DEATH

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I. CULTURAL PERSPECTIVES

What is death? How do we understand its meaning? Since death cannot be directly apprehended by straightforward scientific means, culture provides the key medium for comprehending the final boundary between our existence as living beings and the eventual end of that existence. Death is a fact of life, but awareness of mortality is a social, not a biological, reality. Knowledge about death, which includes how its meaning and value are understood, is socially constructed. How should we account for profound differences across the world and throughout history? (Barley 1997; Blank 2011). In some societies, elders choose to end their own lives via exposure to the elements, to avoid being a burden to the wider community—the perhaps apocryphal Eskimo on an ice floe provides a powerful image, whether supported by the ethnographic evidence or not. Or mothers may withdraw their love and attention from an infant deemed unlikely to survive in an impoverished environment like the slums of northeastern Brazil (Schepker-Hughes 1992).

In contemporary US society, through a combination of technical prowess, institutional arrangements, and bioethics-governed procedures and practices, we elect to maintain the liminal existence of patients suffering from persistent coma, maintaining their biological lives in specialized ventilatory-care units (Kaufman 2000). Others may decide to have their brains or bodies “cryopreserved” after the moment of physical, cardiopulmonary death, in response to Internet advertisements (Romain 2010). The native inhabitants of the Amazon, called the Wari, respect their dead, and assuage their grief, by engaging in ritual mortuary cannibalism (Conklin 2001). How might the profound range of cultural variability in organizing death inform bioethics debates about the morally right management of death and the end of life? This entry examines the intersection of death, culture, and bioethics using an anthropological perspective, since anthropology is the field most associated with the analysis of culture.

The scope is both broad, examining conceptually the ways in which the experience of death is culturally constructed within particular social and historical moments, and deep, detailing the growing body of knowledge about the influence of an increasingly globalized biomedicine (and “the ethics” of that medicine, bioethics) on the experience of death and dying in multi-cultural societies.
INTERSECTIONS OF DEATH, CULTURE, AND BIOETHICS

When cultural difference is considered, we generally think of differences among people from varied backgrounds in a diverse multiethnic society, or of clashes emerging in the face of immigration or forced migration of populations. In homogenous societies, for example, when healers’, patients’, and broad social expectations about death are concordant, differences may be transparent and conflicts rare. In diverse societies, ethnic or cultural background influences all aspects of health care, nowhere more profoundly than when death is near. Even patients and families who appear well integrated into a diverse, multiethnic society such as the United States or the United Kingdom may draw heavily on the resources of cultural background (particularly spirituality) when experiencing or responding to death. When cultural gaps between families and health care providers are profound, accentuated by language barriers and varied experience shaped by social class, negotiating the transitions on the path from life to death, always a daunting challenge, becomes even more difficult.

We argue that all domains of end-of-life care are shaped by culture, including:

- the meaning ascribed to illness;
- the actual language used to discuss sickness and death (including whether death may be openly acknowledged);
- the symbolic value placed on an individual’s life (and death);
- the lived experience of pain and suffering;
- the appropriate expression of pain;
- the styles and background assumptions about family decision making;
- the correct role for a healer to assume;
- the care of the body after death; and
- appropriate expressions of grief.

When the patient’s family and health care providers do not share fundamental assumptions and goals, the challenges are formidable. Even with excellent and open communication—the foremost goal of culturally appropriate care—barriers remain. Differences in social class and religious background may further accentuate the profound challenge of defining and implementing “good” end-of-life care in health care systems serving increasingly diverse societies. The conceptual challenge for bioethics is defining the good in such situations, and making certain that recommendations for respecting cultural difference serve both pragmatic and principled goals.

When dealing with concepts as totalizing but slippery as culture, and as seemingly precise as death, it is useful to begin by considering the definitions and basic concepts used by other disciplines.

ANTHROPOLOGICAL VS. PHILOSOPHICAL APPROACHES TO DEATH

Anthropological, or cultural, approaches to the study of death differ markedly from the approaches taken by philosophy. For thousands of years the mystery of death has been a topic of debate and discussion by philosophers, who have attempted to account for death conceptually and, more recently, by developing criteria for judging when death has occurred. Death is a state following upon the end of life; it is the absence of life. Death is a mystery, but is it more mysterious than other phenomena that we do not understand? Philosophers have tried to ask what death is, and in general have encountered serious definitional difficulties, stemming primarily from the problem of how one defines life.

A question of key philosophical interest was posed by the Epicurean philosophers, and most clearly articulated by Lucretius, who asked, “Is death bad for you?” His basic argument, that since the dead person no longer exists, death cannot be “bad” for the individual who dies, has been influential in the subsequent philosophical discourse on death (Greenblatt 2011). By contrast, cultural critiques begin with a set of social questions that move beyond the individual: How do different societies manage the existential fact that all members will eventually die, and the practical implications of the death of individuals, including the reintegration of survivors after a death? What roles, if any, do healers and healing systems play? Ethnographers, whether of tribal and hunter-gatherer societies or of contemporary intensive care units, have a quite different task than the philosopher: describing the range of culturally patterned responses to the existential realities of human frailty and eventual death.

