Background and Significance

Although death is universal, dying is very much a culturally specific experience. *Culture* refers to learned patterns of behaviors, beliefs, and values shared by individuals in a particular social group. It provides humans with a sense of identity and belonging, and it gives us a framework for understanding experience. When referring to culture in its broadest sense, the term usually implies a group of people with similar ethnic background, language, religion, familial beliefs, and worldview. Culture is a strong determinant of people’s views of the very nature and meaning of illness and death. Culture also influences whether health-related or end-of-life–related decisions can or should be controlled, how bad news should be communicated, and how decisions (including end-of-life decisions) should be made.

As a result of profound demographic changes that affect many Western nations, physicians increasingly care for patients from diverse cultural backgrounds. Differences in beliefs, values, and traditional health care practices are of profound relevance at the end of life. Culture shapes the expression and experience of dying and death as families prepare to lose a loved one. There is growing awareness that the care of the dying is deficient despite many advances in the field of medicine and multiple initiatives to improve this care. The burgeoning field of end-of-life care is receiving increased attention, and experts in the field are attempting to improve the care of...
the dying by clarifying priorities and establishing humane and respectful palliative care standards and practices. Simultaneously, Western nations are being transformed by rapidly changing demographics related to the growing numbers of immigrants from diverse backgrounds. Because culture provides the primary framework for understanding experience, it is critical to consider culture in relation to end-of-life care.

The heart of the problem is that health care providers, patients, and family members may have dissimilar beliefs about the meaning of illness or death, and they may not agree on which strategies are the most appropriate to alleviate pain and suffering or in planning for the end of life. Good palliative care may be compromised by disagreements between physicians and patients, by miscommunication, or by decisions or beliefs that are not understood or valued. Values that are ingrained in a physician may be alien to patients from different backgrounds. Because of the significant potential for misunderstanding, it is imperative that health care workers be cognizant of potential cultural differences and develop the skills necessary to identify such differences.

A way in which we often go wrong in medicine, and especially in palliative care, is that we see “cultural differences” as something rooted solely in the patient’s perspectives. As health care workers, we also represent a “culture” in which perspectives on end of life have a social and cultural history. It is imperative, therefore, to recognize that working with patients new to our society represents the interface of two cultures: theirs and ours. It is naive and unrealistic to believe that differences in patient perspectives can be taken into account without first understanding the genesis of our own perspectives. To this end, we must explore the historic and contemporary perspectives on end-of-life care. The terms Western and non-Western are used in this chapter. This distinction is not geographic, but rather it is philosophical and anthropologic. In the context of medicine, this distinction is grounded primarily in different beliefs about the primacy of the individual as well as the adherence to the biological views of health and illness.

### Sociocultural Development of Palliative Care

An empirical and philosophical analysis of cultural differences in end-of-life care has started to identify significant differences in perspectives that are rooted in culture. However, this limited analysis has not yet had a significant influence on the fundamental assumptions of end-of-life care. When considering culture and end-of-life care, it is important to note that, despite the broadening of perspectives in the field of end-of-life care, moral agency and individual autonomy remain at the heart of contemporary attitudes and may cause cultural conflicts. Many health care workers who deal with people at the end of life recognize the importance of culture, but they argue that despite significant cultural differences, fundamental, inherent, universal ethical principles can and should to be applied across cultures, nations, and all forms of human boundaries as death approaches. The argument is founded in the belief that essential elements are embedded within the world’s apparently diverse moral systems, such as humanness (defined as compassion for the pain and suffering of others) and recognition of the equal worth and basic autonomy of every human being.

These concepts of equal worth and autonomy stem from the European Enlightenment of the 18th century. Moral agency and individual autonomy were strongly expressed by Immanuel Kant, were later refined into the political philosophy of
liberalism expressed by John Stuart Mill, and, in turn, were developed and refined by many subsequent philosophers. These concepts are fundamentally Western and may be truly foreign to many patients.

If these concepts are applied as universal and are seen as our guiding light in the face of death, what then, for example, of Asian philosophical traditions grounded in Taoism, Confucianism, or Buddhism, in which moral perspective and direction are illuminated by interdependence rather than independence? Such cultures are perplexing to most Westerners because they do not contain references to autonomy or self. We often believe that having an “open mind” and “taking our cues from patients” will ameliorate cross-culture misunderstanding. We must first acknowledge, however, that our deepest beliefs related to death and dying are also shaped by culture.

