

Chapter 10

Culture and End-of-Life Care

The ascendancy of medical science has changed clinical medicine dramatically over the last century and a half. That science has emphasized objectivity over subjectivity. As a result, clinicians' observations of disease have gained ever more prominence over patients' descriptions of illness. Scientifically based clinical knowledge almost alone has come to be perceived as "real," [1, 2] and ideal medical practice as objective and value-free, undistorted by subjective feelings or biases [1, 3]. This view has produced powerful consequences including the contemporary "evidence-based" medicine movement, which requires scientific data to justify patient care practices.

Patients, however, have recently rebelled against such "objective, scientific" medical care. They insist once more that health professionals treat them as persons with feelings, relationships, and unique life contexts, and not merely as bodies with diseases. Patients rightly perceive their illnesses as having both a physical aspect and important nonphysical psychological, social, and spiritual aspects. Patients want their health professionals to address all those aspects. This patients' rebellion has coalesced into movements variously called holistic care, humanistic care, hospice, and death with dignity. Health professionals have had to reawaken to the subjectivity of illness.

Culture influences powerfully those subjective, nonphysical aspects of illness [4–6]. Culture determines when the community considers a person ill, how that person communicates his or her distress [3], what benefits and burdens an illness confers, which treatments are considered worthwhile, and what the illness means for the patient and the community at large [6–10]. Culture assumes particular prominence during terminal illness when dramatic, life-saving medical rescue becomes impossible and all can only wait for death to come. At that point the terminal patient and his or her survivors look to culture to provide ways for coping with the mystery and fearsomeness of dying [2, 11, 12]. Attending health professionals must be able to recognize and respect culturally based perspectives at that time.

This chapter addresses such perspectives on the end of life. The chapter defines culture; discusses key concepts derived from it; points out some of the practical

implications for patient care in general and end-of-life care in particular; suggests ways health professionals might initially anticipate the cultural views of dying patients and their survivors; and describes LEARN, a method for eliciting people's culture-based views about illness and for negotiating treatment plans accordingly. The case of a seriously ill Mexican man, a former patient of mine, illustrates many of the points.

I distinguish the terms *ethnic group* and *race* from the outset. Ethnic group refers to an actual group of people who share values and beliefs and are, therefore, identifiable by themselves and others as "an ethnic group." [13, 14] Race, in contrast, refers to a grouping based on some vague perception of skin color [14, 15]. That grouping is merely social convention [16] and has no objective biological basis, not even a genetic one [3, 15, 17]. Some authors claim the concept of race arose in the eighteenth century to perpetuate biases about a human hierarchy grounded in European prejudices [5, 15, 16]. But the concept of race, I believe, has proven specious over time and should now be avoided [18]. For that reason I attribute cultures throughout this chapter to ethnic and other groups but not to races.

The Case

Senor B., an obese 63-year-old Mexican had lived 23 years as an undocumented alien in the USA. He presented one day as a new patient to my public clinic in South Texas. He spoke little English but told me through the clinic's Spanish interpreter that severe shoulder pain prevented him from working his usual jobs as a car mechanic and gardener. As a result he could no longer support his family. He also mentioned long-term heartburn, frequent thirst and urinations (and his suspicions of diabetes), and his erectile dysfunction. When I asked about herbal medications, Senor B. admitted to taking a friend's pills called *El Pajaro*, "The Bird," without relief. Senor B. smoked and drank "a little;" lived with his Mexican wife, also an undocumented alien; and still had a home in Mexico. He had no health insurance.

Over the next year I diagnosed severe shoulder tendonitis and uncontrolled diabetes, and treated Senor B. for both problems. Despite my repeated explanations otherwise, Senor B. steadfastly believed his oral diabetes medications allowed him to eat whatever he wanted. He gained weight. When the oral medications no longer controlled his diabetes, I recommended insulin. He refused, insisting that some of his diabetic friends became "addicted to insulin," went blind, and then died from it. All my efforts to persuade him to take insulin failed. So he continued the oral medications while his diabetic symptoms and blood glucoses worsened. He began to miss clinic appointments but always returned whenever I specifically called him to do so.

Senor B. then began to experience chest pressure and shortness of breath that limited his activity. The new symptoms suggested imminent risk for heart muscle damage, "a heart attack." The electrocardiogram showed prior damage, and the

urine and blood tests showed his kidney function was deteriorating. I recommended immediate hospitalization, a cardiology referral, and cardiac catheterization if necessary. I also explained to Senor B. that he would likely need dialysis soon, and that the kidney specialists could begin preparations for it during hospitalization for his heart problems. Senor B. refused all my recommendations including hospitalization. He said he trusted me “because you take an oath when you go to school,” but he did not trust “the government hospital.” He believed he would die during “the heart surgery.” He also feared the hospital would report his undocumented status to the police, and they would deport him.

I suggested Senor B. discuss his medical problems with his wife and return to the clinic as soon as possible with her afterwards. They returned a few days later. Senor B. refused all recommendations again. He insisted his fate was set, and no treatment could delay his death. He and his wife wanted to move back to the rural Mexican village where they had grown up and had their house. He wanted to die there.

I tried desperately to persuade him to take treatment at the public hospital instead. I pointed out that he could still enjoy some good life ahead but only if he got urgent treatment for his heart. That treatment was available in our hospital but surely not in any hospital in rural Mexico. I also promised that our hospital would not report him to the police or ask him to pay more than what he could easily afford. In fact, the hospital might forgive his entire bill. I finished by saying how sad I would be to see him forego the life-saving treatments we offered.

Senor B. thought for a moment and then replied, “I have to die from something, doctor. This is it. I want to live out my life back home with my family and friends.”

I tried to negotiate a compromise, asking Senor B. to talk at least with the heart and kidney specialists before making a final decision. He reluctantly agreed. I made quick appointments for him with the specialists and a follow-up appointment with me afterwards. Senor B. kept none of those appointments, and I never saw him again. I suppose he and his wife returned to their home village in Mexico, and he died there.

I do not know all the ways Senor B. and I differed over the care I offered. Our differing demographics surely suggested that cultural differences made us see it differently. Senor B. was a Spanish-speaking, undocumented immigrant Mexican, probably Catholic, and educated no more than through primary school. In contrast, I am an English-speaking American citizen, Protestant, and educated through medical school. Even more strongly than the demographic differences, our conflicting general views about medical care also suggested cultural differences. Senor B. distrusted medical science and refused many of the treatments I recommended because he apparently considered them burdensome, ineffective, or even harmful. And he feared “the government hospital” as being evil and serving itself before its patients. In contrast, I trusted medical science and the treatments I recommended, and I believed they offered Senor B. clear benefits. I also viewed the public hospital as beneficent and serving patients well.

Years later I still wonder whether a more knowledgeable, more skilled approach to the cultural differences in this life-or-death situation might have served Senor B.

better than the approach I took. If so, he might have accepted the life-saving treatments I offered, and gone on to live a longer, fulfilling life.

Key Concepts About Culture

Culture is the values, beliefs, and behaviors a distinct group of people shares, uses to interpret their life experiences, and transmits to others [2, 6, 9, 18]. Culture exists in all such human groups. No person or institution avoids it: none is culture-free [2]. In fact, culture comprises a vital part of the conceptual perspectives, or frameworks, we all use to find meaning in our lives [14]. Much of that meaning comes to us through culturally based symbols and rituals [16].

This definition of culture has an important implication: A culture is identified only by its characteristic core values, beliefs, and behaviors—not by demographic labels such as race, nationality, or ethnicity. Still, many researchers including me use such labels to refer to culture because they are convenient and colloquial (though imperfect) markers for it. While I use demographic labels to refer to specific cultures in this chapter, the reader must keep in mind that the true basis for identifying cultures is values, beliefs, and behaviors, not demographic labels.

As universal human experiences, illness and death are core cultural topics [5, 18]. So important are they that medical anthropology, a specialized field within general anthropology, has emerged to focus on them [10]. Work in that field has already identified four common misconceptions about culture, illness, death, and medicine.

Misconception Number 1: Mainstream, Scientifically Based Medicine Offers the Only Valid Forms of Healing

This view, a kind of “cultural imperialism,” rejects any culturally based approaches to healing that differ from mainstream, scientifically based medicine. Those alternative approaches range from acupuncture and chiropractic to folk medicines and spiritual healing rituals. Staunch cultural imperialists in medicine regard those approaches as ineffective at best and dangerous at worst [1]. Yet acupuncture, certain folk medicines, and other alternative healing techniques have recently proven beneficial in some situations. Cultural imperialism has unfortunately deprived mainstream medicine of the benefit of those approaches for many years.

Cultural imperialism contrasts starkly with the cultural humility Dr. Joseph A. Carrese, a doctor, anthropologist, and ethicist, models in his medical practice. His humility involves considering one’s own cultural views as provisional truths subject to change with new experiences. It also involves fostering an interest in learning about patients’ alternative cultural views and taking those views seriously when making

treatment plans for patients. I return to the cultural humility idea later in this chapter when I discuss the LEARN method for resolving cross-cultural conflicts.

Misconception Number 2: Culture Is Homogeneous

This view claims that all members of a culture always think the same way. The logic here is simplistic and incorrect [3]: Because members of a culture share the same core cultural values, beliefs, and behaviors, they must always reach the same conclusions on specific issues. Education about cultural competence may unwittingly promote this view [5]. Lectures and journal articles list the supposedly distinctive views of specific ethnic cultures. And some medical anthropologists even provide clinical consultations focused on general ethnic cultural characteristics that may influence a particular patient's views [19]. Learners may incorrectly conclude they can deduce a patient's views from knowing just, say, his or her ethnic background. Thus, every Euro-American (EA) will insist on making his or her own medical decisions, and every African American (AfA) will distrust the healthcare system [20]. Such well-intentioned efforts at cultural sensitization may simply teach overly rigid stereotypes. Individual variations can get lost, and an inflexible "cookbook" approach to cultural differences can develop [1, 7, 9]. In reality, though members of a culture share its specific core values, beliefs, and behaviors, they may differ on many other values, beliefs, and behaviors that can prove determinative on certain issues [14]. Many commentators thoroughly decry stereotypes, ethnic and others, for that reason [2, 5, 11, 21].

I, however, have a more balanced opinion about stereotypes. I believe they have benefits as well as hazards. I see two benefits in particular. Cultural stereotypes can alert health professionals to views other than their own. (Teaching of cultural competence must always instill respect for those other views within broad limits.) Stereotypes can also help health professionals initially approximate a particular patient's views based on ethnic group, gender, or other characteristics linked to culture. While avoiding overgeneralizing, health professionals can use stereotypes as a place to start, but never to end, explorations of an individual patient's views. Health professionals must always resist the temptation to pigeonhole a patient too quickly or too rigidly and be willing to entertain his or her variations on a general cultural pattern [3, 6, 9, 22].

