

Cultural Considerations



Illustration by Jeff DeWeerd / ImageZoo / Alamy ©

at the end of life

Abstract: It is important for nurse practitioners to understand their patients' cultural backgrounds to provide competent care at the end of life. Understanding the concepts of various cultures can keep the lines of communication open and help providers elicit the necessary information to make the end-of-life experience as comfortable as possible.

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The origin of culture dates back to the 1870s when Sir Edward Tylor defined it as “knowledge, belief, art, morals, law, custom, and any other capabilities and habits acquired by man as a member of society.”¹ Many theorists, such as Campinha-Bacote and Purnell, have identified cultural awareness in nursing since the 1990s.^{2,3} Giger and Davidhizar also identified the need for cultural competency, diversity, sensitivity, and culturally competent care.⁴ Giger and Davidhizar further noted that culture is developed over time as a result of contact with social and religious structures and intellectual or artistic manifestations, rendering each individual unique.⁴ Purnell defines culture as “the totality of socially transmitted behavioral patterns, arts, beliefs, values, customs, ways of life, and all other products of human work/thought characteristic of a population of people that guide their world view and decision making.”⁵ The history of culture brings common themes to light that are discussed in today’s healthcare environment: cultural competency and cultural diversity.

Cultural competency is part of individualized patient care, which demonstrates respect for a patient’s healthcare beliefs and acknowledges that these beliefs play a role in effective healthcare delivery. In addition, cultural competency demonstrates the provider’s understanding that illness occurs in a biopsychosocial context in response to health beliefs and practices.⁶ As the patient receives care,

healthcare providers (HCPs) should examine their own cultural values and beliefs and ensure they do not interfere with care. Part of cultural competency is acknowledging one’s own biases before providing care.

Cultural diversity in patient care refers to accepting individual characteristics, such as skin color, religion, income, gender, and geographical location and facilitating equal access to culturally competent healthcare.⁷ Providing culturally competent care includes referring patients to culturally appropriate resources, such as qualified medical interpreters, appropriate religious or spiritual personnel, and advanced practice nurses specially trained in evidence-based, cross-cultural practices.⁸

The American Nurses Association (ANA) supports the advancement of cultural diversity so that all patients can receive necessary culture-based care.⁹ It is important to develop a culturally competent workforce to help practitioners apply culture and diversity in clinical interventions along the healthcare continuum.⁷

■ Importance of culture in care

Patients entering hospitals in the United States are diverse. As the population changes, HCPs need to incorporate the various needs of their patients into practice. Caregivers who provide direct patient care today have contact with patients spanning a wide variety of races, religions, and ethnicities.¹⁰ The practitioner should recognize that patient responses

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to illnesses, such as a hospital visit or a visit to a practitioner, must include the clinical aspect of care as well as the cultural aspect of care.⁶

The ANA position statement (1991) on cultural diversity in nursing practice states that “Knowledge of cultural diversity is vital at all levels of nursing practice... nurses need to understand how cultural groups define health and illness; how cultural groups understand life processes; what cultural groups do to maintain wellness; what cultural groups believe to be the causes of illness; how healers cure and care for members of cultural groups; and how the nurses’ cultural backgrounds can influence care delivery.”⁹ HCPs should incorporate transcultural nursing practice while providing care to patients with multiple cultural differences. HCPs should also modify care according to the cultural needs of the patient and his or her family members. To organize and plan care for culturally diverse populations, HCPs should recognize and understand culture, culturally appropriate care, and the aspects of culture that should be explored for each patient.^{6,9,11}

■ Cultural assessment

In 2010, the Joint Commission developed new standards for culturally competent patient care and assessment. The new standards took effect in January 2011 and include the provision of culturally competent care as a response to the diverse needs of patients in American hospitals. Aspects of culture, such as religious beliefs, perception of illness, dietary needs, spiritual beliefs, and modesty issues should all be part of the admission assessment process. This assessment should include questions regarding end-of-life care, and it can be modified for any setting.¹²

