

# The Cultural Expression of Death and Dying

Barbara Jones Warren, PhD, APRN, BC

**D**eath and dying are universal experiences for people from all cultural groups. This collective experience is intertwined with issues involving mind, body, and spirit in the context of each person's unique culture. Case managers can be instrumental in teaching other members of the health care team regarding the cultural issues involved in the dying process of terminally ill clients. Successful management of the process for clients and the people important to them requires a culturally competent approach. Moreover, the managers need to understand the cultural process of dying and the death process both for themselves and their clients.

## Culture, Cultural Competence, and World Views

*Culture* is the internal and external manifestation of a person's values, norms, and beliefs that he or she learns or develops throughout a lifetime.<sup>1</sup> Culture is the essence of existence and helps direct and move everyday decisions and interactions with others. Consequently, culturally competent coordination of client care is even more critical when acute or chronic illness results in a terminal prognosis. Case managers need to be adept in the enculturation of cultural competence with personal and client assessment because the assessment process begins with the interpersonal relationship between the case manager, team members, and the clients and the individuals important to them.

*Cultural competence* is the interpersonal, circular process whereby a health care provider, group, or organization acquires knowledge, understanding, and valuing of different world view perspectives and then acculturates this information into their health care management of clients and other providers.<sup>1</sup> Life span, lifestyle, and environmental issues also contribute to the cultural experience for everyone.

*World views* are cultural guidelines for how people think and interact with others.<sup>1</sup> The four world views (listed in Table 1) are culturally bound, initially formulated in childhood, and may become intertwined throughout life. However, individuals often return to their initially formulated world view

when they encounter a terminal illness because it more easily facilitates the death process for them.

Misunderstanding and conflicts may arise when case managers and other providers have different views between themselves or their clients, particularly related to the death process. For example, assessment and health care planning, while needing to be systematic and complete, will not result in positive outcomes for the client and providers if the case manager does not acculturate the needs of clients who use one or more world views to culturally cope with the dying process.

## Cultural Stages of Dying

Death, as mentioned previously, is a cul-

**TABLE 1. WORLD VIEW PERSPECTIVES**

**Primary World View Perspectives**

**Analytic**

Detail to time, calculations  
Values individuality and acquiring material goods  
Prefers learning through visual and written sources

**Relational**

Spirituality is important concept  
Values the development of relationships and interactions with others  
as a means of everyday functioning  
Verbal communication valued as learning style

**Community**

Community needs more important than individual needs  
Meditation and transcendence are learning methods  
Quiet, respectful approach in interactions

**Ecological**

Sees self as interconnected with the world and its inhabitants  
Feels a sense of responsibility to “take care” of the world and environment  
Learns through “taking in” and quiet contemplation  
Conversation quiet and kept to a minimum

**Selected Exemplar Cultural Perspectives**

Health care providers  
U.S. culture

African, Latino(a)/Hispanic, Jewish-American cultural groups

Asian-American cultural groups

American Indian cultural groups

*Adapted from Warren B.J. Cultural and ethnic considerations. In: Antai-Otong D, ed. Psychiatric nursing: biological and behavioral concepts. New York: Delmar Thomson; 2003. p. 151-65.*

tural outcome of the human process of living. Moreover, it may be a slow cultural experience for clients and their providers, as in the case of terminal illness from cancer or AIDS/HIV, or sudden, as with sudden cardiac arrest, aneurysms, natural catastrophes, or accidents. Unanticipated deaths often bring about more imbalance because those affected have not had time to prepare for the loss by working through feelings or making funeral and other future arrangements with the deceased person. Survivors often experience an initial state of shock that lasts approximately 24 hours. After this comes a period of rehabilitation that may last anywhere from 1 to 6 months. Healing and the gradual easing of the initial loss and mourning can last 6 months or longer.<sup>2</sup>

Kubler-Ross<sup>3</sup> defines clients’ longer process of dying in five stages: denial of the illness and the reality of the death associated with it; anger at self, God, and others; bargaining with God to extend life; therapeutic depression, in which the person moves toward the acceptance of the situation; and acceptance of death, which results in freedom and a sense of peace. Kubler-Ross<sup>3</sup> explains, “Death comes through some other windows” of cultural expression.

