Hospice Aide On-the-Go™ In-service

Cultural Diversity

Volume 1 • Number 2

BEACON HEALTH

Cultural Diversity

~ VOLUME I • NUMBER 2 • LESSON ~

At one time the United States was called a "melting pot," meaning that the various nationalities who emigrated here eventually merged their cultural characteristics with other immigrant groups. This created a sort of "stew" in which the combined flavors became "American." More recently the United States has been referred to as a "tossed salad," in which the various ingredients contribute to a tasty, nutritious dish but maintain a recognizable appearance and flavor, at least for one or two generations. In both of these scenarios, the various cultures may hold on to individual beliefs and traditions regarding important issues. One such issue is death and dying.

Hospice patients differ in many ways. Some of these differences are because of age, illness, personality, socioeconomic class, or education. The most important differences may be cultural. In addition to treating patients with respect, becoming familiar with cultural and religious customs will prevent misunderstandings and permit better care.

Especially in large metropolitan areas, a hospice aide may be called upon to care for a terminally ill patient from another culture. The first step is to become aware of the beliefs of your patients that may affect their care. Sometimes this information can be sought directly from the patient; other times it must come from family members. The next step in providing culturally sensitive service to dying patients is to recognize and understand your own beliefs about these issues. It is never appropriate to impose your beliefs on your patient or the patient's family.

Key Terms

Culture
A set of values, beliefs, and standards of behavior shared by a group of people.

Cultural Diversity
A mix of race, ethnicity, gender, and religion. This diversity also includes socioeconomic status, education, and degree of acculturation to the American way of life.

Ethnicity
A quality assigned to a group of people connected by a common national origin or language.

Generalization
A statement about common trends within a group.

Multiculturalism
The practice of acknowledging and respecting the various religions, ethnicities, races, attitudes, and opinions within a population.

Patriarchal
Fathers (the patriarchs) have the primary responsibility for the welfare of the family.

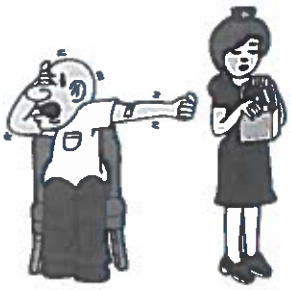
Stereotype
An oversimplified opinion.

Cultural issues surrounding death and dying

Hospice services are affected by cultural and religious beliefs and traditions. Sometimes language barriers are a problem, and sometimes lack of cultural sensitivity interferes with care. Some cultural groups see hospice as threatening. Hospice services may be seen as replacing a family's responsibility to care for a dying member. In another case, it may be seen as a poor alternative to aggressive medical treatment to prolong life. And sometimes cultural factors are entwined with religious tradition and it's easy to forget that not all members of a group share the same attitudes.

- **Planning for death:** American health care emphasizes autonomy and a patient's "right to know." In other cultures, patients don't want to know when death is near, and they don't want to talk about it because that would be predicting the future, which brings bad luck. In those cultures, the family hears the news first and decides how much the patient should be told and when. They want to avoid stress for the patient and loss of hope. These beliefs affect things such a life support, DNR orders, and advance directives.

- **Family and kinship structures:** In some cultures, it would be normal for family to visit a dying relative one at a time or in small, quiet groups. In others, as many as 40 or 50 relatives would try to visit at the same time to pay respects. This could be a serious problem for the hospice aide attempting to provide care. In many cultures the oldest male is responsible for all decision making; in other cultures it's the oldest female.



- **Beliefs and attitudes about pain:** One major goal of hospice is to help patients die comfortably and with minimal pain, but individual patients respond quite differently to pain. Some cultures are vocal and loud in response to pain and demand constant pain medication. Others are quiet and dignified. Some try to hide the symptoms of pain and deny the need for medication.
- **Customs:** Some people in the United States think that the number "13" is unlucky. Tall buildings often don't have a 13th floor. In other cultures, the number "4" sounds like the word for "death" and patients would consider it unlucky to be in room 4 of a hospice or hospital. Something as simple as reluctance to make eye contact could cause problems. It could be interpreted as embarrassment, depression, or lack of interest. In some cultures, it's a sign of respect. In others, it may be that a female patient wishes to avoid sexual impropriety with a male physician or aide. Another problem area is physical touch. In the United States, caregivers are taught the importance of touch. In some religious cultures, contact outside of actual hands-on care is prohibited for patients of the opposite sex.
- **Religion and spirituality:** Some cultures believe that opening a body with surgery allows evil spirits to enter and cause further illness. Others believe that what happens to a body during autopsy affects that person's reincarnation. Yet another major religion traditionally believed that a person couldn't get into heaven if any body parts were missing. That same religion had strict prohibitions against cremation.

