Exam" option located on the course navigation toolbar. Answer each question by clicking on the button corresponding to the correct answer. All questions must be answered before the test can be graded; there is only one correct answer per question. You may refer back to the course material by minimizing the course exam window.

4. **GRADE THE TEST**

   Next, click on "Submit Test." You will know immediately whether you passed or failed. If you do not successfully complete the exam on the first attempt, you may take the exam again. If you do not pass the exam on your second attempt, you will need to purchase the course again.

5. **FILL OUT THE EVALUATION FORM**

   Upon passing the course exam you will be prompted to complete a course evaluation. You will have access to the certificate of completion **after you complete the evaluation**. At this point, you should print the certificate and keep it for your records.

Course Introduction

During basic nursing education, few nurses take classes or receive clinical experience in caring for the dying patient and their family. Yet, hardly a week goes by in which issues related to death and dying do not occur. Most nurses learn to care for these patients and their families from other nurses and from their own clinical experiences. Still, nurses may feel uncomfortable or powerless to help those patients who are at the end of their lives.

This course will address issues related to end of life from select cultural and religious traditions.

Course Objectives

Upon completion of this course, the learner will be able to:

- Discuss components of a cultural assessment.
- Describe communication factors that must be considered from a cultural perspective.
- Conduct a cultural self-assessment.
- Discuss select health practices of selected ethnic groups.
- Discuss select health practices of selected religious groups.
- Examine case studies for cultural and religious factors that impact on end of life care.

About the Author

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Dr. Matzo's most recent research project, entitled "Oklahomans' Knowledge, Attitudes, and Behaviors related to Palliative Care," was funded by the Hospice Foundation of Oklahoma. She was a Soros Scholar for the Project on Death in America undertaking a project entitled "Undergraduate Nursing Students' Responses to Death Education."

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Definitions

Culture is a system of shared symbols, serving as a guide for our interactions with others (Lenkeit, 2006; Lipson & Dibble, 2005; Mazanec & Tyler, 2003). Cultural practices provide safety and security, integrity, and belonging. Culture is fluid, constantly evolving in response to historical and other factors.

Culture is more than race/ethnicity. Race is not specific to a culture and is only one aspect of one's cultural identity. However, race is significant in assessing culture, because of issues of racism and social beliefs. 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 (Andrews & Boyle, 2003). Although studies may reveal different needs for analgesics, consider that opioid dose may be affected by attitudes and beliefs of healthcare professionals towards persons of different ethnic backgrounds (Kagawa-Singer & Blackhall, 2001).

Components within Culture

Ethnic Identity: Although someone may be of a particular ethnic group, they may not identify strongly with that group. Perceptions of end of life, afterlife, bereavement and other aspects of palliative care vary widely by ethnicity and within cultures.

Gender: Gender factors influence care to patients and family caregivers, including in the decision making regarding end of life care and the provision of end of life care. Discussions with family members at end of life may be directed towards the male head of family or oldest son in more traditional cultures (Blackhall, Murphy, Frank, Michael, & Azen, 1995).

Females administer much of the end of life care in the U.S. These females are often elderly wives or daughters of the dying person. In addition, gender biases have been noted. For example, females are less likely to be prescribed opioids for pain (Cleeland et al., 1994; Vallerand, 1995).

Age: Perceptions of pain often vary with age. Elders may perceive that pain is expected or that they should not complain (i.e., be a bad patient). Elders may also feel uncomfortable in collaborative relationships with healthcare professionals at end of life, having grown up with more paternal interactions with doctors or nurses (American Geriatrics Society Panel on Chronic Pain in Older Persons, 1998).

Treatment of children in pain is often poor due to assumptions about their ability to feel pain, as well as fears of addiction and side effects of analgesics (Sheehan & Schirm, 2003). Parents may deny the child's pain to avoid the reality of impending death.

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 insuring that people with disabilities are entitled to the same rights as other individuals.

Sexual Orientation: Gay, lesbian, and transgendered individuals are often stigmatized (Dahlin, 2001). 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 (i.e., the son with HIV/AIDS who was disowned by his mother may attempt to reestablish the relationship). An important role of healthcare professionals is to assist in this process if the patient seeks support. These individuals may have experienced multiple losses, isolation, and different family systems that influence their present experience.

Religion and Spirituality: Religion is a system of faith and worship. Spirituality is the feeling of interconnectedness with a higher power. Some patients and families find comfort in the rituals associated with their beliefs.

The spiritual assessment is represented by the acronym FICA: Faith, Importance, Community, and Address (Sherman, 2004; Taylor, 2001; Putchalski, Larson, & Post, 2000).

> **F = Faith or beliefs:** What is your faith or belief? Or, do you consider yourself spiritual or religious? Or, what things do you believe in that give meaning to your life?
>
> **I = Importance and influence:** Is it important in your life? What influence does it have on how you take care of yourself? How have your beliefs influenced your behavior during this illness? What role do your beliefs play in regaining your health?
>
> **C = Community:** Are you part of a spiritual or religious community? Is this a source of support to you and how? Is there a person or group of people you really love or who are really important to you?
>
> **A = Address:** How would you like me, your healthcare provider, to address these issues in your healthcare?

Financial Status: Socioeconomic status has a strong influence on all aspects of healthcare (Smedley, Stith, & Nelson, 2003). Individuals 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 out of embarrassment or other factors. An estimated 25% of families are financially devastated by a serious terminal illness.

Place of Residency: 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; society and the healthcare system often ostracize them (Rosendahl-Masella, Sansone, & Phillips, 2004; Rosenthal, 2004).