Misconception Number 3: Culture Is Static

According to this view, whatever core values, beliefs, and behaviors have characterized a culture before will always characterize that culture. It will never change. One form of this attitude is essentialism, the idea that a culture's core values,

beliefs, and behaviors are innate in its members and hence do not change [16, 23]. But cultures obviously *do* change in response to changing circumstances. The Industrial Revolution, the American Civil War, urbanization, growing affluence, and the Internet all changed American core cultural views about self-worth, education, communication, freedom, personal rights, and communal obligations. And in medicine the tragic AIDS epidemic produced similarly dramatic cultural changes in attitudes about professional obligations and patient rights. Such powerful external events may force cultures to change in response [16].

Misconception Number 4: All Differences Among People from Different Cultures Are Cultural Differences

This view attributes interpersonal differences to culture first and foremost. We often assume that, when cultures differ, they cause our differences. But different life experiences, education, logic, and communications can also cause differences among people from different cultures [24].

An actual case illustrates differences that initially seemed cultural but were not. EA doctors hospitalized a stuporous, elderly AfA woman with an acute pneumonia [25]. Believing she was imminently dying, the doctors asked her family for permission not to resuscitate, intubate, or ventilate her. The family refused to give that permission. The doctors initially suspected cultural differences between EA tendencies to stop life support early and AfA tendencies to continue it late into a terminal illness. Extensive negotiations eventually revealed another basis for the disagreement. The woman had been treated for a similar pneumonia in the past. Her doctors at the time had told the family she would die. Yet she had surprised everyone by surviving. When facing a similar situation again, the family reasoned that, if the doctors had predicted incorrectly before, they could be predicting incorrectly again. The family refused permission to withhold life support for the second pneumonia because they thought the patient might still survive and they wanted to give her every chance to do so. The patient received full treatment (including mechanical ventilation) and survived to return home again. Thus, not culture but logic based on a similar prior experience prompted that family's second refusal to withhold life-support treatment all along.

Sources for Diversity Within Cultures

I believe diversity within cultures comes from three main sources—idiosyncrasies, subcultures, and variations in acculturation. The reader should note these sources are not mutually exclusive: Some causes for diversity may be categorized as originating in more than one source.

Idiosyncrasies are ideas a person shares with only a few, if any, other people. A patient treated on hemodialysis for long-standing kidney failure, for example, suddenly refuses further dialyses when he learns the dialysate baths contain potassium. He claims to have a “potassium allergy,” a biological impossibility. The patient says exposure to potassium in the baths will cause a severe reaction and he will die. This belief may have arisen from the patient’s peculiar misunderstanding about high blood potassium concentrations in kidney failure. A consulting psychiatrist identifies the man’s idiosyncratic belief about a “potassium allergy” as an isolated fixed delusion. The man’s doctors eventually convince him the baths are safe, and he resumes dialysis.

Subcultures are small groups defined by narrowly shared views within a larger culture defined by other, more widely shared views. Gender-specific views, for example, make the genders distinct subcultures within any larger ethnic culture. In this light one study suggests that men and women view the American healthcare system differently: Unlike men, many women in each of three ethnic groups—EAs, AfAs, and Mexican Americans (MAs)—believe the system empowers patients, benefits them, and respects their wishes [26]. Other narrowly shared views create additional, often partially overlapping subcultures, say, roughly according to age, education, vocation, or location of residence. Thus, every person belongs to many cultures simultaneously [7, 14].

Acculturation is the process by which a person from one culture assumes the values, beliefs, and behaviors of another culture over time [14, 27]. Acculturation usually refers to immigrants who settle in a new dominant ethnic culture. But the term can apply to *any* socialization from one culture to another. Medical school education illustrates acculturation without immigration: Medical students acculturate over time from the general nonmedical lay culture to the professional doctor culture [18]. A contrasting term, *assimilation*, refers to maintaining one’s original cultural views while living in a new dominant culture.

Acculturation proceeds along multiple cognitive and behavioral dimensions at once, prompting anthropologists to track it variously through self-identification with either the former or new dominant culture; language usage; and preservation of former traditions [27, 28], food preferences, and social roles and duties [29]. Despite these multiple dimensions I imagine acculturation as moving along one composite continuum between the opposite poles of mere assimilation and full acculturation [9]. An immigrant starts life in a new dominant ethnic culture at the assimilation pole and moves some distance with time toward the full acculturation pole. How far he or she moves depends on how much of the dominant ethnic culture he or she adopts. The typical immigrant probably never achieves full acculturation.

A recent study supports such an acculturation process. Researchers studying popular views about breast and cervical cancer interviewed three groups of women in Los Angeles: Latinas, women who were born in Mexico or El Salvador; Chicanas, women who had Mexican ancestry but were born in the USA; and EAs, who had no Latin American ancestry and were born in the USA. Responses followed a distinct progression from an “Immigrant Model,” reflecting the assimilation

pole, to the “Biomedical Model,” reflecting the full acculturation pole. The Immigrant Model, embraced wholly by the Latinas and partly by the Chicanas, attributed the cancers to direct physical trauma and generally unhealthy behaviors (such as smoking, promiscuity, or poor hygiene). In contrast, the Biomedical Model, embraced partly by the Chicanas and wholly by the EAs, attributed the cancers largely to recognized epidemiologic risk factors (such as genetics, family history, and exposure to certain sexually transmitted viruses) [30].

Health professionals who attend dying patients from homelands overseas may sometimes find an acculturation assessment helpful. One study provides a template for such an assessment. Researchers interviewed first, second, and third generations of MAs and Japanese Americans [28]. The first generations were the original immigrants, born in their homelands, and mostly elderly. The second and third generations were born in the USA and mostly middle-aged or young, respectively. The researchers assessed acculturation along three dimensions: the balance of knowledge between the homeland popular culture and American popular culture (“cultural knowledge”); the cultural orientation of everyday activities through language, customs, family structure, and gender roles (“cultural orientation in everyday activities”); and “ethnic group self-identification.”

Table 10.1 shows how the three generations differed. The first generations knew their homeland popular cultures better than American popular culture; had general homeland orientations in everyday activities; and claimed both homeland *and* American identifications. The second generations knew both their homeland and American popular cultures; had mixed homeland and American orientations in everyday activities; and split between either homeland *or* American identification. The third generations knew American popular culture better than their homeland popular cultures; split between homeland and American orientations in everyday activities; and split between either homeland *or* American identification. In summary, knowledge and orientation in everyday activities became progressively more acculturated to American culture with successive generations. But ethnic self-identification began as both homeland *and* American in the first generations and split into primarily homeland *or* American in the second and third generations [28].

How might health professionals easily and quickly assess acculturation in patients and family members? Using the same dimensions as in Table 10.1, Table 10.2 lists specific variables by which other researchers have assessed acculturation in these same ethnic groups [29, 31]. The variables suggest three simple, practical, and valid questions health professionals (HPs) might ask: [3] What language do you prefer to use (for immigrants from non-English-speaking homelands)? In which country were you, your parents, and your grandparents born? And which ethnic group do you consider yourself a member of? Though conceptually important, the psychological aspects of nonacculturation (such as keeping homeland values, maintaining connections to the homeland community, and feeling supported by that community) add little *discriminating* power to the three basic questions [29].

Table 10.1 Changes in acculturation over three generations of new immigrants to the United States

Dimensions of acculturation	Generation		
	First	Second	Third
Cultural knowledge	Homeland	Homeland <i>and</i> American	American
Cultural orientation in everyday activities	Homeland ^a	Homeland <i>and</i> American	American
Ethnic-group self-identification	Homeland <i>and</i> American	Homeland <i>or</i> American ^b	Homeland <i>or</i> American ^b

Data from Clark et al. [28]

^aFor cultural orientation in everyday activities, the first generation divides into two distinct populations: one with a high dominant homeland orientation and another with a lower but still dominant homeland orientation.

^bFor ethnic-group self-identification the second and third generations divide into two distinct populations each: one with a dominant homeland self-identification and the other with a dominant American self-identification.

The Case

The obvious demographic differences between Senor B. and me immediately revealed our different ethnic origins. In addition, though I did not realize it at the time, my initial clinical history largely answered the questions for assessing the more subtle issue of Senor B.'s acculturation to American society. That history revealed he had been born in Mexico, spoke only Spanish, and identified himself as Mexican. A full assessment lacked only confirmation that his parents and grandparents had also been born in Mexico. My history supplied other supporting information on the point, too. Senor B.'s speaking only Spanish and his care to avoid detection as an undocumented alien surely made him restrict his close contacts to other Mexican immigrants. And his distress about not being able to support his family and his apparently not having disclosed his health problems to his wife until very late suggested he followed the Mexican family patriarch's traditional bread-winning and protective roles. I should have realized early on that, despite having lived many years in the USA, Senor B. had embraced few of its mores and had not moved far from the assimilation pole along the assimilation-acculturation continuum. He had little acculturation to American culture. Only with more time caring for him could I assess his acculturation to mainstream medicine.

Culture and Medical Care in General

Having laid out basic concepts of culture, I now discuss in the next two sections some perspectives on culture and medicine. This first section addresses general perspectives related to illness and treatment, clinician-patient power differences; and family roles and responsibilities. The second section addresses more specific

Table 10.2 Assessing acculturation in research studies

Dimensions of acculturation [28] ^a	Definitions [28] ^a	Mexican-American examples [27, 31]	Japanese-American examples [29]
Cultural knowledge	Relative familiarity with homeland’s popular culture over US popular culture. Reflects the balance of ethnic cultural influences.	<ul style="list-style-type: none"> • Birthplaces of parents and grandparents: Mexico versus the USA^b • Knowledge of Mexico and US history, customs, and holidays • Most friends, neighbors, and close coworkers come from Mexico versus the USA. 	<ul style="list-style-type: none"> • Birthplaces of self, parents, and grandparents: Japan versus the USA • Place where raised: Japan versus the USA
Cultural orientation in everyday activities	Kinds and degrees of activities that reflect homeland or US culture	<ul style="list-style-type: none"> • Language preference: Spanish or English • Adherence to traditional Mexican or American family structure and gender roles 	<ul style="list-style-type: none"> • Language preference: Japanese or English
Ethnic self-identification	Identification as homeland or US ethnicity, that is, sense of belonging to homeland or US society	<ul style="list-style-type: none"> • Self-identification as Mexican, Mexican American, or American 	<ul style="list-style-type: none"> • Self-identification as Japanese, Japanese American, or American

^aClark et al. originally considered “ethnic identity” the same as acculturation, but I consider them different. I believe “ethnic identity” is only a part of acculturation: Acculturation comprises a subjective component—“ethnic identity,” “ethnicity,” or ethnic self-identification—and an objective component—ethnic group membership based on observed behaviors. The last row of the table addresses the subjective component; the first two rows, the objective one. I use *acculturation* here in its sense covering both components. In addition, Clark et al. labeled what I call *cultural knowledge*, *cultural orientation in everyday activities*, and *ethnic self-identification* as “acculturative balance scale,” “traditional orientation,” and “face,” respectively. I changed the Clark et al. labels to simplify them and to reflect the definition of acculturation in the text.