Table 19-1 is developed from three paradigms from the social sciences: cultural context, as first described Edward Hall; health locus of control, described by Rotter; and the explanatory model of illness, described by Kleinman. This table represents trends in dealing with individual patients and families at the end of life.

The following common clinical situation illustrates some of these conceptual differences in perspective.

A patient who is in a cognitively incompetent state is brought into an intensive care unit (ICU). When the ICU team meets with the patient's family, they focus first on biomedical explanations of illness and the potential for brain death. They then ask whether the patient expressed any personal wishes about treatment before becoming incompetent and thus encourage an open and direct conversation about the severity of the situation and the potential for death. By exploring the patient’s perspectives and values with the family, the team hopes to formulate the best plan for the medical care of the patient.

However, the focus on individual rights and choices, the direct and blunt verbal communication about such a personal and difficult situation, the introduction of the element of choice, and the focus on a purely biomedical explanation of illness and death may be so confusing for this family of non-Western origin that the result is a complete breakdown in communication.

Inherent in this relatively standard approach is a belief in the Western definition of illness and death, a belief that the timing and circumstances of dying can and should be controlled. At the heart of each of these paradigms is the fundamental belief in the inherent value of respect for autonomy, even if the patient and the family are unaware of that concept.

**Elements That Can Limit Cultural Understanding**

MARGINALIZING ETHNOGRAPHIC AND PSYCHOSOCIAL INFORMATION

Many medical approaches and bioethical models rely on comparative cases and examination of competing principles. Although these methods may be useful in defining some ethical issue, to understand end-of-life dilemmas fully, we must examine the social and cultural context within which the situation is embedded. Medical perspectives or comparative cases alone tend to marginalize many relevant factors such as culture or the personal and social meaning of a situation. Thus, the common effort to render end-of-life analyses as objective, rational, and unbiased by defining “value-neutral” concepts such as futility risks making end-of-life decisions socially and culturally neutral. Concepts such as futility and the lived experience of
<table>
<thead>
<tr>
<th>Section</th>
<th>Table 19-1. Trends in Dealing with Patients and Families at the End of Life</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Contemporary Medical Perspectives</strong></td>
</tr>
<tr>
<td><strong>Beliefs about causation of death and dying</strong></td>
<td>Death is biologically determined. Dying occurs when medicine can no longer stave off, treat, or reverse illness. Death most often occurs in hospitals, and the declaration of death is ultimately in the hands of medical personnel.</td>
</tr>
<tr>
<td><strong>Social structures</strong></td>
<td>Equality and independence are valued. Strong acceptance and value are given to autonomy.</td>
</tr>
<tr>
<td><strong>Communication about dying with patients and others</strong></td>
<td>Information should be explicitly communicated. Clinicians have a moral obligation to truth telling because the patient has a right to know and must make autonomous decisions. Information is best communicated overtly.</td>
</tr>
<tr>
<td><strong>Perception of a religiously/culturally meaningful death</strong></td>
<td>Individual choice is valued. There is no direct association to medicine. These attitudes can be an impediment to the acceptance of the futility of further treatment.</td>
</tr>
</tbody>
</table>
patients and families are separated by a substantial distance. Health care workers and medical literature often describe social and cultural factors as external “constraints” and frequently use the term cultural barrier, usually with the intent to analyze and clarify. However, the word barrier implies that culture blocks access to the resolution of the ethical issue, thus implying something universal on the other side of this barrier. Is there?

**SECULAR FOCUS**

Despite the significant Judeo-Christian contributions to end-of-life care and although many health care workers are aware of the profoundly religious and spiritual beliefs and contributions to end-of-life perspectives, health care in general continues to adhere to a largely secular perspective. This is understandable because a secular approach in medicine is a practical, political, and moral response that seeks to apply a unitary approach to the demands of complex and diverse cultures. Many would also endorse the idea that palliative care philosophy is emerging as a secular alternative to religious perspectives and is better able to serve a pluralistic, morally diverse society. However, by doing this we often isolate cultural issues from their spiritual and social context to achieve an institutionally sanctioned method of avoiding potential conflict. Unfortunately, our efforts to examine issues from a nonspiritual or

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**Table 19-1. Trends in Dealing with Patients and Families at the End of Life (Continued)**

