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Continuing Education

Cultural Considerations in End-of-Life Care

How ethnicity, age, and spirituality affect decisions when death is imminent.

By Polly Mazanec, MSN, APRN,BC, AOCN, and
Mary Kay Tyler, MSN, APRN,BC

“Cultural competence” has gained a certain cachet in health care, so much so that an Internet search of the phrase brings up more than 40,000 results. Yet racial and cultural disparities in health and health care persist, perhaps no more heartrendingly so than in end-of-life care. A recent study of the experience of dying in nursing homes noted that “lack of attention to cultural needs,” when it occurred, was a “predominant factor” in a person’s experience of dying.[1] How can this be when there’s so much talk of cultural competence in health care?

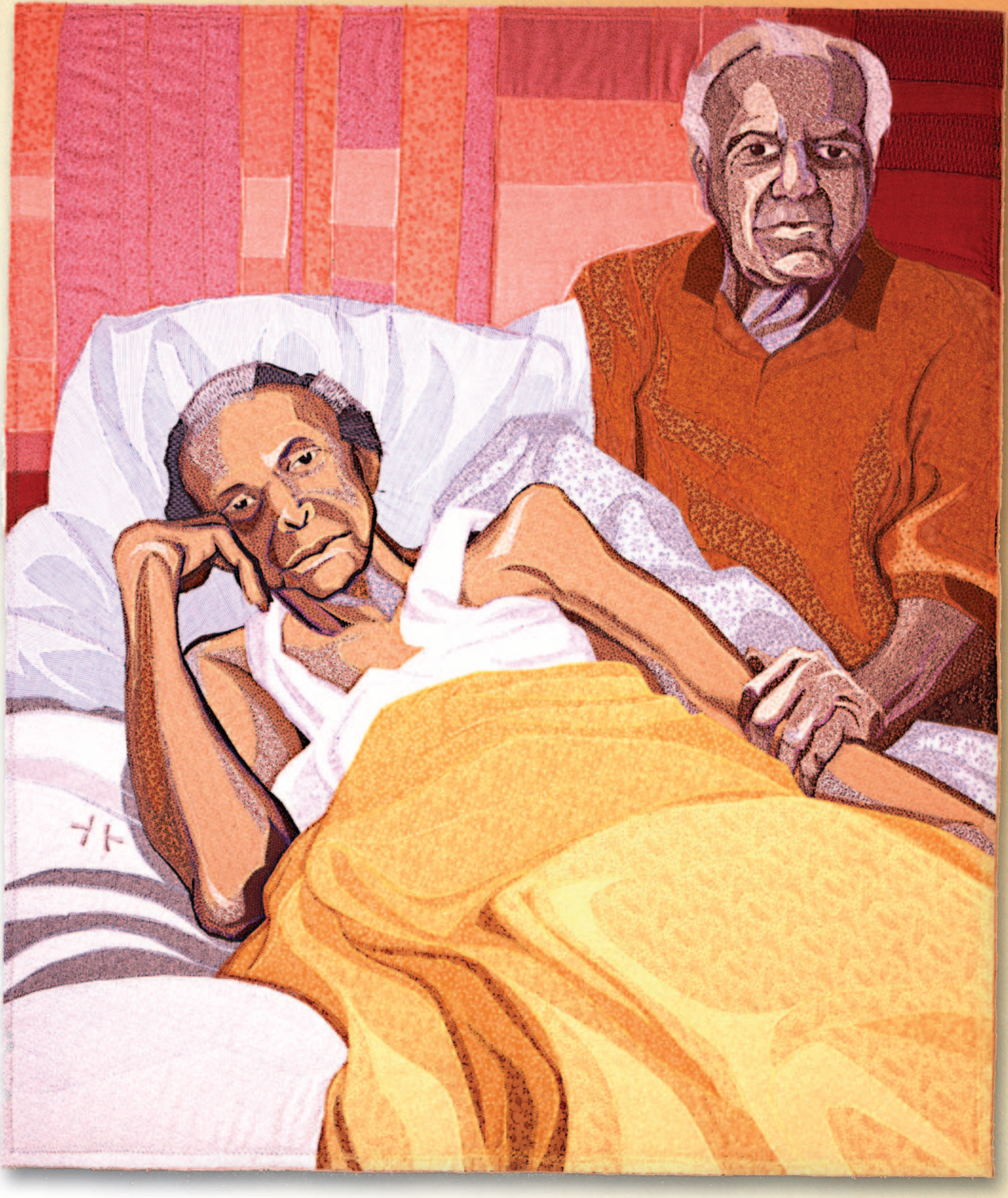
There’s no simple answer. Cultural competence refers to a clinician’s knowledge of various cultures and her skill in applying what she knows to patient care. But because cultures—which *Columbia Encyclopedia* defines as “system[s] of socially acquired values, beliefs, and rules of conduct which delimit the range of accepted behaviors in any given society”—continually evolve, achieving cultural competence is an ongoing process. A person born into a particular cultural group won’t necessarily identify strongly with it[2] or may identify with more than one group. Hence, although cultural competence begins with acquiring general knowledge about various cultures, it’s important not to generalize. It’s also important to understand that how patients identify themselves affects their health and health care, up to the end of their lives. Clinicians therefore can’t expect to provide good care without in-depth knowledge of the practices and beliefs of people from many cultures. Each case must be considered