CULTURE AND NATIONALITY

Various cultural groups and nationalities have traditional approaches to death and dying, and it's important to acknowledge these differences without assuming that all members of the group share the same beliefs.

White people of primarily Western European ancestry make up the majority of the U.S. population. Many of these ethnic groups have been in the United States long enough to have become thoroughly assimilated, and the culture and tradition surrounding this large group could be called "the American way." Part of this thinking is the idea that each patient has a right to know about his diagnosis and prognosis in order to make informed decisions about treatment options. These patients may demand aggressive intervention and life-prolonging technology. Some Americans talk easily about preventing death, but not so easily about how to handle the dying process. Patient privacy guidelines and HIPAA prevent doctors from sharing confidential patient information with anyone, even family,

unless the patient has designated individuals who may receive that information. Other cultures may be quite different.

Hispanic American attitudes and practices

Hispanic Americans (people of Mexican, Puerto Rican, and Cuban origin) make up as much as 13.5 percent of the U.S. population but they represent only about 4.8 percent of reported deaths annually. This may be because the Hispanic American population is very young, and also because many return to their countries of origin to die.

These cultures stress the importance of family. For some, the term 'hospice' has a negative connotation; it implies abandonment. Caring for the ill and the dying is an important responsibility, most often performed by females. Families may resist the use of nursing homes for their loved ones. Many in this culture believe that a person's body must remain whole, to leave the world complete. Talking about organ donation with some families may be seen as an insult, and consent is rarely given. Some families do not like to discuss DNR. Traditionally, many in this culture wish to be with a dying relative so that any conflicts may be resolved. Open expressions of grief are acceptable, although men who wish to appear strong do not grieve openly.

African American attitudes and practices

African Americans make up the second largest minority group in the United States. For many, the concept of "family" includes extended relationships and people who are not blood relatives. They may rely on family, friends, neighbors, and church during times of loss. Many African Americans are suspicious of the medical community, resist nursing homes, and are more likely to die at home. They are less likely to use hospice care, terminate life support, or donate organs after death. Outward expressions of grief and emotion are acceptable.

Asian American attitudes and practices

Asian Americans and Pacific Island cultures (Chinese, Filipino, Indian, Vietnamese, and Korean) make up the third largest minority group in the United States. Traditionally these cultures restrain communication. Many believe that talking about bad things can make them happen, and many prefer that a dying individual not be told the truth. These cultures are patriarchal. If a father is not available, then the oldest male makes decisions regarding care of the dying.

Native American attitudes and practices

Native Americans make up approximately one percent of the U.S. population. Most live in urban neighborhoods, and there is considerable diversity within this group. Many death rituals and customs are specific to a particular tribe. Some believe that talking about death causes it to happen. They traditionally keep personal issues to themselves, and children are often taught to hide their emotions.

Many believe that what survivors do after someone's death will affect that person's journey into the next world, so elaborate post-death rituals are traditional. In some Native American sub-cultures, people prefer to die in hospitals so as not to leave their spirit trapped in the home. Grief is immediate and shared to provide emotional support for those feeling the most loss.

SPIRITUALITY AND RELIGION

Religion may be a source of solace to the dying patient. In the past, helping a patient through the process of dying was usually considered a role for religious counselors and the patient's family. These days, healthcare providers and especially hospice workers find themselves called upon to meet the needs of dying patients from a variety of religious backgrounds. Each hospice has a chaplain to provide spiritual care, but the aide may find it helpful to know a bit about a patient's religious and spiritual beliefs as well.