<table>
<thead>
<tr>
<th>Perception of negotiating death (levels of negotiating treatment)</th>
<th>Contemporary Medical Perspectives</th>
<th>Non-Western Perspectives</th>
<th>Clinical Approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>The timing and circumstances of death can and ought to be controlled as much as possible to respect a patient’s autonomous choices.</td>
<td>Patients are largely responsible for defining the “kind of death” they wish.</td>
<td>Suffering and death are largely a matter of fate and may hold profound spiritual meaning. The timing and circumstances of death and dying are preordained and a matter of fate.</td>
<td>A trial of therapy allows patient outcomes to be determined more by “fate.” Allow as natural a process as possible. If the patient is on life support, withdraw it gradually.</td>
</tr>
</tbody>
</table>

**Nonverbal communication**

| Patients are largely responsible for defining the “kind of death” they wish. | Suffering and death are largely a matter of fate and may hold profound spiritual meaning. The timing and circumstances of death and dying are preordained and a matter of fate. | A trial of therapy allows patient outcomes to be determined more by “fate.” Allow as natural a process as possible. If the patient is on life support, withdraw it gradually. | A trial of therapy allows patient outcomes to be determined more by “fate.” Allow as natural a process as possible. If the patient is on life support, withdraw it gradually. |

Direct communication, even about difficult matters, is the most ethical approach. | Consider body language, and respect silences and rituals. | Listen more than speak. Consider body language. Allow and respect silences; consider their meaning. | Listen more than speak. Consider body language. Allow and respect silences; consider their meaning. |

The timing and circumstances of death can and ought to be controlled as much as possible to respect a patient’s autonomous choices. | Consider body language, and respect silences and rituals. | | |
nonreligious perspective make our approach limited, incomplete, and sometimes devoid of meaning and difficult to understand for many patients and families who are new to Western health care.

**FOCUS ON INDIVIDUAL AUTONOMY**

Although challenges to the principle of autonomy are becoming increasingly apparent in medicine in general and in end-of-life care in particular, this awareness has not deeply affected standard medical practice. For example, much of the contemporary discourse in medical ethics equates autonomy with personhood, as though autonomy exists universally for all people independently of cultural perspectives. The extreme opposite of autonomy would be experienced by people who live in remote tribal societies where the concept of the individual is virtually nonexistent and holds little social relevance. Although we do not have people from remote tribal societies living in Western industrialized nations, this difference in perceptions of the self in relation to others illustrates the power and influence of culture. Despite this, the concept of autonomy remains the intellectual and moral foundation of Western medicine, and it is a direct manifestation of the Western concept of individualism: a belief in the importance, uniqueness, dignity, and sovereignty of each person and the sanctity of each individual life. According to this belief, every person is entitled to individual rights such as autonomy of self, self-determination, and privacy. For most cultures, this focus on individuality neglects the vital role of personal interconnectedness and the social and moral meaning of these interrelationships.

**TRUTH TELLING, NEGATIVE FOCUS**

Generally, Western medicine (and, in turn, end-of-life care) has responded to the cultural trends of placing a high value on truth telling. Yet in the presence of serious illness, many cultures believe that giving negative information may induce negative outcomes. This belief reflects the considerable cultural differences concerning the interaction between mind and body. Some cultures are strongly protective of the critically ill and believe that ill loved ones require the same supervision and protection as well-loved children. Western medicine derives the physician’s obligation to communicate the truth to patients from the rarely questioned belief in the patient’s “right to know,” which, when considered as unconditional, requires that patients must deal with the truth overtly and rationally. The belief is that patients will ultimately be better off, and this perspective is particularly powerful in oncology. Sometimes we meet the patient’s refusal to accept the truth with impatience and believe they are in denial, a state that is understandable but generally considered unacceptable. From a Western perspective, we usually agree quickly about what the truth is as we anticipate outcomes based solely on medical perspectives, yet this view may mystify people of other cultural perspectives.

Attitudes toward truth telling are largely determined by culture. A qualitative study showed that Chinese seniors did not see truth telling as a moral absolute but instead believed that in many cases truth telling could produce more harm than good and should be dealt with in a cautious way that involved the family more than the patient. Another study that examined the attitudes of 200 seniors from four ethnic groups (African American, Korean American, Mexican American, and European American) found that Korean Americans and Mexican Americans were significantly less likely than European Americans and African Americans to believe that patients should be told about a diagnosis of metastatic cancer. A study of American Navajo
perspectives concluded that the Navajo culture views medical information as harmful. In Taiwan, neither Western-oriented nor traditional Chinese doctors give information related to diagnosis and prognosis to patients who are facing life-threatening illness; instead, this information is given to family members, who, in turn, are expected to inform and support the patient. These findings have been supported by further studies involving Asian populations. Neither patients nor physicians view truth telling as an ethical issue. In the West, however, this practice would be considered a direct violation of the principle of autonomy.