Employment: Employment is associated with socioeconomic status. Patients may also derive self-identity and self-worth through their jobs/professions. As illness progresses and participation in work becomes impossible, patients may feel a crisis in knowing their "self."

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

Domains of Culture: There are many domains of culture: ethnicity, communication, and health beliefs.

Summary of the Domains of Culture

Domain	Description
Ethnic Identity	Country of origin, ethnicity/culture with which the group identifies, current residence, reasons for migration, degree of acculturation/assimilation, and level of cultural pride
Communication	Dominant language and any dialects, usual volume/tone of speech, willingness to share thoughts/feelings/ideas, meaning of touch, use of eye contact, control of expressions and emotions, spokesperson/decision maker in family
Time and space	Past, present, or future time orientation, preference for personal space and distance
Social organization	Family structure, head of household, gender roles, status/role of elderly, roles of child, adolescents, husband/wife, mother/father, extended family; influences on the decision-making process, importance of social organization and network
Workforce issues	Primary wage earner, impact of illness on work, transportation to clinic visits, health insurance, financial impact, importance of work
Health beliefs, practices, and practitioners	Meaning/cause of cancer and illness/health, living with life-threatening illness, expectations and use of Western treatment and healthcare team, religious/spiritual beliefs and practices, use of traditional healers/practitioners, expectations of practitioners, loss of body part/body image, acceptance of blood transfusions/organ donations, sick role and health-seeking behaviors
Nutrition	Meaning of food and mealtimes, preferences and preparation of food, taboos/rituals, religious influences on food preferences and preparation
Biologic variations	Skin/mucous membrane color, physical variations, drug metabolism, laboratory data, and genetic variations-specific risk factors and differences in incidence/survival/mortality of specific cancers
Sexuality and reproductive fears	Beliefs about sexuality and reproductive/childbearing activities, taboos, privacy issues, interaction of cancer diagnosis/treatments with beliefs about sexuality
Religion and spirituality	Dominant religion, religious beliefs, rituals, and ceremonies, use of prayer, meditation or other symbolic activities, meaning of life; source of strength
Death and dying	Meaning of dying, death and the afterlife, belief in fatalism, rituals, expectations, and mourning/bereavement practices

Source: Oncology Nursing Society (1999)
http://www.ons.org/clinical/documents/pdfs/multicultural2.pdf

Cultural Competence

Culturally competent nursing care includes sensitivity to issues related to ethnicity, gender, sexual orientation, social class, economic factors, and other factors previously cited. Cultural competence involves knowledge, attitudes, attributes, and skills (Lenkeit, 2006; Lipson & Dibble, 2005; Mazanec & Panke, 2006).

Knowledge about other ethnic and cultural groups is essential, although not sufficient.

Attitudes are derived from the healthcare professional's own cross-cultural experiences and education. Nurses must become aware of their own cultural beliefs and values and how these influence their behaviors and attitudes about others.

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.

Skills include cross cultural communication, cultural assessment, cultural interpretation, and intervention (Campinha-Bacote, 2003).

Importance of an Interdisciplinary Team

Similar to other aspects of palliative care, an interdisciplinary team approach is vital to culturally competent care. Healthcare providers, social workers, psychologists and chaplains offer tremendous support in cultural assessment.

Components of Cultural Assessment

A. Patient/Family/Community

1. 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? Where were their grandparents born?

2. What is the person's ethnic affiliation and how strong is the ethnic identity?

3. Who are the patient's major support people: family members, friends? Does the patient live in an ethnic community?

4. How does the patient's culture affect decisions regarding medical treatment? Who makes decisions, the patient, the family, or a designated family member? What are the gender issues in the patient's culture and in the family structure?

5. What are the primary and secondary languages, speaking and reading ability and education level?

6. How would you characterize the nonverbal communication style?

7. What is the religion, its importance in daily life, and current practices? Is religion an important source of support and comfort? What are other aspects of spirituality?

8. What are the food preferences and prohibitions?

9. What is the economic situation, and is the income adequate to meet the needs of the patient and family? What healthcare coverage is available?

10. What are the health and illness beliefs and practices?

11. 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 do the patient and family wish to know about the disease and prognosis? What are their beliefs about the afterlife and miracles? What are their beliefs about hope? What are their beliefs about pain and suffering?

    Source: Mazanec & Panke (2006)

B. The Nurse

The nurse and all healthcare providers should ask similar questions of him/herself, as well as assess his or her own view of other cultural groups (Zoucha, 2000).

Cultural Self-Assessment

1. Where were you born? If an immigrant, how long have you lived in this country? How old were you when you came to this country? Where were your grandparents born?

2. What is your ethnic affiliation and how strong is your ethnic identity?

3. Who are your major support people: family members, friends? Do you live in an ethnic community?

4. How does your culture affect decisions regarding their medical treatment? Who makes decisions - you, your family, or a designated family member? What are the gender issues in your culture and in your family structure?

5. What are your primary and secondary languages, speaking and reading ability?

6. How would you characterize your nonverbal communication style?

7. What is your religion, its importance in your daily life, and current practices? Is religion an important source of support and comfort?

8. What are your food preferences and prohibitions?

9. What is your economic situation, and is the income adequate to meet the needs of you and your family?

10. What are your health and illness beliefs and practices?

11. What are your customs and beliefs around such transitions as birth, illness, and death? What are your past experiences regarding death and bereavement? How much do you and your family wish to know about the disease and prognosis? What are your beliefs about the afterlife and miracles? What are your beliefs about hope?