^bHazuda et al. also used the father’s surname and the mother’s maiden surname in their algorithm for differentiating Mexican Americans from other US ethnic groups.

perspectives related to end-of-life care including communication styles, advance directives (ADs), and informed consent in terminal illness. This second section presents several contrasts among major American ethnic cultures.

Illness and Treatment

Before modern medicine many cultures attributed illness to disharmonies inside and outside the body [8, 32]. Those disharmonies arose supposedly from imbalances of internal “humors” or from bodily attacks by external forces such as evil spirits. Illnesses occurred so frequently that they seemed like the body’s natural state, and suffering seemed an inherent part of living. Some cultures still hold that belief today.

Twentieth-century medical science, however, radically changed many people’s ideas about illness and treatment. Westerners in particular rethought their ideas about disease causation, treatment methods, and expectations for medical outcomes. The new medical science discovered germs, toxins, abnormal genes, anatomic defects, over- or underactive immune system responses, and other physical causes for disease. Westerners soon dropped many old ideas about nonphysical causes of illness including as a punishment from God or as a hexing by evil people or spirits.

People’s attitudes about treatment changed, too. The old treatments addressing disharmonies had achieved little success [10]. Though the ill had sought treatment and hoped for benefits, they had rarely gotten them. People reacted by developing a pessimistic, fatalistic attitude toward diseases and their treatments. Some diseases such as cancer gave a quick “death sentence,” [24, 33] which the patient had no hope of reversing [33]. Cancer relentlessly eroded the patient’s physical powers, personality, and spirit until he or she died a typical cancer death [34]. Other diseases such as rheumatoid arthritis caused a progressive, crippling illness that defied treatment and lasted years. For both kinds of diseases, families administered at home the few, largely ineffective treatments available.

Then the new medical science introduced treatments that actually affected the course of diseases beneficially, sometimes dramatically. The revolutionary treatments included antibiotics; cancer chemotherapies; mechanized life support and intensive care; organ replacement therapies; and image-guided, minimally invasive surgical procedures. So many cures followed that people began to expect them. The treatment successes reinforced many Western cultural beliefs about the power of medical science, the duty to fight disease actively, the need to exercise self-discipline in pursuing disease prevention and treatment, and the importance of maintaining hopefulness in the face of disease.

The treatment successes also suggested to Westerners that God wishes good health for His people, that it is the body’s natural state, and that good health can be effected by contemporary mainstream medicine. Diseases became problems to be solved.

Accordingly, Westerners abandoned their old fatalistic views. People began to see illnesses as temporary and expected the associated suffering to last only the short time needed for medicine's cures to take effect.

Clinician–Patient Power Differences

All clinician–patient relationships involve power differences [16] arising from the inherent differences in technical knowledge and from the frequent differences in personal health. The clinician has greater power based on greater technical knowledge and better health; the patient, less power based on less technical knowledge and poorer health. Ethnic and other cultural differences between clinician and patient only magnify those power differences.

Yet clinicians usually do not see those power differences. Two reasons may explain why. First, clinicians do not question the typical clinician–patient relationship as it is because medical practice largely mirrors the dominant, surrounding Western culture. Clinicians simply accept that relationship with its intrinsic power differences as the best or only way the relationship can be [8]. Second, clinicians like others with advantage often do not perceive their advantage. Clinicians, for example, usually underestimate their power to influence people and events inside and outside of medicine [3]. Vulnerable patients, of course, sense clinicians' power and patients' own relative powerlessness. As a result patients—especially minority patients—may not fully trust the healthcare system to serve their best interests. Because the clinician–patient power differences are real and important, clinicians must recognize them and manage them responsibly.

Family Roles and Responsibilities

Unlike EA culture, which champions the individual's autonomous decisions for him- or herself, non-EA cultures typically champion the family's collective decisions on behalf of the individual family member. Such family involvement provides the family member with reassuring security, dependability, and solidarity in unfamiliar or threatening situations [8]. In medical situations, for example, non-EA families take quite seriously their duties to keep vigil at the hospital, to monitor the patients' care, and to serve as liaisons with the clinicians [8, 10]. These families also provide some of the patients' direct, hands-on care in the hospital and most of that care at home [6]. For that reason many ethnic minority patients entrust their welfare completely to their families out of the belief, as one patient said, "My family will watch out for me when I need them to." [35].

Culture and End-of-Life Care Communication

Clinicians' bedside communications generally leave many American patients—particularly ethnic minorities—dissatisfied. For example, Hispanic Americans (HAs) and Asian Americans (AsAs) believe doctors do not spend enough time with them, listen to them, or consult them adequately in decisions about care [36]. These groups think they would receive better communications and care if they came from another ethnic group, undoubtedly EAs [36, 37]. HAs, AsAs, and AfAs also believe that either their poor English fluency or different lifestyles cause doctors to disrespect them [36]. These views suggest American clinicians need to improve their overall communications skills with minorities.

Those skills play an especially important role in end-of-life care. Many dying patients and their survivors want to tell health professionals their feelings about the dying experience, and culture fundamentally influences when and how people express those feelings. Health professionals must be prepared to listen and respond in culturally appropriate ways. This next section aims to help health professionals do so. It focuses on three important end-of-life communication topics that culture affects: communication styles, advance directives, and informed consent in terminal illness.

Communication Styles

Culturally determined communication styles range from the high-verbal, low-context to the low-verbal, high-context [2]. The high-verbal, low-context styles communicate most of their meaning by what is actually said or written and relatively little by the context of facial expressions, body postures, symbols, and rituals. Western cultures typically use these communication styles. In contrast, the low-verbal, high-context styles communicate relatively little meaning by what is said or written and most by context. Eastern cultures typically use those communication styles [6].

Matching communication styles between health professionals and patients or survivors assumes considerable importance as death nears. I suggest health professionals identify the communication styles dying patients and their survivors prefer, and try to use roughly those styles with them. Overall, the low-verbal, high-context styles fit end-of-life situations best [2] because they give people conceptual and emotional “space” to interpret the death in their own ways, to develop coping skills, and to reformulate hopes for the future [6]. Health professionals might, therefore, consciously shade their communication styles toward those low-verbal, high-context styles at such times.

Of course, all end-of-life situations involve ambiguities of meaning, which often emerge in the silences. Westerners used to high-verbal, low-context communication typically tolerate poorly the silences and their accompanying ambiguities.

Westerners prefer definitive diagnoses, clear disclosures, explicit treatment plans, and verbal interaction [37]. Nonetheless, health professionals should respect the silences and their ambiguities by resisting the impulse to fill the silences with talk. People need to make their own sense out of the ambiguities. Health professionals should concentrate instead on nonverbal gestures of caring. A hand on the shoulder or just a quiet, supportive presence may communicate the greatest comfort to dying patients and their survivors.

Advance Directives

As Chap. 6 explains, advance directives are documents that permit people to prepare for future mental incapacity by choosing beforehand the treatments and proxy decision-makers they want under those circumstances. Advance directives are grounded firmly in EA values (e.g., personal freedom, self-reliance, and orientation to the future) and beliefs (e.g., the future is not predetermined; one can make choices affecting it; and one should take responsibility for acting on those choices). In fact, one author calls advance directives an “artifact” of EA culture [22]. Advance directives may actually seem foreign, even threatening, to people who do not share those underlying EA values and beliefs. Perhaps for that reason AfAs, AsAs, and HAs are less likely than EAs to know about advance directives or to sign them [8, 12, 38, 39]. Furthermore, many from these minorities reject advance directives out of fear they may prompt discriminatory, adverse practices such as withdrawing life support prematurely.

Informed Consent in Terminal Illness

Medicine’s informed consent standard may be another “artifact” of EA culture and its emphasis on personal autonomy [8]. This standard encourages disclosure of terminal diagnoses to patients and involvement of patients in planning end-of-life care (to the extent they wish). But many non-EA cultures consider such disclosure inhumane for causing patients distress, extinguishing hope, and even causing death to occur too soon [12]. These cultures may obligate families rather than patients to hear terminal diagnoses and to make subsequent care plans. One study in particular showed that more Korean Americans and MAs than either EAs or even AfAs want *not* to know about future metastatic cancer diagnoses or terminal prognoses and want to allow their families to make life support decisions for them under such circumstances [24]. Although I ordinarily try to allow great cultural leeway in end-of-life matters, I actively discourage withholding terminal diagnoses from *any* patients. I believe patients learn their diagnoses from context anyway, and most patients and survivors benefit from talking openly about the death to come.

Specific Ethnic Group Cultures and End-of-Life Care

I imagine American society as a tiered hierarchy of cultures. At the base sits American core culture. Its values include the preciousness of human life, the equal worth of human beings, and respect for the dead; [40] its beliefs include the existence of an all-powerful God or some other supreme focus for life; the inevitability of human death; and the existence of an afterlife [41]. Virtually all Americans hold those values and beliefs. Atop that core base sit the specific American ethnic group subcultures. They contain not only all the American core values and beliefs but also their own distinctive ones. Atop each ethnic group subculture sit even finer subcultures corresponding roughly to gender, age, or other characteristics.