In Her Room, by Deidre Scherer, fabric and thread, 39″ × 30″, 2001; photo by Jeff Baird. ▶

In Her Room came in part from the artist’s desire to include people from diverse backgrounds in her work. “After introductions, we brought chairs into her room and settled down to draw a double portrait,” the artist writes. “She hardly spoke or moved but looked directly into my eyes. It was a beautiful, bare look. She asked for a copy of the drawing.”

For more about the artist and her work, go to www.dscherer.com.

Polly Mazanec is the nurse practitioner for the Palliative Care Team at the Hospice of the Western Reserve, Cleveland, OH. She is a faculty member on the End-of-Life Nursing Education Consortium project and a clinical associate in the MSN Palliative Care Program at Ursuline College, Pepper Pike, OH. Mary Kay Tyler is a pediatric nurse practitioner and team leader of the Pediatric Team, Hospice of the Western Reserve. Contact author: Polly Mazanec, pmazanec@hospicewr.org. This article is the sixth in a series on palliative nursing that is supported in part by a grant from the Robert Wood Johnson Foundation. Betty R. Ferrell, PhD, RN, FAAN (bferrell@coh.org), and Nessa Coyle, MS, NP, FAAN (coylen@mskcc.org), are the series editors.



individually, as the following scenario shows.

Michael Cantos, a 15-year-old who has recurrent metastatic Ewing sarcoma, has been hospitalized with fever and neutropenia, common complications of his recent chemotherapy. Michael lives with his parents, two younger siblings, and his paternal grandmother. His parents and grandmother were born in the Philippines and emigrated to the United States about 30 years ago; all three of the Cantos children were born in this country. When Michael was first diagnosed, he was told that this type of cancer was aggressive and had already spread from the primary site in his pelvis to his lungs. Treatment consisted of surgery, a year of chemotherapy, and six weeks of radiation. During the past year, whenever Michael asked if the cancer could kill him, the team members (who include a pediatric oncologist, a palliative care pediatrician, a palliative care pediatric nurse practitioner, a primary care nurse, a social worker, a physical therapist, a spiritual care counselor, and an expressive arts therapist) have responded both truthfully and with reassurance, saying, “Some patients die, but we’re all fighting very hard to cure you.” Michael hasn’t forgotten a word.

