

# Cultural Relevance in End-of-Life Care

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## Methods

The author performed a literature review and incorporated published literature, interviewed health care providers experienced in end-of-life care, and drew from her own clinical experience. The author, a community health and hospice clinician, has over 30 years' experience with hospice care.

## Introduction

The discussion a health care provider, including physicians, advanced nurse practitioners, nurses, and social workers, has with a patient about end-of-life care is often a challenge. The challenges can be influenced by a number of variables, such as the provider's training and experience in this area, the provider's comfort level in discussing the subject, and the availability of adequate time for having the discussion (Kamaka, 2010; Tait & Hodges, 2009). A provider may be challenged further when the patient's cultural norms differ from the health care provider's, particularly around end-of-life care, which can impact the provision of quality end-of-life care. American core values emphasize autonomy and individual rights to make life choices, especially health care choices. The Patient Self Determination Act (PSDA) of 1990 was developed to ensure those rights were protected, including the fundamental rights to treatment choices, informed consent, truth-telling and open communication with health care providers, and control over the individual's own life and death (Electronic Code of Federal Regulations, 2011). These American core values may often be in conflict with the values of many ethnic and culturally diverse groups in the United States. These conflicts can lead to health disparities resulting in fragmented care, inadequate or inappropriate symptom management, miscommunication with the patient and family, and a difficult and poor death for the patient. There are numerous studies that support these conclusions (Campinha-Bacote, 2011; Doorenbos et al., 2010; Eues, 2007; Giger, Davidhizar, & Fordham, 2006; Huff & Kline, 2007b; Searight & Gafford, 2005a).

Enhanced cultural competency with regard to improving end-of-life care continues to be an identified need for hospice nurses, social workers, family practice physicians, psychiatrists and other health care providers (Braun, Ford, Beyth, & McCullough, 2010; Rushton, Scanlon, & Ferrell 1999; Schim & Doorenbos, 2010; Schim, Doorenbos, & Borse, 2006). The focus of this article will be on cross-cultural issues at the end of life for ethnically and culturally diverse groups in the United States.

The health care provider must have a clear understanding and recognition of the unique and specific influences culture has on a patient's behavior, attitudes, preferences, and decisions around end-of-life care. It is important to remember that simply because a person is identified as a member of a particular ethnic group or practices a particular religion it does not necessarily mean that the person or person's family maintains beliefs that may be associated with the ethnicity or religion. Additionally, an assessment should be made of how acculturated a person and their family are, their language skills, and whether an interpreter is needed. Be aware of some of the overall cultural values of the community and then explore the pertinent themes as they relate to providing health care for individual patients. Remember there is great diversity within a community. Experiences will vary greatly depending, for example, on whether people lived in rural or urban communities in their countries of origin, how long they have been in the United States, their immigration experiences, former occupations, and levels of education. Keep in mind that patients are individuals. The examples included are to illustrate concepts and are not meant to be all inclusive or representative of everyone within a particular community or of all ethnic groups.

This resource will address three major areas of cultural relevance in end-of-life care:

- *cultural competency in clinical practice;*
- *advance directives; and*
- *pain management*

## Cultural Competency in Clinical Practice

### Diversity in Our Society

The United States is rapidly moving towards becoming a more ethnically and culturally diverse country, with whites expected to account for less than fifty percent of the population by 2040 (Frey, 2012). The national trends continue to see ethnic minorities dominating national growth, with continuing immigration (largely from Latin America and Asia) resulting in an increase in the “minority majority” population (Frey, 2012). Four states and an increasing number of metropolitan areas and their suburbs have a minority majority population composed of over fifty percent non-whites and Hispanics (Frey, 2012). When immigrants relocate, they don’t leave their culture behind, but bring those values, beliefs, and norms to their new home. And depending on how acculturated a person is, aspects of his or her culture may have a strong influence on the person’s response to illness and health care.

As America evolves into a multiethnic society, how health care providers manage that shift is critical in establishing culturally appropriate and effective care. Through cultural competency in clinical practice, health care providers can provide care that ensures the individual receives high quality of care regardless of culture or ethnicity.

## **Cultural Competency**

Cultural competency can be viewed as an ongoing journey of commitment and active engagement through the process of cultural awareness, cultural knowledge, cultural skills, cultural collaboration, and cultural encounter (Kachingwe & Huff, 2007; Leininger, 2002a). Cultural competency allows for the delivery of individualized health care services within the cultural context of the patient and the avoidance of stereotyping (Kagawa-Singer & Backhall, 2001). Trust is the underlying purpose behind cultural competency in the development of the health care provider and patient relationship. Without trust there cannot be an effective relationship, which increases health disparities (Campinha-Bacote, 2011; Huff & Kline, 2007b; Kachingwe & Huff, 2007; Leininger, 1999; Schim & Doorenbos, 2010; Tervalon & Murray-Garcia, 1998).

## **Key Elements of Cultural Competency**

The following are the key process elements that require a health care provider to commit to lifelong learning in order to enhance health care services (Campinha-Bacote, 2009, 2011; Kachingwe & Huff, 2007; Leininger, 2002b).

**Cultural Desire** is the process of wanting to become culturally competent. It is the motivation that is behind the health care provider’s desire to actively engage and commit to becoming culturally competent. Humility is the key factor in this process. Humble health care providers have a genuine desire to discover what the patient is thinking and feeling. Also of critical importance is seeing each individual as a unique and worthy person to be treated with dignity, fairness, and deserving of quality of care.

**Cultural awareness** is the process of becoming more sensitive, respectful, and attentive to the patient’s cultural beliefs and practices. Through this process the health care provider becomes cognizant and reflective of his or her own cultural identity, attitudes, biases, and prejudices and how they shape his or her behavior, specifically in the provision of health care services.

**Cultural knowledge** is the process of developing an understanding of the differences and similarities between and within cultural groups. This includes learning about various cultural groups’ values, beliefs, lifestyle practices, and perspectives on life. Culture is a powerful determinant of behavior towards illness.

**Cultural skill** is the process of cultural assessment, which obtains relevant information about the patient’s beliefs, values, and practices. A critical component of cultural skill is the development of interpersonal communication skills that convey respect, appreciation, and sensitivity to other cultures.

**Cultural collaboration** is the process that requires a partnership approach between the health care provider, the patient, and the family. An important part of the collaboration is the development of mutually agreeable goals between the health care provider, patient, and family.

**Cultural encounter** is the process of obtaining cultural experience through active engagement and, if possible, immersion in another culture. Meaningful encounters require being open to learning, understanding, and appreciating the other person’s viewpoint.

## **The Relevance of Cultural Competency in End-of-Life Care**



Incense burning at Buddhist Temple, Ho Chi Minh City, Vietnam. Photo by Patrick Coolen.

Working within the cultural context of the patient and family is an essential underpinning of end-of-life care. Cultural influences can significantly impact the patient's reaction to the dying process and the decisions the patient and family make (Giger, et al., 2006; Kagawa-Singer & Backhall, 2001; Koenig & Gates-Williams, 1995; Searight & Gafford, 2005a).

Fostering trust is vital to the care of the patient and family during this difficult time. End-of-life care means more than treating physical symptoms, but extends to the psychosocial, existential, and spiritual aspects of the patient's needs.

Numerous studies devoted to understanding culture's relevance to death and dying found that communication was the greatest barrier between the health care provider and the patient and family during end-of-life care (Eues, 2007; Jovanovic, 2011; Klessig, 1992).

A provider needs to consider the following (Lopez, 2007):

- the patient and family's perspective on death and dying
- the patient and family's perspective on health and suffering
- the patient and family's perspective on hospice and palliative care services
- the patient and family's acceptance of Western health care practices and their use of alternative traditional practices
- the role of spiritual and religious beliefs and practice
- the role of the family, including who is considered part of the family
- how the patient and family communicate (such as the need for interpreter services or that only certain words are acceptable when discussing illness and dying)
- the patient's own role in problem-solving and in the process of decision-making

## **Cultural Factors to Consider in End-of-Life Care**

### **Death as a Taboo Subject**

In some cultures, talking openly about death and dying is not acceptable because it is considered disrespectful, bad luck, or causes loss of hope (Giger, et al., 2006; Kagawa-Singer & Backhall, 2001; Searight & Gafford, 2005a, 2005b). Many cultures actively protect dying family members from knowing their prognosis (Carteret, 2012; Giger, et al., 2006; Searight & Gafford, 2005a, 2005b). For example, some Filipinos may request the family member not be told he or she is dying because of concern for the person's loss of hope and the belief that only God can decide a person's fate. For many Southeast Asian families, the dying family member is not to be told about a terminal diagnosis because talking about death would bring it on sooner or doing so is disrespectful to the soon-to-be ancestor. Some Somalis consider it uncaring for the health care provider to tell the terminally ill family member he or she is dying (Stratis Health, 2010). And for some Muslims, talking about death is taboo and a religious leader may be needed to facilitate the conversation with the male family leader and the health care provider about end-of-life care.

### **Collective Decision-making**

Collective decision-making is the norm in many cultures, but it often clashes with the American value of autonomy and an individual's right to make one's own decisions about health and dying (Giger, et al., 2006).

Collectivism's core values can cause a treatment dilemma for the health care provider whose focus is on getting the patient involved in the treatment plan. In collective decision making, the family decisions will be family oriented. In these circumstances, it is important to understand and respect that the power of collectivism is more important than an individual (Huff & Kline, 2007b; Logan, Fukuda, & Baldwin, 2006).



