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Cultural Competence Module 17
End of Life Decisions

Rosanna Balistreri, B.A., M.A.
Cultural & Linguistic Subject Matter Expert & Consultant
REACH - reaching diversity
www.reach-diversity.com
Rosanna@reach-diversity.com

Rosanna Balistreri is a trilingual speaker of Spanish, Italian & English. She has dedicated her professional and academic background to foreign languages and applied linguistics and holds a B.A. in Applied Linguistics with a Certificate of Teaching English as a Second Language (TESL), an M.A. in Spanish Linguistics, and has undergone extensive training in Healthcare Interpreting, Cultural Diversity, and Leadership Skills.
Ms. Balistreri has served as President of the California Healthcare Interpreting Association (CHIA) for 2010 and 2011, and currently serves in several Advisory Boards as Cross-Cultural Communication & Language Access Expert. In 2007 she founded REACH - reaching diversity to provide Cultural & Linguistic Consulting Services and Solutions to the Health Care and Hospital sectors to enhance quality of care, increase patient safety and maximize customer satisfaction.

Module 17: End of Life Decisions

Module Estimated Time: 30-40 minutes

Statement of Purpose:

The purpose of this module is to stress the importance of understanding culture during the provision of End of Life care since cultural values of sickness, death, dying and grief are very distinct. Many times the opportunity to glean better knowledge of the patient's cultural beliefs around death and dying is presented during the provision of Palliative and Hospice Care. For that reason the module introduces the concept of Palliative Care and Hospice in order to understand how to best facilitate the culturally sensitive End of Life Decision process.

Objectives:

Upon the completion of this module, the learner will:

1. Be able to distinguish Palliative Care and End of Life Care
2. Be able to indentify cultural aspects linked with the concept of Death and Dying
3. Be aware of at least two specific cultural customs about after death observed by different cultural groups

Terminology

Health Beliefs
Holistic Approach
Alternative Medicine
Palliative Care
Hospice
End of Life Care
Pain Management
Comfort Care
Diagnosis
Serious Illness
Emotional Support
Buddhism
Judaism
Infant Mortality
Suicide
Monotheistic Religion
Truth telling the Patient
Cause of illness
Euthanasia
Muslims
Jehovah's Witness
Grief Counselor

1. **Death and Dying across cultures (Introductory Lecture)**
   Discuss the difference of the cultural concept of Death and Dying across multiple cultures

Time: 5 minutes

Materials: None

Although the feeling of loss and grief are universal, how we respond to loss is very much dependent on our cultural interpretation of Death and the practices related to Death and Dying, which vary from culture to culture.

In Judaism, for example, it is valued that someone be present with the dying person at all times. Patients must not be left alone at time of death or the soul would feel abandoned when it leaves.

In rural Greek Orthodox groups, the mourning process takes five years. Only after the fifth anniversary, when the bones are exhumed and reburied in the village ossuary, can the family member rejoin the community life.

In many Asian cultures, on the other hand, it is believed that each person has three souls: a vegetative, an instinctual and a spiritual. These souls leave the body at different times after death: The first day of death, the body loses the vegetative soul; on the seventh day the instinctual soul leaves; and on the 49th day the spiritual soul leaves the body. Ceremonies are held for each of these significant days.

In Muslim cultures, Allah decides when death will occur. Hence, the morning prayer begins with contemplation of one's own death. Grief behavior for the loss of loved ones requires loud wailing to indicate the intensity of pain for the loss.

In Hindu Culture, the soul is believed to reside in heaven until the rebirth occurs in the ongoing cycle of life. Male family members cremate the body and women are not allowed to be present at the cremation, rather they must remain at home to mourn. If the spouse dies, so does the social identity of the spouse. She will no longer be able to participate in community celebrations.

In Latin cultures, Death is celebrated on November 1 (Día de los Muertos) by visiting the graveyard where celebrations and picnics are held. Although death is accepted as a part of life, the painful emotion of loss of a loved one is never healed.

In African Cultures it is believed that as long as the dead loved one is remembered and missed, the spirit continues to exist.

2. Palliative Care, Hospice and End of Life Decisions (Lecture)

Time: 15 minutes

Materials: Laptop/Computer
LCD Projector/Screen
PowerPoint of Module 17

Preparation: Before class, prepare laptop, screen and LCD projector. Have remote control at hand to advance PowerPoint Slides.