Cultural resources for practitioners

Transcultural C.A.R.E. Associates
www.transculturalcare.net

Transcultural Nursing
www.culturediversity.org/assesmnt.htm

Center to Advance Palliative Care
www.capc.org

American Academy of Hospice and Palliative Medicine
www.aahpm.org

Ethnomed
ethnomed.org

End of Life Care Resources—The National Hospice and Palliative Care Organization
www.nhpc.org/i4a/links/?pageid=3287

Specific assessment questions at end of life should include the following:

- Which cultural background does the patient identify with?
- Are there cultural beliefs or traditions that the patient adheres to?
- What is the role of the family in the patient’s care?
- Does the patient want family involved in the treatment plan?
- Who makes the decisions about advance directives and treatment options at the end of life? Is it the family, patient, or someone else?
- Does the patient have any religious or spiritual beliefs?
- What is the role of religion in making decisions about illness and treatment?
- Would they prefer a visit from a religious leader or clergy member?
- Who can be present for the death?
- What do they believe about the body after death? In addition, how is the body to be treated?^{13,14}

Specific questions/items that may be needed for the care around the time of death include the following:

- How does the patient want to manage comfort and pain?
- How does the patient want to say goodbye?
- Does the patient want to die at home or in the hospital?
- Who will make final plans?
- How can the HCP honor the patient’s spiritual beliefs as death approaches?
- Who will communicate between the patient and HCP?¹⁵

■ Culture at the end of life

Providing culturally competent care at the end of life requires the practitioner to develop cultural awareness. Many cultural issues will affect patients and families at the end of life, and cultures will differ in their preferences and practices. Here are just a few examples to help guide nurse practitioners (NPs) when interacting with patients from varied cultures:

■ Black American culture

Black Americans have a long documented history of mistrust regarding the American healthcare system. Mistrust in the healthcare system can cause obstacles in communication and planning at the end of life, such as advance directives. Blacks believe that advance directives may influence HCP decision for care, and they could receive lesser quality healthcare or treatment. In addition, Black Americans are less likely to formally prepare for the end of life.¹⁶

Religious beliefs also influence decisions at the end of life. Black Americans believe that a higher power such as

God and faith controls their destiny. Blacks believe that God is an “intervener” in healthcare, that God is a “healer,” or that God will control the future.¹⁷

Finally, family, and faith-based support is used as a mechanism for joint decision making. Black Americans often consult family members, church members, and clergy in the decisions for care at the end of life.¹⁸ Identification of acceptable individuals with community and cultural ties to the patient, to consult with the patient, or who have decision-making abilities for care at end of life should be part of the planning.

■ Hispanic culture

The role of family, is an important part of the Hispanic culture. The Hispanic culture utilizes a group decision-making model, incorporating immediate and extended family to assist with decisions for end-of-life care.¹⁹ The family structure is based on a hierarchy, and the head of household (generally a man) makes the decisions. In cases where there is undefined hierarchy, the oldest child usually makes decisions for an adult.²⁰

The Hispanic culture believes that death is part of the continuum of life and expects death at an advanced age. Hispanics believe that participating or planning for death will lead to its occurrence; therefore, many Hispanics may not start planning until the final stages of illness²⁰; therefore, Hispanics are less likely to have advance directives.^{16,20} Many Hispanics prefer to receive care at home and also wish to die at home, surrounded by their family.²⁰

■ Chinese Americans

Chinese culture at the end of life is focused on family and communication of information. Family members in the Asian culture may wish to avoid discussing (sometimes withholding) information from a patient with a terminal illness or impending death. The discussion of death in the Chinese culture is usually considered forbidden and offensive. The Chinese do not discuss death with HCPs. They feel discussing death can lead to hopelessness; instead, the silence regarding the patient’s condition is designed to maintain hope and alleviate undue stress on the patient. Reluctance to discuss the patient’s condition, especially making life-sustaining treatment decisions, often leads to a lack of preparation for advance directives.^{21,22}