Filipino/Kamaaina Couple. Photo by Phyllis Coolen.

A family may expect information to be given to them first, so they can make the health care decisions (Countries and Their Cultures, 2012; Giger, et al., 2006; Klessig, 1992; Koenig & Gates-Williams, 1995). For example, Koreans and Mexican Americans are more likely to consider the family as the decision-maker regarding withholding of aggressive treatment, rather than the patient alone (Maly, Umezawa, Raliff, & Leake, 2006). For many Asians and Pacific Islanders, filial piety, as supported by Buddhism, Confucianism, and Christianity, requires family members to take over the decision-making role for the seriously ill elderly patient (Giger & Davidhizar, 2002). Family and extended family ties are extremely important to the Filipino and Hawaiian communities, with the extended family participating in the discussions and decision-making for the seriously ill family member. Some Somalis believe that health care decisions involve the whole family, with a male family member being the spokesperson for the family and the father being the bearer of bad news to the patient (Carteret, 2012). When death is imminent, the Asian Indian male head of the household is responsible for deciding when the patient is to be told and when to inform the rest of the family members (Stratis Health, 2010).

### **Perception of the Physician's Status and Health Care Experience in Country of Origin**

Immigrant patients may come from countries where the physician makes all health care decisions and patients are unaccustomed to being asked to choose among treatment options (Kingsley, 2010). The patient and family may have the expectation that it is the physician's role to decide on end-of-life care (Searight & Gafford, 2005b). For many Filipinos, physicians are held in high esteem and are given extensive authority, so questioning the physician's treatment decision or being asked to make a decision about one's own health care is not expected. They would expect the physician to make all decisions about their health care. Additionally, some immigrant patients may not be accustomed to or comfortable asking questions of the physician, even if aspects of the illness or treatment plan are not understood because of concern that they will be perceived as challenging the physician (Shavers, Bakos, & Sheppard, 2010). For example, Southeast Asian cultures value politeness and respect for authority, so questions or voicing concerns about the family member's terminal illness or treatment may not occur.

### **Perception of Pain and Request for Pain Relief**

Culture can affect a person's response to pain, both in the meaning and expression of pain. Pain may be seen as something positive, that it is a sign that the body is fighting towards recovery or as a test of one's faith through suffering or even as a punishment (Giger, et al., 2006; Shavers, et al., 2010). Therefore for some individuals, asking for pain medication may be considered a sign of weakness.

Culture can influence the initiative a patient takes in asking for pain medication. For example, Cambodian culture values an indirect communication style, avoiding public display of emotion and confrontation, so rather than asking directly for pain medication, the patient may wait to be asked if medication is needed (Mahloch et al., 1999). For many Somalis, the concept of autonomy is foreign and they may wait for the health care provider to ask if the patient is experiencing pain (Countries and Their Cultures, 2012). For more information about pain, see the Pain Management section below.

### **Role of Religion and Faith**



Maori statue at Maori Cemetery,  
New Zealand. Photo by Phyllis  
Coolen.

For many ethnically diverse cultures, the approach to health and illness is through the 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 (Countries and Their Cultures, 2012; Huff & Kline, 2007b; Kachingwe & Huff, 2007; Koenig & Gates-Williams, 1995; Mark & Lyons, 2010; Yee, 2007).

For example, in the Vietnamese culture, health and religion are connected and therefore, suffering and illness are part of life. Death cannot be avoided or ignored as it is part of life. Vietnamese Buddhists believe that a person's life is predetermined and prolonging life is futile. The family may want a monk to pray at the bedside to assist the person for a peaceful journey to the next life (Braun, Beyth, Ford, & McCullough, 2008).

Maori spiritual healers strongly believe in reconnecting with their culture, their land, and their genealogy to restore the sense of identity and sense of belonging during serious illness. So, in order to heal the person's spirit, the person must relearn the culture as part of a ritual health passage (Mark & Lyons, 2010).

For Filipino Catholics, a priest would be requested to give the sacrament of the sick, so that the person may ask forgiveness for their sins in order to gain strength and peace as they go through the dying passage. In addition, some families will hold evening prayers with family and friends gathering together for support as they all go through the journey with the patient.

Traditionally, Hmong believe that the soul is lost due to an evil spirit or that a curse is the cause of the illness. Spiritual ceremonies by a shaman are crucial to bringing back the lost soul. However, the Hmong also believe in reincarnation; when the person is dying, religious ceremonies by the shaman are conducted for the purpose of helping the person have a good journey to the next life (Carteret, 2012).

As in other Asian and Southeast Asian cultures, such as in the Cambodian and Vietnamese cultures, there is a belief in the importance of harmony in and between the body, mind, and soul with the universe. Imbalance in these elements can cause a mild to life-threatening "wind illness." Wind illness is associated with fever, dizziness, and sickness; however the more severe manifestation might be likened to a stroke or heart attack. Traditional healing practices are often used to treat wind illness. For more on wind illness, see EthnoMed article *Ethnographic Study among Seattle Cambodians: Wind Illness*.

For many African Americans there is a strong belief that prayer and the power of God will heal the patient. In comparison with non-Hispanic whites, African Americans are more likely to consider religion as a coping strategy in dealing with end-of-life issues and advanced planning. It is important that the health care provider consider the role of spirituality and partner with spiritual leaders in end-of-life care discussions (Shrank et al., 2005).

Native Hawaiians have a strong belief in a higher spiritual God and that prayer, chanting, and music will restore the balance of mind, spirit, and body (Logan, et al., 2006). To show respect to a dying elder, Hawaiian families – including extended family and community members – will gather, even in the hospital, to tell stories, pray, and play music.

For some Thai Buddhists, when a person is dying, an effort is made to have the person focus upon Buddhist scriptures or repeat one of the names of the Buddha, such as *Phra Arahant*. If the person is too weak, then the name is whispered in his ear. Sometimes four syllables (*ci, ce, ru, and ni*) which represent the heart of the Buddhist teachings (Abhidharma) are written on a piece of paper and put in the mouth of the dying person. It is thought that if the person's last thoughts are the teachings of the Buddha, the person will have a good next life (Buddhist Studies, 2012).

Among many Somali Muslims, prayers assume a pivotal role at the end of life. Reciting from the Quran at the patient's bedside is done to ensure that the last words the person hears before death are the words from the Quran, as the prayers allow the person's soul to enter paradise after death. Also Muslims pray towards Mecca, so asking the family if the patient would like his or her bed positioned to face towards Mecca, if possible, would be an important part of the patient's care (Klessig, 1992; Schim & Doorenbos, 2010).

## **Use of Traditional Healing**

The use of Western medicine is generally acceptable by ethnically diverse patients in the care of terminal illness, although the level of acceptance depends on a number of factors, including how assimilated the individual is to American culture (Le & Le, 2005). Alternative practices may be used simultaneously with Western medicine because of the perceived or real effectiveness of the treatments as experienced by the patient. Symptoms often experienced as a result of the disease and dying process include pain, nausea and vomiting, breathing difficulties, skin wounds, bowel and bladder problems, anxiety and depression, and sleep disturbances. To address these symptoms, patients may seek the care of spiritual healers and the use of alternative practices, such as coining, cupping, moxibustion, palm reading, use of astrological computations for life guidance, and herbal and folk remedies.

Some Filipinos may seek medicinal healing through the use of *halaman* (herbs) and an *herbolaryo* (witch doctor), if they believe that evil spirits entering the body caused the illness. For more information on traditional medicine, see EthnoMed's collection of articles.

## **Hospice and Palliative Care**

Although the hospice and palliative care movements have been instrumental in increasing awareness in end-of-life issues, many people are still not familiar with these services. For some cultures, hospice and palliative care's focus on comfort, harmony, family and support fits nicely with the culture's values and beliefs. For cultures where dying at home is a valued norm, those values are congruent with hospice care. Providing services in the home is a hallmark of hospice care.

Palliative care, which is generally provided on an inpatient basis, is designated for patients regardless of their life expectancy, who have a progressive, debilitating and/or life-limiting illness that adversely affects their daily functioning or will predictably reduce life expectancy (National Guideline Clearinghouse, 2011). The palliative care team works in conjunction with the primary care physician and can offer assistance with end-of-life care. This includes the treatment of pain and other symptoms, emotional and spiritual support, assistance with communication of bad news, support for patients and families in medical decision-making, and navigating the complex medical system (National Guideline Clearinghouse, 2011).

Hospice also provides palliative care. However, hospice services are for patients who are no longer seeking curative therapy and have a prognosis of less than six months. Hospice care is provided in any setting that is considered the patient's home, which includes the patient's home, skilled nursing facilities, assisted living facilities, retirement homes, and even the hospital.

## **Cultural Assessment**



Siem Reap, Cambodia. Photo by Phyllis Coolen.

There are numerous cultural issues germane to end-of-life care. A critical step in understanding cultural relevance in end-of-life care is performing a cultural assessment. A cultural assessment provides a systematic way of gathering and documenting information about the patient's cultural beliefs, meanings, values, patterns, and expressions as they relate to the patient's perception and response to an illness (Leininger & McFarland, 2002). Gathering of information is conducted through asking the patient and family specific questions and also through observations of the patient, including family behavior patterns. A cultural assessment can be performed by any health care provider, with modifications of the assessment tool based on the health care provider's particular discipline, interests and therapeutic goals (Leininger, 2002a). It is critical that the assessment by each discipline and the documentation of the assessment be coordinated and incorporated into the patient's treatment plan to ensure continuity of care. It is also important to remember to communicate the cultural assessment findings to all members of the patient's health care team, including specialists to whom the patient is referred. Sharing the patient's cultural assessment with the other health care team members lays the foundation for care and can provide a smooth transition for the patient as he or she moves through the health care system.