DIFFERENT DEFINITIONS OF DEATH

Although many of us accept the standard medical determinations of death, there can be profound cultural variation in this area. The following example illustrates this variation.

In Western health care, organ donation from brain-dead patients may be seen as something positive and without a great deal of moral ambiguity. This is not the case from some non-Western perspectives. Japanese views of brain death and organ transplantation clearly illustrate such differences. One study, for example, suggested that in Japanese society, Shinto and Buddhism have strongly supported “natural” processes and approaches to dying. According to Buddhist belief, aging, illness, and death are inevitable once a person has entered the cycle of life. From a traditional Japanese perspective, a human being is the integration of body, mind, and spirit. After death, a person remains an integrated whole. The metaphorical center of the body, kokoro, has traditionally been located in the chest. Therefore, removal of an organ from a brain-dead human, especially from the chest, may be perceived as disturbing this integrated unit. The Japanese find a fragment of the deceased’s mind and spirit in every part of a deceased person’s body. It follows that the Japanese believe a dead person goes to the next world as a soul. Similar to a living person, this soul has its own body, senses, and feelings. The dead body must remain whole because if some parts are missing, the soul becomes unhappy in the next world. Such latent yet formative cultural views are not specific to the Japanese. For example, although not homogeneous in their views, many North American aboriginal people are profoundly uncomfortable with organ donation. In many non-Western cultures, death is viewed as a social event rather than a scientific phenomenon.

What are the cultural, historical, philosophical, and religious influences that have made certain ideas about death acceptable in the West? Perhaps it is because in the West, human beings have often been perceived as the blending of body and soul. Christianity has shaped the West just as Buddhism, Shinto, and Confucianism have shaped Japan. In Christianity, people are expected to respect the body after death because it was an essential part of the person during life; however, a body without a soul is no longer considered a person. With regard to organ procurement, many Christians perceive the donation of one’s organs as an act of love and generosity. The spiritual value of nonreciprocal giving is central to Christian belief. This, in part, may have contributed to the widespread social acceptance of organ donation. In general terms, Western medicine and, in turn, end-of-life care, have accepted brain death as death and have embraced transplantation. Clearly, there are profound cultural differences in perceptions of validity of brain death and the moral value of organ transplantation; this cultural difference cannot be addressed by the oft-stated need for better education of new immigrants.
Communication and Context

It is imperative to understand the influence of culture on communication. All cultures have verbal and nonverbal approaches to giving and receiving messages. Although we as health care providers working the realm of end-of-life care can easily acknowledge the medical and ethical complexities of end-of-life decisions, we have barely begun to acknowledge the psychological and sociocultural complexities. For many people new to scientifically advanced Western nations, several factors—including the absence of life-sustaining technology, a far shorter life expectancy, a higher child mortality rate, and a closer geographic proximity for many families—made death a more frequent, home-based experience that had little to do with choice. In Western nations, however, end-of-life decisions abound, and the stakes are high. These decisions involve life or death, views about the quality and meaning of life, high costs, moral principles, and legal rights. Not surprisingly, such decisions can generate intense emotions, particularly for those with no familiarity with the concepts involved, and can increase the potential for conflict.

Moreover, substantial differences in culture, combined with social class and education, often exist between physicians and families. What is known or valued by health care workers may be elusive or irrelevant to families. When differences exist, so too will perspectives on choices, and this disparity creates a greater opportunity for conflict. Conflicting perspectives become increasingly obvious when major decisions must be made. Large health care teams with shifting and inconsistent members, each trained in specific professions with separate working cultures, often fracture communication and make for an environment that is not conducive to balanced discussion and negotiation. Furthermore, all these factors occur in the climate of continuing change that defines the contemporary health care system. For families, end-of-life decisions are not abstract philosophical questions or matters of clear-cut clinical judgment; rather, they are painful emotional experiences, greatly shaped by cultural and religious beliefs that can generate profound revelations about mortality and family relationships. As previously stated, rather than viewing culture as an integral part of a patient’s identity and life, much of the health care literature depicts culture in terms of a barrier. Families, central to the end-of-life experience in most cultures, are frequently described by health care workers as being a help or a hindrance, as supportive or difficult. Furthermore, the cultural meaning of illness in the context of the family is often not identified and is poorly understood by health care workers. This patient-centered perspective in health care may be rooted in the strong focus on patient autonomy and the sanctity of the physician–patient relationship.

