

***Honoring Cultural Values,
Beliefs and Traditions
at End of Life***



Today's Learning Objectives

- ~ Consideration of Culture
- ~ The Personal & Professional
- ~ White Privilege
- ~ Strategies & Best Practices



Consideration of Culture



When you hear the word CULTURE, what do you think of?



Culture is...



Shared values, traditions, norms, customs, teachings, arts, history, folklore, and institutions of a group of people.



Dimensions of Diversity

- ~ Personality ~ Physical abilities
- ~ Race ~ Parental status
- ~ Gender ~ Family Structure
- ~ Ethnicity ~ Sexual Orientation
- ~ Age ~ Gender Expression
- ~ Education ~ Gender Identity
- ~ Military ~ Geographic Location
- ~ Citizenship ~ Religion/Spirituality
- ~ Income



***Diversity Within Prescribed
Categories***

Black Populations:

Africa (Ethiopia, Egypt) Caribbean
Islands (Haiti, Jamaica)

Asian Populations:

Laos, Korea, China, Japan, Vietnam,
Thailand, Cambodia



***Diversity Within Prescribed
Categories***

Latinos:

Central America, Puerto Rico,
Mexico, South America, Cuba

American Indians:

Hopi, Navajo, Ojibwe, Mohican,
Potawatomi, Ho-Chunk, Iroquois



Why Consider Culture?

- ~ Helps us to understand the values, attitudes and behaviors of others
- ~ Helps us to avoid stereotypes and biases that undermine work with patients
- ~ Plays critical role in development and delivery of services responsive to patient needs
- ~ Potential for value conflicts is great



Varying Cultural Values

- ~ Individualism vs. Collectivism
- ~ Independence vs. Interdependence
- ~ Self-Reliance vs. Interconnectedness
- ~ Future Oriented vs. Present Oriented



Varying Cultural Beliefs

- ~ Medicine
- ~ Illness Attributions
- ~ Familial Determination
- ~ What is said matters



Potential for Value Conflicts

- ~ Dominant culture values concerning illness and dying have shifted regarding truth telling & decision-making; yet, other cultures may....
 - Avoid telling bad news directly to the patient regarding a serious illness or terminal diagnosis
 - Avoid disclosing risk prior to surgery



The Personal & Professional



Develop Self-Awareness of...

- ~ Your beliefs, values, attitudes and customs
- ~ That people from other cultures may not share your beliefs, values, attitudes and customs
- ~ Your assumptions of other's beliefs, values, attitudes and customs
- ~ Your stereotypes and biases



Challenge Self

- ~ To understand your culture and how it relates to your approach to service delivery
- ~ To possess warmth & genuineness for others different than yourself
- ~ To respect those different than yourself



The Professional

- ~ Helps clients express their thoughts and feelings
- ~ Facilitates exploration of alternatives
- ~ Provides information to make informed choices
- ~ Recognizes factors affecting people's ability to choose among viable alternatives



The Intersection...

- ~ Plays critical role in development & delivery of services responsive to needs of our clients
- ~ Influences...
 - How we listen
 - What we hear
 - How we process information
 - How we make decisions
 - How we carry them out



Ask yourself: What are some of the values, beliefs, attitudes, behaviors, life experiences, level of stress, stereotypes and biases I bring to my work with patients?



White Privilege

What is it?

- ~ Privilege that is NOT earned
- ~ The privilege to know you have unearned privilege and to ignore what that means
- ~ Not viewed as threatening: school, employment, rent , buy, etc.
- ~ Evaluated as “better”
- ~ Appears to be strength but really a permission to escape or dominate

How do we know we have it?

- ~ When a person wonders why people still talk about issues of race
- ~ When a person says “I don’t see race”
- ~ When a person fears affirmative action programs will take their spot, which assumes they have a spot
- ~ When a person never has their intellect questioned

Strategies & Best Practices



Cultural Cautions

Avoid:

- ~ Generalizations and assumptions
- ~ Stereotypes
- ~ Belief that limited command of English language means a patient's capacity to make informed decision is compromised
- ~ Ethnocentrism



Approaches

- ~ Walk with the individual - not ahead and not behind
- ~ Be open to his/her emotions & thoughts
- ~ Ask open-ended questions
- ~ What does his/her nonverbal communication say?



Art of Listening

- ~ Do not need something to say
- ~ Allow for silences
- ~ Listen, listen, listen
- ~ Listen in non-judgmental manner
- ~ Listen to nonverbal communication



Honor Word Choice

- ~ Use of different phrases: pay attention and use
 - Cross the river
 - Walk on
 - Passing to other side
 - Going to the spirit world



Honor Feelings

Do not use phrases such as “I know exactly how you feel” or “I understand how you are feeling” or “I can imagine how you are feeling.