There are a number of assessment tools available. Regardless of which is utilized, the focus must be on the uniqueness of the individual patient and how culture shapes his or her response to dying and end-of-life care. An approach to beginning an assessment might be to say, "I would like to learn more about you and your culture, so that I can be sure and meet your needs and provide the best care for you."

### **Kleinman and Campbell's Patient Explanatory Assessment Model**

Kleinman's (Kleinman, Eisenberg, & Good, 1978) patient's explanatory assessment model devised eight simple questions that clarify cultural generalizations and provide insight into the patient's personal meaning of the illness. Campbell et al. (Campbell, McDaniel, & Cole-Kelly, 2003) added family-focused questions to be included along with Kleinman's questions. The questions may be varied and individualized depending on the patient's problem or if the questions are being asked of the family members. The term "illness" can be substituted with a specific symptom or a term that may be commonly used by the patient, such as "sickness," "pain," or "fluid in your stomach area" to help the health care provider understand the patient's perception of the effects of the illness. The questions are:

1. What do you think has caused your illness?
2. Why do you think your illness started when it did?
3. What do you think your illness does to you? How does it work?
4. How severe (serious, terrible) is your illness? Will it have a short or long course?
5. What kind of treatment do you think you should receive?
6. What are the most important results you hope to receive from this treatment?
7. What are the main (biggest) problems your illness has caused you?
8. What do you fear most about your illness?

9. What do your family members believe caused the illness?
10. What do your family members believe could treat the illness?
11. Who in your family is most concerned about your illness?
12. How can your family be helpful to you in dealing with your illness?

## Giger-Davidhizar's and Huff's Cultural Assessment Models

Geiger-Davidhizar's Cultural Assessment Model considered six components relevant to end-of-life care: communication, space, time, environment control, social organization, and biological variation (Giger, et al., 2006). The author added additional assessment from her own practice as well as from Huff's assessment model to the table below in order to enhance information gathering (Huff & Kline, 2007a). Click to view PDF of this table [📄](#).

Components	Assessment Questions for the Health Care Provider to Consider	Sample Scripts
<p><b>Communication</b> (Note: If the patient's and family's education levels are unknown, a good rule of thumb is to present information at a 6<sup>th</sup> - 8<sup>th</sup> grade level. Also minimize the use of medical jargon.)</p>	<ul style="list-style-type: none"> <li>▪ What are the usual and customary communication patterns and practices? For example, the Cambodian Sampheah greeting (placing hands together like praying at chest level and bowing to the person) is more than just a way of saying hello, but it is also a sign of respect, which is central to Cambodian culture.</li> <li>▪ How do the patient and family expect to be communicated with on death and dying issues?</li> <li>▪ Who will be the decision-maker in the family regarding health care issues?</li> <li>▪ Who will be the spokesperson for the family?</li> <li>▪ Are there certain terms that are used to describe illness or terms or subjects that are taboo?</li> <li>▪ What traditional explanations may be used to explain a terminal illness?</li> <li>▪ Does the family freely ask questions or voice their concerns?</li> <li>▪ Are there gender and age rules governing interpersonal interaction?</li> <li>▪ Are there trust issues between the health care provider and the patient and family? Are there trust issues if the patient and provider are not the same gender?</li> <li>▪ Would the patient or family be more comfortable with a provider of the same ethnic group as themselves?</li> <li>▪ What types of non-verbal cues are observed with the patient and family?</li> <li>▪ What seem to be major barriers for the patient and family in the use of health care services?</li> </ul>	<ul style="list-style-type: none"> <li>▪ <i>Your condition is very serious. Some people like to know everything that is going on with their illness. What would you like? How much do you want to know?</i> (Note: If the patient does not want to know or only wants the information given to the family, remain flexible by letting the patient know, <i>"If you change your mind about wanting information I will be glad to talk with you and answer any questions."</i>)</li> <li>▪ <i>"Do you make your own decisions about your care, or do you want someone else to make those decisions (who specifically)?"</i></li> <li>▪ <i>"Since ___ will be making decisions about your care, is it ok for me to talk to them about your illness and your situation?"</i></li> <li>▪ For the patient who asks that the discussion be with the family: <i>"Do you want to be there when we talk?"</i></li> <li>▪ To seek clarification from the family: <i>"I want to make sure that I am being clear in explaining your father's condition and treatment options to him. Could you please tell me what you understand about your father's situation and his treatment options?"</i></li> </ul>



## Space

- Is family closeness valued?
- How is the family defined, that is, who is included? Extended family members? Community? Spiritual leaders?
- *“Your family seems very important to you. Sometimes family members include aunts, uncles, cousins, religious community. How do you describe your family?”*
- *“Who in the family do you want to be involved in the decision about your care?”*

## Time

- Are the patient and or family present, past, or future oriented? (Present oriented takes each day as it comes. Past oriented holds on to significant past traditions. Future oriented looks to the future for a “better life.”)
- *“What do you think the illness does to you?”*
- *“How do you usually deal with a serious situation, such as now with your illness?”*
- *“How does the illness affect your day-to-day living?”*

## Environmental Control

- Whom do the patient and or family believe holds control over the future?
- Where does the locus of control lie? Internal locus of control means that the power to change lies within oneself, while external locus of control means the power of change is due to luck, fate, or to chance.
- *“Can you tell me what you understand about your illness? What do you think caused it?”*
- *“What concerns you most about your illness and the treatment?”*


## Social Organization

- Is there a belief in a supreme being?
  - What role do faith or spirituality play in the patient's and/or family's beliefs and what influence do they have on behavior?
  - What role does the spiritual leader play with respect to the dying patient?
  - Are traditional healers consulted routinely or under what circumstances?
  - What is the function and role of each family member within the family system? What specific impact do social class, gender, age have on the person's role in the family?
- *"Is there anything that would be helpful for me to know about how you or your family (or your community or your faith/ religion) view serious illness and treatment?"*
  - *"Please let me know if there is anything in your cultural background that is important to you and your family that would be helpful to me in taking care of your father. I want to be able to provide the best care possible for your father."*
  - *"How is your family dealing with your illness? What concerns them the most?"*
  - *"Spirituality or faith provides some people with strength in coping with difficult times, such as your father's illness. Where do you find strength to deal with difficult situations?"*

## Biological Variation

- Are pain or any other symptoms expressed freely or only if asked?
  - Is pain considered a suffering to be tolerated?
  - What are the usual or traditional responses to an illness, to pain or other symptoms?
  - What are the patient's and /or family's perception of the use of Western health care practices and treatment?
- *Are you having any pain? What do you think is causing your pain? What is the main problem your pain is giving you?"*
  - *"I want to make sure you are comfortable. Do you feel comfortable asking for medication to help make your pain go away?"*

## Kagawa-Singer & Blackhall's ABCD Cultural Assessment Model

Kagawa-Singer and Blackhall developed a cultural assessment mnemonic approach to assess the degree of cultural adherence to help avoid stereotyping and decrease the risk of miscommunication (Kagawa-Singer & Blackhall, 2001). The **ABCD** cultural assessment is outlined below. Click to view PDF of this table .

## Relevant Information

### Attitudes of parents and families:

- What attitudes does this ethnic/cultural group in general – and the patient and family in particular – have about truth telling with regard to diagnosis and prognosis?
- What is their general attitude towards discussion of death and dying?
- Do they have positive or negative attitudes about particular aspects of care?

### Beliefs:

- What are the patient's and family's religious and spiritual beliefs, especially relating to the meaning of death and dying, the afterlife, and miracles?

### Context:

- Determine the historical and political context of the patient's and family's lives, including place of birth, refugee or immigrant status, poverty, experience with discrimination, health disparities, language spoken, and degree of integration within their ethnic community and the degree of assimilation into Western culture.

### Decision-making style:

- What is the general decision-making style of the cultural group and specifically of the patient and family?
- Is the emphasis on the individual decision-making process or the family decision-making process?

### Environment:

- What resources and support are available to the patient and family?
- What resources are available to assist the health care provider to interpret the significance of the patient's culture?

## Questions and Strategies for the Health Care Provider

- Increase one's knowledge about the values, beliefs, and attitudes of the cultural group most frequently seen in your practice.
- Determine the patient and family's perception of an illness: *"What does your illness/sickness mean to you?"*
- Determine if the patient uses traditional healing practices and for what problems.
- Determine if the patient or family has positive or negative attitudes about a particular aspect of care being addressed, such as advance directives.
  
