



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

Module 8

CULTURE



Case Scenario

Mr. Y is a 75-year-old Chinese Canadian man who has been admitted to the ICU following respiratory failure. Mr. Y has a long history of difficult respiratory function. He is intubated and ventilated, but is oriented to time, person and place. Mr. Y spends much of his time reading and visiting with family. All attempts to wean him from the ventilator have failed. The physician in charge wishes to inform Mr. Y that he is unable to get him to a point where he can be taken off the ventilator and introduce the option of gradually weaning him off the ventilator and keeping him comfortable so that nature may take its course and he may die in peace. The patient's eldest son is described to the health care team as "the decision-maker". He approaches the physician and asks emphatically that his father not be told that he is permanently dependent on the ventilator as it would take away his hope, terrify him and, in turn, make him sicker. The son feels that telling his father would be cruel and is therefore unjustifiable.

Introduction

Attitudes toward end-of-life care are highly influenced by cultural perspectives that are rarely acknowledged. Cultures are maps of meaning through which people understand the world and interpret the things around them. When patients and health care workers have different cultural backgrounds, they frequently follow different “maps,” which can hinder effective communication.

Culture is a strong determinant of people's views of the very nature and meaning of illness and death, of how end-of-life decisions can or should be controlled, how bad news should be communicated and how decisions – including end-of-life decisions – should be made.

Canada, which has a substantial aboriginal population and, increasingly, a multicultural population, has made a commitment to cultural pluralism and equality. Unfortunately our health care system does not always reflect this diversity; this is particularly problematic in end-of-life care, a time that produces intense feelings, when patients and families draw heavily from cultural beliefs and traditions.

In addition, we tend to neglect the substantial differences in the way people of different Cultures perceive, experience and explain illness and death. Often, when patients and health-care workers come from different cultural backgrounds, they interact under the influence of unspoken assumptions about health, illness and dying that are so different that they prevent effective communication.

Culture is frequently perceived as something brought to Canada from foreign shores, yet in reality no one has more culture or less culture than anyone else. We are all "cultural beings", our view of the world being shaped by cultural blueprints we are often not conscious of. Furthermore, our health care system itself is strongly patterned by culture, with multiple sub-cultures, shaped by the values and practices of teams, departments and professional disciplines, embedded within it. Understanding how our own multifaceted cultural perspectives affect our attitude toward end-of-life care is critical to understanding the cultural perspectives of others.

This module focuses on three perspectives from the social sciences that are useful in analyzing cultural differences, and by identifying four aspects of end-of-life care that give rise to particular problems in cross-cultural application. The terms "Western" and "non-Western" are used here in a philisophic, rather than cultural context.

Objectives

- ❑ Construct a plan for end-of-life care that identifies and accommodates culture as a central feature of end-of-life care.
- ❑ Be able to discuss and negotiate cultural perspectives directly with patients and families.
- ❑ Be able to identify the 3 salient perspectives of culture, demonstrate understanding of their importance clinically with respect to end-of-life care and end-of-life decision-making.
- ❑ Be able to identify common differences between western and non-western cultural perspectives in relation to end-of-life care.
- ❑ Be able to identify a clinician's own cultural perspectives on end-of-life care.
- ❑ Be able to identify the ethical importance of understanding and negotiating cultural differences in end-of-life care.

Social Science Perspectives and End-of-Life

Cultural Considerations

- ❑ No one has more culture or less culture than anyone else.
- ❑ What we consider to be 'common sense' is determined by culture.
- ❑ Culture is passed from generation to generation without being articulated.
- ❑ It is inaccurate to believe that if we do not participate in our cultural traditions we are not affected by them.
- ❑ We are not fully conscious of the influence of culture in our lives.
- ❑ Our cultural background has a significant influence on our clinical practice.
- ❑ The first step in effective cross-cultural work in health care is to understand our own cultural values and beliefs.

- ❑ **Health care workers' religious/cultural background is likely to influence clinical practice.**

Understanding ourselves culturally

- ❑ What is our cultural background, what elements of this background do we express or believe?
- ❑ How much may this background affect us in ways we are not conscious of?
- ❑ How aware are we of western attitudes toward end of life?
- ❑ How deeply do we hold these attitudes?
- ❑ What are the attitudes in our hospital, team and profession toward the end of life?
- ❑ How much of these attitudes might we have we personally absorbed?