This section describes the most distinctive end-of-life values and beliefs of that middle tier of ethnic group subcultures. I focus on four major ones—Euro-Americans (EAs), African Americans (AfAs), Asian Americans (AsAs), and Mexican Americans (MAs) (Table 10.3). An additional section of text but not of

Table 10.3 Contrasting common end-of-life values and beliefs among four major American ethnic groups

Value or belief	Euro-Americans (EAs)	African Americans (AfAs)	Asian Americans (AsAs)	Mexican Americans (MAs)
Person’s control over the future	High [5, 42] ^a	Moderate [42, 44, 59]	NR ^b	Low[34, 59, 95]
Desire for medical information	High [24]	High [24]	Low [24]	Low [24]
Main medical decision-maker (s)	Individual patient [24, 42, 43]	God and individual patient [5, 24, 44, 47]	Family [20, 24]	God, clinician, and family [24, 45, 59]
Spirituality	Low-moderate [44, 54]	High [44–46, 54]	NR	NR
Purpose of suffering	To regain health and function [20, 45]	To test faith and grow spiritually [45, 55]	To promote family harmony and maximize longevity [8, 20, 22]	To test faith [45]
Preference for life support	Low [20, 24, 38, 42, 45]	High [20, 38, 42–44, 54, 55]	High [8, 20, 22, 54]	Moderate to high [20]
Tolerance for disability	Low [45, 56]	High [45, 56]	NR	NR
Preference for hospice	High [5]	Low [5, 55, 56]	Low [3]	Low [3]

^aSpecific references for data occur in brackets.

^bNR = Not reported.

the table addresses Native Americans (NAs). A subsequent section describes distinctive end-of-life values and beliefs of men and women and of young and old across the ethnic groups. I mention here only those values and beliefs addressed in the professional or academic literatures.

Although the text and table make unqualified statements (e.g., “EAs value medical information.” or “MAs believe suffering tests one’s faith.”), the reader must not understand them as applying rigidly to everyone in a particular subculture under all circumstances. Many values or beliefs permit varied interpretations depending on circumstances. The reader, therefore, must avoid overgeneralizations and rigid stereotypes. The values and beliefs I mention here provide merely a starting place for health professionals to negotiate individualized care for patients.

I discuss EA values and beliefs first because EAs dominate contemporary American life by their numbers and influence. I then go on to discuss the comparable values and beliefs of the other three American ethnic groups, using the EAs’ values and beliefs as an implicit foil.

Euro-Americans

Core Euro-American (EA) culture contains at least four beliefs relevant to end-of-life care. One belief, which I mentioned earlier, is that people *can* usually control their lives [16, 42] and should do so. (But one exception exists: An all-powerful God intervenes occasionally to override people’s life plans for themselves.) Another belief is that people should be allowed considerable leeway, short of excessive interference with others, to make and implement their life plans [5, 24]. Yet another belief is that people’s fundamental identities derive more from themselves as individuals than from their membership in families, ethnic groups, social classes, or other demographic groups. And still another belief, undergirded by the values of self-reliance and personal productivity, is that individuals earn self-worth through their deeds.

How might these beliefs affect EA wishes about end-of-life care? As patients, many EAs want as much information as possible about their illnesses even when that information is bad (Table 10.3). Furthermore, many EAs want to make as many of their own end-of-life decisions as possible. Accordingly, they more than other American ethnic groups try to control the end of their lives by signing ADs [42] to ensure the dying experiences they want and to relieve their families of difficult end-of-life decisions [20]. EAs are also most likely to discuss their personal treatment wishes beforehand with their clinicians [42] and families [43] and to expect those wishes to be followed in the end-of-life crisis.

In addition, among these four ethnic groups EAs take the most scientific, least spiritual perspective on end-of-life care [44, 45]. They tolerate suffering only for a reasonable chance to recover health and function, especially the ability to do self-care [20, 45]. They also hold the least favorable attitudes about life support and want to stop it sooner than do the other ethnic groups [20, 42, 45]. Thus, when

treatment offers little chance for recovery to high function, EAs often exert their personal decision-making authority to refuse life support for themselves. Many want hospice care instead.

African Americans

Core African American (AfA) culture contains at least five distinct religious or spiritual beliefs relevant to end-of-life care [45]. One belief is that an all-powerful God actively controls human events [5, 44, 46, 47], has a plan for each person, and intends it for good [46]. Another belief is that life always presents hardships: illness is one [44]. The individual may never consciously reconcile the apparent inconsistency between these two beliefs: an all-powerful God's good will towards people on the one hand and their hardships (including illnesses) on the other. The individual may simply have to accept God's plan—the good and the bad together—without ever fully understanding it [46].

The next two beliefs, however, may provide some reconciliation by asserting unexpected benefits from illness or death. One of these beliefs is that, while sorely testing one's faith [48], the suffering that accompanies illness provides an opportunity for spiritual growth, [45], a source of hope, and important lessons in coping [44, 46, 49]. The other belief is that dying and death are a part of God's plan for everyone's good. The dying process ennobles a person as much as it disempowers him or her [33]. And death itself can sometimes appear to the dying person like a "welcome friend," a "going home," [44, 48] or the start of a better existence in the afterlife [46]. Still another belief relevant to end-of-life care is that clinicians serve as God's instruments of that care [44], but God alone ultimately controls the outcome of illness. [45]. He sometimes even saves lives unexpectedly through miracles [44, 47]. As an AfA woman explained in one study, "God has priority over living ... (He can always) heal you." [5].

Evidence conflicts over whether core AfA culture also includes distrust for the American healthcare system [42, 50]. One recent study suggests AfAs believe the system generally "controls treatment" and "does not serve patients well." [39] In addition, some commentaries cite the many mistreatments of AfAs in the past as reasons why they *should* distrust the system: the involuntary medical experimentation on AfA slaves in the 1800s, the denial of curative antibiotics to AfA men during the Tuskegee Syphilis Study of the 1920s to the 1970s, the coerced sterilization of Southern AfA women in the mid-twentieth century, the federal government's sickle cell screenings and subsequent discrimination against test-positive AfAs in the 1970s, the suspicions about AIDS as a plot to control AfA reproduction in the 1980s [51, 52], and the stigmatization of AfA men in the 1990s due to a purported aggression gene. Present-day poverty, disproportionate incarcerations, and other ongoing social disadvantages of American minorities perpetuate the idea that America cares little about its AfAs and other minorities [52]. Such

considerations convince many AfAs, so some commentators claim, that “racism (still) pervades American institutions” including the American healthcare system [51–53].

Nonetheless, other evidence contradicts that distressing view about AfA distrust of the American healthcare system. Some studies suggest AfAs *do actually trust* their clinicians based on perceptions of the clinicians’ competence [45] and compassion [25, 49]. And, of course, AfAs still seek out clinicians’ care. AfAs may, therefore, distrust the American healthcare system as a whole but trust their own particular doctors and nurses.

Gender differences complicate the issue further. One study suggests AfA men feel disempowered by the American healthcare system, but AfA women feel empowered by it. And, overall, AfA men fear harm from it, but AfA women expect benefit [26]. Conclusions about distrust of the American healthcare system, therefore, may really apply only to AfA men, not to AfA women.

In light of this confusing state of research and commentary, one expert’s conclusion appears reasonable: Suspicions of AfA distrust are speculative and “largely unsubstantiated,” but American medicine must still guard against even isolated instances of “insensitivity, neglect, injustice, or racism.” [48].

Whatever distrust actually exists, AfAs appear to want considerable medical information from their attending clinicians (Table 10.3). AfAs also appear to use their generally deep spirituality to cope with serious illness. They interpret the suffering associated with illness as testing their faith and providing opportunities for spiritual growth. Furthermore, AfAs believe that both God and they have the power to make decisions affecting the course of illness. In addition, AfAs have strong wishes favoring life-saving treatment. Several reasons may explain those wishes. Religiously based sanctity-of-life values [48] may make life especially precious to AfAs. They may also believe they can (and should) live longer than other people [49]. And suspicions about ongoing discriminatory treatment practices may make AfAs especially wary about withdrawing life support prematurely [5, 44, 50, 54].

AfAs’ disposition favoring life-sustaining treatments powerfully influences their views about many end-of-life matters. AfAs often reject advance care planning as fostering hopelessness [44], as decreasing a person’s decision-making authority, and as diminishing his or her subsequent quality of care [42]. They also accept far greater disability and suffering to stay alive than do, say, EAs [55]. Furthermore, AfAs usually insist on aggressive life support and reject do-not-resuscitate (DNR) orders until late in a terminal illness [38, 42, 56]. And they consider talk about futile life support, hospice care, or costs of terminal care during the life-threatening crisis as devaluing life [54]. They completely reject suicide [49].

Asian Americans

Of the four American ethnic groups highlighted here, Asian Americans (AsAs) have the smallest professional medical literature on culture, health care, and end of

life. The term *AsAs*, of course, encompasses many different nationalities, ethnic groups, and tribes, but I focus on the largest and most researched—ethnic Koreans, Japanese, and Chinese.

All these *AsA* core cultures emphasize the subordination of the individual's welfare to the group's [22]. The most important group is always the family [8], and all members have a responsibility for promoting the family's cohesion and harmony [56]. For instance, filial piety—faithfulness in duty to one's parents and other family elders—requires the young and healthy to care for the old and infirm [11]. Therefore, the dying process with its care rituals becomes more a relational experience for the whole family than just a physiologic one for the individual patient [8].

Other strong *AsA* traditions govern the dying process, too (Table 10.3) [12]. *AsA* clinicians and family members, for example, spare the patient from hearing a terminal prognosis due to the belief that merely mentioning death extinguishes the patient's hope for the future and precipitates death [5, 8, 22, 57]. Clinicians and family members sometimes even try to bolster the dying patient's spirits by making intentionally overly optimistic statements about prognosis. At the same time filial piety requires the adult children—particularly the eldest son [56]—to hear the true terminal prognosis and to make key life-support decisions on the elderly parent's behalf [24, 57]. The children often opt to keep the parent alive as long as possible. Ironically, terminal *AsA* parents may not want life support but accept it in deference to the obligation the children feel to give it [8, 12, 20, 56]. The power of this obligation and the perceived unpredictability of death discourage *AsAs* from performing advance care planning beforehand [57]. They may also reject home hospice care out of the belief that a dead person's spirit haunts the place where that person dies [5, 8].

Differences between the Western, typically high-verbal, low-context communication style, and the Eastern, typically low-verbal, high-context communication style, [2] complicate Western clinicians' end-of-life care for *AsA* patients. In such situations Western clinicians must consciously observe patients and families for meaningful nonverbal interactions. Trained interpreters can help. Still, misunderstandings will occur and may account for some of *AsAs*' dissatisfaction with their Western clinicians [58].

Mexican Americans

Hispanic or Latin Americans include people from typically Spanish- or Portuguese-speaking American countries. While each Latin ethnic group has its distinguishing cultural characteristics, I focus here on Mexican-Americans (MAs) because they are the largest Latin-American ethnic group in the USA and because Senor B. was one.

