Culture in End-of-Life Care

Ian Anderson Continuing Education Program in End-of-Life Care
Culture

Maps of meaning through which the world is understood and interpreted

Determines views of:
1. nature and meaning of illness and death
2. how EOL decisions are controlled & made
3. how bad news should be communicated
Importance of Culture in EOL Care

- Attitudes towards EOL decisions are influenced by culture

- Unspoken assumptions regarding meaning of health, illness and death may hinder communication

- National commitment to cultural pluralism and equality not always evident in health care
Objectives

- Identify salient perspectives of culture and understand their importance in EOL decision-making and care
- Discuss and negotiate cultural perspectives with patients and families
- Construct a plan for EOL care that identifies and accommodates culture as a central feature
- Identify your own cultural perspectives in EOL care
Cultural Considerations

- No one has more or less culture than anyone else
- Culture determines notions of common sense
- Culture is passed from generation to generation without being articulated
- Cultural traditions affect us even if we do not participate in them,
- The influence of culture in our lives may not be recognized
Healthcare Providers and Culture

- Religious/cultural background influences clinical practice

- The 1st step in cross cultural healthcare is to understand your own values and beliefs
Understanding yourself culturally... 

- What is your cultural background?

- What elements of this background do you express or believe?

- How much does this background affect you in ways that you may not be conscious of?
How does your cultural background affect the EOL care you provide?

- How aware are you of western attitudes towards EOL?
- How deeply do you hold these attitudes?
- What are the attitudes of the hospital, team and profession towards EOL?
- How much of these attitudes have you personally absorbed?
## Cultural Context

<table>
<thead>
<tr>
<th>High Context (Non Western)</th>
<th>Low Context (Western)</th>
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</thead>
<tbody>
<tr>
<td>Information drawn from context</td>
<td>Information explicitly communicated</td>
</tr>
<tr>
<td>Group</td>
<td>Individual</td>
</tr>
<tr>
<td>Interdependence</td>
<td>Autonomy</td>
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<tr>
<td>Hierarchy</td>
<td>Equality</td>
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<tr>
<td>Traditional ways</td>
<td>Question belief</td>
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<tr>
<td>Present time orientation</td>
<td>Future time orientation</td>
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</tbody>
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Adapted from E. Hall, *Beyond Culture*
Culture and Explanatory Model of Illness

Culture determines:

- Perception of health problems
- Labeling of health problems
- Meaning of health problems
- Trajectory of health problems
- Communicating about health problems
- Evaluating health care
Practically Speaking

- Different cultures = different explanatory models of illness
- Western = biomedical basis of disease
- Non-Western = constant state of balance between health and illness even in absence of symptoms
- May lead to major, unidentified discrepancies in perception of the problem, values and goals
Clarify

- What do you think has caused your problem/symptoms/illness?
- How does it work?
- How severe is it?
- What kind of treatment do you believe is best?
- What worries you the most about your illness?
Locus of control

- Internal: determine own fate through actions
- External: events are determined by fate
- Western = internal
  Non-Western = external
Advance Care Planning

- Assumes internal locus of control
- Main emphasis is on individual and rights
- Differences in cognitive processes, perceptions, values and beliefs → breakdown in communication
- Need to accommodate and value relationships with others, different perceptions and values
Limitations of a Western Medical Model in a Multicultural Setting

- Symptoms differ among ethnic groups
- Need to know frame of reference of patient and healthcare provider to diagnose and treat
- Focus on disease course instead of cultural experience of being ill
- Inadequate to understand attitudes towards prevention, community health and help-seeking behaviour
Problems in Quality Cross-Cultural EOL Care

- Marginalizing cultural and contextual information
- Secular focus
- Focus on autonomy
- Truth telling
- Negative focus
Assessing the Influence of Culture in EOL Care—Questions to Ask…

- Does the patient/family have a purely biomedical view of illness?
- Does the patient/family believe the timing of illness should be controlled and that the timing and nature of death can be influenced?
- Is individual decision-making valued? Or collective family decision-making?
- What personal/cultural beliefs does the patient/family hold about critical illness and death?
How do I know if I am accommodating culture in EOL care?

- Do I understand how the patient/family perceives the cause and nature of this illness?

- Do I understand how the patient/family perceives the nature and meaning of death?

- Are there any death related rituals or observances they wish to honour or perform?
Ethics, Culture and EOL Care

- Respect for diversity = responsibility to respect peoples’ differences and values at EOL
- Autonomy is not a universal concept
- Moral responsibility to respect cultural differences in how EOL is understood, experienced and reacted to
Implications for Practice

- Autonomy vs. Interdependence
- Differences in who receives information and how
- Differences in who makes decisions and organizes care
- Different notions of self
- Each person = a cultural being
- Open communication
What should I do in practice?

- Approach with a spirit of inquiry
- Listen carefully
- Ask the right questions
- Negotiate a treatment plan