Cultural Relevance in End-of-Life Care

Phyllis R. Coolen, DNP, RN
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Presentation Overview

- The Relevance of Cultural Competency in End-of Life Care
- Cultural Factors to Consider in End-of Life Care
- Cultural Assessment
- Advance Directives
- Pain Management
- Case Studies
United States moving towards a more ethnically and culturally diverse country

- 2040 white are expected to account 50% of population
- Continued immigration Latin American and Asia
- “Minority Majority “in a number states and cities
Challenge patient’s cultural norms different from the healthcare provider’s own American norms and culture values

- American core values emphasize autonomy and individual rights to make life choices, especially healthcare and end-of-life choices.
- The 1990 Federal Patient Self-Determination Act (PSDA) ensures individual rights.
2010 National Healthcare Disparities Report

- Disparities in palliative and end-of-life care for ethnically diverse groups
  - Less likely to receive right amount emotional support
  - Less likely to receive end-of-life care consistent with their wishes
  - More likely to report poorer communication with their physicians and nurses
  - Had a greater misunderstanding about care options; less knowledge about end-of-life care and advance directives

Wenger et. al (2001) found that practitioners discussed end-of-life care less with Blacks, Latinos, HIV via IV drug users, those less educated, and the poor.
Nurse: “I was having a difficult time understanding why this Asian family was making all the decisions and not allow the patient to do anything for himself.”

Nurse: “It is difficult when the family does not want us to talk about dying to the patient and even use the term “cancer” or “dying”.

Social worker: “Often make assumptions about what the person wants or says and we are so off the mark, because we don’t know enough about the culture.”

Chaplain: “We aren’t intentionally giving bad care, we simply lack the knowledge and training.”

Physician: “It is not easy to talk about end-of-life care or advance directives, especially if we use an interpreter - not sure if what I am telling the patient is actually being translated correctly”.

Communication = Greatest Barrier
Death as a Taboo Subject
- Not acceptable to discuss
- Considered disrespectful, bad luck, cause a loss of hope, despair
- Protecting the dying family member

Collective Decision-making
- Norm in many cultures
- Family is the decision maker; Filial Piety
- Power of collectivism more important than individual
Perception of the Physician’s Status

- Physician only one with authority
  - Discussion is a sign of disrespect
  - Asking questions means challenging authority

Cultural influences on preference of where to die

- Home = Samoans, Vietnamese, Asian Indians, Koreans
- Hospital = Chinese
Role of Religion and Faith

Many ethnically diverse cultures, approach to health and illness is through interconnection of mind, body, spirit with nature or the environment.

Faith and spirituality can play a significant role in the perception and response to the dying process.
Cultural Assessment

- Kleinman and Campbell’s Patient Explanatory Assessment Model
- Giger-Davidhizar/Huff
- Kagawa-Singer & Blackhall’s ABCD Assessment Model
Kleinman’s explanatory model uses 8 simple questions that clarify cultural generalization and provide insight into the patient’s personal meaning of illness.

- What do you think has caused your illness?
- Why do you think your illness started when it did?
- What do you think your illness does to you? How does it work?
- How severe is your illness?
- What kind of treatment do you think you should receive?
- What are the most important results you hope to receive from this treatment?
- What is the main/biggest problem your illness has caused you?
- What do you fear most about your illness?

(Campbell added 4 other questions to Kleinman’s relating to family’s viewpoint.)
### Geiger’s Model:

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>What’s the usual pattern of communication? Who’s the spokesperson/decision maker? Terms used?</td>
</tr>
<tr>
<td>Space</td>
<td>Family closeness valued? Family defined</td>
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<tr>
<td>Time</td>
<td>Present, Past, Future Oriented?</td>
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<tr>
<td>Environmental Control</td>
<td>Locus of control?</td>
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<tr>
<td>Social Organization</td>
<td>Spiritual beliefs? Use of traditional medicine</td>
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<tr>
<td>Biological Variation</td>
<td>Usual responses to medication</td>
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<tr>
<td>Kagawa-Singer &amp; Blackhall Nemonic Approach ABCDE:</td>
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<td>-------------------------------------------------</td>
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<tr>
<td><strong>Attitude</strong> – About truth telling, positive or negative attitudes about health care</td>
<td><strong>Do you use any traditional healing practices?</strong></td>
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<tr>
<td><strong>Beliefs</strong> – Religious/Spiritual beliefs</td>
<td><strong>How can we support your needs and practices? Where do you find your strength to make sense of what is happening to you?</strong></td>
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</tbody>
</table>
| **Context** – Historical, political, immigrant, refugee, acculturation | **• Where were you born and raised?**  
 **• How long have you been in the US? What language are you most comfortable using?**  
 **Decision-making style** – who is major decision maker, collectivism, filial piety | **• How are decision about health care made in your family?**  
 **• Is there anyone else I should talk to in your family about your condition?**  
 **Environment** – Available resources | **• Identify community resources** |
Advance Directive

- Document expressing person’s wishes concerning certain life sustaining medical treatment when a person is seriously ill or at the end of life, should the person not be able to communicate his or her wishes.
- Differences in each state

- WA used only when life-sustaining treatment would artificially prolong life in a terminal condition or when individual is in an irreversible coma. Signed by two witness, not be notarized. Texas – signed two witness/notarized.