On this admission, a routine chest X-ray reveals a large lesion in his right lung. Additional X-rays reveal multiple smaller lung lesions and a large pelvic tumor. Just two months earlier his routine surveillance scans were normal. Now, on learning the results of the chest X-ray, Michael asks if his mother can stay overnight in the hospital with him; on past admissions, he has preferred to spend time alone or with friends. Michael also tells his parents that he wants to hear his scan results and treatment options at the same time they do (previously, the team has initially reviewed such information with them alone). His parents are shocked. They’d prefer withholding certain “bad news” from Michael, but they agree to honor his wishes. This decision deeply upsets Michael’s grandmother, however, and on their next visit Michael says, “Why does Grandmother always have to pray the rosary over me—doesn’t she know it doesn’t work?”

In the team meeting, a new RN expresses frustration with the grandmother’s “constant interference,” noting that the grandmother questions the parents’ decision to share information with Michael; she says that by praying the rosary over him, the grandmother may be upsetting Michael further. The nurse says she can’t support the grandmother and the boy at the same time, and asks the team for help. The team decides to meet every two weeks, or more often if necessary.

The team also schedules a meeting to discuss Michael’s prognosis and communication within the family. As usual, the patient and his parents are encouraged to bring anyone they want. Michael immediately says that he wants only his parents present, and his parents agree. (The grandmother generally hasn’t attended such meetings.) At the meeting the pediatric oncologist initially presents information, with the palliative care nurse practitioner summarizing or restating important points to ensure that everyone understands. Decisions are made by consensus.

This case illustrates how ethnicity, age, and religious and spiritual beliefs can affect end-of-life care. (Although there are many other components to consider, including race, sex, sexual orientation, physical and mental abilities, and socioeconomic factors, this article will just examine ethnicity, age, and spirituality.) Data from the 2000 U.S. Census demonstrate that by the year 2030, immigrants and their children will account for nearly one-half the growth of the total U.S. population.[3, 4] And by 2050, according to the Bureau’s most recent projections, roughly half of all Americans may be considered members of an ethnic minority.[4]

DEVELOPING CULTURAL COMPETENCE

Although ethnocentrism, the belief in the superiority of one’s own ethnic group, can be a deeply ingrained tendency and thus understandable, it’s a limiting view. Cultural competence demands that nurses look at patients through both their own eyes and the eyes of patients and family members.

The first step is to define and understand one’s own perspective, and cultural self-assessment tools can help. For example, the Cultural Self-Assessment for Health Care Professionals[2] asks the clinician to respond to questions such as “What is your ethnic affiliation?” “How strongly do you identify as a member of an ethnic community?” “What are your primary and secondary languages for speaking and reading?” and “What is your religion and how is it important in your daily life?” Similarly, as part of its Multicultural Tool Kit, the Oncology Nursing Society offers the Pre-Assessment: Cultural Knowledge and Beliefs tool (www.ons.org/xp6/ONS/Clinical.xml/MulticulturalToolKit.xml).[5] Directions to clinicians include “List two cultural groups to which you belong” and “List three rituals that you practice that have been learned from each cultural group.”

Cultural assessment tools are also available for use with patients and families. Communication style, family structure, and ways of responding to illness

Diversity & Death

Ethnic group	Role of family	Environment	Preparation of the body
African American	Providers should communicate with the oldest family member; public displays of emotion should be expected.	Families frequently care for dying elders at home. Some believe that a death in the home brings the family bad luck.	Families often want the health care team to clean and prepare a loved one's body. Some may consider organ donation taboo but may agree to an autopsy.
Chinese American	A family may prefer that the patient not be told of terminal illness or imminent death, or may prefer to tell the patient themselves.	Some believe that a death in the home brings the family bad luck. Others believe that the patient's spirit will get lost if death occurs in a hospital. Family members may make use of special amulets or cloths.	Some families prefer to bathe the patient themselves. They may believe that the body should be kept intact; organ donation and autopsy are uncommon.
Filipino American	Providers should communicate with the head of the family, out of the patient's presence. Public displays of emotion may be expected.	Terminally ill patients may prefer to die at home. If the family is Catholic, they may ask that a priest perform the "sacrament of the sick" and may use religious objects (such as rosary beads) and prayer.	Family members may want to wash the body and are likely to want time for all family members to say goodbye. The family may not permit organ donation or autopsy.
Hispanic or Latino American	Extended families care for loved ones who are ill, sharing information and decision making. Wailing is considered a sign of respect.	Dying in a hospital may not be desirable; some believe that the patient's spirit will get lost there. Special amulets, religious objects such as rosary beads, and prayer are used.	Relatives may help with care of the body, and are likely to want time to say goodbye. Organ donation and autopsy are uncommon.