Each religion has its own views on death and beliefs in an afterlife. One study found that those who attend religious services regularly have lower levels of death anxiety than those who do not, mainly because they believe in a life after death. Another study compared people of the three main religions in India: Hindus, Muslims, and Christians. They found that Hindus, who had the greatest belief in life after death, tested lowest for death anxiety. Christians, who believe in an afterlife, showed the highest death anxiety, and Muslims fell somewhere between the two extremes.

Traditional Catholics believe it is important to receive the sacraments of holy communion and last rites from a priest during their final hours. Some believe that prayer can change what happens to a loved one, and may hold a "prayer vigil" at the dying person's bedside. In Judaism, a religion that focuses more on good works in life and less on an afterlife, it is a sign of respect for relatives and friends to watch as a loved one passes away. Muslims believe the dying person should be turned toward Mecca (east) before and after death. And Buddhists, who believe in Reincarnation, may use chanting to calm a patient at the time of death because they believe it will affect a person's character at the time of rebirth. Some Buddhists favor lying on the right side because an unobstructed heart supports a happy, peaceful mind. For these patients, a calm and peaceful mind at the time of death is vitally important.

Some religious denominations have beliefs about **medical treatment** that may affect the care they receive:

Adventists (also called Seventh Day Adventists) believe in the healing power of prayer but also accept most forms of standard medical treatment.

Some *Baptist* groups believe in faith healing or the "laying on of hands" by preachers empowered by God to heal. They may refuse ventilators or resuscitation, believing that it interferes with God's will.

Mormons (Church of Jesus Christ of Latter Day Saints) also believe in divine healing with anointing and the laying on of hands, but do not prohibit standard medical care.

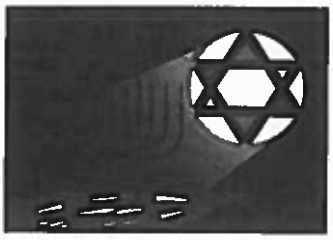
Members of the *Church of Christ, Scientist* (also called Christian Scientist) are generally opposed to all medications and medical treatment.

Jehovah's Witnesses are opposed to blood transfusions and to vaccines made with blood components. They accept most standard medical care.

Native American spiritual beliefs vary by tribe. Some practice spiritual healing and the use of herbs. Harmony

with nature is important. Illness is sometimes seen as the result of an individual's offenses, to be treated by a ritual purification or ceremony. They accept most standard medical care.

Some religions have beliefs about **food**.



Observant *Jews* follow strict dietary guidelines. If you are assigned to care for a Jewish patient in an observant home, follow instructions carefully when working in the kitchen and preparing meals for your patient.

Some *Roman Catholics* have restrictions on when they may eat meat. Traditional Catholics may abstain from food and liquids for an hour before receiving the sacrament of communion.

Muslims normally fast from sunrise to sundown during the holy month of Ramadan. Consult your hospice supervisor for guidance if your assignment includes meal preparation.

Sometimes it's **tradition** rather than religion that comforts the dying. For example, some Chinese American patients must not be told of their condition because it might sadden the spirit and bring on death even sooner. Hispanic culture has similar beliefs about spirits that hasten death, and may wish to have a patient die at home, not in the hospital.

It's unrealistic to think that any aide could know all about other cultures and beliefs, and it's important to resist the temptation to act based on stereotypes. If you find yourself caring for a patient whose background is unfamiliar to you, don't make assumptions. The best idea is to simply ask. *Would you like to have your family here with you? Would you like me to call your priest or rabbi? Is there anything you want me to know about your beliefs or customs while I'm taking care of you?* If the patient is unable to respond, ask a family member. Even if you share the cultural background of a particular patient, don't assume the patient follows the same religious practices you follow.

Guidelines for working in a culturally diverse world

- Understand your own personal and cultural values about life, death, and dying.
- Learn to communicate with a terminally ill patient through verbal and nonverbal means.
- Recognize and accept a patient's desire for closeness or distance.
- Understand some patients' need to have constant contact with family members of all ages.
- Avoid judgmental comments or behaviors as you deliver care.
- Be available for the patient with needed.

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THE AIDE'S ROLE

As a hospice aide, you must develop cultural competence in three major areas: awareness, knowledge, and skill.