- *"Spiritual or religious strength sustain many people in times of distress. What is important for me to know about your faith or spiritual needs?"*
- *"How can we support your needs and practices?"*
- *"Where do you find your strength to make sense of what is happening to you?"*
  
- *"Where were you born and raised?"*
- *"How long have you lived in the United States?" What has your experience been since coming to the U.S. (or the city)?"*
- *"How has your life changed since coming to the U.S.?"*
- *"What language are you most comfortable using when talking about your health care?"*
- *"What were other important times in your life that might help us better understand your situation?"*
  
- *"How are decisions about health care made in your family?"*
- *"Who is the head of the family?"*
- *"Is there anyone else I should talk to in your family about your condition?"*
  
- *Identify community resources that may be of assistance to the health care provider and the patient and family, such as translators, health care workers from the same community as the patient, community associations, religious leaders, and healers.*

## Advance Directives



The Patient Self-Determination Act (PSDA) of 1990 (Electronic Code of Federal Regulations, 2011) requires health care facilities to ask patients if they have an advance directive and if not, requires them to provide patients with information about advance directives. The intent of the advance directive is to improve end-of-life care.

There are two types of advance directives: a document called an advance directive which is also known as a living will, personal directive or advance decision, and a durable power of attorney for health care (WSMA, 2012).

### Key Points to Know About an Advance Directive

- An advance directive is a document expressing a person's wishes concerning certain life sustaining medical treatment when the person is seriously ill or at the end of life, should the person not be able to communicate his or her wishes.
- Although the advance directive is legally valid throughout the United States, each state may have different laws governing advance directives.
- In Washington State, the advance directive is used only when life-sustaining treatment would artificially prolong the process of dying in a terminal condition or if the individual is in an irreversible coma and there is no reasonable expectation of recovery.
- The advance directive becomes a legal document once the individual signs it and it is signed in front of the two required witnesses. The witness must not be the attending physician, an employee of the physician or the health care facility in which the individual is a patient, or any person who has a claim against any portion of the patient's estate upon the death of the patient.
- The completed advance directive form does not need to be notarized, but it is advisable.
- The advance directive form does not need to be filled out by a lawyer.
- The advance directive does not have an expiration date.
- The individual can change or use his or her own words on an advance directive form or even create their own form; however, individual and witness signatures are still required.
- *Five Wishes* [<https://fivewishesonline.agingwithdignity.org>] is considered a legal advance directive document in Washington State (*Five Wishes*, 2012). It is translated into 26 languages. There is a cost associated with obtaining the document in an online or booklet format. The health care provider could utilize the online version of the *Five Wishes* as a discussion tool with the patient and family, and take the opportunity for the patient and family to fill out the form and have it printed and signed during the office visit.
- The Physician's Orders for Life Sustaining Treatment (POLST) is not the same as an advance directive. The POLST are specific *orders by the physician* that indicate what type of life-sustaining treatment the individual wants, or does not want at the end of life.

### Key Points to Know About a Durable Power of Attorney for Health Care

- A durable power of attorney for health care is a legal document in which an individual designates a person to make medical decisions when the individual is incapacitated.
- The designee can be a family member and more than one person can be designated, including a back-up person if the designee is not able to fulfill the role.
- In Washington State, the document does not need to be notarized or witnessed. However, it is advisable to have a lawyer prepare the document and notarize it.
- The Washington State Medical Association provides information on advance planning, including forms available for download for advance directive, POLST, and for durable power of attorney for health care: <https://wsma.org/advance-directives> [<https://wsma.org/advance-directives>]

### Cultural Issues around Advance Directives

Studies indicate that ethnic minorities in comparison to whites continue to have lower rates of completing advance directives (Kwak & Haley, 2005). These lower rates are due to a lack of knowledge and understanding by the patient and family about the advance directive; a distrust in the American health care system and concern that the person's wishes won't be carried out; fear of death; and cultural differences regarding the need for an advance directive, which relate back

to “death is a taboo subject” (Campinha-Bacote, 2009; Giger, et al., 2006; Searight & Gafford, 2005a). The key in discussing advance directives is in the planning process. Fostering a trusting relationship between the health care provider and the patient and family is a critical component in the planning process which requires discussing the patient’s values, preferences, and options with the health care provider (Braun, et al., 2010).

The following are specific areas of concern:

- Lack of knowledge and understanding about advance directives. Major misconceptions about the advance directive are that it is related to a will or treatment consent, that it requires an attorney, and it pertains to funeral and burial arrangements (Perkins, Geppert, Gonzales, Cortez, & Hazuda, 2002). Surrogate decision-makers may lack knowledge of the patient’s preference. Studies of African Americans, Hispanics, and Asian surrogate decision-makers revealed their concerns about the lack of knowledge of the patient’s preference on advance directive; the tremendous burden they felt in trying to make a decision without knowing the patient’s preference; feeling under pressure to make a decision in a short period of time; feeling guilty about losing the patient; and preference for the physician to make end-of-life decisions (Perkins, et al., 2002; Washington, Bickel-Swenson, & Stephens, 2008). From the author’s experience, some of her patients thought signing a legal document like an advance directive meant they were also signing over their house to the health care facility.
- Distrust of the health care system. In the U.S. health care system, there is a long history of mistreatment of African American patients and evidence of health disparities. As a result, some people distrust the health care system and may view it as having control over all treatment and worry that their wishes will be ignored (Koenig & Gates-Williams, 1995). For some minorities and the poor, stopping treatment or referring to hospice services may raise a patient’s suspicions of receiving poorer quality of care and neglect (Washington, et al., 2008). Trust issues between the patient and provider can cause discord, leading to non-compliance with treatment suggestions and unwillingness to complete an advance directive.
- Acculturation. Acculturation refers to the process of adopting the cultural norms of the dominant culture, which in this case is how acculturated the individual is regarding American core values and beliefs relevant to end-of-life issues. A study of English-speaking Japanese Americans found that despite acculturation, many of the subjects retained some of their Japanese cultural values and beliefs influencing end-of-life care and decision-making process, such as a strong preference for the group surrogate decision-making model (Matsumura et al., 2002). Some Filipino Americans, although they may have lived in the U.S. for over forty years, as they have gotten older may rely more on traditional health care beliefs and practices as a means of comfort and enhancing their ties to the Filipino culture, which may include an unwillingness to talk about death and dying.
- Collectivism. When the family is the decision-maker on health care issues, this may include the discussion and decision around an advance directive. For example, many older Koreans believe that their children will decide about their end-of-life care and therefore there is no reason for an advance directive (Kwak & Haley, 2005). However, for some Filipinos the thought of burdening one’s children with end-of-life decisions is stressful. Having advance directive planning discussions with the patient, before a serious illness, can eliminate this stress at end of life.
- Preference for physician to make health care decisions. Some cultures may feel that initiating discussions about advance directive planning may be a sign of disrespect. Therefore, family members may prefer the health care provider initiate the discussion and make decisions about life-sustaining treatment (Kwak & Haley, 2005).
- Taboo. Talking about death and dying is taboo in many cultures. This taboo may contribute to resistance and lack of acceptance of advance directives.
- Influence of faith and spirituality. Among many African Americans the strong belief that an illness is a test of their faith requires that there not be any barriers put up, such as discontinuation of life support or aggressive treatment (Koenig & Gates-Williams, 1995). Likewise, some Hispanics view life as a gift from God and therefore life must be protected (Klessig, 1992).



Young monks,  
Cambodia. Photo by  
Phyllis Coolen.

Many Southeast Asians are Buddhist and believe in the cycle of life, karma, reincarnation, and that death is part of life. Aggressive treatment may be viewed as disturbing the natural ebb of life and a sign of a bad death (Jagaro, 2004). The palliative and hospice focus of comfort care with peaceful and family support aspects may be more acceptable and in line with Buddhist beliefs and values. Patients and families may be more open to the discussion about and acceptance of advance directive planning.

In some cultures, such as the Samoan, Vietnamese, and Asian Indian cultures, there is belief that dying away from home can lead to disturbances of the spirits. Some people may also believe that there are too many disturbing spirits in the hospital, so dying in the hospital should be avoided (Countries and Their Cultures, 2012; Yee, 2007). For Koreans, dying at home is a norm encouraged in the culture (Kwak & Salmon, 2007). Patients and families from these cultures may consequently be more open to discussion about advance directives and hospice services. On the other hand, many Chinese avoid dying at home, because of the belief that ghosts will linger in the home (Koenig & Gates-Williams, 1995).

## Approaches to Consider When Discussing Advance Directives

The following are approaches to consider when discussing advance directives in order to provide an open and supportive environment:

- Ideally, discussions on advance directive planning should be performed in advance of an impending health care crisis. For example, it should be part of the patient's routine care. It should also be a continuing discussion as patient's views change, they grow older, or their health status declines and their perspective on advance directives may change. Incorporating an advance directive discussion on a yearly basis is advisable.
- When the family is the designated decision-maker on health care issues, the discussion about advance directive planning must be done with the family. It is also important to determine the patient's preference for being present at the discussion.
- Sufficient time must be allocated for the discussion. Setting up a separate time for the discussion allows for a more thorough discussion and question and answer session. Also the patient may need to make arrangements for family members to attend the discussion.
- The discussion should be done in private. The health care provider should encourage the patient and family to ask questions. The health care provider should reassure the patient and family that the advance directive will only be shared with those who are on the patient's health care team.
- Determine if the patient and family understand the purpose of an advance directive. Common misconceptions are that it is a will, that if the person signs the document he or she will lose their home, that it requires an attorney, and that it addresses funeral and burial arrangements.
- Provide detailed information including the natural course of the disease, the prognosis, and chance of survival. Many family members will pursue less aggressive treatment if the chance of survival is poor. Help the patient and family understand that "doing everything" may also bring about additional pain and suffering. However, recognize that for some people, even in the face of a low survival rate, aggressive treatment is expected and supporting those decisions is important. When the patient or family wants "everything possible done," an exploration of what that means can provide a greater understanding of what's behind the request. Consideration may be: denial of the illness or the progression of the illness, unrealistic goals, fear of dying, and loss of self-control, false hope, or a sense of familial duty (Braun, et al., 2008).
- Patients and family members need to be assured that an advance directive that excludes curative treatment does not mean the patient will be abandoned by the health care system. The health care provider must provide reassurance that stopping curative or life-supporting treatment does not mean no treatment, but that the focus of the patient's treatment will be aggressive management of any pain and symptoms the person may experience.
- For some cultures, the concept of present orientation is to "take each day as it comes." The health care provider may suggest having a trial intervention to help with the decision-making process. A trial intervention is time limited and takes the approach of *"Let's see what happens to your mom's condition in the next few days and we can then revisit the discussion on life-sustaining treatment. Meanwhile if you have any questions for me, please feel free to ask them."*
- A religious leader can play an important role in facilitating the discussion and decision-making process in advance directive planning through clarification of how certain aspects of a religion's principles or beliefs may influence the decision on providing life support measures. The religious leader can also act as a crucial intermediary in helping the patient connect with his or her faith or spiritual life.
- When the discussion of death and dying is a taboo subject, the health care provider might initiate having the patient do a life review. Xiao et al.'s study on Chinese patients with advanced cancer found that encouraging patients to do a life review prepared them for death (Xiao, Kwong, Pang, & Mok, 2011). Encouraging the patient to review and value his or her life experiences and complete unfinished business may enable the patient to work on advance directive planning.
- More subtle, indirect and implicit non-verbal communication may be preferred when discussing advance directive planning (Matsumura, et al., 2002). Non-verbal communication includes active listening with pauses between sentences, silence, and holding the patient's hands.
- Development of educational tools in collaboration with a targeted culture community can increase awareness of the value and usefulness of advance directive planning and end-of-life choices.

The following are examples of scripts for the discussion on advance directives. Adjust the script if the discussion is with the family. Remember, asking permission to have the discussion shows respect.

- *“I would like to talk to you about what kind of care you (your mother) would like if you (she) got really sick. Is that ok?”*
- *“If you get really sick, I would be afraid of not knowing what you want or how you would like to be cared for. Could we talk about it now? I would feel better if we had this talk.”*
- *“What kind of medical care would you want if you were too ill or hurt to let someone know your wishes?”*
- *“There is a way to let your family, friends, and health care providers know what your wishes are and to avoid any confusion later. This is called an advance directive. It is a legal document that helps make it clear what you want and do not want if you are very seriously ill.”*
- If the patient is terminally ill and does not have an advance directive: *“I realize these are hard questions for you to think about, but because you are so seriously ill, if your heart stopped or you stopped breathing what would you like to have done?”*
- Instead of saying to the patient *“Nothing more can be done”* say *“The focus of your care will be aggressively managing your symptoms, so that you can be more comfortable and have the best care possible.”*
- Some patients avoid discussing or completing an advance directive because of a belief around “hope or a miracle for a cure.” One way to support the patient is being open and honest, and refocuses on the possibility of different types of hope and miracles: *“I believe in hope and miracles, but sometimes a cure doesn’t happen. However, there may be other types of hopes and miracles to consider, such as a good death, a peaceful death with having all your family around you, or for the relief from pain and suffering. What do you think?”* This can lead to further discussions with the patient on advance directive planning.

## Pain Management

### Health Disparities in Pain Management



There is strong evidence that health disparities continue to exist among ethnically diverse groups. In comparison to their white counterparts, ethnic minorities experience higher rates of mortality, shorter life expectancy, greater difficulty with access to health care services, higher rates of chronic disease, lower rates of cancer screening, and higher rates of having a more advanced stage of cancer at the time of diagnosis (Ho, Muraoka, Cuaresma, Guerrero, & Agbayani, 2010; Kline & Huff, 2007; Minority Health Initiatives, 2006; Politzer, Yoon, Hughes, Regan, & Gaston, 2001; Shavers, et al., 2010). The 2010 National Healthcare Disparities Report indicates that disparities in quality of care and access to care are common, and that ethnically diverse groups such as African-Americans, Hispanics, American Indians/Alaska Natives, Asians/Pacific Islanders, and the poor receive worse care than whites and people with higher incomes (Agency for Healthcare Research and Quality, 2011).

With regard to palliative and end-of-life care, the 2010 National Healthcare Disparities Report (Agency for Healthcare Research and Quality, 2011) found when comparing African-Americans, Asians/Pacific Islanders, American Indians/Alaska Natives, and Hispanics to whites:

- The ethnically diverse hospice patients were less likely to receive the right amount of emotional support.
- The ethnically diverse hospice patients were less likely to receive end-of-life care consistent with their wishes.
- The ethnically diverse hospice patients were more likely to report poorer communication with their physicians and nurses.

Health disparities in quality of care and access to care have also lead to disparities in the treatment and management of pain during end-of-life care. Shaver et al.’s review of the literature found disparities in pain management for ethnically diverse patients (Shavers, et al., 2010). These disparities are likely due to a lack of access to care, lack of appropriate access to analgesics and opioids, lack of access to pain specialists, and language barriers. The patient’s fear of addiction and the provider’s lack of knowledge about effective pain management during end-of-life are other contributing factors. Examining the cancer pain experience among non-Hispanic whites, African American, and Asian participants, miscommunication between the provider and patient regarding the patient’s perception and expression of cancer pain

was a common theme found across all ethnic groups (Im et al., 2010). Chung et al. (2009) found that Chinese- and Japanese-American cancer patients' pain intensity was significantly underestimated by both physicians and nurses, while Anderson et al. (2000) found that physicians significantly underestimated the pain severity of African American and Hispanic patients with recurrent and advanced cancer. Other studies found that minorities were more likely not to receive pain medication or would receive a lower dose of an analgesic even if the patient had advanced cancer or was receiving end-of-life care (Green, Montague, & Hart-Johnson, 2009; Mossey, 2011; Payne, Medina, & Hampton, 2000; To, Ong, Rawlings, Greene, & Currow, 2012). Additionally, underreporting of pain intensity by minority patients was a significant barrier to effective pain management (Dhingra, 2008; Mossey, 2011; Shavers, et al., 2010).

## **Cultural Influence on Pain Response**

Pain is more than a response to a physical/biological injury. It is a complex event that encompasses psychosocial, emotional, and social components, which any treatment of pain must take into consideration (Fortier, Anderson, & Kain, 2009). A key element of palliative and hospice services is to assess and relieve suffering from not only physical pain, but also from psychological, social, and spiritual distress (National Guideline Clearinghouse, 2011). In order to provide culturally sensitive pain management, a patient's pain must be considered within the context of the individual's beliefs and values, as culture may influence the individual's perception and response to pain, whether or not the patient will ask for pain medication, or whether the use of traditional healing practices take precedence over Western medical treatment (Dhingra, 2008; Im, et al., 2010; Mossey, 2011; Narayan, 2010; Shavers, et al., 2010). It is important to remember there are variations among individuals within a cultural group with regard to their perception and expression of pain. However, understanding the broader aspects of cultural influence affecting response to pain can provide the health care provider with the necessary foundation for assessing specific and individual cultural influences and providing effective pain treatment.

The use of certified medical interpreters for limited English proficient (LEP) patients can facilitate effective communication between the health care provider and the patient about end-of-life care, including the difficult issues around pain management (Norris et al., 2005). Supporting the use of the interpreter as a cultural broker can also enhance the communication between the health care provider and patient through greater understanding of the cultural aspects and perspectives of the patient (Norris, et al., 2005).

The following examples of miscommunication are based on several of the author's clinical observations and experiences and are intended to illustrate the issue.

When a Cambodian hospice patient was asked if he had pain, he pointed to his heart. The clinician assumed that the patient was having cardiac pain and further assessment and treatment focused on eliminating the cardiac pain, without effective results. Upon further discussions with the family it was revealed that the patient's "heart pain" was referring to his health and how painful it was to him and his family to see him so ill, as well as worrying about his family and the burden his illness placed on them. For Cambodians, the heart symbolizes love, kindness, willingness to help others, and health (National Head Lung and Blood Institute, 2010).

Another example of miscommunication is that of an elderly Chinese woman, who when asked if she had any pain, she pointed to her head. The hospice clinician's treatment was then focused on treating the patient's "headache." Much time was spent on treating the patient's headache without effective elimination of the pain. It was finally realized through persistent assessment and working with the family that the patient's reference to the pain in her head was not due to a headache, but that the patient had been referring to her anxiety and stress about her illness.

In these two examples the patient and family were frustrated by not being able to effectively communicate their concerns, and the health care providers were frustrated by not being able to effectively manage the patient's pain. The use of a medical interpreter as a cultural broker would have improved communication between the health care providers, the patients and their families, with greater likelihood of positive results in more timely, effective, and appropriate treatment and support.