This chart is intended as a general guide only.

Source: Lipson J. Culturally competent nursing care. In: Lipson J, et al., editors. *Culture and nursing care: a pocket guide.* San Francisco: UCSF Nursing Press; 1996. p. 1-6. Adapted by permission.

are just some of the areas in which cultural groups may vary.[6] For example, clinicians should consider the ways patients and families express themselves verbally when discussing illness and death, evaluate their beliefs about and attitudes toward pain, determine who among them has decision-making authority, and consider the spiritual beliefs of each patient alone and in the context of his family and community.[7] Other resources such as textbooks, Web sites, and local community groups can also be helpful. At best, though, all such resources are only general guides. The needs of a given patient and family will depend on how closely they identify with a particular group.[8] (See *Resources*, page 56.)

Barriers to cultural competence can be grouped into two categories: those related to providers and those related to systems. The former arise when individual providers lack knowledge of their patients' cultural practices and beliefs or when providers' beliefs differ from those of their patients. Those who expect their patients to respond as they themselves would to issues such as medical decision making, artificial nutrition and hydration, and death and mourning will be unprepared when patients respond differently. Resources for learning about other cultures provide information on the most common practices of a particular group.

System-related barriers exist because most facilities haven't been designed for cultural diversity, favoring instead a one-size-fits-all approach to care. Limitations in personnel or materials may hinder a facility's ability to adjust care to the various ways people approach death and dying. Some settings, such as the ICU, may be unable to accommodate certain needs. For example, some Pacific Islanders may ask that a window remain open when a family member is dying, to allow the soul to leave. Certain practices after a death may not be possible when other patients are waiting for beds. Unit restrictions on the number of visitors may interfere with communication, and reduced staffing may limit the time a nurse has to meet specific needs.

COMPONENTS OF CULTURE: ETHNIC IDENTITY

It's important to consider the role ethnicity plays in communication, family values such as respect for elders, and beliefs about and practices related to illness and death.

Consider again the case of Michael. According to the U.S. Census Bureau, Filipino Americans constitute the second largest Asian group in the United States.[3] Most Filipinos speak and understand English; about 90% are practicing Roman Catholics.[9, 10] According to Villanueva and Lipat, many believe in *bahala na,* leaving one's fate to God, and that great suffering must be endured because it's "God's will."[10] Filipino Americans tend to emphasize loyalty to family, respect for religion, and deference to elders and authority. Avoiding confrontation and conflict and maintaining cordial relations are important.

To people from cultures that place the family's needs above those of the individual, the concepts of informed consent and full disclosure may be distressing.

Michael has grown up in a Western culture, one that emphasizes the needs of the individual over those of the group.[11, 12] His parents hold more traditional Filipino values, such as respect for elders, but they also think their son is mature enough to have his wishes honored. Michael's grandmother does not agree, believing that Filipino values must be upheld: she says that it's God's will that Michael is ill, that prayer is the only force that can save him, that it's the parents' duty to "protect" the boy from knowing his terminal prognosis, and that her wishes must be respected because she is the family elder. Michael's grandmother's beliefs conflict not only with those of Michael and his parents but also with those of the team members.