Hispanic Perspectives

BACKGROUND

Although cultural generalizations as a means of anticipating behavior are not useful and run the great risks of stereotyping and producing further conflict, exploring the general cultural trends outlined in Table 19-1 can be a useful means of examining existing behavior (as opposed to prediction). The first point that must be considered when referring to Hispanics is that the term is a label of convenience for a cultural group with a common cultural heritage stemming from Spain’s colonization of the Americas. Hispanics can be of any racial group (e.g., indigenous American, black,
Asian, white, or of multiple racial ancestry). Hispanic immigration to most Western nations has been rising steadily and is particularly extensive in the United States, where the Hispanic population of 31 million will soon surpass African Americans as the largest minority group in the country. Although significant differences exist among Hispanic subgroups, virtually all share a common language, religion, and traditional family structure and have many common values. In addition to differences in subgroups, they differ in terms of their level of acculturation or assimilation into mainstream culture. Language use is one very good example of these differences. For instance, although many Hispanics are bilingual, the degree to which they speak either Spanish or English varies considerably.

**CULTURAL FEATURES**

**Religion**

One value shared by most Hispanics, as evident in the Carillero family in Box 19-1, is religion. Although the degree of practice and church participation varies, most Hispanics are Christian, predominantly Roman Catholic. However, many Hispanics practice other religious beliefs that they have incorporated into their Christianity, such as forms of ancestor worship with rituals dating back to pre-Columbian times among Central American Indians. For example, many Caribbean Hispanics practice **Santería**, a fusion of Catholicism and the Yoruba religion that was brought to Cuba by African slaves. Such rituals are described as **Espiritismo**, a belief in good and evil spirits that can affect health and well-being and that includes views on dying and death. The rituals performed by the Carillero family that others found loud and disruptive and the attending Roman Catholic nurse felt were not Catholic in nature were likely rooted in this cultural trend. As evident with the Carillero family, it is common to hold a continued vigil over an older family member with a terminal illness. These and other practices honor the loved one and form part of the bereavement ritual.

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**BOX 19-1. CASE STUDY: THE CARILLERO FAMILY**

Mrs. Carillero is a 70-year-old Hispanic woman who was admitted to the ICU with metastatic bone disease from a primary site of breast cancer that has now spread to her lungs and possibly her brain. Mrs. Carillero has a large extended family that essentially never leaves her side. Earlier in the illness, the Carillero family had been asked to consider a palliative care facility in the future because of the possibility that Mrs. Carillero’s care could become complex and demanding. The family steadfastly refused and asked that the topic not be brought up again. These family members have consistently advocated for full and aggressive treatment. The ICU rule of two visitors at a time is rarely being followed, and the ICU staff is becoming frustrated and upset. When visitors are asked whether they are immediate family, they fall silent.

Although the ICU staff assured the Carillero family that prayer was welcomed, the family repeatedly engages in fairly loud ritualized prayer sessions. The ICU staff members now feel that these sessions have become disruptive to the unit and disturbing to the other patients and their families.
In addition, the Carillero family had identified themselves as Catholics. A Roman Catholic nurse has stated that at first she had joined them in prayer, but many elaborate rituals have been introduced, and many of the prayers are unfamiliar to her. She has openly questioned whether they are truly Roman Catholic and respectful of Catholic traditions.

Through negotiation, Mrs. Carillero’s son Everett was chosen as spokesperson. When the physician told Everett about his mother’s poor prognosis and the “futility” of further treatment, Everett appeared to not acknowledge the severity of the situation and insisted that his mother be fully treated. He told the doctor that he had the skill to do miracles. The health care team repeatedly asked Everett and other family members whether Mrs. Carillero had previously expressed wishes about what she would want if she were in her current circumstances. The family did not respond to this question. The team also asked: “If she could speak to us now, what would she tell us she wanted?” The Carillero family was again consistently silent on this question.