**Selected Windows of Cultural Expression**

Persons from culturally and ethnically diverse groups have a variety of belief systems regarding dying and death. The case manager needs not only to adhere to the “common” diagnostic approaches for the client who is dying but also make certain that a cultural assessment is conducted within the biopsychosocial evaluation. Discussions need to center on the mind, body, and spirit of the dying client and others important to her or him. This careful and thoughtful approach helps acknowledge the client’s cultural beliefs and direct the entire dying health care process.

It is important that case managers and other providers learn the culturally appropriate language to better communicate with and meet the needs of non-English-speaking clients and their family members. Furthermore, cultural verbal descriptions of dying and death need to be used when case managers interact with culturally and ethnically diverse clients. The references used in this article provide excellent resources.

It is also essential to realize that the cultural exemplars within this article are not representative of every diverse

group or universal for the cultural group described. The use of compartmental information creates a consciously incompetent or biased health care approach instead of a culturally competent one. Moreover, a number of subgroups live in the United States—for example, American Indian, Arab, African, Hispanic, and Vietnamese-American population groups. Hence, descriptions are provided to give some direction regarding what case managers need to consider in the care of diverse dying clients or in the teaching and management of other health care providers who provide such care. The descriptions are not prescriptive approaches!

In the United States death is often seen as an enemy that needs to be avoided at all costs. Hence, clients may avoid speaking about the upcoming death. Some clients attempt all means of treatment, and physicians may encourage this approach to “save” the patient and avoid death.<sup>4</sup> Even funeral preparations attempt to make the person look “as normal as possible” to avoid acknowledging death.<sup>4</sup>

However, other cultural groups may more readily embrace the dying experi-

ence. People from indigenous American cultural groups often approach the experience through family meetings of the dying person and relatives, including children. Other important cultural approaches may include open windows, turning the dying person toward a cardinal or universal cord direction, and the use of touch, hugs, singing or wailing, and crying after death occurs. Women of the tribe may conduct purification rites with sweet grass smoke.

Some American Indian tribes keep the dead person at rest for a designated time to bring him or her closer to the earth and allow the departure of the soul. Such things as autopsy and organ donation are often not acceptable to the family.<sup>5</sup>

Individuals from Arab-American cultural groups generally do not use an anticipatory grieving approach within the dying process. The eldest man of the family needs to be the first person informed regarding the family member's future death. He in turn then decides how and when to inform other family members. The family prefers a private area in which they can talk and have the presence of a minister or imam. Issues such as do not resuscitate orders, autopsy, and organ donation generally are not acceptable to this group.<sup>6</sup>

African-American people often have a strong religious and spiritual basis for their everyday functioning that is incorporated in the process of dying and death. Death is viewed as a natural outcome within life, and the family is comforted with thoughts that the dead person is now at peace, happy, and with God. Family members may include kinship ties and blood relatives, and they are encouraged to physically and spiritually care for the dying person. The eldest man is often the family spokesperson, and emotions are encouraged in dealing with the death of a loved one. Ministers and the funeral service are important elements for the family; prayers are a source of consolation in time of distress.<sup>7</sup>

Similar to the African-American cultural perspective, people of Mexican-Ameri-

can descent have strong religious and spiritual practices associated with dying and the death process. As with African-Americans, the eldest is often the one to notify other family members regarding the diagnosis of a terminal illness or death. Families often prefer to have their loved one in a home environment instead of the hospital. Family members prefer to be in attendance during the dying process.