Awareness: Start by identifying your own culture and belief system. When you understand the reasons behind your actions and beliefs, you will be able to adjust your actions when you work with patients and families who have cultural and religious beliefs other than your own. Don't make assumptions based on appearances or family names. Even when a person belongs to a particular background, he or she may not share the beliefs and practices of the group. Learn to meet every patient as an individual.

Knowledge: Talk with your supervisor or educator about the various cultural and ethnic groups within your agency's service area. Then consider how these groups view and relate to health care providers. Focus on dietary preferences and restrictions, religious prohibitions, and family dynamics, especially as they relate to communication and the decision-making process. Notice how people in the home interact with one another and what they consider "normal" behavior.

Skill: identify skills needed to work with the agency's population. This involves both sensitivity to a particular culture and the ability to accommodate differences while providing care. Each home you visit will have its own rules and standards. One of your main responsibilities is to respect your patient while you follow the established care plan. If you observe cultural practices that are harming the patient, notify the hospice registered nurse immediately. Do not interfere directly. If you discover that an important part of you assignment must be revised in order to respect the patient's culture, contact the hospice registered nurse to discuss appropriate changes for the plan of care.

OUTCOMES AND THE HOSPICE AIDE

Cultural competency positively affects the quality of care provided to the terminally ill patient. The hospice aide must be aware of cultural considerations to complete care and promote the patient's and family's participation. In turn, the hospice's outcomes will improve and the patient will receive the full benefit of the services.

CMS' Expectations

A hospice must maintain a quality assessment and performance improvement (QA/PI) program that involves all services, including hospice aides. This program, among other things, will take actions to demonstrate improvement in hospice care and palliative outcomes.

CASE STUDY

Martha is a new hospice aide who works for an agency that serves patients of many different cultures in a large metropolitan area. Recently Martha was called in to meet with her supervisor, who had received several calls from Martha's patients and their families. The patients and families had disturbing complaints: Martha is in the habit of praying loudly with them during her visits. Because her religion is not the same as theirs, this makes them uncomfortable. Martha has also left a copy of her church's literature with each of her patients, even those who declined her gift. On top of that, Martha has been heard to criticize family eating habits and attempted to prevent one patient's children and grandchildren from visiting as a family, saying they should come back one at a time, like decent folks.

Martha began by stating how important her church is to her. "That's why I won't work on Sundays, so I can go to church," she said. "And I pray with them because they don't know any better. I'm only trying to help." To defend herself, Martha then began to criticize each of the families that had called to complain about her.

"That Mrs. Goldstein is rich but she's crazy," Martha said. "Do you know they have two refrigerators in that kitchen? And they expect me to pay attention to what food I put in which refrigerator. As if it matters. I can't believe it's even in the plan of care."

She went on to complain about other patients assigned to her care. "Mr. Johnson has all those statues around," she said. "I accidentally broke one that was in my way, and he became upset. Can you believe that?" About Mr. BevanNyen: "The way that house smells! I don't know why they can't eat like the rest of us." About Mr. Ahmed: "I actually had to delay his bath because he said it was time to pray. I know he prays five times a day. It wouldn't hurt to put it off for a few minutes." About a Chinese American patient: "All I did was promise to make his last few weeks comfortable," she said. "His son jumped all over me because he didn't want his father to know he had such a short time left. Can you believe that? They're keeping it a secret. I think he should know the truth. That's what I told my friends last night." About Mrs. Washington: "I hate it when that grandson comes to visit. Those kids are all druggies, with their pants hanging down to their knees." And about Mrs. Morales: "I know she's old, but she has been in this country a long time. She should learn to speak English."

As Martha continued to talk about her patients, she explained to her supervisor that she was only trying to help. "Here's how I look at it," she said. "If they want to live here, they should act like an American. If not, they should go back where they came from."

THINK ABOUT IT

1. What are some indications that Martha does not respect other cultures?
2. What would you say to her if you were her supervisor?
3. Does your agency have a policy about sharing your religious beliefs with patients? If not, what are your thoughts about it?
4. Think about patients you've cared for recently. Can you identify some of their cultural beliefs?