In the United States, decision making at the end of life is based on the values of the dominant Euro-American culture. For example, American providers have generally advocated full disclosure of the facts of illness and treatment, especially since the passage of the Patient Self-Determination Act in 1991—even to a pediatric patient, as long as the child is capable of comprehending such information,[11, 13, 14] which would allow him to participate in his care. Thus, although children under a certain age (generally 18, though it varies from state to state) can't legally give *consent,* many consider seeking their *assent* an ethical responsibility.[15-17]

Indeed, much of the pediatric literature concerns the importance of obtaining the assent of children. For example, Olechnowicz and colleagues recently studied its role in decision making in families with terminally ill children.[15] They reviewed 14 cases, selected because the patients were both present at the informed consent conference and over the age of seven. Twelve cases entailed some discussion about the child's assent. Clinicians differed in the way they assigned responsibility for decision making. Some viewed the decision to participate in clinical trials as the child's alone; some thought it should be a family decision; and some thought that although the decision was primarily the parents', the child's assent was required. The 14 patients' ages ranged from 10 to 18; their mean age was 14. The researchers found that the clinician's designation of a primary decision maker was unrelated to the patient's age. Six patients (50%) signed an informed consent form; this also was unrelated to the patient's age. Suggestions for further study included examining how clinicians determine the decision-making capacity of individual children.

In many non-Western cultures, however, families generally prefer to receive information first and filter what is given to the patient, regardless of the patient's age.[11] Reasons often cited by family members include the fear that the truth will cause the patient to lose hope and their need to protect the patient from bad news.[11-13] Conflict occurs when the beliefs and wishes of family members differ from those of the patient, the team members, or both. If the patient desires and is capable of understanding full disclosure, his wishes should be respected and the matter discussed with family members who may have differing views. Helping the family to understand the patient's need for information and teaching them that hope can coexist with terminal illness are among the team's responsibilities.

COMPONENTS OF CULTURE: AGE

Adolescents (ages 13 to 18), as a group, tend to have certain behaviors, beliefs, and attitudes in common.[18, 19] Developmental issues such as establishing career goals, gaining the acceptance of peers, and breaking free of parental control loom large.[18, 19] Most adolescents have little reason to think about their own mortality, and many behave as if "bad things can't happen" to them. Life-threatening illness will affect the adolescent patient profoundly; fears about diagnosis, treatment, and prognosis, as well as how the illness will affect relationships with peers, are likely to seem overwhelming.

It's important for interdisciplinary teams to approach adolescents who are terminally ill in a straightforward manner. Active listening and a calm demeanor are vital.[18, 20] Deering and Cody note the importance of conveying a nonjudgmental attitude through neutral speech and body language "even if you're actually startled or disturbed by what they are saying."[18] They also suggest giving adolescents the opportunity to talk privately with caregivers.

Michael, like most teens, strives for normalcy; he wants to go to school and attend parties despite his advanced cancer. His needs for independence and privacy often conflict with his parents' need to protect him. Although his parents are reluctant to tell Michael much about his condition and prognosis for fear it might cause him to lose hope, they believe he has a right to certain information. They also worry that Michael will stop trusting them if he hears reports that are inconsistent with what they've told him. Michael's grandmother sees no need for the parents' struggle: she doesn't believe that Michael has a right to any information and believes it will cause more harm than good. Legally, a patient's right to accurate information is included in the Patient Self-Determination Act, which doesn't specifically address age.

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The team's challenge is to support not only Michael but his family. The team acknowledges that the parents' desire to keep their son from suffering is both common and normal. Team members suggest questions that will clarify Michael's level of comprehension, such as "Can you explain what's different about the tumors in your lungs now?" and "Can you tell us what the doctor said about the side effects of chemotherapy?" The team also instructs the parents in active listening. To support Michael, team members meet with him alone so that he can speak freely. (When the family first met with the team, it was explained that offering such private time to pediatric patients is a routine part of care.) Also, a music therapist helps Michael write a song that expresses his feelings. The team, the family, and Michael agree to discuss new information and potential choices as a group first; then Michael and his family will take time to consider them individually and together; everyone will meet again as a group to make decisions.