Core MA culture contains several key beliefs that influence views about end-of-life care. One belief is *familismo*, the idea that family plays the central role

in one's sense of self and duty. Family forms the foundation for an MA's personal identity [59]. Therefore, as with AsA culture, MA culture expects each person to fulfill his or her duties within the family so that it can function as a cohesive, integrated unit. The resulting interdependence means the incapacitation of one family member, say, through serious illness, affects the whole family. Perhaps for that reason MA families together—not patients alone—often make major treatment decisions [24]. The senior men take the formal lead in those decisions, but the senior women wield great influence behind the scenes [56, 59].

Another belief asserts that powerful external forces control much of one's life, leaving relatively little control to the individual. Those forces include God, human authorities (such as governments, healthcare institutions, doctors, and other health professionals), and fate [34, 59]. As with AfAs and perhaps other ethnic groups, MAs believe a benevolent, all-powerful God can (and sometimes does) effect miraculous cures. This belief obviously inspires hope in the darkest life-threatening crises. MAs also believe that three specific values should govern relationships with powerful others. *Simpatia* involves maintaining harmony by avoiding unpleasant confrontations with others in general [59], *personalismo* involves keeping up a formal friendliness with perceived authorities, and *respeto* involves showing due respect to such authorities [56, 59]. Individual professional authorities (such as doctors and other health professionals) earn MA respect for their education; competence; [45] and selfless, trustworthy service to people in need. That respect prompts MA patients to defer many treatment decisions automatically to their attending clinicians [20]. In contrast, impersonal institutional authorities such as governments or hospitals command MA respect out of fear. MAs may fear institutional discrimination in health care due to their poor English, uninsured status, or difficulty in navigating the delivery system. Undocumented MA aliens, of course, always fear discovery and deportation by the government. MAs naturally respond to such fears with a general wariness towards institutions. Another possible external force in one's life is fate. Many MAs believe in *fatalismo*—the idea that fate has sealed their personal futures and fighting to change them is useless. In addition, one's personal future invariably involves suffering, and MAs must accept it when it comes. Yet another key MA belief mirrors a key AfA faith-based belief: that serious, life-threatening illness not only tests one's faith but also offers opportunities for spiritual growth [45].

These beliefs may directly affect MA preferences about end-of-life care in several ways (Table 10.3). Fatalismo may make expressing end-of-life care wishes beforehand seem pointless. MAs may expect little control over the end of life because they have sensed so little control in prior life. Advance care planning and informed consent may, therefore, bewilder these patients by trying to empower them at what seems to them an especially powerless moment [39]. MAs may also see those procedures as inviting institutional discrimination through intentional misapplication of patients' wishes. In addition, some MAs may *not want* to know their terminal diagnoses. These patients may believe knowing such diagnoses is the responsibility of other family members alone. And some family members may agree, asking clinicians to disclose serious diagnoses only to them and to allow

them to make all important treatment decisions without patients' knowledge of diagnoses [24]. Clinicians, therefore, should ask MA patients before the crises the exact role they want for themselves and their families in knowing serious diagnoses and making treatment decisions. The high cohesiveness of MA families suggests that, if patients prefer collective family decisions, clinicians try to involve as many immediate family members as possible in making them [45]. Collective decisions themselves, of course, can cause problems. Disagreements may arise over the "right" decisions for the patient, and family members may regret their decisions later or blame each other if the illnesses go badly.

These key cultural beliefs may also explain MAs' tendency to continue life support until late in a terminal illness and to avoid hospice [20]. MAs' acceptance of life with inherent suffering [45] may promote this tendency. The suffering of earlier life may simply appear to transform naturally into the suffering of terminal illness. In addition, MAs may sometimes misinterpret a clinician's offer of life support as a recommendation for it. Such an offer may, therefore, unintentionally communicate false hopefulness to MA patients and families. MAs may also feel obligated to accept the offer just to try to maintain harmony with the clinician and to show him or her respect.

Two gender-specific cultural beliefs may also influence end-of-life care for MAs. One is *machismo*, or MA male identity, that requires a man to care for his family in two ways. The MA man must earn a living for his family. This breadwinning duty forms a core part of the man's self-respect. Thus, whenever the MA man becomes too ill to earn a living, his self-respect suffers. The MA man must also protect his family from unnecessary distress and difficult decisions. He does so in part by not discussing his medical problems with the family and by deciding about his end-of-life care on his own. The one other influential gender-specific belief is the women's strong sense of duty to care directly for dying family members. This belief may cause MA women to refuse hospice because it makes them feel they have not fulfilled their care-giving duty to the dying and thereby failed the whole family [6].

The Case

I realize some years later now that Senor B. took a typical MA man's view of his illnesses. He confronted them seriously only when he could no longer perform his primary cultural role as the family's breadwinner. That inability to support his family must have shamed him into coming to "the government hospital," an institution he deeply distrusted for the possibility it might initiate deportation proceedings against him. In addition, even when coming to the clinic, Senor B. always took a fatalistic attitude toward his illnesses. They would run their course, he thought, regardless of treatment. Furthermore, Senor B. appeared to shield his wife from the seriousness of his illnesses by not discussing them with her until that last clinic visit. Only then did Senora B. learn the gravity of his condition. At that point we three discussed the potentially life-threatening nature of Senor B.'s illnesses and the possible treatments

for them. Senora B. was surprised at what she heard but appeared to have little say in what to do: Senor B. just declared that he did not want the treatments, that he and his wife would move back to Mexico, and that he would die there.

Unlike Senor B. I took a typical EA view toward his illnesses. I believed he could control much about them and about the rest of his future. I urged him to take that control by at least trying my treatments. All along I also urged him to bring Senora B. to clinic visits and to keep her fully informed about his illnesses and treatment.

Despite our different culturally based views about his illnesses, Senor B. and I did build a solid respect for each other. Senor B. respected me for my medical education and listened carefully to my advice though he rarely followed it. He also respected me enough to return (except for his last appointment) whenever I asked him to. And he trusted me. His trust arose from knowing, as he explained, that “you (doctors) take an oath when you go to (medical) school.” I, in turn, respected him for having lived the hard life of an undocumented alien. I also admired him for being definite about what he wanted out of life and for being fiercely independent in his views.

Still, I could not understand Senor B.’s refusal of seemingly ordinary treatments (insulin, dialysis, and perhaps coronary bypass grafts) that might save his life. *Fatalismo* surely influenced his attitude. He appeared to believe the diabetes and the atherosclerotic heart disease would run their courses no matter what. He simply concluded, “I have to die from something, doctor. It might as well be these things.”

Though I reluctantly accepted Senor B.’s refusing those life-sustaining treatments, I could not understand his refusing palliative end-of-life care, too. Senor B. steadfastly refused the advance care planning I offered, and he again took an attitude of *fatalismo*. “My wife already knows what I want. I don’t need to tell her,” he explained. “When that time comes, she will do whatever she needs to do.”

Perhaps *familismo* played a critical role, too, in Senor B.’s decision to move home to Mexico. He may have realized that, as he died, he would need the care and companionship of his whole family back in his native village. In addition, his family would have to meet a need of their own to provide him that care and companionship. Senora B. and the other women of the family, for instance, would expect to take care of him as he died and would feel cheated if they could not. And family members would need each other’s emotional support as they watched him die. I see now that, though medically questionable, Senor B.’s decision to go home may have been culturally well grounded.

Native Americans

In addition to these four large groups, other smaller but still important ethnic groups also live in the USA. Native Americans (NAs) are one. Over 5.2 million NAs, divided among 535 officially recognized tribes and perhaps another 100 unofficial tribe-like groups, reside here [www.census.gov/prod/cen2010/brief/c2010-10.pdf,

accessed November 22, 2013]. Yet only a tiny professional medical literature describes NA culture [60], and an even tinier one describes NA end-of-life care.

Hepburn and Reed have written one of the few articles on general NA end-of-life care. These authors describe it in terms of beliefs about the natural life cycle, the individual's place in the community and his or her decision-making authority in medical matters, and NA customs of communication [60]. The natural life cycle, of course, entails birth, growth, and death. NAs believe people must never disrupt this cycle, and, in particular, must accept death when it comes. They must not fight it.

NAs also seek a proper allocation of decision-making authority among the individual, the family, and the tribe. With proper allocation the individual makes decisions (including end-of-life care decisions) for him- or herself and receives support for those decisions from family and tribe. Adult children never challenge the decisions of parents for themselves. But NAs may initially react warily to outside medical authorities: Non-NA health professionals must prove their trustworthiness before NAs participate in sensitive end-of-life discussions with them.

NA thinking also affects end-of-life communications in an important way: NAs believe language not only describes reality but creates it. Mere mention of death, therefore, causes it to occur, making NAs communicate about death in nuanced, indirect ways. Such communications may reference a hypothetical dying patient or another actual dying patient but not the immediate dying patient [61]. The resulting discussion may strike time-urgent, action-oriented, direct-speaking Western clinicians as meandering and oblique, but they must have patience with it. NAs may make decisions so subtly that non-NA clinicians may not realize the decisions have been made. I, therefore, urge non-NA health professionals to consult informants knowledgeable in NA culture before discussing death and other sensitive medical topics with NA patients or their families.

Despite many NA tribes the professional medical literature addresses only one in particular: the Navajos, the second largest tribe after the Cherokees. Carrese and Rhodes describe end-of-life care with the Navajos based on Dr. Carrese's service as an Indian Health Service doctor [61, 62]. The authors emphasize the importance of culturally appropriate communications. "With the tongue we have," one traditional Navajo healer tells Dr. Carrese, "we must be very careful what we say ... (when) treating the patient." Specifically, Navajos insist on always speaking positively and thereby communicating *hozho*, the "Beauty Way." The term encompasses the Navajo ideas of beauty, goodness, order, and harmony. Contrasting with *hozho*, direct negative speech (including talk about death) must be avoided. This prohibition obviously complicates end-of-life care planning with Navajos. Carrese and Rhodes point out that the Patient Self-Determination Act of 1991, the law requiring mention of advance directives to all newly hospitalized patients, encountered a severe unforeseen obstacle in Navajo hospitals. Compliance with the law mandated explicit discussion of death, alarming the Navajos because they believed such discussion would actually cause patients' deaths.

Another author describes Navajos' view of dying as a sacred journey that ends with the dead person's living eternally in the Great Spirit's presence [63]. Rituals, connecting the dying person to the rest of the universe in harmony, play a key role

in sending him or her on this journey. I think health professionals who attend Navajos may be able to cite this belief as a comfort to dying patients and their survivors.