Adapted from: Zoucha, (2000)

C. Other Healthcare Providers

Evaluate the cultural beliefs of co-workers. There is increasing cultural diversity among healthcare professionals and one should not assume that the team providing care at end of life holds common beliefs, such as the concept of autonomy (Blackhall et al., 1995; Koenig, 1997; Lipson & Dibble, 2005).

Brief Cultural Assessment: The CONFHER Model

C= Communication
Does the client speak English?
Understand common health terms, such as pain or fever?
What nonverbal communication is used?

O= Orientation
What are the client's ethnic identity, values, orientation and acculturation?
Do they identify with a specific group?
Where were they born?
How long have they lived here?

N= Nutrition
Food preferences and taboos. Food has meaning for most people and is a source of comfort. There may be some foods the person must avoid eating because they are taboo in their cultural group. *Consider addressing issues of artificial nutrition and hydration based on assessment findings.*

F= Family Relationships
Family structure is important…
How is family defined and who is in the family?
Who is the head of the household?
Who makes decisions in the family?
What is the role of women and children?
Is it important to have family present when someone is sick?

H= Health and health beliefs
Not all cultural groups subscribe to the germ theory of disease. Illness may be the result of evil spirits or something being out of balance.
What does the person do to stay healthy?
Who do they consult for health problems?
How do they explain illness?

E= Education
What is the person's learning style and educational level?
How much formal education did the person complete?
What is their occupation?

R= Religion
What is that person's preference?
Does the client have any religious beliefs or restrictions that have an impact on health care and illness?

Source: Fong (1985)

Cultural Considerations of Communications

Communication is important in all interpersonal relationships; however, at the end of life it is critical.

Use of Interpreters: If possible, avoid the use of family members as translators. They may interject their own beliefs and values. Some ethnic groups may represent a very small or tight knit community. It may be difficult to find translators who are not socially known to the patient and their family. Telephone translation services may be available.

Ask the translator to meet with the family before hand to establish trust and determine their level of understanding of the situation, their beliefs about the illness, and their need for information.

Speak to the patient and family, not the interpreter. Use short simple sentences, avoid medical jargon. Wait patiently for responses. Recognize that some patients may respond, "yes" even when they do not understand. Ask the patient to repeat what they understood to verify comprehension. This takes significant time. If possible, schedule several blocks of uninterrupted time for these conversations.

Conversational Style: Ask patients how they would like to be greeted (e.g., first or last name?). Assess whether the patient wishes to speak for him or herself or have a family member or other make decisions and serve as spokesperson (Lipson & Dibble, 2005).

Personal Space: Observe the patient's reactions to posturing and space. If too close, the patient may back off and view the healthcare professional as aggressive. Some cultures have very little requirements for personal space. In these cases, if the professional is physically not close enough, the patient may view them as distant and uncaring.

Eye Contact: As with personal space, 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: Avoid imposing own attitudes, beliefs, etc. on the patient.

Auditory versus Visual Learning Styles: Supplement oral communication with visual teaching materials. Question patients/family members whether they would like materials in English or another language and whether they prefer written materials or audio/videotapes.

Role of the Family: Another important aspect of communication is the role of the family relative to the patient. Who makes decisions in the family? Who is the spokesperson? Is it the patient or a family member? Who should be included in discussions?

Confidentiality: There is also the matter of respecting confidentiality. Many family members and friends may contact the healthcare staff asking for information, particularly if communication within a family is strained (e.g., families where divorce has caused conflict). Professionals may ask the family to select one person to serve as the key contact for information.

Disclosure to Patient: Another important consideration is disclosure of information to the patient. Is full disclosure (i.e., telling the patient their diagnosis and/or prognosis) acceptable (Mazanec & Kitzes, 2003)?

For more information on translation service, check-out the National Council on Interpreting in Healthcare (NCIHC – http://www.ncihc.org/mc/page.do) and Diversity Rx (www.diversityrx.org).

Beliefs Regarding Death and Dying, Afterlife and Bereavement

The groups and religions that are summarized below comprise a large percentage of cultures within the United States. These are generalizations regarding these groups. Keep in mind that individuals may not identify with their respective ethnic group. Others may have strong affiliations with these groups. It is imperative to avoid stereotyping. Many other groups although not mentioned here, are represented in the U.S. (Hallenback, 2002; Kagawa-Singer & Blackhall, 2001; Lapine, Wang-Cheng, Goldstein, Nooney, & Derse, 2001; Mazanec & Panke, 2006; Paice & O'Donnell, 2004).

Throughout the dying process, and particularly at the very end of life, the nurse must be aware of cultural and religious values, practices, and traditions of the patient and the family. Customs and rituals have tremendous significance in the healing process following death. The grief response is often structured by these rituals. The nurse's role is to help the family carry out the rites and practices that provide solace and support. The nurse should be open-minded and understanding of the physical and psycho/social and spiritual needs of the dying patient and their family and, offer them respect and privacy (Hallenback, 2002; Kagawa-Singer et al., 2001; Lapine et al., 2001).

> **"Any discussion of the influence of culture on end-of-life decision-making must be tempered with the admonition to proceed cautiously. We can never assume that all members of the group will act the same or share the same beliefs."** (Mitty, 2001, p. 29)

Some patterns tend to be true for many cultural and racial groups in the United States (Mitty, 2001):

- Elders tend to have and prefer a passive voice "Doctors and nurses do the best they can."
- Several studies report that the poor expect to be denied care and see advance directives as legal ways for the healthcare system to deny care.
- Research does not support the presumption that people prefer a moderate quality of life to living longer.
- If able to choose, most people would elect length of life over quality of life.
- Close-knit families see advance directives as destructive.
- Older adults consider pain to be a normal companion of aging.