The Chinese culture maintains a patriarchal or hierarchical family structure. Traditional Chinese culture is focused on family decision making rather than individual decision making, with the family providing care at the end

of life. It is the responsibility of the eldest son to provide care and respect the parents. The males in Chinese culture are the decision makers in terms of final treatment decisions, disclosure of information, and filtering health information delivered to the patient.²²

■ Muslim culture

When working with the Muslim culture at the end of life, the following must be considered: religious preferences, discussion of the diagnosis and prognosis, HCP involvement in care, and family responsibilities. In the Muslim culture, both life and death are under the control of God. The decision for death comes from God; however, patients should seek medical attention when ill. Muslims may accept life support, but they do not believe in euthanasia.^{23,24}

Communication between patients and HCPs is essential, especially related to Muslim spiritual beliefs and needs

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at the end of life. Communication between the HCP and patient at the end of life respects the expression of Muslim beliefs and practices during this time. Muslim patients want to know their diagnosis, but without specific time frames, since they consider their life to be controlled by God. Care at the end of life in the Muslim culture is based around reducing the patient’s pain and suffering.²⁵

Family plays an important role in caring for individuals at the end of life. Families should be given the opportunity to pray with, or for, the patient. The family may have certain requests, such as having the patient face Mecca. Family presence at end of life helps the patient with fear of death.²⁵

■ Integrating and assessment into end-of-life care

Cultural care at end of life is approached through the assessments available in a variety of arenas. Hospice and Palliative Care Organization and End of Life Nursing Education Consortium curriculum have identified several tools to augment an assessment of the patient and his or her family experiencing the end stages of illness. These cultural assessment tools are also available in several basic nursing texts.²⁶

Mazanec and Panke’s address “Cultural Considerations in Palliative Care” in the context of end-of-life trajectories as well as basic, cultural assessment tools. “Cultural knowledge

and beliefs: a self-assessment questionnaire,” provides an organized approach to collecting culture-related information for accessing important cultural facts and beliefs from the individual’s perspective.²⁷

However, working with the patient and the family on issues related to end of life requires utilizing the information available about the culture, about diversity, and competent cultural care approaches; it begs the issue of self-awareness.



It is possible that expanding the dialog to issues of QOL will enhance intervention strategies.

Furthermore, it is important for every NP or clinician to listen to his or her thoughts as they interact with the patient, their cultural rituals and values, and map the illness’s trajectory. If this is not done, ethical dilemmas and other ethical issues of care may surface.

As an NP, it is important to be culturally aware of individual and general cultural aspects in order to develop appropriate responses and ways to augment culturally competent care.²⁸ However, once this is done, it is most helpful to expand the boundaries of the language and move toward people with sensitivity to their culture.

As the approaches to hospice and palliative care continue to be nuanced by culture, societal responses, and changes in illness trajectories, hospice and palliative care can be seen as two separate and distinct approaches to both chronic and terminal illness. The focus of end of life has shown itself in some cultures to limit opportunities to examine dialog with the patient and his/her family’s quality of life (QOL), which is often a concern of palliative care. According to the World Health Organization (WHO),

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial, and spiritual problems.²⁹

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NPs need to recognize that end of life is less a focus on “the end” as opposed to “the quality” of life, which can happen with an open-ended dialog: What does this person want, need, or hope for in order to enhance his or her health?

Changing the perspective to create a good QOL amidst difficult situations begins with the NP and his/her engagement with the individual and their family. Palliative care has morphed into approaching illness from the beginning of a diagnosis to the end by discussing what will make life meaningful and important. NPs can participate in this journey through an illness to its end by recognizing the importance of the process or the journey of oneself amidst illness. How

can NPs improve and enhance QOL at different points along the disease trajectory in a gentle, reassuring manner?

A focal point for integrating culturally sensitive care lies in the context of the person’s understanding and meaning of a disease. What is a meaningful life for a patient in one culture may

look, sound, and be experienced in a very different manner than a patient with the same disease in another culture. Yet the commitment toward living quality—especially in this stage of life—can be difficult and delicate. With the use of meaningful questions from an informed and astute NP, the patient may continue to attain a QOL as he or she progresses through to the end of life.