Many adhere to the teachings of the Catholic religion. The anointing of the sick is done by a priest to prepare the person for death. Rosaries, candles, and religious medals are common methods of comfort to the dying person and his or her family. Emotions are encouraged when the person dies, and family members often want to be involved in preparing the body. Such issues as organ donation and autopsy are often a family decision.<sup>8</sup>

The Vietnamese people are a diverse group of individuals: some fled southern China with professional skills, higher educations, and intact families; others came from the military or unskilled trades and have fragmented families. Decisions, while made by the family, generally are directed by the eldest member. A priest or monk is often an important consultant. Prayers and religious practices generally are directed according to Catholic or Buddhist rituals. Families like to have time with their loved one after death and may prefer washing and preparing the body themselves rather than having hospital or other health care staff prepare it. Cremation may be preferred by people practicing the Buddhist faith. Organ donation or autopsy generally is not permitted but may be allowed if the family decides it is necessary.<sup>9</sup>

### **Pulling It All Together**

The case manager and other health care providers who are providing support and care of dying clients need to be aware of their own cultural perspectives regarding life, living, death, and dying. It is not simply a matter that they "take care" of others; they also must understand what "cultural windows of expression" they come from. They need to ask themselves some of the following questions:

1. How do I feel about dying and death?
2. What are the cultural formulations for my feelings?
3. What are my cultural and religious biases?
4. What is my predominant world view?
5. What is the client's world view perspective and those important to him or her?
6. What stage of dying is the client experiencing?
7. Can I adopt my cultural style and world view to meet the needs of my client and the other health care personnel with whom I work?
8. Where can I go for assistance and additional knowledge related to culturally and ethnically diverse approaches regarding dying and the death process for clients?

Answering the above questions will facilitate professional cultural growth not only for a case manager but also for the client and those important to him or her as they move through the dying process.

### **Conclusion**

The process of dying is a complicated biopsychosocial process within the lives of clients and the health care professionals who care for them. The stages of death, as defined by Kubler-Ross,<sup>3</sup> can provide another important cultural perspective regarding how people interpret the entire dying process. It is extremely important that case managers be aware of the need for culturally competent health care as people pass from this life. It is a time for reflection on world views and cultural perspectives that are intricate components within others' lives. The inclusion of culture and cultural competence is the basis from which interpersonal relationships develop and grow.

Careful and thoughtful evaluation and processing with other members of the health care team are other essential components of the culturally competent process for clients and providers. Finally, it is the responsibility of the case manager to make certain that this process is adhered to as he or she facilitates movement of other team members through dying and the death process of each client. □

## References

1. Warren BJ. Cultural and ethnic considerations. In: Antai-Otong D, ed. *Psychiatric nursing: biological and behavioral concepts*. New York: Delmar Thomson; 2003. p. 151-65.
2. Kneisl CR. Psychiatric mental health clients with HIV/AIDS. In: Kneisl CR, Wilson HS, Trigoboff E, eds. *Contemporary psychiatric mental health nursing*. Jersey City (NJ): Pearson Prentice Hall; 2004. p. 571-88.
3. Kubler-Ross E. *The tunnel and the light: essential insights on living and dying*. New York: Marlowe; 1999.
4. Mahon PN. Death and dying. In: *Psychiatric mental-health nursing: adaptation and growth*. Philadelphia: Lippincott; 1993. p. 855-69.
5. Champagne D. *Native America: portrait of the peoples*. Detroit: Visible Ink Press; 1994.
6. Kulwicki AD. People of Arab heritage. In: Purnell LD, Paulanka PJ, eds. *Transcultural health care: a culturally competent approach*. 2nd ed. Philadelphia: Lippincott; 2003. p. 90-105.
7. Glanville CL. People of African American heritage. In: Purnell LD, Paulanka PJ, eds. *Transcultural health care: a culturally competent approach*. 2nd ed. Philadelphia: Lippincott; 2003. p. 40-53.
8. Zoucha R, Purnell, L. People of Mexican heritage. In: Purnell LD, Paulanka PJ, eds. *Transcultural health care: a culturally competent approach*. 2nd ed. Philadelphia: Lippincott; 2003. p. 264-78.
9. Nowak TT. People of Vietnamese heritage. In: Purnell LD, Paulanka PJ, eds. *Transcultural health care: a culturally competent approach*. 2nd ed. Philadelphia: Lippincott; 2003. p. 327-43.