Despite best efforts, clashes will occur. The key is to continue attempts to understand each perspective, and take time to understand your own reactions.

Failure to take the culture seriously means we choose to place our own values over those of differing backgrounds. For example, assuming a Chinese woman would not want to be told her diagnosis because she is Chinese is stereotyping. Insisting that she be told, and disregarding her rights, is akin to cultural imperialism (Kagawa-Singer et al., 2001).

Suggestions to address cultural conflicts (Lapine et al., 2001):

- 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.

<u>Ethnic/Cultural Groups</u>

Hispanic/Latino (Munet-Vilaro, 1998)

- The primary language is Spanish and the predominant religion is Roman Catholic. When communicating, patients may avoid eye contact as a sign of respect. The family, rather than the individual, generally makes decisions. Reverence is shown to elders. Family may withhold the diagnosis and/or prognosis from the patient.
- Patients tend not to complain of pain, although it is more culturally acceptable for women. Stoicism is highly regarded (Villarruel & de Montellano, 1992).
- Extended family members are often involved in end of life care. Vocal expression of grief and mourning is acceptable and expected.
- Pregnant women are prohibited from caring for the dying or attending funerals.
- Prayer and folk remedies are common, as are the use of religious medallions, candles, and rosaries.
- For some individuals, dying in the hospital means their spirit will be "lost." These patients would prefer to die in the home.
- Spiritual amulets, rosary beads, or other religious artifacts are kept near the patient.
- After death the family may wish to attend to the body and spend time alone with their loved one. Most will not agree to procedures that might alter the body, such as organ donation or autopsy. Strong belief in the afterlife and eventual resurrection of the dead.
- When death occurs, family and friends will often come from long distances for the funeral. A *velorio* is a festive watch of the deceased body before burial. Traditional families may exhibit hyperkinetic shaking and seizure like activity called *ataque de nervios* which is a way to release emotions related to grieving.
- Wakes may be prolonged and the deceased is often worshipped. The Novena is held for the day after the person has been buried and continues for 9 days. The rosary is said each day at the home of the deceased. The home is kept closed to allow undisturbed mourning. Family members wear black, white or purple.
- The deceased are worshipped on the Day of the Dead, *La Dia del Muertos*, held on November 2. Some families conduct picnics at the gravesite of the deceased. Family may erect altars in their homes in honor of the anniversary of their relative's death. Candles, decorations, and having the deceased's favorite meal at a grave-side picnic may also be included (Purnell & Paulanka, 1998). Children are given candies in the shapes of skeletons, teaching them not to fear the dead.
- Cuban-Americans who are dying are usually attended by large groups of family and friends. Depending on their religious affiliation, a Catholic priest, Protestant minister, Jewish rabbi, or *santero* may be called to perform death rites. For followers of santero these rites may include animal sacrifice, ceremonial displays, and chants (Purnell et al., 1998). After the ceremony, death candles are lit to light the path for the spirit to the afterlife. Burial is the common custom although there is no restriction to cremation

African American

- Pain may be reported openly, but there is often a strong fear of addiction. This concern may also complicate treatment of dyspnea at end of life.
- Reluctance to report depression. May use "tired" as alternate term.
- Home remedies are frequently used for symptom management.
- Distrust of the healthcare system.
- Many see advance directives as a way to neglect or deny treatment to the dying.
- Discuss issues with the spouse or the oldest family member; elders are held in regard.
- Illness is viewed as a test of faith.
- Death is sometimes preferred in the hospital; it is considered bad luck to have someone die in the home.
- Open displays of emotion are acceptable and common. Grief is expressed openly and publicly.
- Organ and blood donation may not be accepted. Religious restrictions may also apply (e.g., Jehovah's Witness, Islam, etc.).

- Strong belief in the afterlife. Primary religions: Baptist, other Protestant religions, and Islam.

Native Americans

Native Americans have different traditions in each tribe. For example, in some tribes there is a belief that the spirit of the deceased remains where the person has died therefore, family members may not want the person to die at home. At the same time, it is considered inappropriate for the person to die alone. If the person dies at home, the house must be abandoned or a ceremony is held to cleanse it. Families gather together at the time of death and material possessions are dispersed. When a person dies, a cleansing ceremony is performed or else the spirit of the deceased may try to take over someone's spirit. Those who work with the dead must also have a ceremonial cleansing to protect themselves from the dead person's spirit. No embalming is used; the deceased are buried in sacred ground with their shoes on the wrong feet, rings on their index fingers, and with many gifts surrounding them, or the body is cremated (Purnell et al., 1998).

- Family meetings are useful at end of life to make decisions about the type of treatments that should be pursued.
- Avoid eye contact and maintain a respectful distance.
- Stoicism is common; thus patients may not report pain. Listen for other statements, such as vague complaints of "not feeling good."
- The use of traditional medicines is common.
- Some tribes avoid contact with the dying. These individuals may prefer to die in the hospital.
- Even though the outcome of the patient's illness may be obvious, family members may display hopefulness and a positive attitude. The family may avoid discussing impending death. Mourning is not displayed in the patient's presence.
- Native Americans may not openly express their religion, in part due to fears of stigma or fears of prosecution when using items such as eagle feathers or peyote.

Appalachians

For Appalachians, a death is an important event, even for extended family. The funeral is a significant social occasion and family and friends will come from long distances to be in attendance. The body is displayed for long periods of time so all that wish to see the body can. The deceased is buried in their best clothes and some people have custom-made clothes for burial (Purnell et al., 1998). At the funeral home personal possessions are displayed and it is common to bury these items with the person. Gravesites are typically on hillsides because of the fear that they will be flooded out in low-lying areas (Purnell et al., 1998).