Instead...

“I cannot begin to imagine how you are feeling”



Unhelpful Comments

- ~ “Things will look better tomorrow”
- ~ “It all happens for the best”
- ~ “Everything will be ok”
- ~ “You’re still young”
- ~ “It’s time to put it behind you now”
- ~ “This will all get easier”
- ~ “Be strong”

Language

- ~ Use professional translators or community leaders when possible
- ~ Caregiver translator may change words to:
 - Match his/her own beliefs
 - Protect dying individual
 - Protect his/her own interests

What to Listen for...

- ~ Pay attention to what words the patient and family members do or do not use when discussing the illness or dying process
- ~ Are the words explicit or ambiguous?
- ~ Does the patient and the family use the same type of words?

What to Listen for....

- ~ Follow the patient's and family's lead, and use similar language
- ~ If the patient does not appear to know his diagnosis and/or prognosis because the family has not disclosed it to him, then explore this separately with the family



What to Listen for....

- ~ Always be respectful - start discussion with statement of respect – “I respect that different people have different ways of approaching situations”
- ~ Explore previous situations and how they had been handled



Ask Family....

- ~ Why they have chosen to not disclose diagnosis and/or prognosis with patient
- ~ If they think the patient would agree with the nondisclosure decision
- ~ If they have had discussions with the patient prior to the illness regarding this issue
- ~ How has the patient dealt with similar situations in the past



Communication Strategies (Smith, et al., 2009)

- ~ Assess Prior Knowledge
 - *What have you already been told about your illness?*
- ~ Use Simple Language
- ~ Confirm Understanding
 - *I've just said a lot of things today and I want to be sure I did a good job explaining them clearly. In your own words, would you please tell me what you heard me say?*
- ~ Encourage Questioning

After the Conversation

- ~ Provide the type of support the individual or family feel they need
- ~ Allow time for the discussion to sink in
- ~ Allow the individual and family to move at their own pace

Cultural Reflections

- ~ Language differences?
- ~ Open discussions on dying?
- ~ Who are the decision makers?
- ~ Preferences regarding place of death?
- ~ How client & family think about illness?

Cultural Reflections

- ~ How client and family communicate about illness?
- ~ Spiritual beliefs?
- ~ Predeath rituals?
- ~ Postdeath rituals?



Asking About Cultural Beliefs in Palliative Care
(Lum & Arnold, 2009)



Who Should Be Involved...

~ “Some people want to know everything about their medical condition, and others do not. How much would you like to know?”

Preference is family involvement:

~ *Would you like me to speak with them alone, or would you like to be present?*



Unique Cultural Values?

- ~ *Is there anything that would be helpful for me to know about how you and your family view serious illness?*
- ~ *Are there cultural beliefs, practices, or preferences that affect you during times of illness?*

Unique Cultural Values?

- When open to discussing death:
- ~ *What concerns do you have about dying?*
 - ~ *Are there things that are important to you or your family that I should know about?*

Decision-Making?

- Communal or Individualistic?
- ~ *Do you prefer to make medical decisions about tests and treatments yourself, or would you prefer that others in your family or community make them for or with you?*

Practices and/or Restrictions

- ~ Are there specific practices you would like to have in the hospital or home?
- ~ Are there aspects of medical care that you wish to forgo or have withheld because of your cultural beliefs? Is anything discouraged or forbidden?

Practices and/or Restrictions

Terminally ill & open to discussing death:

- ~ Are there specific practices that are important to you at the time of death or afterwards that we should know about?

Beginning the Discussion

“Are there any special customs or beliefs that I should know about as we begin working together?”

Who Should be Involved?

“Some people want to speak with me alone and some prefer family members be present. What do you prefer?”

Preference is family involvement:

Would you like me to speak with them alone, or would you like to be present?

Decision Making?

Communal or Individualistic?

Do you prefer to make decisions about yourself, or would you prefer that others in your family or community make them for or with you?

Practices or Restrictions?

~Are there specific practices _____?

~Is anything discouraged or forbidden?

Community Resources

- ~ Identify resource people from client's community
- ~ Talk with an individual's family & friends
- ~ Be aware of interpretive services



Unique Cultural Values

- ~ *Is there anything that would be helpful for me to know about how you and your family view _____?*
- ~ *Are there cultural beliefs, practices, or preferences that affect you during times of _____?*



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