Gender and Age as Additional Cultures

Although ethnic cultures most easily come to mind, they constitute only one kind of culture. Other demographic characteristics suggest other kinds of cultures. I, therefore, believe every person belongs to multiple cultures at once, and most are nonethnic [7]. Each culture influences the person's total cultural make-up: The more closely a person embraces a particular culture's core values, beliefs, and behaviors, the more that culture shapes the person's views.

To illustrate nonethnic cultures, I briefly consider here gender- and age-associated cultures as they relate to patients. Because the literature on those cultures is vast, I cannot cover them comprehensively. I, therefore, limit my discussion to just a few points.

Patient Gender

Recent articles suggest that women and men patients differ dramatically in their descriptions of illness, the amount and kind of information they want from clinicians, their expectations for treatment outcomes, and their preferences for life support. Women often describe in their histories not only the physical symptoms but also the emotional and relational effects of their illnesses. Women also want considerable information about their illnesses and ask their attending clinicians relatively many questions. For example, women recovering from heart attacks often want detailed explanations of atherosclerosis and high blood pressure. Yet the amount and comprehensibility of the medical information they get leave some women dissatisfied [64]. Furthermore, women often want to share decision-making with their clinicians, prefer treatment plans based on clinician–patient consensus, and do not always expect treatment to cure their illnesses [65]. And women tend to prefer “a dignified death” to aggressive life support near the end of life [66]. Perhaps for those reasons terminally ill women often “hear” and accept clinicians' recommendations for comfort care only [67]. Overall, women feel empowered in the American healthcare system [26].

Men, in contrast, typically describe in their histories only the physical symptoms and not the emotional or relational effects of their illnesses. Men prefer relatively little information about their illnesses and ask relatively few questions of their

attending clinicians [65]. The questions men do ask differ from women's. For example, men recovering from heart attacks ask mostly about sexual activity. Men tend to be satisfied with the information they get from their attending clinicians. Men also tend to leave medical decisions to the clinicians but *do* expect treatment to cure their illnesses eventually. And they tend to prefer aggressive life support even near the end of life. Perhaps for that reason terminally ill men do not always "hear" clinicians' recommendations for comfort care only. Overall, men do *not* feel empowered in the American care system [26].

Patient Age

Studies also suggest age differences in the preferences critically ill patients have about decision-making style and outcomes for care. Although many patients of all ages prefer to share decision-making with their clinicians, more elderly patients than younger ones prefer leaving decision-making completely to their clinicians [67]. In addition, fewer elderly patients than younger ones want to exchange quantity of life for quality of life (which may include symptom relief, control over one's surroundings, or financial and emotional support for the family) [68]. Yet among the terminally ill, more elderly patients than younger ones "hear" and accept clinicians' recommendations for comfort care only [67].

Characteristics such as education, income, military service, and vocation represent other cultures to which people may belong. But one pair of cultures plays a huge role in medical care especially near the end of life: the clinician culture and the patient culture. Both of those cultures appeared to have had important effects in Senor B.'s case. I contrast the two cultures in the next section.

The Contrasting Cultures of Clinician and Patient

Clinicians commonly make two assumptions about clinical medicine and culture: First, clinical medicine is scientifically based and, thus, culture- or value-free. And, second, cultural differences in clinical medicine arise only from *ethnic cultural* differences between clinicians and patients [25]. Both assumptions are incorrect and require explicit rebuttals before I can offer a better way for clinicians to think about culture in patient care. (Here, as elsewhere in this book, I use the term *clinicians* to mean all health professionals trained in the basic clinical sciences such as anatomy, biochemistry, and physiology. Although medical doctors may be the quintessential "clinicians," the word also applies to nurses, pharmacists, and other scientifically trained health professionals).

The First Incorrect Assumption: Medicine Is Culture- or Value-Free

Many claim that value-free, objective science characterizes all sound medicine. As such, clinical medicine, the applied branch of medical science, treats patients' bodily problems by supposedly objective scientific principles. Clinicians often see themselves as scientists pursuing benefits defined by objective scientific truth, not subjective views [69, 70]. According to these clinicians, any other clinical approach represents an interesting but misguided curiosity [1]. As culture-in-medicine expert Dr. Carrese observes wryly, scientifically trained clinicians believe they "have 'truth' but others merely have 'culture.'" [70].

Still, in treating the body, clinical medicine is always promoting some values over others. It may, for example, promote extending life over easing suffering, or treating disease over preventing it. Furthermore, clinical medicine cannot avoid the existence of multiple subjective medical realities. No single reality dictates the same presentation, response, and course of a particular disease in all patients. To the contrary, the variability of a disease strongly suggests the variability of subjective patient experiences with it. In that way disease—the objective abnormalities of structure or function in cells, tissues, organs, or organ systems—[19, 71, 72] differs from illness—the patient's subjective experience of feeling unwell. Renewed appreciation for that subjective reality has begun to refocus patient care back from disease to illness. Therefore, I am convinced the first assumption is wrong: Clinical medicine is neither value-free nor completely objective.

The Second Incorrect Assumption: Cultural Differences in Clinical Medicine Arise Only from Ethnic Cultural Differences Between Clinicians and Patients

Restated, this incorrect assumption claims that clinicians and patients share all the same *medically relevant* values, beliefs, and behaviors though sometimes differing over other, *ethnic cultural* ones. If so, clinicians and patients from the same ethnic culture would agree on every medical issue. But I have cared for many EA patients who differ from me and other EA doctors over diagnostic tests, vaccines, smoking cessation, exercise, diet, weight control, megavitamins and other alternative treatments, and adherence to mainstream treatments. These firsthand observations suggest to me that clinicians and patients often view the same medical circumstances in vastly different ways [71]—some consistent with mainstream medicine and some not [73].

A recent study supports this impression [74]. Researchers contrasted patients' stated beliefs and their doctors' perceptions of those beliefs about whether the patients' medical problems had a biological cause, the patients bore responsibility for causing those problems, the patients could control the problems, nonmainstream

interventions could alleviate them, the problems had significant existential meanings, and the patients wanted a therapeutic partnership with their doctors. The doctors misperceived all six patient beliefs, often mistaking them for the doctors' own beliefs. Specifically, the doctors *overestimated* patients' belief that their medical problems had a biological cause and *underestimated* patients' beliefs that the patients bore some responsibility for causing the problems and could control them, that nonmainstream interventions could alleviate them, that the problems had some significant existential meanings, and that the patients wanted a therapeutic partnership with their doctors. The findings did not vary by patient ethnic group or doctor–patient ethnic concordance.

I believe clinical education creates much of the difference between clinician and patient perspectives. Such education, a form of socialization, instills a special, noninnate worldview in clinical trainees. That worldview, called “the clinical perspective,” [75] grounds itself in specific values, beliefs, and behaviors often not held by the general population. The clinical perspective values hard work, initiative, and self-sacrifice in the service of others; encyclopedic knowledge of a specialty field; future orientation (especially concerning preventative measures to avoid future disease-related problems); scientifically tested, “evidence-based” interventions; clinical research with big sample sizes and quantitative results; strict deductive logic in diagnostic workup and treatment; and optimism about treatment outcomes. This perspective also employs specific concrete symbols (such as the white coat symbolizing authority and cleanliness) and ritual behaviors (such as daily inpatient rounds) [75].

These considerations convince me the second assumption is also wrong. In fact, I now believe its opposite: Even within the same ethnic culture, clinicians and patients belong to separate cultures: [69] A specific cultural gap *always* divides the two groups between a “clinician culture” and a “patient culture.” [19, 71] The gap may be great or small, depending on the particular clinicians and patients, but it exists in every clinical encounter [5, 16, 19, 21, 75]. Bridging that gap requires recognizing it, understanding it, and planning creative ways to bridge it [74, 76]. To help do so in practice, Table 10.4 and the next subsections detail differences between the two cultures.

The Clinician Culture

So-called objective science, rationality, and a highly technical language characterize this culture [18, 19, 69, 71]. A typical perspective derived from these characteristics tries to reduce seemingly complex biological processes to simple concepts or laws [19, 75] and forms this culture's overall approach to patient problems. This “reductionistic” perspective appears in at least three ways. First, the science behind clinical medicine seeks the simplest explanations for complicated phenomena

Table 10.4 Clinician–patient cultural contrasts

Characteristic	Clinicians ^a	Patients ^a	Reference(s)
Overall approach to patient's problem	"Objective," reductionistic ^b	Subjective, holistic	[1, 19, 25, 70, 73, 74, 76]
Basis for approach	Medical science	Personal experience	[1, 19, 25, 70, 74, 76]
Focus of concern	Disease	Illness	[25, 71, 74, 76, 77, 83]
Language used	Technical	Colloquial	[19, 25, 71, 77]
Meaning(s) of patient's problem	Few: a puzzle to be solved, a defect to be repaired, or a foe to be defeated	Many: same as clinicians' meanings but other meanings, too (e.g., divine punishment, a way to command attention, a release from life's duties, or a reminder of mortality)	[73, 74, 76, 77]
Aim of medical care	Diagnosis and treatment	Symptom relief, functional improvement, and reassurance	[19, 25]
Weapons to be used	"Evidence-based," scientifically tested treatments	Established medical treatments and alternative "folk" treatments	[1, 4, 10, 70, 76]
Views of medical care	Egalitarian, personal, compassionate, sensitive, benevolent, altruistic. Time-efficient, objectively accurate. One objective truth, one reality	Technically competent, hope-inspiring. Sometimes elitist, power-wielding, callous, malevolent, bureaucratic, or self-serving. Many subjective truths, many realities	[1, 19, 70, 72, 76, 77, 79, 80, 83]
Control over medical events	Doctors only	Combination of God, doctors, and patient	[73, 83]
Grounds for medical decisions	Technical knowledge	Patients' values, experiences, and wishes	[19, 25]

^aThe word *clinicians* refers to all scientifically trained professional caregivers, quintessentially medical doctors; the word *patients* refers to all medically untrained recipients of medical care.

^b*Reductionistic* refers to the view that all complex natural phenomena can be distilled into simple concepts or laws.

related to the human body [1, 77]. Second, in focusing narrowly on physical disease, clinical medicine often overlooks problems of the mind and social environment. And, third, practicing clinicians use mental “filters,” which they learn and refine over years, to reduce patients’ often bewildering constellations of symptoms and signs to recognizable patterns of disease [19, 75].

Decisiveness and focused action also characterize the clinician culture [21]. The urgency of some situations, of course, demands quick decisions, effective action, and time efficiency [69]. But in all clinical situations, diagnosing and treating disease are the main objectives, and “evidence-based” interventions the main tools. Clinicians see their work as solving pathophysiologic puzzles, repairing bodily defects, and defeating the disease foe. Once having diagnosed a disease, clinicians want to treat it, and they aim to cure it. Their professional stature depends on keen observational skills, an encyclopedic knowledge of diseases, sound deductive logic, insightful judgment, and extensive technical know-how about treatments.