Cultural Context

As described by Edward Hall, generally speaking Western culture is low-context and non-Western culture is high context. Although cultural context has many features, the most salient for consideration at the end of life, particularly in relation to decision-making is that low-context cultures emphasize independence, the individual and a future-time orientation. Communication takes place almost exclusively through language. High-context cultures emphasize interdependence, interconnections with others and a present time orientation. In high-context communication, less information is conveyed by verbal expression and most of the message is embedded in the social context or internalized in the communication process itself. For example a person in a high-context culture may show their support to a dying person solely through their actions rather than ever directly discussing their loss.

Cultural Context	
High Context information drawn from context group interdependence hierarchy traditional ways	Low Context information explicitly communicated individual independence equality question belief
<small>Adapted from Edward Hall <i>Beyond Culture</i></small>	

Explanatory Model of Illness

Explanatory Model of Illness
Definition: <ul style="list-style-type: none">□ What illness is, why it occurs, and what measures can prevent or control it.
Culture Determines: <ul style="list-style-type: none">□ perception of health problems□ labeling of health problems□ meaning of health problems□ trajectory of health problems□ communicating about health problems□ how we evaluate health care
In Practice: <ul style="list-style-type: none">□ Patient-health care interactions between people of different backgrounds often represent differences in explanatory models of illness.□ These interactions often involve major, unidentified, discrepancies in the perception of the problem, values and goals.
Clarification: <ul style="list-style-type: none">□ What do you think has caused your problem?□ How does it work?□ How severe is it?□ What kind of treatment do you believe is best?□ What worries you most about the illness?
<small>Adapted from A. Kleinman</small>

Explanatory models of illness reflect the cultural understanding of what illness is, how it occurs, why it exists and what measures can be taken to prevent or control it. Many non-Western people hold different views of clinical reality than the Western biomedical view. In Western medicine, the primary explanatory model of illness focuses on abnormalities in the structure and function of body organs and systems, for example, pneumonia is due to pneumococcus. Most non-Western cultures tend to perceive illness in a much broader and far less tangible manner; for example, they may perceive health and disease as separate entities, with each one varying in intensity, even in the absence of symptoms. Care planning at the end of life and end-of-life decisions can be particularly problematic if the fundamental causes of illness unto death are neither identified nor agreed upon.

Locus of Control

One has an internal locus of control if he or she believes that a person can determine their fate through their own actions. One has an external locus of control if he or she believes that events occur independent of individual actions and that the future is determined by luck or fate. Beliefs about locus of control are highly

influenced by one's culture. In general terms, Western peoples hold an internal locus of control and non-Western peoples hold an external locus of control. Clearly, planning for end of life involves adheres to an internal locus of control because it is a system based on human choices, an adherence that is highlighted by such concepts as living wills.

The following example illustrates some of the potential differences these three differences in perspective can generate in relation to end-of-life care and planning. A patient comes into an intensive care unit in an incompetent state. In its meetings with the patient's family, the health care team focuses on biomedical explanations of illness, the patient's wishes about treatment before the incompetent state substituted judgment, and encourages an open and direct conversation about the patient's wishes. The team hopes thereby to arrive at the best plan for this individual's medical care. However, for this family of non-Western origin, the focus on individual rights and choices, direct and blunt verbal communication, the introduction of the element of choice and the focus on a purely biomedical explanatory model of illness may be so confusing that it leads to a complete breakdown in communication

Although, increasingly, end-of-life care identifies and values inter-relationships with others, autonomy and, in turn, the individual, remain at the heart of most values and choices in relation to dying patients. These factors lead to substantial differences in cognitive processes, perception, social structures, values and beliefs about which individuals often are not conscious. Unless the health care worker dealing with end of life identifies and adapts to these factors, our efforts to improve end-of-life care will be greatly limited in a pluralistic society.

Western Medicine

Covert Assumptions

- ❑ Generally health care workers expect patients to hold a biomedical perspective of illness, be punctual, future-oriented, willing to work on therapeutic goals and motivated by the prospect of change before them.
- ❑ The assumption behind these expectations, however, is grounded in a western cultural perspective. It is based on a western biomedical view of illness, low context cultural perspective and an internal locus of control.

Limitations of a medical model in a multi-cultural setting

- ❑ Symptoms differ substantially among ethnic groups, bringing into question the validity of diagnostic nomenclature.
- ❑ Problems can be neither diagnosed nor treated without examining the frame of reference of the patient and the health care provider.
- ❑ Focuses on the disease course rather than the (culturally based) experience of being ill.
- ❑ Greatly inadequate for understanding attitudes toward prevention, community health and help-seeking behaviour

Areas of consideration in Cross-Cultural End-of-Life Care

There are four areas of consideration that are particularly problematic in relation to providing good end-of-life care cross-culturally.