*Barbara Jones Warren, PhD, APRN, BC, is an associate professor at The Ohio State University College of Nursing in Columbus, Ohio, and the executive nurse for the Ohio Department of Mental Health. She is also a past president of the American Psychiatric Nurses Association and is a board-certified advanced practice psychiatric mental health nurse who has a private practice.*

Reprint orders: Elsevier Inc., 11830 Westline Industrial Dr., St. Louis, MO 63146-3318; phone (314) 579-2838; reprint No. **YMCM 248** doi:10.1016/j.casemgr.2004.11.012

## Special Calling

*Continued from page 42*

and illnesses. Are there any medical procedures the patient does not want to undergo? Are there life-saving measures that the patient deems unnecessary or excessive? What are their feelings about organ donation? What does the family think about it? How many of us have been at the bedside with people thrown into turmoil because a loved one chose to sign an organ donation form?

Case managers not only face the issue of death: they also face issues of continued living. How many drugs, unproved treatments, or severe pain will a patient and family endure? Some patients desire treatment even when there is only a 1% chance of success, whereas others who have a 75% chance of remaining alive but face a different way of life choose to forgo treatment. In these difficult situations, the case manager must provide the objective viewpoint. She or he can answer a patient's questions that are not fully addressed by the provider and serve as a strong advocate if the patient wishes to decline continued treatment.

The New York nonprofit group Choice in Dying (212-366-5540) has created a Patient Advance Directive Checklist that offers case managers guidance on the types of issues and subjects that need to be brought into the open. At first glance, some points might seem self-evident, but in practice, the "obvious" is very often not so clear to families facing traumatic decisions. This organization suggests that individuals:

- Consider and discuss their wishes regarding EOL care with family, friends, and health care providers
- Obtain copies of advance directives (a living will and a medical power of attorney) for the state. These are available through Choice In Dying, each state's department of health, and some local hospitals.
- Choose a trusted family member or close friend who is willing to accept the responsibility to advocate for patients who cannot speak for themselves. This person should be appoint-

ed as the patient's agent on the medical power of attorney form.

- Complete the living will and medical power of attorney forms according to state law.
- Keep the forms in a safe yet accessible place. Give copies to the agent, physician, family, and friends. If the patient enters a hospital or nursing home, photocopies of the advance directives should be placed with the medical chart.
- Talk with their agent, physician, family, and friends about their wishes regarding medical treatment. Discuss these wishes often, particularly if the medical condition changes.

## Conclusion

Case management is as rewarding as it is demanding, which means practitioners must acknowledge that we need respite, too. Times arise when it is best to remove ourselves from the center of family discussions to retain our ability to assist them effectively. We must remember to be as kind to ourselves as we are to our patients. □

## References

1. Mullahy C, Jensen D. *The case manager's handbook*. 3rd ed. Sudbury (MA): Jones and Bartlett; 2004.
2. Beerman S, Rappaport-Musson J. *Eldercare 911*. Amherst (NY): Prometheus Books; 2002.
3. Hoffmann LF. CMSA finds American families and physicians need help addressing end-of-life Issues. Case Management Society of America press release, June 7, 2002.
4. Associated Press. Study shows priorities at death. *Newsday* 2000;61:A21.

*Catherine M. Mullahy, RN, CCM, is editor of The Case Manager and president of Options Unlimited in Huntington, New York. Deborah K. Jensen is a freelance writer and publicist.*

Reprint orders: Elsevier Inc., 11830 Westline Industrial Dr., St. Louis, MO 63146-3318; phone (314) 579-2838; reprint No **YMCM 249** doi:10.1016/j.casemgr.2005.11.013