Palliative care, from a clinical perspective, is an invitation for the patient to encounter the meaning of life. In doing so, the NP must bring a developed and conscious sensitivity to the case on two levels: the patient’s cultural background and needs integrated with the NP’s own cultural perspective. This becomes a subtle yet important aspect of self-awareness, integral to the process of both the patient and the NP. Beginning with the NP’s own cultural self-awareness, the NP can come to the discussion and target QOL by addressing issues related to the meaning of life questions for the individual. What essential elements would an NP pose? What might an NP consider necessary for “having a good quality of life?” How might an NP struggle with conflict between his or her values and beliefs and those he/she will be in dialog with? Furthermore, what are some techniques that could enhance an NP’s ability to be open and expand their horizons during illness and at end of life?

Based on this informed sensitivity, the NP learns to articulate questions targeting meaning of life, tailor those questions to the specific patient, and efficiently use the time allotted to a case. The NP’s proficient use of words on both a practical and philosophical level is the last factor to consider. Utilizing language thoughtfully is important. Thinking about the issues that will be approached in addition to being careful to leave room for dialog can help the NP and patient decide the top three concerns that need to be addressed.

In each culturally rooted family comes the struggle with specific meanings as well as more general meanings. Is the illness related to the specific behavior of this person or does a general view of spirituality oversee the situation for everyone? How does the individual, family, and communal relationships affect decision making in the individual's QOL? This implies that NPs understand the perspective of the person, the perspective of the person's family, potential issues for pain management, and the willingness to tolerate symptoms. It might also include an awareness of taboos, which may resurface throughout the course of the illness. Finally, the NP must have a solid command in regards to the trajectory of the illness and understand that potential trajectory influences the culture, environment, and meaning of time itself.

In practice, the NP focuses on "process" as opposed to "product." Process is the meaning of life. One way to help the conversation unfold is to look at the symptoms and illnesses that the patient has at that time. This approach allows for a freedom of response. It is also a philosophical tact as opposed to an approach that may utilize answering questions with a calculated tool.

■ Interventions and approaches to culture and end-of-life care/palliative care

The interview begins with questions about the meaning of life. Examples include: Tell me about your illness; what do you think it means; and do you have concerns about the feeling of being tired or short of breath? At times, this mirrors the NP's concerns, and at other times, it does not. What is set in motion is trust, safety, and control. It is also a very gentle way to give the person permission to examine the thoughts and hopes that lay quietly in the background. Therefore, the person determines what a need or desire might be that could enhance the individual's QOL.

At times, a patient asks a concrete question as a message within a message. The concrete question becomes the entrance into what the emerging question might be. Listening on one level leaves the NP with only the concrete option, and a chance to meet the real issues of "meaning" or "quality of life" might be missed. The NP must address the first level of the narrative with concretely, succinctly, and consistently leaving room to address the metamessage of meaning. In each answer, the next question addresses the issue of QOL. For example, does this symptom enhance or detract from your QOL? Throughout the process, the facilitator (NP) always personalizes the exchange with questions such as: What do you want me to do or How can I help that happen?

For example, the use of opioids and antidepressants can carry personal fears for some cultures. Certain medications are correlative to suffering, and the suffering carries a meaning or value within each culture.³⁰ Another question of meaning revolves around the reality of how debilitating the person becomes and the impact this has on the family. The NP in a North American setting now interfaces with dozens of cultures in a typical caseload. So a question pointing to a culture's strengths and challenges must be included—it is essential. The NP may ask, "How does your culture deal with support as your father declines?" One is trying to ascertain if the support would enhance or detract from QOL. The NP within a team environment can utilize the strengths of the group. For example, if the daughter is the decision maker, then the NP must be willing to have dialogs with the daughter. The Health Insurance Portability and Accountability Act can be respected here by asking the following question: Whom would you like us to include in important issues and decisions of your needs? Many palliative teams include other disciplines, such as social worker, grief counselor, and volunteers. This is also a useful way to create an individual quality approach to care.