Patient care here often resembles car repair: Any significant deviation from normal functioning requires fixing. The patient presents his or her malfunctioning “body vehicle” to the clinician-mechanic, who diagnoses the problem and makes the necessary repairs [4, 78]. (Doctors actually call this process “tuning up” the patient.) Unfortunately, the clinician-mechanic model sometimes focuses so intently on the patient’s physical body problems that it overlooks pressing non-physical problems [75]. Still, clinicians see their patient care as genuinely humanistic. They consider it beneficent, sensitive, kind, compassionate [79], and patient-centered. They also consider it rigorously egalitarian and nondiscriminatory [79, 80] such that patients with similar clinical needs receive similar attention regardless of income or other demographics.

Clinicians, of course, play the lead role within the clinician culture [75]. Supposedly they alone have the expertise to control clinical outcomes [75]. They thereby command great authority in that culture while patients and families often feel powerless and vulnerable [19].

But like ethnic group cultures the clinician culture is not uniform. It contains subcultures of its own created by particular clinical professions and specialties. Doctors and nurses, for example, belong to separate subcultures due to their different professional goals and methods. Doctors focus on diagnosing diseases, improving physical symptoms and function, and studying their care scientifically. They rely heavily on medical technology to achieve those goals. Nurses, in contrast, focus on helping patients live independent and fulfilling lives. Nurses rely heavily on building positive relationships to achieve that goal [81]. Even among doctors, different specialties and therapeutic goals create different subcultures. Several doctor subcultures, for example, may coexist in intensive care units (ICUs). The attending surgeons may aim primarily to keep patients alive while the attending “intensivists,” usually anesthesiologists or internal medicine-trained pulmonologists, may aim primarily to maximize patients’ quality of life [82].

The Patient Culture

This culture differs dramatically from the clinician culture. Patients, not clinicians, play the lead here [75]. Patients understand medical problems as illnesses, that is, their own personal experiences of feeling unwell, [19, 71] and are the experts in them. Patients also use colloquial language to describe their illnesses: [19] A myocardial infarction is “a heart attack;” diabetes mellitus, “sugar;” and syncope, “a dizzy spell.” That language helps shape patients’ understanding of their illnesses.

In addition, illnesses are holistic, that is, affecting the whole patient. As such, they have multiple dimensions, including not just the physical but also the emotional, social, vocational, financial, existential, and spiritual [19, 73]. Different perspectives on those dimensions permit different interpretations of what an illness means. Like clinicians facing diseases, patients facing illnesses may see them as problems to be solved or alien attacks to be avoided, warded off, or surrendered to [75]. But patients may also see illnesses as moral weaknesses, divine punishments, ways to command attention, convenient releases from life’s demands, reminders of bodily deterioration and mortality, or catalysts for spiritual growth [75, 77].

In the patient culture medical care exists to provide symptom relief, functional improvement, reassurance, and hope. Diagnosis and treatment are not ends in themselves but merely means to these other ends in patients’ lives. Because patients determine those ends, they often want to participate in medical decisions. Patients want to make sure that decisions about their care accurately reflect their core values, experiences, and wishes [19].

This patient culture also suggests that, because patients’ worldviews differ considerably from clinicians’, patients’ specific views about modern medicine also differ from clinicians’. Mixed feelings lie at the heart of patients’ views. On the one hand, patients are awestruck at modern medicine’s power over some diseases. Pneumonia, kidney failure, atherosclerosis of heart vessels, and other formerly deadly diseases now often yield to treatment. Modern medicine appears to work miracles in these cases. Its successes feed patients’ hope for recovery in their own life-threatening crises [83]. On the other hand, patients often regard warily this highly specialized, highly technical care because they do not understand it [72, 79]. Modern medicine can seem like a dangerous monster [72], serving itself or clinicians better than the needy patients. Its care can sometimes seem callous or bureaucratic. Patients often feel modern medicine focuses too much on the physical and too little on the nonphysical or humanistic (especially during terminal illness). They crave meaningful, personalized relationships with their clinicians. Unfortunately, clinicians must often guess at such wishes because most patients, intimidated by clinicians’ authority, do not ask explicitly for what they need [69]. Patients fear retaliation if they ask too much of their attending clinicians and thereby earn a reputation as being “difficult.” Such mixed feelings, then, create for patients a curious combination of awe, trust, and wariness about modern medicine, and clinicians may have difficulty deciphering the exact combination for particular patients.

The patient culture also contains one other important existential element: the perception of limited control for patients over disease, illness, care, life, and death. Many Americans see God as having ultimate control over medical events despite the power of modern medicine [83]. They also see God as relinquishing some of His control to them. Some patients wish to exercise their control by making all important medical decisions themselves; others wish to share it with their clinicians.

The Case

The ethnic cultural differences in Senor B.'s case were obvious from the start, but the clinician–patient cultural differences were subtle. They occurred to me only later. As a typical doctor, I am disease- and action-oriented. I viewed Senor B.'s shoulder pain and chest pressure as disease puzzles to be solved. I felt obligated to diagnose the causes for his pains and looked to the medical sciences, mostly anatomy and physiology, for answers. The shoulder pain was the less serious problem: Strain or possibly a tear of the shoulder tendons was likely causing it. The chest pressure was potentially the more serious problem: Compromised blood flow to the heart muscle was likely causing it. I believed Senor B. could suffer a full “heart attack” at any time, thereby permanently damaging his heart muscle and perhaps dying. I wanted to take immediate action to treat the heart by admitting him to the cardiac ICU. I automatically assumed “the government hospital” would give Senor B. competent, compassionate, and nondiscriminatory care despite his status as a poor, undocumented alien. And I believed the cardiac ICU doctors would treat him with proper monitoring and interventions and save his life in the process. I tried to reassure him the hospital would give him whatever life-saving treatment he needed at a cost he could afford and would not initiate deportation proceedings against him.

As a patient, Senor B. took quite a different view of his case. He had illnesses, not merely diseases. First, the shoulder pain (among other symptoms) and then the chest pressure made him feel unwell. These illnesses had multiple dimensions for him including physical, social, vocational, financial, and emotional ones. Senor B.'s resulting inability to support his family jeopardized his position as patriarchal head of the family and compelled him to come to the public clinic, which he dreaded. He cared little about getting exact diagnoses but cared a lot about getting enough pain relief to work again. In fact, Senor B. was so desperate for relief that he sought treatment wherever he could find it: He used both mainstream treatments and alternative folk treatments. In addition, where I saw only clinical puzzles, Senor B. may have seen moral weakness (say, for his excessive eating, smoking, and drinking), divine punishment, or reminders of bodily deterioration and mortality.

He also felt a deep ambivalence about the public healthcare system he had landed in. He respected my clinical knowledge and wishes to help but also feared mistreatment at “the government hospital.” Despite my optimism about treatment, Senor B. was always fatalistic. He was sure he would die from either his heart

disease or “that heart surgery.” Refusing my pleas to work him up for an impending heart attack, he said repeatedly, “God wants me to die from something. This must be it.” Senor B.’s prior nonadherence to his diabetes regimen should have alerted me that he and I were often working at therapeutic cross-purposes.

As I recall his case now, I see that relatively few of our clinical management disagreements arose from ethnic cultural differences. Most of those disagreements actually arose from differences between my clinician culture and his patient culture.

Resolving Cultural Conflicts at the End of Life

One expert says cultures shape patients’ perceptions of clinical reality [4]. Those perceptions differ from culture to culture, patient to patient, situation to situation, and time to time. Thus, clinician and patient are constantly renegotiating their different, culturally based factual interpretations, values, and expectations to reach agreement on the clinical reality they face together. I certainly tried mightily to negotiate with Senor B. a shared perception about the reality he and I faced. But I did not succeed much. A huge cultural gulf always separated us, and I needed a much broader perspective than I had to bridge it.

In searching for such a perspective, I have concluded recently that some of every person’s cultures address death. We all derive so much identity, purpose, and meaning from our cultures [78] that we surely find in them insights about that momentous event. Cultures explain what death means to us and provide ways for us to cope with it. Cultures also shape our expressions of grief and can give us spiritual guidance [2, 5].

Unfortunately, cultures are so deeply ingrained and so rarely discussed that many of us do not know or cannot articulate our culturally based beliefs about death [11]. “Culture hides itself from its own,” one writer observes [2]. Defining such beliefs for the first time at the end of life may be especially difficult just when they matter most. Yet patients and family members may find themselves doing that in front of health professionals as the end-of-life drama plays out. Health professionals must respond with insightful, practical, and compassionate help.

In doing so, health professionals must overcome the typically human discomfort at discussing death. They must also resist their usual time urgency and exercise the patience necessary to listen and to consider cultural differences thoughtfully [84]. Health professionals must always respect beliefs different from their own and never dismiss them as mere obstacles to doing what the health professionals want to do anyway [85]. Of course, respect for opposing beliefs does not mean automatically accepting them. But it does mean trying to understand those beliefs and to negotiate workable compromises within reasonable professional and personal bounds [86]. Health professionals should have a sensitive, systematic approach to do so. One is LEARN, the acronym for *Listen, Explain, Acknowledge, Recommend, and Negotiate* [87]. The next few paragraphs describe it.

Listen means eliciting the patient's perspective on the situation. I suggest the health professional take cues from the patient's ethnicity, gender, and age and on that basis make a preliminary mental list of culturally based views the patient might hold. This chapter's general descriptions of common American cultures, ethnic and otherwise, may help. The health professional can then ask specifically about those views if the patient draws a blank at first inquiry. (A reminder: Because this process does not set out rigid, preconceived ideas about what the patient *must* think, it is not cultural stereotyping. The process merely provides a place to start a focused inquiry [61]. Of course, the health professional must always keep an open mind and be prepared for deviations from prior culture-oriented expectations.) The health professional should use good listening techniques throughout. In general, he or she should respond to the patient with attentiveness and sympathy. The health professional should use the patient's own words whenever possible in replying, asking clarifying questions, or summarizing what the patient has said [87].

Explain means understanding one's own relevant cultural views and being able to explain them to others. A person's greatest cultural influences surely come from ethnic group, religion, gender, and education [88]. Those influences may emerge most powerfully in the critical-care or end-of-life crisis. The health professional, therefore, must be able to identify the possible sources of his or her cultural views, to explain those views clearly, to hear opposing views, and to anticipate the implications of all views for care.