DEATH AND THE BIRTH OF BIOETHICS

Death has been an essential focus of bioethics since the inception of the field over four decades ago (Jonsen 1998). Dealing with the challenges of a dramatically changed biomedical landscape was, in fact, one of the driving forces behind the birth of the field. One could argue that bioethics in its current form exists partly in relationship to its encounters with death, to birth pains peculiar to the unique cultural environment of the United States, where the field first crystallized into a new discipline. Following the successes of post–World War II clinical medicine, in particular the development of the mechanical ventilator and its increasing use outside of its original site—in operating theaters and post-anesthesia recovery—the question arose: When is a patient beyond hope for a meaningful recovery and when is a patient whose heart and lungs are being continued by artificial means actually dead? (Veatch 1976). The first heart transplant in 1968 added the complexity of figuring out when someone was “dead enough” for their organs to be harvested for transplant recipients (Fox and Swazey 1974).
In the United States, a series of pivotal legal cases—many, such as the cases of Baby Doe and Karen Ann Quinlan, receiving widespread attention—revealed the fundamental ambiguities of medicine’s power to combat death. Recognition of these ambiguities led to the creation of a series of presidential commissions to debate and reflect on topics such as criteria for establishing brain death, and appropriate procedures for withholding or withdrawing potentially life-sustaining technologies.

Cultural analysis takes account of developments in technology but does not require a determinist position. The argument is not that new medical technologies transform cultural understandings of death in a straightforward, linear way. Rather, the meaning of any new medical procedure to forestall death is developed and gains significance against a specific cultural background. Since understandings of technologies are inevitably culturally shaped, they are never neutral, but their development is affected by the existing cultural milieu; and, once in use, cultural context affects how they are used. Thus, the meanings of new medical technologies are co-constructed, rather than determined. They are in a way amalgams of social practices and technical objects, and one must understand both in order to have the full picture. The development of a totally implantable defibrillator to save patients from sudden death will not be questioned in an environment where medicine’s goal is to intervene in every death. Another society might question the use of certain procedures, such as resuscitation, in the situation of an expected death. The same dynamic affects “low-tech” interventions like the use of feeding tubes or hand-feeding the ill. Against the backdrop of a long-standing cultural adage that “dying on an empty stomach” is a horrific fate, the feeding tube will take on one sort of meaning. In another environment, where freedom from tubes and bodily interventions is highly valued, another outcome is likely. As the use of technologies intensifies, indeed, as patients begin to be defined as dying only after they have failed all readily available interventions, we might speak of death occurring in technological time (Muller and Koenig 1988; Lock 1996). Callahan describes Western biomedicine’s approach to death as “technological brinkmanship” (Callahan 2000, 2012). In societies where cultural beliefs in rebirth, such as in traditional Buddhism, influence patients to pass naturally (i.e., without drugs, tubes, and needles) from one life to the next (Keown 2005), we observe less of a dependence on life-sustaining technologies.

CULTURAL PERSPECTIVES ON DEATH

Exact definitions of culture are elusive. At the most general level, culture is defined as those aspects of human activity that are socially rather than genetically transmitted. Thus culture can be thought of as patterns of life passed among groups of humans. But definitions are often so broad as to be meaningless, applying to every domain in society: religious beliefs, folk practices, language use, material objects, worldview, artistic expression, etc. According to pioneering anthropologist Robert Lowie, culture “is, indeed, the sole and exclusive subject-matter of ethnology [anthropology], as consciousness is the subject-matter of psychology, life of biology, electricity as a branch of physics” (1917, 5). And, as Alfred Kroeber and Clyde Kluckhohn wrote in 1952, “In explanatory importance and in generality of application it is comparable to such categories as gravity in physics, disease in medicine, evolution in biology” (Kuper 1999, x).

With a concept this broad, boundaries are difficult to delineate. Anthropologists have become critical of the application of the concept culture (Kuper 1999). The work of Clifford Geertz moved the field of anthropology in the direction of interpretation, transforming culture from a passive noun to an active verb. “Man is an animal suspended in webs of significance he himself has spun; I take culture to be those webs, and the analysis of it to be, therefore, not an experimental science in search of law, but an interpretive one in search of meaning” (Geertz 1973, 5). In biomedicine the dangers of an essential view of culture are clear. We cannot simply read culture in patients facing death or indeed in any clinical encounter, discerning people’s views, desires, and needs with false security based on knowledge that culture A holds view B about disclosing a terminal prognosis to a patient, and culture C holds view D.