Everett says that he wishes to deal with things one day at a time and states that his mother’s fate should be in God’s hands, not determined by decisions made by either the doctors or the family. The family’s unresponsiveness to these questions and their insistence on continued treatment have been interpreted by some as a means of focusing on their “agenda” rather than on Mrs. Carillero’s wishes and best interests.

The Carilleros told a patient relations officer that they are very upset by the constant staff changes. They said that they feel like they have no one really to talk to and they are feeling pressured to end Mrs. Carillero’s life. Everett has also demanded that should his mother regain consciousness even briefly, she not be told about her condition or asked questions about her wishes, because it would “kill her spirit.” The physician explained to Everett that he had a legal and ethical obligation to inform his mother of her medical situation and to clarify her wishes should she become conscious and capable. Family members are now refusing to leave even when procedures are being done and state that they are afraid that medical staff will give up on their mother. Tension is growing, and the ICU team has deemed this case a serious ethical dilemma.

Lack of Focus on Individual Patient Perspectives and Large Number of Visitors
The large extended Carillero family network can be understood in a context of the strong role of family for many Hispanics, highlighted by powerful ties within an extended network of uncles, aunts, cousins, grandparents, and family friends. Included in this is the important role of the family in the concept of familismo, an emphasis on the welfare of the family over that of the individual, perhaps illustrated by the family’s silence and reluctance to identify Mrs. Carillero’s independent wishes.

Discomfort with Constant Staff Changes
The Carillero family informed a patient relations representative that they found the constant staff changes very disturbing at such a difficult time. This could possibly be
attributed to the Hispanic concept of *personalismo*, a term that refers to trust building over time and is based on the display of mutual respect.

**Reluctance to Partner with Physicians for Planning and Unrealistic Expectations**

Everett’s reluctance to discuss family issues and values with the physician as well as his potentially unrealistic expectations of physicians could be related to *jerarquismo*, a term that refers to respect for hierarchy.

**Focusing on the Present and Avoiding Long-Term Plans**

Everett’s persistent wish to take things day by day may be tied to the concept of *presentismo*, defined as maintaining important focus on the present instead of on the past or the future.

**Avoiding End-of-Life Decisions**

The family’s fervent wish to avoid human influence in the timing of Mrs. Carillero’s death may be seen as *fatalismo*, the belief that fate determines life outcomes, including health, and that fate is basically unbeatable.

**TRUTH TELLING AND ADVANCED MEDICAL PLANNING**

In a study that compared beliefs of Mexican Americans, Korean Americans, African Americans, and European Americans on several issues related to patient autonomy, researchers found that Mexican Americans and Korean Americans were less likely to believe that a patient should be told about a terminal diagnosis or make decisions about using life support. The researchers also found that Mexican American and Korean American elders were more likely than African American and European American elders to want family members to make these decisions.20

**LIFE-PROLONGING TREATMENTS**

When it came to the issue of life-prolonging treatments at the end of life, Hispanic Americans and African Americans were more likely than non-Hispanic whites to report wanting their doctors to keep them alive regardless of how ill they were (42% and 37% vs. 14%, respectively). Furthermore, only 59% of Hispanics and 63% of African Americans agreed to stop life-prolonging treatment, compared with 89% of non-Hispanic whites.21 It is possible that this trend reflects a mistrust of the system or religious beliefs related to not killing and the sanctity of life.

**Palliative Care Perspectives**

As seen in the Carillero family, some studies have suggested a significantly low use of palliative care services in Hispanic populations. Reasons may include unfamiliarity with palliative care, language barriers, and unpleasant experiences with or distrust of the health care system. Cultural factors may well be at play, however, and further research is required in this area.

**HOW COULD THE CARILLERO FAMILY BE BETTER RESPECTED?**

Because Hispanics have a significant demographic representation in our culture, it is wise to increase our knowledge about Hispanic culture by becoming familiar with the history of the subgroups we dealing with, as well as the family, social, and religious values associated with Hispanic culture. This will help providers to display
respect and to build trust. The provider should include family members in discus-
sions with the patient regarding treatment planning and palliative care. There may
be situations in which the patient does not want to have the family included, and
this wish, of course, should be respected.