1. Marginalizing cultural and contextual information

When we face difficult decisions in end of life we often rely on an examination of competing principles or comparative cases. Although these methods may be useful in defining an ethical issue, to fully understand end-of-life decisions, we must examine the social and cultural context within which the situation is embedded. For example moral reasoning for many non-Western cultures may be shaped by context rather than principles. Thus the Western effort to render our analyses objective, rational and unbiased, risks making end-of-life considerations socially and culturally neutral.

Furthermore, both health care and end-of-life literature often describe social and cultural factors as external “constraints,” frequently using the term “cultural barrier,” usually with the intent to analyze and clarify. However the word “barrier” implies that culture blocks access to the resolution of an issue, which somehow is regarded as absolute and lies beyond culture.

Questions about families' cultural perspectives in end-of-life care

Does the patient/family have a purely biomedical view of illness?

Does the patient/family believe this illness should be controlled and the timing and nature of death can be influenced?

Does the patient/family value individual decision-making? Or defer to collective family decision-making?

What personal/cultural beliefs does this patient/family hold about critical illness and death?

2. Secular Focus

Despite the significant religious contributions to end-of-life care and even though many of us are aware of the religious and spiritual aspects of end-of-life care we continue to adhere to a largely secular perspective. A secular approach in end-of-life care is a practical, political and moral response that seeks to apply a unitary approach to the demands of complex and diverse Western cultures. Unfortunately, this effort to establish neutral territory may make our approach to end-of-life care difficult to understand for many patients and families of non-western origin for whom end-of-life is inextricable from religious/spiritual experience.

3. Focus on Autonomy

Although the limits of autonomy are becoming increasingly apparent, to date many would argue this awareness has not deeply affected end-of-life care. This concept, which remains the intellectual and moral foundation of western health care, is a direct manifestation of the Western concept of individualism – a belief in the importance, uniqueness, dignity and sovereignty of each person and the sanctity of each individual life. According to this belief, every person is entitled to individual rights such as autonomy of self, self-determination and privacy. For non-Western cultures, however this focus on individuality may neglect the vital role of personal interconnectedness and the social and moral meaning of these inter-relationships. If we are to understand autonomy in a cross-cultural context, we must consider how each person sees themselves in relation to others.

4. Truth Telling, Negative Focus

Many of us in end-of-life care place a high value on truth telling, yet in the face of serious illness, many cultures believe that giving negative information may induce negative outcomes. This belief partly reflects the considerable cultural differences concerning the interaction between mind and body. Some cultures are strongly protective of the critically ill, believing that they require the same supervision and protection as a well loved child. Western medicine derives the physician's obligation to communicate the truth to patients from the rarely questioned belief in the patient's "right to know," which, when considered as unconditional, requires that patients must deal with "the truth" overtly and rationally. Sometimes we meet the patient's denial of the "truth" with impatience because it complicates the process of truth telling and may create uncertainty about the received truth. From a Western perspective, we usually agree quickly about what the truth is as we anticipate outcomes based solely on biomedical perspectives, yet this view may mystify people of other cultural perspectives.

Conclusions

Like Western medicine, contemporary end-of-life care is as much a cultural construction as any non-Western philosophic or health-related belief system. When faced with the moral complexity at the end of life, many non-Western cultures use alternative values and beliefs, perception, and social structures. Before we can design a high standard of end-of-life care for our patients and families, we need to further explore these described factors.

To ensure you are accommodating culture into good end-of-life care ask yourself:

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

- ❑ In a society that values respect for diversity, we have a responsibility to respect, as much as possible, people's differences and values at the end-of-life.
- ❑ Autonomy is not a universal concept, therefore using it as a guiding principle at all times, may be greatly unfair to some of our patients and families.
- ❑ Because end of life is a major life event, we have a moral responsibility to respect cultural differences in how it is understood, experienced and reacted to.

Implications for Practice

Perhaps the most important factor when weighing decisions about care at the end of- life is to consider that Western and non-Western cultures hold sharply divergent views about autonomy. Autonomy is generally a Western concept reflecting a belief in the importance, uniqueness, dignity and sovereignty of each person, and the sanctity of each individual life. Accordingly, every person is entitled to self-determination. This stands in bold contrast to non-Western cultures in which interdependence is often valued over independence. Profound social and moral meaning rests in these interrelations.