In addition to language barriers, the way a person expresses pain due to cultural influences can make it difficult for the health care provider to effectively assess the patient's pain. For some elderly Chinese patients, stoicism and fatalism can create barriers to effective pain management (Carteret, 2011; Dhingra, 2008). Fatalism as influenced by Buddhist and Confucian beliefs proposes that pain should be endured, as it could lead to spiritual growth (Carteret, 2011). Stoic patients may be less likely to openly express their pain verbally and non-verbally, and may prefer to be left alone in order to bear their pain and suffering. Being stoic and hiding one's pain may influence requests for pain medication or result in the underreporting of pain. Studies have found stoic pain behavior is more often found among Mexican Americans, American Indians, and Asian Americans (Carteret, 2011; Narayan, 2010; Shavers, et al., 2010). Health care providers may assume that if the patient is not expressing pain, that pain does not exist, resulting in under treatment. On the other hand, patients from Middle Eastern or Mediterranean cultures may be more expressive in their communication and more likely to openly express their concerns about their pain. Being openly expressive does not necessarily mean their pain is intense, but may indicate the need to validate their suffering (Carteret, 2011; Im, et al., 2010; Shavers, et al., 2010).



According to a study by Im et al. (2010), some Asians and Hispanics felt that since cancer was related to death, increasing pain meant their cancer was getting worse and since death was a taboo subject, talking about pain was not appropriate or they minimized the amount of pain they were having (Im, et al., 2010). Not acknowledging pain or the intensity of the pain also results in barriers to effective pain management.

In many cultures, religious or spiritual belief in fate and karma (“God’s will”) explain why an individual has developed a life threatening illness and that pain is seen as a test of one’s fate, spiritual beliefs, as a means of achieving higher religious status, or even as a punishment for a sin (Carteret, 2011; Shavers, et al., 2010; Yee, 2007). If these beliefs are held, patients may not ask for pain medication or expect pain relief. On the other hand, the role of religion and spirituality can be considered a positive pain coping strategy, as seen in some studies of African-Americans, with the result of lowering pain scores, more positive pain and symptom attitudes, and greater acceptance of pain medication (Shavers, et al., 2010).

In some cultures, not wanting to be a burden to the family by not complaining may lead to increasing pain intensity. Pain that is out of control may be more difficult to effectively manage. The following is an example taken from the author’s experiences: A Hawaiian woman with stomach cancer was experiencing abdominal pain but did not inform the family about her increasing pain because she did not want to be to a burden. Only when the pain became so severe that it was affecting her ability to eat and sleep did she finally tell her daughter. The daughter, who was her caregiver, was very frustrated with her mother for not sharing that she was in pain and that it took a long time before her mother’s pain was brought under control.

Some patients may not want to take opioid pain medication for a variety of reasons, including preference for traditional healing practices, fear of addiction, fear of being overly sedated, a lack of access to insurance coverage, and a lack of access to opioids at their local pharmacies (Narayan, 2010). In the author’s experience, sometimes even hospice clinicians have difficulty obtaining opioids for their patients as the local pharmacies either stock a very limited supply or do not stock them at all due to an increased risk of robberies. In addition, studies have found that some health care providers associate some minority groups and low income people with drug-seeking and drug addiction behavior, with the result of under treatment of legitimate pain (Coolen, Best, Lima, Sabel, & Paulozzi 2009; Narayan, 2010).

## **Pain Assessment**

Obtaining a comprehensive, culturally sensitive pain assessment will allow the health care provider to have a better understanding of the patient’s pain and to effectively manage it. The nurse or physician can perform the pain assessment, which should then be documented in the patient’s treatment plan. The pain assessment results should be shared with the patient’s health care team in order to ensure continuity of care and eliminate pain management disparities.

Utilizing Kleinman’s assessment questions can provide cultural insight into the meaning of the patient’s pain (Kleinman, 1980):

- What do you think caused the pain?
- Why do you think your pain started when it did?
- What do you think your pain does do you?
- How severe is your pain?
- What are the main problems your pain has caused you?
- What do you fear most about your pain?
- What kind of treatment do you think you should get?

The Explanatory Model Interview for Pain Assessment is another tool that provides cultural insight into the patient’s perception and response to pain (Lasch, 2000; Narayan, 2010):

- What do you call your pain? What name do you give it?
- Why do you think you have this pain?
- What does your pain mean to your body?
- How severe is it? Will it last a long or short time?
- Do you have any fears about your pain?
- If so, what do you fear most about your pain?
- What are the chief problems that your pain causes you?
- What kind of treatment do you think you should receive? What are the most important results you hope to receive from the treatment?
- What cultural remedies have you tried to help you with your pain?
- Have you seen a traditional healer for your pain? Do you want one?
- Who, if anyone, in your family do you talk to about your pain? What do they know? What do you want them to know?

- Do you have family and friends that help you because of your pain? Who helps you?

There are a number of scales available for assessing pain among culturally diverse populations, such as the Wong-Baker FACES™ Pain Rating Scale, the 0-10 Numeric Rating Scale, the Visual Analogue Scale (VAS), and the Memorial Pain Assessment Card (MPS), which have been validated for appropriate use with ethnically diverse populations, including African-Americans, Hispanics, Asian Americans, and Native Alaskans (Badr (Zahr), Puzantian, Abboud, Abdallah, & Shahine, 2006; Hunter & Cassey, 2000; Kim & Buschmann, 2006; Luffy & S., 2003; Newman et al., 2005; Ramer et al., 1999; Shavers, et al., 2010; Shin, Kim, Kim, Chee, & Im, 2008; Tomlinson, von Baeyer, Stinson, & Sung, 2010). Patients usually indicate on the various scales by pointing to the area that best depicts their level of pain.

**The Wong-Baker FACES™ Pain Rating Scale** has a series of 6 gender-neutral face circles that range from depicting a neutral facial expression of “no pain/no hurt” to the “worst possible pain/hurt worst” depicting a crying face. The Wong-Baker FACES™ Pain Rating Scales is available in 13 different languages, including Spanish, French, Vietnamese, Chinese and Romanian (see Figure 1). Free access to download the scale can be obtained at <http://www.wongbakerfaces.org/resources> [<http://www.wongbakerfaces.org/faces-download>]. The Wong-Baker FACES™ scale has been validated with African American, Thai, Asian, Hispanic, and older Korean American populations. A modified Wong-Baker FACES™ scale used on fabric dolls with Lebanese children also validated the effectiveness of the scale. Curtin and Goldstein (Curtin & Goldstein, 2010), who work with the Native Alaskan Yup'ik culture, effectively utilized the modified Wong-Baker FACES™ scale, known as the Northern Pain Scale, which depict Native Alaskan faces to improve communication about pain with patients (Curtin & Goldstein, 2010; Ellis et al., 2011).

## Translations of Wong-Baker FACES™ Pain Rating Scale

						
	<b>0</b>	<b>2</b>	<b>4</b>	<b>6</b>	<b>8</b>	<b>10</b>
English	No Hurt	Hurts Little Bit	Hurts Little More	Hurts Even More	Hurts Whole Lot	Hurts Worst
Spanish	No Duele	Duele Un Poco	Duele Un Poco Más	Duele Mucho	Duele Mucho Más	Duele El Máximo
French	Pas Mal	Un Petit Peu Mal	Un Peu Plus Mal	Encore Plus Mal	Très Mal	Très Très Mal
Italian	Nessun Dolore	Dolore Lieve	Dolore Moderato	Dolore Forte	Dolore Molto Forte	Il Più Forte Dolore Immaginabile
Portuguese	Não Doi	Doi Um Pouco	Doi Um Pouco Mais	Doi Muito	Doi Muito Mais	Doi O Máximo
Bosnian	Ne Boli	Boli Samo Malo	Boli Malo Više	Boli Još Više	Boli Puno	Boli Najviše
Vietnamese	Không Đau	Hơi Đau	Đau Hôn Chút	Đau Nhiều Hôn	Đau Thất Nhiều	Đau Quá Đói
Chinese	無痛	微痛	較痛	更痛	很痛	劇痛
Greek	Δεν Πονάῖ	Πονάῖ Λίγο	Πονάῖ Λίγο Πιο Πολύ	Πονάῖ Πολύ	Πονάῖ Πιο Πολύ	Πονάῖ Παρα Πολύ
Romania	No Doare	Doare Puțin	Doare Un Pic Mai Mult	Doare Și Mai Mult	Doare Foarte Tare	Doare Cel Mai Mult
Mongolian	Зовиургүй байна	Бага зэрэг өвдөж байна	Өвчин нэмэгдэж байна	Их өвдөж байна	Маш их өвдөж байна	Тэсэхийн аргагүй өвдөж байна
Japanese	痛みはない	わずかに痛い	少し痛い	かなり痛い	ひどく痛い	耐えられないほど痛い
Bahasa Malaysia	Tidak Sakit	Sangat Sedikit Sakit	Sedikit Sakit	Sakit	Sangat Sakit	Teramat Sakit

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[<http://www.wongbakerfaces.org/resources>]

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**The 0-10 Numeric Pain Rating Scale** consists of a vertical line that has been evenly marked with numbers from 0-10, with 0 being “no pain” to 10 being the “worst possible pain.” This scale was considered reliable and validated for measuring pain in older African-Americans and older Koreans (Kim & Buschmann, 2006; Shavers, et al., 2010).

**The Visual Analog Scale (VAS)** consists of a 10-centimeter horizontal line with “no pain” anchored on the left side and “worst possible pain” anchoring the right side. The patient marks the area on the line that indicates the intensity of his/her pain and the mark is then measured from the left side of the anchor (Kim & Buschmann, 2006). A VAS color-coded slide ruler can also be used, which the patient moves to indicate the intensity of his/her pain. The far left side of the ruler is color coded blue, indicating “no pain,” and the far right side is color coded red, indicating “pain as bad as it could possibly be.” The back of the ruler has a 100 millimeter scale that quantifies the pain intensity (Ramer, et al., 1999). The VAS scale was considered reliable and validated for measuring pain in older African-Americans, older Koreans, non-Hispanic whites, and Asians with cancer pain (Kim & Buschmann, 2006; Shavers, et al., 2010).