Asians

Subgroups from China, Vietnam, Laos, Thailand, and Burma are collectively called the Hmong. The Hmong believe that proper burial and worship of the dead and other ancestors directly affects the safety, health, and prosperity of the family. The belief is that the spiritual world co-exists with the physical world and that the spirits are able to influence human life. The preference is to die at home because they believe that their soul will wander for all of eternity without a resting place if they die elsewhere. There are some groups who believe that death should take place in the hospital so as not to bring bad luck into the home. Autopsy and cremation are acceptable practices to some families. For these groups burial occurs in the afternoon.

The **Chinese** will place a coin in the deceased's mouth so that they have money to pay anyone who interferes in their journey. In northern China the body is placed in burial clothes and an unpadded quilt is used as a shroud. The face is covered with cloth or paper and the feet are tied

with colored string. The wife or oldest son wipes the corpse's eyes with cotton floss before the coffin is closed. Instead of being buried immediately after the funeral the body may be stored so that a husband and wife can be buried together (Iserson, 1994).

Chinese-American

Some cultural considerations include (Martinson, 1998):

- Eye contact is often avoided; it represents disrespect to persons in authority. Distances between the patient and healthcare professional are respected. Affection between family members is rarely exhibited in public.
- "Saving face" is very important. Patients may not report pain since this may seem as if they are accusing the professional of inadequate care. They may also not want to disclose information that might be private or embarrassing.
- When observing patients and family members, the conversation may appear loud and even argumentative to non-Chinese people.
- Family members often do not tell the patient their diagnosis at end of life. There is a fear the patient may become despondent.
- Terminating treatment is seen as murder and can adversely affect the fate of the living.
- Patients may take a passive role, with family members making decisions about their care at the end of life.
- Foods, traditional Chinese medicines, and acupuncture are commonly used to treat the disease and symptoms in combination with modern medicines.
- A good death includes dying with their stomach full. This can raise issues for the use of food and fluids at the end of life.
- For some dying at home may be considered bad luck. For others dying anywhere else but home means that the soul will wander with no place to rest.
- Belief in the afterlife and religious practices varies widely. Religion was outlawed in the People's Republic of China (beginning in 1949). Persons who practiced their beliefs were persecuted. Many at end of life may wish to reconnect with past religious beliefs. Often Chinese patients and families may practice a combination of Buddhist and Christian religions.

The **Japanese** bathe their dead, shave some of the hair, and dress the person in white. The corpse wears a ceremonial hat or triangular piece of white paper tied to the forehead. **Koreans** use perfume to wash the body and dress the body in silk or hemp clothes tied in seven places that correlate with the seven stars in the Ursa Major constellation (Iserson, 1994).

Religious Groups

Roman Catholic priests will give the "Sacrament of the Anointing of the Sick" which in the past was called the "Last Rights". The sacrament is for those who are seriously ill; the family, friends, and priest gather at the bedside to pray for healing. If it is God's will that the person not recover from their illness, then the prayer is that God will accompany the dying person toward the rewards of heaven (Miller, 1993). The nurse can ask the family if they would like the priest to be called. The priest will hear the patient's confession of sins, absolve them, and offer the Sacrament of the Sick. The comfort that this ritual can bring to the dying Catholic and their family cannot be underestimated.

A **Hindu** who is dying may also request holy rites before death; readings and hymns from holy books are also comforting. Some may wish to lie on the floor to symbolize their closeness to the earth. A Hindu priest would administer the holy rites, which may include tying a thread around the wrists or neck of the dying person, sprinkling blessed water from the Ganges, or placing a sacred tulsi leaf in their mouth. Some Hindus may wish to return to India to die, especially to the holy city

of Banaras. Many believe that to die in Banaras insures a rebirth in Heaven or even a release from continued rebirth. At a minimum, a Hindu will request to die at home because death in the hospital is very distressing. Only a Hindu should touch the dead body. If it is necessary for a non-Hindu to touch it disposable gloves should be worn. Sacred threads, jewelry and other religious objects should not be removed. The body should not be washed, only wrapped in a plain sheet. Washing of the body is a part of the funeral rite and is typically carried out only by family members; a mixture of milk and yogurt is used to cleanse the body. In India, a funeral takes place within 24 hours; adult Hindus are cremated but young children and infants may be buried (Green, 1989a).

The dying person of the **Islamic faith** may wish to lie or sit facing Mecca. If it is possible, the bed should be positioned to accommodate this wish. The **Muslim** believes that the body belongs to God and therefore autopsies are forbidden unless ordered by the Coroner. Likewise, organ donation and cremation are not acceptable. In Iran, a person is immediately placed in a casket if they have died during the day. If they die at night, a copy of the Koran is placed on their chest and a lighted candle at their head (Iserson, 1994); the body is watched during the night by a person reading the Koran (Qur'an).

Following the death, non-Muslims should wear gloves when touching the body. If there is no family available to carry out post-mortem care, the nurse may carry out the preparation of the body. However, the body is not washed and hair or nails are not cut; wear gloves when administering care and close the eyes. The "normal Muslim procedure" is that the body is straightened immediately after death. This is done by flexing the elbows, shoulders, knees and hips first, before straightening them. This is thought to ensure that the body does not stiffen, thus facilitating the washing and shrouding of it. Turn the head towards the right shoulder. This is so the body can be buried with the face towards Mecca (Green, 1989b). The body is then covered with a sheet that cloaks the whole body until a Muslim is available to perform the ritual bath. The body is usually washed three times, first with lotus water, then camphor water, and lastly with plain water (Iserson, 1994). This bathing is done from head to toe and front to back. All body orifices are closed and packed with cotton (to prevent body fluid leakage that is considered unclean).