Slide 1

Although fewer people die today of chronic disease, and the lifespan of a human being is longer in the U.S., many patients still live with serious diseases that cause much functional, emotional and physical discomfort. For this reason, Palliative Care emerged in the medical field to alleviate or make pain less severe. The goal of Palliative Care is not to cure, rather to improve the overall quality of life. While Palliative Care can prevent, treat or relieve symptoms associated with serious illnesses, it does not cure.

Slide 2

Palliative Care can be offered in combination with Curative Care when a cure is still possible. When a medical condition cannot be cured, Palliative Care alone is offered.

Slide 3

When a patient is close to the end of life, he/she may also use Hospice Care, or Comfort Care. They are both a specialized form of Palliative Care offered to patients who no longer desire life-prolonging treatments. Unlike Palliative Care, Hospice Care and Comfort Care are not offered in the hospital.

Slide 4

All forms of Palliative Care are aimed at improving the quality of life not only for the patient, but also their family and friends by providing holistic care – spiritual and psychological support to patients and their families.

Slide 5

Since Palliative Care provides the time for meetings and counseling, it offers the best time to understand and address concerns that come from the patient's cultural beliefs and values in order to negotiate a plan that can meet the care goals for both the medical team and the patient. Palliative Care provides the needed team effort or patient-provider partnership that takes both medical and patient cultures into account.

Slide 6

End of Life decisions involve very complex and highly emotional conversations. Many ethnic groups prefer not to be directly informed of a terminal illness diagnosis, or family members may want the physician to discuss the diagnosis and prognosis with family members only as these may be the most appropriate individuals to make treatment decisions based on cultural family structure, gender role, generational level and other cultural factors.

Discussions about Advanced Directives may not be well-received as Directives may not have an equivalent concept in the culture of the patient. Discussing these may be viewed as potentially harmful to the patient's well-being.

When patient and/or family members have an English Proficiency limitation, a qualified medical interpreter on site may be preferred to a telephonic interpreter or any non-qualified and untrained bilingual functioning as an interpreter.

Lastly, consider learning about the cultural communication style and pattern of the patient prior to discussing End of Life decisions. Some cultures value a more indirect communication style or may put emphasis on non-verbal communication, such as touch or eye contact.

3. **Cross-Cultural Interview Questionnaire (Group Activity)**
Students will break in groups of 4 and will create a small questionnaire that providers can use with patient for family member to help them understand cultural values around death, dying, family dynamics and communication.

Time: 15 minutes

Materials: Flip Chart Paper with adhesive back or Tape
5 Markers of different colors

Before activity-
1) Instruct students to form groups of four
2) Give a Flip Chart Page to each group and 1 Marker
4) Instruct to create a list of questions that Providers can use with Patient and Family Members to glean better knowledge about the patient's Cultural Values on receiving diagnosis of a terminal illness, discussing the diagnosis and treatment and any communication, spiritual or other beliefs that should be taken into account as conversations about End of Life decisions may happen.

Provide an example, such as: *"Some people want to know everything about their medical condition, and others do not. What is your preference?"*

After Activity – Students share with whole class the questions that they have chosen to include in a Cross-Cultural Questionnaire and debrief on what they found easy or difficult to address during the activity.

4. **Final Thoughts on End of Life Decisions (Closing Lecture)**

Time: 2 minutes

Materials: None

Close this lesson with these points:

- Dying and Death are two concepts shaped by cultural norms and celebrated in a variety of tradition. Some people believe in a life after death; others see death as the end of life in every way. Whatever the belief may be about what happens once a person has departed this life, it can be difficult to engage in conversation about a patient whose life is threatened by a medical condition.
- Palliative Care is a form of care that improves the overall quality of life when a cure may not exist. As the patient approaches the end of his life, a more specialized form of Palliative Care is provided: Hospice.
- Because Palliative Care provides teamwork between patient, family and medical providers, the health care provider may want to leverage this time to glean a better understand of cultural values, traditions, and beliefs around the concepts of death, grieving, or the appropriateness of Advanced Directives in the cultural context.
- Every patient comes with unique religious beliefs, social contexts and cultural values. Health care providers can actively develop rapport with ethnically diverse patients simply by demonstrating an active interest in their cultural heritage.