Another important evolution in the approach to palliative care is recognizing the importance of a narrative. The narrative can often be fictive or not exact. The process of creating and telling the story of what is helpful or not through the narrative can be adjusted as the person unfolds the story. The story is also a process told in the present and corrected in the emerging self-understanding. NPs can listen in a different way, allowing that this may be neither the beginning nor the end of the story. What becomes an impediment to the person's "end of life" care is often an inability to surrender or let go. Reconstructing the narrative is highly beneficial and reaffirming. It allows for culturally relevant metaphors that helps give the patient meaning to life through QOL.

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A recent intervention with a patient may help illustrate the use and value of narrative reconstruction.

Mr. C, an 81-year-old male with an Asian background, was diagnosed with amyotrophic lateral sclerosis. He had lived in the United States for many years, and his English was moderately accented. The author was called into consult regarding his palliative care plan and addressed the illness

and the management of symptoms. The author then said to Mr. C to tell him a story about who you are and the important things of life for you. This enabled the patient to construct meaning about his values, fears, and his beliefs around those fears. He was the head of the family and the primary decision maker for most of his life. His need for 24-hour care, the reality of disease not changing, the fear was having dialog about his role and fear for his family; however, his death was not the issue. Rather, the effect of his acute dyspnea on his QOL and on the stress it caused his wife...he wanted to know how to deal with dyspnea...meaning given to that experience...machines/infections... should he terminate the ventilator?

As it turned out, Mr. C needed a dialog on the meaning of living and not on the meaning of dying. His family, on the other hand, was most concerned about him dying in the

around her heart: "It's like...no...it's like hurt...no, the pain is like something is broken. My heart...my heart is broken." She wept. She was able to access the meanings through moving the boundaries of the language and hearing her own corrections, which unveiled self-understanding. This opened up a new way of listening.

Using narratives, metaphors, and listening to meanings emerge can be challenging for NPs; however, the experience of listening to meaning emerging and allowing for QOL with all its meaning to be dynamically adjusted is very powerful for both the patient and NP.

■ Cultural perspective

What is portrayed here when caring for patients is a different approach to QOL, for patients in life, until the end of life within a cultural perspective. Asking questions that target meaning of life invites a freedom for the patient to be open and honest with his or her answers. In their own words, patients articulate expectations of the illness, of the NP, of the family, and of issues speaking to physiological, emotional, and cultural value. This intervention might be the first time the

patient has had the opportunity to state the value of his or her pain. In that alone, a QOL experience is provided.

NPs should become familiar and understand the cultural background and influences that can assist them in providing culturally competent care at the end of life. NPs should learn the concepts of various cultures to keep the lines of communication open. NPs should also involve patients in their care and elicit information needed to make the experience comfortable. **NP**



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home and beliefs regarding the spirits he would leave behind. This approach allows for different concerns from different members of the patient's world.

The "economy of words" should be noted in a narrative reconstructive work, as noted above. This is helpful for both the patient and the NP. Parameters around the questions help to avoid rambling. Parameters around the patient's answers rely on a multifactorial approach that is culturally competent. The NP breaks down the answer into pieces. For example, what is the meaning of taking medications for a patient if continued pain is interfering with the patient's QOL? The assumption is that the patient knows what is best for him or her. What might not be readily available are the words to give the story its meaning. This might be a challenge for an NP. At times, all clinicians need to do is ask, "Is that it...is that what it means?"

An older adult Italian woman visited the author's office complaining of chest pain. The author asked all the appropriate questions about her pain but did not seem to understand what she was trying to say. Her spouse had died several weeks prior, and she was now trying to deal with her life alone. She sat clutching her chest, trying to find the right words, unable to capture it. The patient was asked to share the story of her pain. For patients who are struggling with meaning, it is wise to ask for a metaphor that can allow the boundaries of language to broaden and give a way to access new meanings. The patient responded by feeling

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