Western health care teams may therefore assume that the person experiencing the illness is the best person to make health care decisions. However, many non-Western cultures vest in the family or community the right to receive and disclose information, and to make decisions about and organize patient care. In order to provide ethical cross-cultural care, applying the concept of autonomy cross-culturally will therefore mean accepting each person's terms of reference for their definition of self. Specifically, we should respect the autonomy of patients and families by incorporating their cultural values and beliefs into the decision-making process. Each health-care provider must discover how to see each person as a “cultural being.”

The most effective way to address cultural differences in end-of-life care is through open and balanced communication. When health care workers are uncertain about how a patient or family perceives a situation, it is best to simply ask. Frequently, differences can be easily negotiated. Many people now living in Western cultures already hold blended views of culture, illness and death. The mere acknowledgement of such differences will usually lead to improved communication.

When dealing with patients and families at the end of life, it is important to consider the following questions: Do patients/families value individuality and personal choice, or do they focus more on family and collective choices? Do they value open communication, or do they tend to draw cues from the context of the situation? Do they believe a person can and should influence their health or their death? How do they feel about truth telling? What are the religious spiritual views in relation to the

impending death? Do they believe in a Western biomedical view of illness, or do they hold an alternative, or blended, view of illness?

What to do in practice

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

Factors to consider beyond culture

- People are unique
- Culture exists in nexus with a patient's psychosocial situation
- Intra-cultural variation is often higher than inter-cultural variation

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Detailed Case Scenario

Mr. Y:

In the Confucian social hierarchy, the elderly sick person can expect to be cared for by his/her family. The patient is relieved of a large share of personal responsibility, including the decision-making, even though he/she may be rational and competent. Furthermore, patients are not to be given the news of a terminal illness because, from a Confucian point of view – which is governed by the rule of filial piety to protect – it is considered morally inexcusable to disclose any news that may cause further harm to the patient.

In the face of serious illness, the Y family, as with many people of non-Western cultures, believed that focusing on the negative may be a way of creating negative. The Y family made it clear that hope was central to their concern for their father. All societies seem to recognize "the need for hope", yet each differs in understanding the conditions for hope. In contemporary North American health care, the doctor is often perceived to be someone who shares a sort of partnership with the terminally ill patient in order to maintain the patient's dignity, quality of life, personal choice over treatments, and hope. In Western terms, therefore, hope appears to be upheld through autonomy and active participation in treatment choices and regimens.

However, the Y family believed that hope was best maintained through the family's absorption of the impact of the illness and diagnosis, and through the family's control of medical information transmitted to Mr. Y. Their wishes reflected a belief in the shared responsibility of the illness with other family members, and an awareness of the potential physical or emotional harm that truth telling might bring.

The negotiated approach resulted in asking Mr. Y if he would like to receive medical information and be involved in his treatment planning or, as his son had requested, use the son as decision-maker. Mr. Y indicated the latter preference. A consultation between the physician and the family took place. The negotiated treatment plan consisted of two further days of ventilation and then a gradual withdrawal of ventilation with comfort care given the highest priority.

Teaching Tips

1. Distribute the case scenario and allow time for participants to read
2. Identify topics for discussion which could include:
 - What is culture and how does it influence end-of-life care?

TIP: Ask participants to reflect upon how their own values, beliefs and culture affect their decision-making in day-to-day life and in medical context. Do they base their decisions on medical facts as dictated by their professional culture or do personal beliefs and values also affect their decision-making?

- How does culture affect the perception of illness?
 - How does concept of autonomy vary cross-culturally?
 - What is the role of culture in end-of-life decision-making?
 - What factors are important to consider beyond a person's culture?
3. Ask participants to discuss how Mr. Y's cultural background may be influencing his son's request.
 4. Ask participants to discuss the role of autonomy in end-of-life decision-making.
 5. Ask participants what they would say to Mr. Y's son.

TIP: It may be useful to have participants role-play the discussion they would have with Mr. Y's son.

6. Ask participants what they would do if Mr. Y's son insists that Mr. Y not be told his diagnosis.
7. Ask participants how they have accommodated cultural differences in their practice before.

TIP: Ask participants if they have encountered situations in which differing beliefs regarding the nature of illness, the locus of control or religious background have lead to conflict. What did they do in these situations?

8. Discuss any remaining learning objectives and assign tasks.