Other Health Care Decision Documents

- **Durable Power of Attorney for Healthcare**
  - Legal document designating person to make medical decisions when individual is incapacitated.
  - WA - Not need to notarized or witnessed, advisable to have lawyer prepare
  - Texas – signed and notarized

- **WA POLST – Physician’s Order for Life Sustaining Treatment**
  - Not the same as an advance directive
  - Specific Orders by the physician or ARNP indicates what type of life sustaining treatment individual wants.
Ethnic minorities have lower rates of a completed advance directive
- Lack of knowledge
- Lack of understanding
- Distrust in the health care system and concern wishes won’t be carried out
- Acculturation
- Collectivism decision-making
- Preference Physician to make decisions
- Fear of death, death is a taboo subject
- Influence of religion or spirituality

Key is in the planning process and developing a trusting relationship with patient and family
Approaches to Discussions About Advance Directives

- Private
- Sufficient time
- Who needs to be involved in the discussion
- Interpreter – Understand the purpose of
- “Aggressive treatment” - education
- “Nothing can be done”
- Use of community support – leaders, religious or spiritual leaders
Health disparities among ethnically diverse groups and the poor receive worse care

Disparities in Pain Management
- Less likely to receive pain medication or receive lower doses even if patient has advanced cancer
- Miscommunication and perception of pain needs
  - Common theme across all ethnic groups (Im, et.al)
- Chung et.al – Chinese and Japanese Americans’ cancer pain significantly under estimated by nurses and physicians.
- Anderson et. al – African American and Hispanic patients’ pain severity significantly under estimated by physicians despite having recurring or advanced cancer.
- Coolen et.al – many healthcare providers associated minorities and low income patients with drug seeking behavior/addiction = result is under treatment of legitimate pain.
Disparities in Pain Management
- Lack of access to care
- Lack of appropriate access to analgesics and opioids
- Lack of access to pain specialist
- Language barriers

Patient’s pain must be considered within the context of the individual’s beliefs and values – culture influences person’s perception and response to pain
Perception of pain and request for pain
- Culture affect person’s response to pain both in meaning and expression of pain
- Create barriers

Use of traditional practices

- Coin Rubbing
- Cupping
- Herbal Remedies
Assessment – Explanatory Model (Kleinman)

- What do you call your pain? Why do you think you have this pain?
- What cultural remedies have you tired to help you with your pain?
- Have you seen a traditional healer for your pain?
Wong-Baker FACES Pain Scale

- Face 0: Doesn’t hurt at all
- Face 2: Hurts a little bit
- Face 4: Hurts a little bit more
- Face 6: Hurts even more
- Face 8: Hurts a whole lot
- Face 10: Hurts as much as you can imagine (although you do not have to be crying to have this worst pain.

Ask the patient to choose the face that best describes how much pain he/she has.


Numeric Pain Scale

Case Study 1

Mr. S is a 53 year old Cambodian immigrant with incurable metastatic colon cancer diagnosed 3 months ago. He has limited English proficiency. He is admitted to inpatient care for placement of a peritoneal drainage for malignant ascites. The only pain medication ordered is Vicodan, 1-2 tablets every 6 hours as needed. His wife speaks English well. Night shift notes that patient did not ask for any pain medication. Early am visit by the hospice nurse notes that patient is in severe pain – moaning and groans with slight movement. Wife states he has had a bad night and can anything be done to make him more comfortable.

- Sampeah Greeting
- Cultural Assessment Performed
- Pain Assessment Performed
Mrs. V. is a 68 year old Filipino Hawaiian with end-stage chronic obstructive pulmonary disease. She is also an insulin dependent diabetic. She lives with her son, daughter-in-law and four grandchildren. She has gotten weaker and has fallen several times, tripping over rugs and stuff. She also only likes to eat peanut butter and jelly sandwiches for breakfast and lunch, despite nutritional counseling. She has been on hospice for a month and staff are frustrated with her continued high risk of falling and “noncompliance” with her diet.

- Every questions asked of client – client needed to “talk story”
- Take time to listen to her stories to separate out her issues and concerns
“Their surrounding should be as beautiful as possible; a calm peaceful, serene, holy environment is so important. There should be beautiful views, beautiful art, flowers, images of deities and holy beings. The point is to make a positive imprint on the person’s mind. The person’s mind is elevated and they are not afraid to die. “

_Lama Zopa Rinpoche_

Thank You
References


- http://www.wongbakerfaces.org/resouces

References