Prayers from the Qur'an are read (especially verses of hope and acceptance) and the body is wrapped in a special cotton shroud. This shroud is made from three pieces of white, unsewn cloth, nine yards long that are wrapped above, below, and around the mid-section. Muslims are buried in a brick or cement-lined grave with their head facing Mecca. In Iran, the body is buried directly in the earth with the shroud removed from the face and one side of the face turned to be in contact with the earth (Purnell et al., 1998).

The **Jew** who is dying may want to hear or recite special prayers, such as the Shema, which confirms belief in one God, or psalms, in particular psalm 23, The Lord is my Shepherd, as well as holding the written prayer in their hand (Green, 1989c). A relative remains with the dying person to ensure that the soul does not leave the body when they are alone; it is a sign of disrespect to leave the body alone. Even after death, the body is not left alone until the funeral, so that the body is not left defenseless (Purnell et al., 1998). The eyes should be closed after death, preferably by a child of the deceased; the body should be covered and left untouched (Green, 1989c). Autopsies are not permitted, although organ transplants are. The body should be handled as little as possible by non-Jews and burial should take place within 24 hours. Burial is usually only delayed for the Sabbath. Embalming and cosmetics are not a part of traditional practice. Orthodox Jews are always buried, although more liberal Jews may select cremation. The body is wrapped in a shroud and a prayer shawl. The casket is made of wood, so that the body and the casket decay at the same rate. There is no wake or viewing of the body. At the funeral, a prayer for the dead is said (the Kaddish), which praises God and reaffirms faith (Purnell et al., 1998).

For the **Buddhist** an important consideration is the state of mind at the time of death; dying thoughts and desires are crucial in determining their next rebirth. A Buddhist monk or minister

should be notified at the time of death. The length of time between death and burial can vary between three and seven days depending on the Buddhist tradition. Family members plan the burial; the tradition is to wear white to the funeral.

Church members of the same gender as the deceased, who have permission to be admitted into the temple, dress deceased members of the **Church of Jesus Christ of the Latter-Day Saints (Mormons)**. The body is dressed in white undergarments that are covered by a robe, cap, and apron. Prior to burial white caps are placed on the men and women's faces are veiled (Iserson, 1994).

Conclusion

There are many dimensions of culture, including ethnic identity, gender, age, differing abilities, sexual orientation, religion and spirituality, and other factors. Culture influences all aspects of life, especially illness and end of life care. Various cultures hold different beliefs about death and dying and healthcare providers must be aware of the beliefs of patients in their care. It is important to be able to conduct a cultural assessment of patients, families and communities.

Evaluate region of healthcare service area/agency

Nurses should evaluate the region serviced by their healthcare agency. What are the primary ethnic groups within that region? Develop an understanding of these groups and learn their cultures (Nishimoto, 1996).

In addition to being knowledgeable about the culture of the patients and families to whom we provide care, nurses must be aware of their own cultural identity and be aware of how it may impact on their nursing practice.

Culturally sensitive care is a major goal in providing end of life care.

Case Studies

Case Study #1 - "Mr. Li"

Mr. Li is a 65-year-old Chinese-American man, diagnosed one year ago with Amyotrophic Lateral Sclerosis (ALS). The patient has been told he has a "muscle and nerve disease", but despite the fact that his disease is clearly advancing, he has not been told of his diagnosis or prognosis. Mr. Li is losing weight (20 lbs. in the previous two months) and appears to have difficulty swallowing. He lives with his wife in a second floor apartment. His two sons are both married and live in the area. He denies any religious affiliation. While performing a thorough physical assessment, the home hospice nurse observes round bruises over several areas of the patient's back. As Mr. Li's disease progresses, he becomes more weak and unable to move from bed. When asked how he is feeling, he always whispers "fine" and denies any symptoms. His wife, Mrs. Li, is fearful that her husband's appetite has not only diminished, but that he is having difficulty swallowing. She believes he will be cured if only he will eat and that he must try harder. The nurse observes the patient having difficulty swallowing, potentially aspirating, when given soft food. The nurse explains this to Mrs. Li, who appears unable to understand. During a later visit by the home care nurse and social worker, the sons also are present. Mr. Li is minimally conscious, febrile, tachycardic, and diaphoretic. The oldest son tries to encourage Mr. Li to eat. He refuses to listen to the hospice nurse about the possible outcome of feeding his father and the gravity of his father's condition. He angrily states that his father is going to get better and requests antibiotics for the fever. The youngest son, speaking privately to the nurse, understands that his father is dying. When the nurse speaks about preparations for Mr. Li's death, the wife and oldest son are unable to participate in the conversation. The next day, the family admits Mr. Li to the hospital, where he dies within 24 hours.

- What are essential components of cultural assessment for this family?
- What aspects of Chinese-American culture are displayed in this scenario?
- How should the nurse respond to the patient's use of moxibustion? (Note: Moxibustion is a form of traditional Chinese medicine in which a cup is placed over the skin and the top of the cup is heated. This often produces a round burn-like bruise. It is believed to relieve toxins. It is occasionally misunderstood by healthcare professionals as a sign of physical abuse. These may also be Mongolian spots, which are discolorations of the skin that look like bruises.)
- What could an interdisciplinary team have done to improve care at the end of life?