Copies of the 0-10 Numeric Pain Rating Scale, the Visual Analog Scale, as well as other pain assessment scale tools can be downloaded for free through the National Initiative on Pain Control™ at

[http://www.painedu.org/Downloads/NIPC/Pain\\_Assessment\\_Scales.pdf](http://www.painedu.org/Downloads/NIPC/Pain_Assessment_Scales.pdf) 

[[http://www.painedu.org/Downloads/NIPC/Pain\\_Assessment\\_Scales.pdf](http://www.painedu.org/Downloads/NIPC/Pain_Assessment_Scales.pdf)].

## Case Studies

The following three case studies have been developed to address the complex issues surrounding cultural relevance in end-of-life care. These case studies are a compilation of a number of clinical situations and the purpose of the case studies is to examine real-life situations and provide the reader with guidance for reflective practice in the clinical setting. After reviewing the case studies, the reader may want to reflect on the following questions:

- How does this relate to my previous experiences?
- Would I handle this differently in a similar situation?
- What are my own emotions, values, and biases that may affect the way I would handle a similar situation?
- What have I learned from these case studies?

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### Case Study 1: Mr. S

#### Scenario

Mr. S is a 53-year-old Cambodian immigrant with incurable metastatic colon cancer diagnosed three months ago. Mr. S has been in the United States for 25 years and has limited English proficiency. His wife is Cambodian, 35 years old, and has been in the U.S. for 10 years. English is her second language. They have three young children. Mr. S worked as a day laborer. His wife has never worked outside the home. They follow Theravada Buddhism. Mr. S has been referred to hospice services.

Mr. S has been admitted to inpatient services for placement of a peritoneal drainage catheter for malignant ascites. Nurses' notes indicated that since admission "Mr. S has been stable with no complaints of pain or discomfort. His wife accompanied him on admission and stayed until evening. Mr. S was given one Vicodan tablet before bedtime. Neither the patient nor the wife appears to understand English well. Interpreter services will be needed when his wife is taught how to manage the peritoneal catheter." The only medication the physician has ordered is Vicodan, 1-2 tablets every 6 hours as needed for pain.

Upon entering his room, the hospice health care provider, who is not Cambodian, greets Mr. S and his wife with the traditional Cambodian *Sampheah* greeting of bowing with the hands together at chest level and says in English, "Good Morning. How are you this morning?" Mr. and Mrs. S return the greeting with a smile, although it is clear that the effort of putting his hands together and bowing is very taxing for Mr. S. Mrs. S immediately expresses her concerns about her husband's pain. She is obviously distressed and explains that Mr. S has been suffering with severe pain in his stomach, did not sleep last night, and has been sick to his stomach. She states that he threw up this morning, but that she cleaned him up and had not told the nurse. She wonders if something can be done to make him more comfortable. She also revealed that she does not want to bring their children to visit because they are too young to understand and she does not want them to see their father in so much pain. Mr. S. has not participated in the conversation but lies quietly in bed. However with any slight movement he grimaces, moans, and opens and closes his fist.

The health care provider asks Mr. S the following questions and verifies with Mr. S's wife that he understands the questions:

**HCP:** "Mr. S, you seem to hurt. Can you tell me if you are in pain and where is your pain?"

**Mr. S:** "Pain here" (pointing to his stomach and back).

**HCP:** "What does your pain do to you? How does it work?"

**Mr. S:** "It make me very sick. I cannot do anything. I cannot walk. Too weak. I cannot sleep."

**HCP:** "What do you think caused your pain?"

**Mr. S:** (He does not answer, but moans and grimaces.)

**Mrs. S:** "He wants to go home. He suffers, but it is too much for him. Doctor told him he has a tumor. Can he have a stronger pill to take the pain away?"

**HCP:** "Mr. S, how bad is your pain? Is it there all the time or does it go away sometimes?"

**Mr. S:** “Pain very bad. No sleep, no eat, no move. I suffer much.”

**HCP:** “Do you take anything for your pain that helps?”

**Mrs. S:** (She explains he uses Tylenol and *koah kshal* (coining) but that they do not seem to help. She said the pill the nurse gave him last night also did not help his pain.) (For more information on coining and other traditional Cambodian healing practices, see the Traditional Medical Practices section of the EthnoMed Cambodian Cultural Profile.

**HCP:** “Mr. S, when you are having pain, will you ask the nurse for a pill?”

**Mrs. S.** “He will not ask for anything. He will wait for the nurse to bring him something.”

## **Reflective Questions and Discussion**

### **What are your impressions regarding this scenario?**

A limited cultural awareness and sensitivity on the part of some of the health care providers added to the inadequate management of Mr. S’s pain and symptoms. Interpreters should be used for initial and ongoing assessment, not only for teaching at discharge.

### **How could an understanding of the cultural beliefs assist the hospital staff in providing effective end-of-life care?**

If the staff performed a cultural assessment on Mr. S they would gain valuable information and insight into his behavior, reactions and decisions. The assessment would guide the staff in the development of appropriate interventions within the cultural context of Mr. S and his family. For example, an assessment would ascertain how well Mr. and Mrs. S understood English and if interpreter services were needed to prevent misunderstandings with his treatment. For many Cambodians, pain and other symptoms are often endured with stoicism. Questions must be asked directly and specially about each symptom the patient may be experiencing. General questions or fleeting questions are meaningless. An assessment, such as using Kleinman’s Eight Questions (see Cultural Assessment in this unit) would help providers understand Mr. S’s behavior, his response to his pain, and his expectations about treatment. This would result in pain and symptom management, including providing pain medication on a routine basis, rather than waiting for him to ask for medication.

### **What are some key elements that should be included in Mr. S’ treatment plan in anticipation of potential problems or concerns?**

- Identify who is the health care decision maker: Mr. S or Mrs. S, both, or other family members.
- Although the nursing notes indicated that Mr. S did not complain of any discomfort, based on his diagnosis, symptoms, and prognosis, comfort measures should be in place. Adequate treatment orders should be written to ensure effective pain and symptom management, including: adequate pain medication on a routine basis to provide a constant level of analgesic and to avoid the roller coaster effect of worsening pain; medication for breakthrough pain; medication for anxiety, nausea and vomiting, pruritus, and bowel management. Frequent assessment and monitoring of his pain and symptoms must be included in the treatment plan.
- In addition, the health care provider should have assessed Mr. S’ perception of and expectations about pain and its management, as negotiations may need to be made regarding the treatment plan. For example, Mr. S may want a lower dose of pain medication in order to maintain alertness or he may want to avoid medication in order to experience that pain and suffering as an important part of his spiritual beliefs.
- Determine Mr. S’s preference for continued use of traditional practices, such as coin rubbing or herbal remedies. It is important to know about Mr. S’s expectations from traditional remedies. The provider needs to determine if there are contraindications to their use with Western medicines.
- Determine what role Mr. S’s religious beliefs play in his life and if he would like arrangements to be made to ensure access to his religious community.

A variety of resources including information on specific cultures and cultural practices, end of life care, and guidelines on cultural assessments should be made available to staff. This may include having access to consultation services with palliative care or hospice providers or access to resources on the internet such as The National Cancer Institute website at <http://www.cancer.gov/cancertopics/> [<http://www.cancer.gov/cancertopics/>].

### **What assessment and strategies are needed to improve communication between the health care providers and Mr. and Mrs. S?**

An assumption was made that Mr. and Mrs. S did not speak or understand English well. Consider how that information was determined and passed on to other staff, as well as the impact it had on his care. An initial assessment should include

determining how well the patient and family speak and understand English and if there is a need for a certified medical interpreter. If the family does not want interpreter services, check with the organization's policy on the use of interpreter services. Having a family member translate is not ideal and can result in significant misunderstandings.

Listening with empathy and patience to Mr. and Mrs. S's perceptions of pain and other symptoms is an important part of effective communication. Clarifying and acknowledging the differences and similarities in the practitioner's perception of Mr. S's pain and other symptoms can provide an understanding of Mr. S' behavior and response to his pain and vomiting. The information can then be incorporated in the development of an effective treatment plan, such as routinely monitoring and asking Mr. S about any pain or symptoms he may be having, rather than waiting for him to tell the nurse.

Respect is central to Cambodian culture. Greeting the patient and family with the traditional Cambodian greeting shows great respect and can open the door towards a trusting relationship. The health care provider in this scenario knew that the initial greeting of respect would be helpful to establishing good rapport. Though it may not be practical for health care providers to learn phrases of greeting for all their LEP patients, demonstrating an interest in the patient's culture or language in other ways can go a long way towards building rapport.

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## **Case Study 2: Mrs. V**

### **Scenario**

Mrs. V is a 68-year-old Filipino Hawaiian widow with end-stage chronic obstructive pulmonary disease (COPD). She is also an insulin dependent diabetic. Last year she moved in with her son, daughter-in-law, and four grandchildren because she was no longer able to live independently. Mrs. V is by herself all day. She is very short of breath with minimal activity and uses oxygen. She uses a wheeled walker to get around the house. In the past couple months she has gotten weaker and has fallen a couple times, tripping over rugs and "stuff" on the floor. In addition, her diabetes is not well controlled as she continues to eat peanut butter and jelly sandwiches, juice, and cookies for both breakfast and lunch, as "that is the only thing I like to eat." Mrs. V is Catholic and her faith is very important to her. English is her primary language.