Finally, it is important to have open and clear communication with the patient
and family, because deference to and respect for the provider as a result of jerarquismo
may lead the Hispanic patient to withhold information or to hesitate to communicate
honestly. The provider must ascertain whether the patient understands the treatment
being offered and whether he or she fully agrees with the treatment plan. This is
particularly important when it comes to end-of-life decision making and advance
directives, because several cultural factors discourage discussions of these topics. Jerarquismo
may lead the patient and family to have unrealistic expectations about
what conventional treatment can offer. The family may be expecting a miracle cure
for the terminally ill patient and thus may refuse to consider palliative care treatment
options. Appropriate religious representation is imperative to avoid perceived conflicts
between the patient’s religion and the withdrawal or withholding of treatment.

**Cross-Cultural Awareness in Practice**

Keep in mind the following questions when working cross-culturally with patients:

- Does this patient value individuality and personal choice, or does he or she
  focus more on family and collective choices?
- Does he or she value open communication, or does the patient tend to draw
cues from the context of the situation?
- Does he or she believe a person can and should influence his or her health or
death?
- Does he or she believe in a Western explanation of illness, or does the patient
  hold an alternative culturally based view, and is this view blended with Western
  perspectives on illness?

**PEARLS**

- Cultural differences vary extensively. Do not assume; always ask.
- When working cross-culturally, there is a good chance that your patient and his
  or her family may not value individuality over interdependence. Ask your
  patient how he or she would like decisions to be made.
- Not everyone believes in Western medicine. To understand your patient’s
  perspective better, ask: “What do you think is causing your illness, and how
  should it best be treated?”

**PITFALLS**

- Be careful when assessing emotional reactions cross-culturally.
- Do not assume to know another’s cultural views. Always ask.
- Do not assume that patients are aware or accepting of a Western biomedical
  view of illness. Inquire, give your perspectives, and negotiate a treatment plan.
Summary

Cultures are maps of meaning through which people understand the world and interpret the things around them. When patients and health care workers have different cultural backgrounds, they frequently follow different “maps,” and this can hinder effective communication.

As a result of profound immigration and the resultant demographic changes, health care workers increasingly care for patients from cultural backgrounds other than their own. Culturally constructed differences in beliefs, values, and traditional health care practices are of profound relevance at the end of life. Culture greatly determines the expression and experience of death and dying as patients and families prepare to lose a loved one. As much as contemporary end-of-life care critiques and acknowledges cultural differences, it remains questionable whether we have truly explored the profound significance of the cultural differences of the values given to independence and interdependence, present or future orientation, intervention with the timing and circumstances of death, and the way in which families and patients understand the nature and meaning of death. Nor have we compensated for how greatly these factors lead to substantial differences in cognitive processes, perception, social structures, values, and beliefs in both patients and health care workers.

Those who work in the domain of end-of-life care must undertake a deeper exploration of those social and cultural realities that shape end-of-life experiences. Although end-of-life care increasingly identifies and values interrelationships with others, autonomy and, in turn, the individual, remain at the heart of end-of-life analysis. Our organizational and legal structures assume that the person experiencing the illness is the best person to make health care decisions. This raises profound questions about the adaptability of end-of-life care in a culturally pluralistic society. Because many cultures vest the family or community with the right to receive and disclose information, and to organize and make decisions about patient care, we must be constantly cognizant that the cross-cultural application of the concept of autonomy will mean accepting each person’s terms of reference for their definition of self. Specifically, we should respect the autonomy of patients and families by incorporating their cultural values and beliefs into the decision-making process. Although this may sound straightforward, it is easy to lose sight of this principle in our busy practices.

Ultimately, the most effective way to address cultural differences in end-of-life decision making is through open and balanced communication. When health care workers are uncertain about how a patient or family perceives a situation, it is best simply to ask. Differences can frequently be negotiated easily. Many people now living in Western cultures already hold blended views of culture, illness, and death. The mere acknowledgment of such differences will usually lead to improved communication. In health care, we often assume that respect and acceptance of cultural diversity are givens, yet it is important for us to remember that despite our openness to other cultures, our attitudes toward end-of-life care are as much an effect of our cultural beliefs as they are of the many diverse cultures we see in practice. We must make a significant effort to raise our awareness and to alter our practices in this crucial area.
Resources

AT&T LanguageLine. The AT&T language bank does translation. These interpreters are not trained in medical interpretation. Further, because they are on the telephone, they do not have access to the visual information in the setting.
1–800–752–0093, extension 196
www.languageline.com


Xculture. This web site has a short and long glossary of medical terms in several languages.
www.xculture.org

References