Case Study #2 - "F.L., a Near-Drowning Victim"

F.L., a 14-year-old Pakistani boy suffered a near-drowning episode that compromised his central respiratory drive mechanism and left him neurologically devastated. His family was informed that life-sustaining medical interventions were futile. They agreed to move him to the Butterfly Room to achieve a family-centered death. Orders not to resuscitate were written in a clear and detailed manner. All laboratory analyses were discontinued, and all monitors were removed. Medications were reviewed and all were discontinued. Morphine and lorazepam were added for the management of dyspnea, I.V. fluids were discontinued, and scopolamine was administered for terminal secretions. One intravenous catheter was left intact, but all other invasive monitors, such as nasogastric tubes, urinary and arterial catheters, etc., were removed. During his transfer from the ICU to the Butterfly Room, he remained mechanically ventilated.

Although F.L. has a small family, he belonged to a close-knit community. Thirty people of all ages came to be with him on his final day of life. They encircled the boy's bed, chanting but not

touching him. After approximately 30 minutes, they approached the team and announced their readiness for the discontinuation of mechanical ventilation. One caregiver stated that she was unfamiliar with Pakistani traditions and customs, but had not observed anyone touching F.L. She suggested that if touching was allowable and desirable for them, they were welcome to do so. The whole tenor of the group changed, with the circle drawing nearer the bed and men openly grieving and weeping, holding the boy and their wives, as well as each other. People stroked F.L.'s face and body. After an hour, they again informed the team that they were now ready to have the mechanical ventilation discontinued.

F.L. was suctioned and extubated and needed little pharmacologic intervention. His loved ones chanted from the moment the endotracheal tube was removed. Each visitor, in turn, put small amounts of holy water in his mouth. Although the water bubbled out of his nose, a caregiver wiped it away, giving "permission" for the next person to engage in the ritual. After 27 minutes of non-stop changing, F.L. died. A peaceful hush fell over the room, and all eyes turned to the same window, leading to the outside.

Source: Levetown, M. (2001). Pediatric care: The inpatient/ICU perspective. In B. R. Ferrell & N. Coyle. (Eds.). *Textbook of Palliative Care*. New York, NY: Oxford University Press.

- What culturally based beliefs and practices are evident in this case?
- What are the strengths and weaknesses of the care reported in this case?

Case Study #3 - "Mrs. Mendez"

Mrs. Maria Mendez is a 72-year-old Hispanic patient with advanced left breast cancer with metastasis to the lungs and bones. She is referred to your home care agency for wound care services. She has seven children: five daughters and two sons (all living in California). Her five daughters live within the Los Angeles area. Her eldest son lives in San Diego and the younger son has been distant from the family and has not had contact with the family for the last 18 months. Mrs. Mendez's husband died seven years ago of lung cancer. Since that time she has lived with her youngest daughter, Maria.

Initially, Mrs. Mendez discovered the breast lump herself but did not seek medical care for over a year. When Mrs. Mendez was diagnosed, her disease was considered advanced. She refused to have a mastectomy based in part by her cultural belief that the soul resides in the breast and it should not be removed. At the urging of her children, she did undergo chemotherapy but recently has experienced increased bone pain and decided to discontinue the treatment regimen. The tumor in the left breast is now approximately the size of an orange with malodorous, purulent drainage. Home care was initiated for wound care and other symptom management services. Under the terms of her managed care/Medicare insurance plan, her care is referred back to her family care practitioner in her local community rather than her oncologist since she is no longer receiving cancer treatment.

Mrs. Mendez's condition continues to decline and her physician encourages her to seek hospice care. Mrs. Mendez has become very close to the home care nurses who provided the wound care and requests that her care continue with the home care agency rather than a referral to hospice. At this time, changes in her living arrangements are also made. Living with Maria over the last seven years has been very positive, but Maria has three young children and the intensive care of her mother at this stage of the illness is becoming a problem. The family emphasizes that Mrs. Mendez should move in with her eldest daughter, Gloria, who no longer has children living at home. Although her daughters have always been close to their mother and more involved in her care, the eldest son of the family, José, who resides in San Diego, is consulted for all decisions and has been the father figure of the family since Mr. Mendez's death. Mrs. Mendez's managed care plan allows for only two RN visits per week and must be reevaluated every three weeks by the case manager. In addition to the symptom management provided by the home care agency,

Mrs. Mendez and her daughters use many alternative therapies which includes "cat's claw," herbs, and visits by a healer. Mrs. Mendez is religious and uses prayer to help cope with her illness. Her middle daughter, Christina, is devout in her religion and is in absolute denial that her mother will die. Christina comes nightly and holds a prayer vigil with her mother and also brings herbs and remedies that "will cure the disease." Mrs. Mendez becomes increasingly withdrawn as conflicts arise among her children. Gloria and Christina are at odds because Gloria is most accepting of her mother's impending death. Gloria was also the primary caregiver during her father's illness with lung cancer.

After three weeks of care by the home care agency (HCA), Gloria calls requesting that a nurse come as soon as possible because her mother's pain is worse. On physical assessment, the nurse notes that the breast tumor remains dry, however the tumor mass has increased and the breast is inflamed. Mrs. Mendez describes the pain as an intense pressure pain at the site of the tumor in the base of the breast. She also describes a sharp stabbing pain in the left upper quadrant of the breast. In addition, Mrs. Mendez complains of intense pain in her mid-back which has made it very difficult to lie in bed and she has been unable to sleep for the last week. She has been taking one to two Vicodin every four hours PRN although yesterday Gloria reports that out of desperation the Vicodin was given approximately every two hours until Mrs. Mendez became extremely nauseated. The nurse recalls that morphine was ordered for the patient a few weeks ago in anticipation of increased pain not controlled with the Vicodin. Upon questioning, the daughter states that they have not used the morphine as they were "Saving it for the end." Gloria also reports that the family is trying to minimize the use of the medicine since their mother is extremely constipated. Gloria continues to relate that the reason her mother is constipated is because Mrs. Mendez has not been able to continue her herbal remedies due to nausea. Mrs. Mendez appears very stoic with minimal expression of pain. Her only complaint is that she no longer is able to have her grandchildren over to visit due to her declining condition.

