

# 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 1<sup>st</sup> 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

## High Context (Non Western)

- Information drawn from context
- Group
- Interdependence
- Hierarchy
- Traditional ways
- Present time orientation

## Low Context (Western)

- Information explicitly communicated
- Individual
- Autonomy
- Equality
- Question belief
- Future time orientation

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