The health care provider asked Mrs. V a series of questions to assess Mrs. V's condition. Mrs. V did not answer the questions directly.

**HCP:** "How is your breathing today?"

**Mrs. V:** "You know, when I lived in Hawaii, I loved to watch and smell the burning sugar cane fields. I felt so free and relaxed. I moved to the mainland to be near my son and daughter. I used to have my own house, but my son, he wants to take care of me, and so I moved in with him. I don't like being a burden to him. I miss Hawaii. I wish I could go back there to die. I think the air is much cleaner in Hawaii. Some days I have a very hard time breathing. It can be scary."

**HCP:** "How is your strength? Have you fallen lately?"

**Mrs. V:** "I took care of my mother when she was very sick and we never left her alone. That is expected in our culture—to take care of our parents. My son takes good care of me, but his wife is not a good housekeeper. The house is cluttered, but this is not my home. I am here by myself until the family comes home from school or work. I usually stay in my room and watch TV and only get up to eat or go to the bathroom. I still manage. I don't want to be a burden. God watches over me and gives me strength and protection. He gives me the strength not to be afraid of dying."

**HCP:** "It is noted that for breakfast and lunch, you only like to eat peanut butter and jelly sandwiches with juice and a cookie. Why is that? You know that is not a good choice because of your diabetes."

**Mrs. V:** Laughing she says, "I was a great cook. I loved cooking Filipino and Hawaiian dishes. It is important in our culture to welcome guests into our home and to share our food. The kitchen belongs to my daughter-in-law and I do not feel comfortable cooking in her kitchen. It is hard to get around and I don't have the strength to do a lot of cooking. I don't want to be a burden and make waves with my daughter-in-law. My youngest grandson, he likes to do things for me. He likes to make my breakfast and lunch. He is only in the third grade. Peanut butter and jelly sandwiches are easy for him to make. I don't like to make a fuss and complain."

### **Reflective Questions and Discussion**

#### **What would be helpful in understanding the cultural aspects of communication by Filipinos/Hawaiians?**

For many Filipinos and Hawaiians, "talk story" is a common means of communicating. Instead of answering a question directly, "talk story" is a sharing of personal experiences and opinions, which may initially appear unrelated. It is a powerful communication tool, if the provider takes the time to listen and participate in the conversation, because often it reveals in-depth insight into the thinking and concerns of the individual. However, allowing the patient to "talk story"

requires the willingness to take the extra time to listen, and to follow up by asking open-ended questions to encourage the individual to talk, and share some of one's own personal insights.

### **What are some key points Mrs. V revealed during her “talk story”?**

The key points Mrs. V revealed were:

- She was having increased difficulty in breathing, which is scary to her;
- She was afraid of being alone;
- She did not want to be a burden and did not feel it was her place to express her concerns to her son;
- Custom dictates that the house belongs to the son and his wife; therefore, Mrs. V felt she could not request changes to be made even for her health and safety;
- Her faith is important in helping her cope with her terminal illness;
- She felt like a guest in her son's home, which made her feel uncomfortable.

### **What cultural issues may be influencing Mrs. V's response to her health care issues?**

- Family comes first, before the individual. In the Hawaiian language, this value is called *'Ohana* (family, including extended family and the community) and is the foundation of all Hawaiian and Filipino values. Maintaining harmony is essential so as not to be a burden to the family.
  - The son is the head of the family and deference is made to the wife.
  - Taking care of an elder or sick parent is an expectation of the family, with the son usually having the biggest responsibility.
  - Communicating though the common form of “talk story” is a way of expressing a person's concerns.
  - Custom dictates that the house belongs to the son and the elder parent has no say in making household changes.
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## **Case Study 3: Mr. W**

### **Scenario**

Mr. W is a 70-year-old Chinese American man who lives with his wife of 40 years. Mr. W was diagnosed with lung cancer two years ago, but is now failing rapidly. He is very weak. He can no longer eat due to increased difficulty swallowing and breathing. He does not complain of pain, but his wife says that his back hurts. His two sons live nearby. His daughter moved in recently to help her mother care for him.

Mr. W's primary care physician wants to make a referral to hospice services. Mr. W says the doctor must talk with his sons first. In a telephone conversation with the sons, the sons agree to hospice services. However, the older son does not want his father to know he is dying and does not want the word “death” to be used when talking with his father. The son tells the doctor, “We do not tell our father that he is dying. Telling him is harmful, causing undue emotional burden for him. We are responsible for protecting him from harm.” Mr. W does not take part in the conversation nor does he make his wishes known. Mr. W does not have an advance directive.

A week later, Mr. W is admitted to the hospital with aspiration pneumonia. He is barely conscious, febrile, and his breathing is slow and irregular. The family continues to encourage Mr. W. to eat. The older son is considering aggressive treatment and the use of a feeding tube and antibiotics. The wife and older son refuse to discuss or participate in the conversation regarding end-of-life care with the nurse or physician. However, the younger son acknowledges that his father is dying. After much discussion and tension within the family, the family agrees to allow Mr. W to die peacefully with comfort measures only and without aggressive treatment. Mr. W dies within 24 hours of admission.

### **Reflective Questions and Discussion**

**For this case, describe ways in which the issues of self-determination and informed consent can be approached with the family that respect their cultural values/wishes.**

- When discussing medical issues with the family, it is important to confirm their understanding of the situation. Ask the family to explain what they understand about Mr. W's condition and treatment.
- While Mr. W is cognizant and able to participate in a discussion, the health care provider should assess Mr. W's preference for wanting to know everything about his medical condition and if he prefers that the discussions occur with the family and in his presence. It is also very important to ask Mr. W if he prefers making his own decisions about his medical treatment or if he would prefer that someone else (who specifically) make those decisions for him.
- Ask the family if there are preferred terms to use when talking about terminal cancer, whether in front of Mr. W or even with the family.
- Ask the family if Mr. W has any religious or spiritual beliefs that he might rely on in helping him deal with a serious situation, such as his illness. Let the family know assistance can be provided in meeting his religious or

spiritual needs, such as arranging a visit by a religious leader (i.e., monk, minister, priest).

- The health care provider might describe elements of informed consent and offer to provide information about advance directives and durable power of attorney to the family.
- If the patient does not have an advance directive, the health care provider should have an initial discussion with the family about life-sustaining treatment, such as cardiopulmonary resuscitation (CPR) or artificially administered nutrition and allow the family time to discuss these issues among themselves before making a decision. If the patient did have an advance directive, the health care provider should discuss and support the patient's desires with the family.
- In this situation where there are strong cultural influences in the perception and response to a serious illness, it might be good to assess the comfort level of the family in working with a health care provider from a different background (if that is the case). An approach might be for the provider to acknowledge that he/she is from a different cultural background and ask if they are uncomfortable discussing these issues with someone who is from a different race or cultural background and asking them, "Will you please let me know if there is anything about your background that would be helpful for me to know in working with you or your (mother, father, sister, brother)."

### What essential components of a cultural assessment should be performed relevant to end-of life care?

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Components	Questions to consider
Communication	Who will be the decision maker in the family regarding health care issues? Who will be the spokesperson for the family? Does the family easily ask questions or express concerns? Are there trust issues between the health care provider and the family? What type of non-verbal cues are observed with the patient and family? Are there certain terms that are to be used to describe illness or terms that are considered "taboo"? What traditional explanations may be used to explain a terminal illness?
Space	Is family closeness valued?
Time	Is the individual and or family present, past, or future oriented? Present oriented takes each day as it comes. Past oriented holds on to significant past traditions. Future oriented looks to the future for a "better life" and therefore being open to change may be more acceptable.
Environmental Control	Who holds control over the future? Where does the locus of control lie? Internally (i.e., that the power to make changes lies within oneself), or externally (i.e., that the power of change is due to luck, to chance, to fate or to a supreme being?).
Social Organization	Does the patient believe in a supreme being? The family? What role does faith or spirituality plays in the patient's belief and/or influences his/her behavior? Are there traditional healers who are consulted routinely and under what circumstances? What is the function and role of each family member within the family system?
Biological Variation	Are pain or symptoms expressed freely or only if asked? Is pain considered a suffering to be tolerated? Are there traditional healing or herbal remedies used when someone is seriously ill or dying?

(Giger, et al., 2006; Huff & Kline, 2007a)

### What could an interdisciplinary team do to improve end-of-life care for Mr. W and his family?

- Ask the family what they would like to see happen to make Mr. W more comfortable, such as helping to ease his breathing or ease his pain.
- Offer ways the family can participate in his care to make him more comfortable.
- Minimize the use of medical jargon to explain what is happening with Mr. W's condition. For example, although they would like to see him eat, ask them what their greatest concern is if Mr. W does not eat. Assure the family that not eating is a natural process as Mr. W no longer needs food for energy as his body slows down.
- To help the family make an informed decision regarding aggressive treatment, such as artificial tube feeding, provide them with information, such as the pros and cons of the treatment. Explain that as the body begins to shut down, it is difficult for the body to absorb and use the antibiotics or the extra fluids. The extra fluids can accumulate in the body making Mr. W more uncomfortable.

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