RESOURCES

BOOKS

Andrews M, Boyle J, editors. *Transcultural concepts of nursing care,* 3rd ed. New York: Lippincott, 1999.
Includes cultural assessment tools for use with patients and families.

Giger J, Davidhizar R, editors. *Transcultural nursing: assessment and intervention,* 3rd ed. New York: Mosby, 1999.
Includes cultural assessment tools for use with patients and families.

Lipson J, et al., editors. *Culture and nursing care: a pocket guide.* San Francisco: UCSF Nursing Press; 1996.

WEB SITES

The Transcultural Nursing Society
www.tcns.org

The Bureau of Primary Health Care Cultural Competence: A Journey
www.bphc.hrsa.gov/culturalcompetence/default.htm

The Cross Cultural Health Care Program
www.xculture.org

The Office of Minority Health
www.omhrc.gov

COMPONENTS OF CULTURE: SPIRITUALITY

Spirituality involves matters "of, concerned with, or affecting the soul," according to most dictionaries, and may or may not involve organized religion. Spirituality can be especially significant in end-of-life care, offering the patient a way to find meaning and purpose in dying as in life.[14, 21, 22] Some people explore spirituality through connection with others,[23] while religion is a more concrete concept; Davies has defined it as a structured system of shared beliefs and practices that help individuals express a sense of connection to a "higher power."[22]

Spiritual or religious practices (customs) and rituals (more formal ceremonies) often play important roles. Rituals are generally performed at a time of significant transition in one's life. For example, a Roman Catholic ritual known as the Anointing of the Sick might be performed for a seriously ill person. Considered a "sacrament of healing," it's intended to bring the recipient physical and spiritual strength and to convey "God's grace." A Muslim family might request that immediately after death, the patient's body be turned east to face Mecca, their holiest city.

To assess a patient's religious affiliation and spiritual beliefs, providers can use the mnemonic FICA, conceived by Christina M. Puchalski, MD[24]:

Faith—What is your faith or belief? Do you consider yourself a spiritual or a religious person? Does religious faith or spirituality play an important part in your life? What do you feel gives your life meaning?

Influence—How does your religious faith or spirituality influence your thoughts about health? How does it affect the way that you take care of yourself?

Community—Do you consider yourself part of a spiritual or a religious community or congregation? How is that community or congregation a source of support for you?

Address—Do you have any religious or spiritual issues or concerns that you'd like me to address with you? Is there someone else you would like to speak with about these matters?

Some researchers have studied children's spiritual beliefs in relation to health and palliative care. Pehler observed that a child's spiritual development parallels his physical and psychosocial growth.[23] Davies advocated including spiritual assessment of sick children, and of their parents, grandparents, and siblings, as part of palliative care.[22] Regardless of the patient's age, performing a spiritual assessment can help providers better adapt the plan of care.

The use of expressive arts therapy (art, music, movement, and writing) can help in the exploration of spiritual issues.[22] Encouraging patients and families to tell their life stories helps them to recognize meaning and purpose in their lives.[21] The team can arrange visits from clergy or prayer or scripture readings for patients who find comfort in them. It's also important to determine if there are specific rituals that should be integrated into the plan of care of the dying patient.

CULTURALLY CONTROVERSIAL ISSUES

Ethical conflicts may arise when providers and patients and their families have different beliefs about matters related to health care, such as patient autonomy. The practices of informed consent and of full disclosure of diagnosis, prognosis, and treatment are generally accepted in Western cultures, which place a high value on individual rights and autonomy. In our health care system, ethical decision making is based on three values: the sanctity of life, patient autonomy, and the absence of suffering.[12] In most non-Western cultures, the welfare of the group takes precedence over individual life.[12] Decisions are made by consensus.