Good, clear expression is a key to effective explanations. Both the verbal and nonverbal components of expression deserve forethought. Even when sharing the same native language with patient and family, the health professional must speak slowly, distinctly, and deliberately. He or she must explain key ideas, minimize the use of technical words, and clearly define the technical words whose use is necessary.

Not sharing the same native language naturally increases the difficulties of communication and the risks of miscommunication. When lacking easy fluency in the language preferred by the patient or family, the health professional *must* use a trained, skilled professional interpreter [89, 90], never untrained staff or family members of patients, to translate. Accurate medical interpretation requires specialized language use, exact transmission of meanings, and keen observation of interpersonal interactions (including nonverbal communications)—all of which a trained professional interpreter can provide. American law now requires hospitals and clinics to make available in person or by telephone the professional interpreters for many languages. The health professional should use these interpreters liberally. I prefer using in-person interpreters (whenever available) specifically to get their observations about nonverbal communications.

Even when using interpreters, the health professional should speak slowly and deliberately. He or she should look directly at the patient or family member; use short, simple sentences; and stop frequently, perhaps every sentence or two, to allow the interpreter to keep pace. The health professional should also never divert his or her attention, say, to writing progress notes or speaking to others, during interpreted conversations. To ensure accurate understanding in both directions, he

or she should repeat back for confirmation any important information coming from the patient or family member and ask the patient or family member to repeat back any important information coming from the health professional.

As I said before, communication is nonverbal as well as verbal, and the health professional should appreciate both kinds. Good listening and good explaining, therefore, require good observation. With the emphasis in many non-Western cultures on the nonverbal, and the taboo in some about talking explicitly about death, the professional interpreter may be most valuable in helping the health professional understand indirect, nonverbal communications. Any face-to-face interpreted conversation, whether between Western and non-Western cultures or among strictly Western cultures, deserves a debriefing afterwards in which the health professional asks the interpreter in private for insights about the nonverbal communications.

Acknowledge means to identify explicitly a situation's cultural conflicts. This acknowledgment does not require a comprehensive knowledge of all cultures represented. Such knowledge is impossible even for professional anthropologists [91]. But the acknowledgment should reflect an appreciation for the main conflicts, a willingness to hear all perspectives, and a respect for each one. Otherwise, some parties may feel their views are not taken seriously.

I find that stating cultural conflicts as action questions, that is, questions about which actions to take in response to the conflicts at hand, helps start the resolution process [92]. Action questions in Senor B.'s case might have included the following: Should I insist he stop the *El Parajo* and all other nonmainstream medicines before I treat him? Should I even propose expensive life-prolonging procedures such as cardiac catheterization and hemodialysis when I know he is a poor, uninsured, and undocumented alien and worries about not being able to pay for them? [93] And should I require him to sign an outpatient do-not-resuscitate order if he steadfastly refuses my recommended life-saving treatments?

Recommend means offering preliminary proposals for resolving the cultural conflicts. Once those conflicts and relevant action questions get articulated, proposals for resolution often follow quickly [78]. Those proposals should acknowledge all perspectives represented, reflect whatever consensus exists, and suggest initial actions to take. The proposals should permit any necessary adjustments later on.

Negotiate means performing a give-and-take about the proposals until the parties reach a generally agreed-upon, workable solution. The negotiation process sometimes requires persistence, patience, and flexibility [78]. And the success of any solution should be assessed in terms of accommodating as possible the basic cultural beliefs of patients first [85], families next, and health professionals and institutions last.

Some people advise negotiating until reaching a solution fully acceptable to all. That goal is sometimes impossible: Harmonizing seemingly conflicting cultural beliefs may never fully occur. Beliefs may be logically incompatible; parties may harbor hidden agendas, perhaps unconscious, that leave them unable to compromise; and life-threatening crises may limit the time available to formulate the

perfect plan. Actual solutions, therefore, are often compromises, which may satisfy nobody fully. Neither ethics nor law provides clear guidance about when to accommodate and when not to in such highly charged crises [76]. I believe dying patients, through their proxies if necessary, should generally have the dominant say in end-of-life questions. Health professionals and institutions may have to extend themselves to accommodate patients' beliefs. Those beliefs may be overridden only when they will likely do serious, irreversible harm to others. Surely few patient beliefs meet those conditions.

The Case

Senor B.'s case still baffles me years later. Adhering to my professional training, I focused on his diseases. To me, they constituted his total medical reality. They also had established, "scientifically proven" treatments, which I was eager to use: insulin for the diabetes, aspirin and possibly arterial bypass grafts for the atherosclerotic heart disease, and eventual hemodialysis for the progressive kidney failure. I considered such care for him state-of-the-art, personal, and compassionate. Still, my approach rarely persuaded Senor B. to accept the treatments I recommended.

I realize now my perspective as a clinician blinded me to Senor B.'s quite different perspective as a patient. I had assumed we both saw his medical reality in the same highly clinical way. But his increasingly missed appointments and his steadfast refusals of nearly all my treatment recommendations should have made me suspect important differences between us. I should have explicitly asked his perspective, using the questions in Table 10.5 [4, 85]. The clinical history I had learned in medical school did not include them.

Though not explicitly asking these questions, my original clinical history with Senor B. answered some of them anyway. I only needed to see the answers in it. *How long do you think your illness will last?* His fatalistic attitude ("I have to die from something. This must be it.") strongly suggested Senor B. believed these medical problems would last unabated until he died and, in fact, would cause his death. *What problems does your illness cause you in everyday living?* Senor B. explained at the outset that his shoulder pain bothered him most because it prevented him from earning a living. He was thereby failing his family in his most important cultural duty. *How does this illness affect your body? How does your illness "work"?* Senor B. initially described not only his shoulder pain but also his thirst, frequent urinations, and erectile dysfunction. He had friends with diabetes and surely compared symptoms with them. He probably knew before his appointment with me that uncontrolled diabetes was causing these symptoms. *How serious are these problems to you?* Senor B. must have considered his symptoms serious enough to take the risk, as he perceived it, of coming to the public clinic. Of course, his inability to earn a living or to have intercourse with his wife surely undermined his sense of "macho" virility and, thus, played an influential role in

Table 10.5 Questions for eliciting a patient’s perspectives on his or her illness

1. What do you think caused your illness?
2. Why did it start when it did?
3. How long do you think it will last?
4. How does your illness affect your body? That is, how does your illness “work”?
5. What problems does this illness cause you in everyday living?
6. How serious are these problems to you?
7. How have you already tried to treat your illness? How well did your treatments work?
8. How can I help you? What specific treatments do you think you need from me?
9. What results do you hope for from treatment?
10. What do you think is a realistic outcome?
11. What does this illness mean to you in thinking about yourself and your life?
12. What do you fear most about your illness?
13. Who else should be told about your illness?
14. Who helps you make decisions about your illnesses?

Data from Kleinman et al. [4]; Carter and Klugman [85]

prompting him to come. Furthermore, the frequent urinations from the uncontrolled diabetes must have caused him embarrassment at work and inconvenience at home. The later chest pains and shortness of breath must have also made him wonder about heart attacks and sudden death. *How have you already tried to treat your illness?* Because Senor B. was a Mexican immigrant, I did ask in my initial history whether he had tried Mexican herbals for his symptoms. He reluctantly admitted to using the traditional folk treatment, *El Pajaro*. *Who else should be told about your illness?* and *Who helps you make decisions about your illnesses?* Senor B. attended alone all his appointments except the last one. Although he occasionally mentioned his wife in our conversations, I did not know for a long time how much Senora B. asked about Senor B.’s medical problems, how much he told her, and whether he wanted to make medical decisions himself or to share them with her. However, I *did* know that MA women generally feel responsible for medical matters in the family, and that many MA husbands conceal their medical problems to keep their wives from worrying. I did not know Senor B. well enough to determine whether he and Senora B. fit these cultural patterns.

Unfortunately, my initial history did not answer most questions concerning Senor B.’s understanding of his illness: What do you think caused your illness? Why did it start when it did? What specific treatments do you think you need? What results do you hope for? What do you think is a realistic outcome? What does this illness mean to you? and What do you fear most about it? I surely could have gained a better understanding of his perspective by asking those questions. The answers might have helped me understand why Senor B. steadfastly rejected my life-saving treatments. The answers might have also enabled me to use the LEARN approach to reach with him a compromise treatment plan, incorporating many of his wishes and some of my recommendations.

Three points in Senor B.'s perspective continue to puzzle me today. I do not understand the fatalism that caused him to surrender to his disease without a fight. He apparently believed that mainstream medicine could not help him, and foresaw little use in even trying much of it. I also do not understand his belief that powerful external forces—individual human authorities (like me), powerful human institutions (like the hospital, the local police, and the federal immigration department), God, and fate—thoroughly controlled his life.

And I do not understand why Senor B. preferred to risk his life to return to his home in Mexico [93]. One expert says many dying immigrants have this wish. She gives several explanations for it [94]. First, many immigrants like Senor B. come to the USA to improve life materially for themselves and their families but never intend to stay permanently. Second, as these immigrants age, they become increasingly homesick, wanting more and more to return to familiar customs, familiar surroundings, and family back in the homeland. Third, when these immigrants become ill, they may need considerable care that only family will give. The many relatives back home can give it; the few, overly busy relatives in the USA cannot. And fourth, returning home may allow these immigrants to reestablish continuity among their past, present, and future; to resolve long-term, unfinished business back home; to gain a sense of closure for their lives; and to find comfort in the familiar when facing the vast unknown of death. This expert claims that returning home is a basic human need and an “organizing principle” for many immigrants at the end of life.

In sum, I do not know exactly why Senor B. left the clinic. The many cultural differences between us—ethnic, age-related, clinician–patient, and perhaps others—likely played a role. I also do not know what happened to him. He may have indeed returned home to Mexico and died there. But other cross-cultural cases since Senor B.'s have awakened me to the importance of cultural influences in end-of-life care. I have tried to change my practice habits as a result.

Summary Points

1. *Culture* is the values, beliefs, and behaviors that a distinct group of people shares, uses to understand life events, and transmits from generation to generation. Culture is not a race, nationality, or language group but a perspective that provides group members identity, meaning, and purpose for their lives.
2. Because health professionals and patients embrace markedly different health-related values, beliefs, and behaviors, every medical encounter involves at least two different cultures—the one of health professionals and the other of patients.
3. Health professionals might use the LEARN approach to identify and help resolve cross-cultural issues in patient care. LEARN stands for Learn, Explain, Acknowledge, Recommend, and Negotiate.
4. Cross-cultural issues are especially prevalent at the end of life.

To Learn More ...

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