Mrs. Mendez is initiated on a regimen of long-acting morphine, 60 mg at bedtime with 15-mg morphine immediate release (MSIR) for rescue dose. Over the next week, the long-acting morphine is increased to 120 mg BID supplemented with Imipramine 50-mg BID and Ibuprofen 800 mg TID. Christina has now moved into Gloria's home and continues her evening prayer vigils. José calls several times a day to dictate his wishes regarding his mother's care but has not been able to visit often from San Diego as he is in risk of losing his job. Gloria seems increasingly burdened with her mother's care and her siblings' involvement. Gloria follows the home care nurse to the car weeping because of the stress.

Approximately one week later, the nurse receives a call from Gloria reporting that her mother has seemed to decline rapidly over the weekend. Mrs. Mendez awoke during the night with difficulty breathing and has been terrified of the possibility of suffocation. On exam, the nurse notes that Mrs. Mendez has developed extreme shortness of breath. She is also increasingly fatigued and the combination of exhaustion, dyspnea, and general decline has resulted in minimal intake of foods or fluids. José called this morning with strict orders that his sisters continue to feed their mother at all costs. He hopes to be able to come up from San Diego the following weekend to visit. Mrs. Mendez relates to the nurse that she knows she is dying and does not want to continue being a burden to her family.

Mrs. Mendez's physical condition had briefly improved due to aggressive symptom management by the HCA. The morphine dose has increased to 240 mg BID supplemented with 40 mg of MSIR approximately every two hours for dyspnea. With her breathing improved, she has been able to take sips of water and occasional amounts of other liquids. Mrs. Mendez's condition, however, continues to decline and the home care nurse anticipates that she will die within the next two weeks. The HCA schedules a meeting with the primary nurse and social worker to discuss the growing tension in the family. Four of the daughters are now present in the home taking shifts to be at Mrs. Mendez's bedside at all times. To make the family situation more difficult, José has learned that the young brother Pablo is living in Los Angeles and asks Pablo that he please visit his mother before she dies. Christina continues her prayer vigils and has asked members of her

church to visit daily to hold prayer meetings with her mother. Mrs. Mendez tells the nurse that she cannot discuss her impending death with her family because they do not want to talk about it or hear that she is dying. At this point, Mrs. Mendez is very withdrawn and has little interaction with her family. Mrs. Mendez has now developed a pressure ulcer on her buttocks and requires a Foley catheter due to incontinence, which has intensified the physical demands of her care.

The HCA receives a call on Saturday evening requesting assistance with Mrs. Mendez as her condition is declining rapidly. The younger son, Pablo, arrived two days ago and has had a very tearful reunion with his mother and his sister, Gloria. The social worker and the nurse were very successful in the family meeting with facilitating communication among the children and establishing common goals for Mrs. Mendez's comfort. All of the children with the exception of Christina, seem accepting of the impending death. Gloria's husband, Michael, has been quite supportive of his mother-in-law's care throughout her illness, but has strong feelings against death occurring within his home.

The priest is called to give Mrs. Mendez communion and the Anointing of the Sick. The extended family is at Mrs. Mendez's bedside, except for Christina who is in the kitchen crying.

Source: *HOPE: Home care Outreach for Palliative care Education Project*. (1998). Funded by the National Cancer Institute. B.R. Ferrell, Ph.D., FAAN, Principal Investigator.

- Use a cultural assessment tool to identify factors that influence care in this case.
- How did culture influence communication with patients and family caregivers in this case?
- Describe the roles of various professional disciplines in this case. How best could these professionals coordinate their care?

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Cultural and Religious Aspects of End of Life Care

Course Exam

After studying the downloaded course and completing the course exam, you need to enter your answers online. **Answers cannot be graded from this downloadable version of the course.** To enter your answers online, go to e-leaRN's Web site, www.elearnonline.net and click on the Login/My Account button. As a returning student, login using the username and password you created, click on the "Go to Course" link, and proceed to the course exam.

1. Culture includes all the following EXCEPT:

    A. Ethnic identity
    B. Religion/spirituality
    C. Intelligence
    D. Gender

2. Cultural competence includes sensitivity to issues related to ethnicity, gender, sexual orientation, social class and economic factors.

    A. True
    B. False

3. When engaging in cultural assessment, it is important to assess the patient, the family, the community, oneself and one's co-workers.

    A. True
    B. False

4. Components of a cultural assessment include all the following EXCEPT:

    A. Identifying the patient's major support people.
    B. Identifying the patient's religion and its importance in daily life.
    C. Identifying beliefs held by all members of a particular nationality.
    D. Identifying the patient's customs and beliefs about illness and death.

5. Personal space, eye contact and touch are variable across cultures.

    A. True
    B. False

6. All members of a particular cultural group will have the same beliefs.

    A. True
    B. False

7. Generally speaking, vocal expression of grief and mourning is acceptable and expected among Hispanics.

    A. True
    B. False

8. “Saving face” is an important concept among Chinese-Americans.

    A. True
    B. False

9. The “Sacrament of the Anointing of the Sick” is often called the “Last Rites.”

    A. True
    B. False

10. Among Hindus, the thoughts and state of mind of the dying person are considered to be crucial in determining the next rebirth.

    A. True
    B. False