Excluding a patient from discussion about a recurrence of a life-threatening illness, or allowing a patient his suffering if he wants it, may conflict with a provider's values and beliefs. Yet to people from cultures that place the family's needs above those of the individual, the concepts of informed consent and full disclosure may be distressing and even disrespectful. And patients from cultures that place value on suffering—for example, those that view suffering as a means to an important end—may need to be supported in their suffering. For example, some Chinese patients may believe that suffering before death is a way to atone for past sins, and that if they don't suffer while alive, they'll have to suffer later.[25] Such patients may refuse pain medication. Providing emotional support rather than pain relief may be the respectful choice. It's important, though, to make sure that such a patient is aware of pain relief options. Also, staff might call upon a spiritual counselor familar with the religion to help determine whether the patient's expressed need to suffer is a misinterpretation or is indeed mandated by the religion.

CASE REVISITED

Before he became ill, Michael had been struggling against his parents' authority and questioned his Catholicism. He stopped attending mass at age 13, and after he became ill, he still refused to participate in formal religious practice. His parents and his grandmother have always looked to their priest and to Catholic practices and rituals (such as anointing the sick, praying the rosary, attending mass, and making novenas) for support and hope.

During a conversation with team members about spirituality, Michael stated that one of the ways the team could help him would be by "taking care of" his grandmother. To Michael, she seemed anxious and worried all the time. He said he thought it has something to do "with church," because she tried to get him to pray the rosary and meet with the priest. Michael said he couldn't talk to his grandmother about how angry this made him.

The team met with Michael's grandmother and determined that her anxiety was related to religion. She'd been praying "for a miracle," but thought it wouldn't happen unless Michael developed a stronger faith. She feared that if Michael died without going back to church, he wouldn't go to heaven. At her request, the spiritual care counselor met with her weekly to read the Bible and pray. The goal was to help her to see that although Michael's relationship with God was different from her own, it was as meaningful to him as hers was to her. After one visit, she commented that, "the God I love and believe in would never punish a child; I know Michael will go to heaven." The team also facilitated a conversation between Michael and his grandmother; team members present included the palliative care nurse practitioner (at Michael's request) and the spiritual care counselor (at his grandmother's request). Michael explained that even though he didn't go to church, he still believed in God, and his grandmother said she felt better knowing this.

With the help of the team, the family priest, and the parish's youth minister, Michael and the members of his family were able to explore their individual spiritual beliefs and needs and to gain respect for their differences. Michael remained firm in his refusal to participate formally in Catholicism, but he explained to his family that he believed in God and felt comfortable "just talking to Him." He was willing to let his grandmother pray for him in his presence, acknowledging that this was helpful to her, as long as she didn't "talk about religion all the time."

As his death became imminent, Michael told his family that he was "seeing" his deceased grandparents on a regular basis and found this very comforting. He said they promised him that they were waiting for him and told him that heaven was a safe and wonderful place. Michael's sharing of his spiritual experience brought great comfort to his family. He became more accepting of his grandmother's praying in his room and of the priest's frequent visits. He agreed to allow his family to plan a Catholic wake and funeral mass for him, and with the music therapist, he chose the music for these events. Michael's death seemed peaceful. His parents, siblings, grandmother, and family priest were at his bedside and had just finished praying the rosary together when he died. ▼

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CE 1.5 HOURS
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GENERAL PURPOSE: To offer registered professional nurses an overview of how ethnicity, age, and spirituality affect decisions as death approaches.

LEARNING OBJECTIVES: After reading this article and taking the test on the next page, you will be able to:

- Define cultural competence as it relates to palliative care.
- Compare Western and non-Western cultural beliefs about death.
- Discuss spirituality as a component of end-of-life care.
- Outline some culturally appropriate interventions for terminally ill patients and families.

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