The origins of the culture concept date back to the work of early post-Enlightenment folklorists such as Herder, who made use of the concept to avoid the uniform, totalizing theories of human capabilities that were characteristic of the late eighteenth century. The modern concept of culture developed much later, partly in response to racist (and biological determinist) ideologies of the nineteenth century, most incorporating an evolutionary framework based on social Darwinism. According to this theory, the species Homo sapiens can be divided into separate sub-species or races, each with engrained, essential characteristics, and each of which can be accorded a particular value in a hierarchy of moral worth.

Philosophers maintain that a general problem with the concept of culture as it has been understood in the last two centuries is that it is often linked with a naive relativism that precludes judgments about the unique cultural practices found around the world. They charged that anthropologists’ recognition of the intrinsic value and worth of each culture seemed to preclude criticism of specific practices. Indeed, in some instances this criticism is warranted; attention to the diversity of cultures and the
need to judge each on its own terms is central to the field of anthropology. However, such attention to cultural relativism at the empirical level does not necessarily lead to a stance of ethical relativism. Often practices dealing with death that were unsettling to Europeans, such as head hunting and cannibalism, were the focus of disproportionate attention, supporting efforts to justify and document a radically different “other” (Conklin 2001).

The history of anthropological engagement with mortality dates back to the origins of the discipline, and is bound up with concerns about the origins of religion. Early theorists focused on small-scale societies where magic, science, and religion are not separate cultural domains. For example, the nineteenth-century anthropologist Edward Tylor, who worked from an evolutionary paradigm of explanation, saw the origins of human society and culture in efforts to explain the fact of mortality, and in particular, in the recurrence of dreams and other visions about deceased close kin. The “savage philosopher” reflected on the everyday experience of human mortality and developed the notion of the soul. In Magic, Science and Religion Malinowski writes,

Of all sources of religion, the supreme and final crisis of life—death—is of the greatest importance. Death is the gateway to the other world in more than the most literal sense. According to most theories of early religion, a great deal, if not all, of religious inspiration has been derived from it. ... Man has to live his life in the shadow of death, and he who clings to life and enjoys its fullness must dread the menace of its end. Death and its denial—immortality—have always formed, as they form today, the most poignant theme of man’s forebodings. [Experience] at life’s end condensed into one crisis which provokes a violent and complex outburst of religious manifestations.

(Malinowski 1992, 47 [1916–26])

Social theorists influential to the development of anthropology, such as Emile Durkheim and, later, Robert Hertz, have argued that all societies exert institutional controls to protect and preserve the lives of members, including rules governing appropriate and inappropriate killing. Many actions that appear to be individual choices, such as suicide or the expression of emotion during grieving, are actually socially patterned. Studies such as Durkheim’s comparative analysis of suicide rates, one of the first uses of statistics in social science, illustrate this (Durkheim 1951 [1897]). Hertz used cross-cultural comparisons of mourning rituals to suggest that the human expression of grief can also be best understood as a social fact, particular to each society (Hertz 1960 [1907]).

For reasons that have been the subject of extensive internal critique within anthropology (Behar 1996; Rosaldo 1989), until fairly recently the field concerned itself primarily with the rituals following death (Huntington and Metcalf 1980; Counts and Counts 1991). This included ceremonies that focus on the disposal of the body, usually after cardiopulmonary death, but not always. This concern in the discipline of anthropology with ritual practices and symbolic meaning precluded a full engagement with the profound emotional significance of the process of dying, grief, and loss. Scholars focused on the recurrence throughout the world of death rituals that expressed fertility and rebirth (Bloch and Parry 1982). The emphasis on sexuality, and the connection between sex and death, fit well with anthropological interpretations of ritual behavior that emphasized function. Death rituals focusing on reproduction, these scholars determined, served the function of reintegration of society following a death.

In some societies this symbolic link between death and regeneration is expressed explicitly; funerary practices incorporate the abandonment of usual standards of sexual propriety for a confined time period, or allow and encourage sexual relationships between categories of kin where such contact was generally excluded (Barley 1997).

In contemporary US hospitals, the practices of bioethics developed in the last decades have become the new rituals guiding these transitions between life and death (Kaufman 2005; Green 2008; Chapple 2010). A number of studies in anthropology (and medical sociology) examine contemporary death practices in biomedical settings, such as Bluebond Langer’s 1978 account of disclosure of a terminal diagnosis to children under treatment for leukemia, or Sudnow’s 1967 account of dying in a public hospital. Christakis examines contemporary practices in foretelling death (Christakis 1999). Other recent ethnographies chronicle the experience of death and extreme old age for specific populations, for example, elderly Jewish immigrants (Myerhoff 1994).

DEFINING THE BOUNDARY BETWEEN LIFE AND DEATH

The concept of “social death” has been of considerable utility in describing the varied boundaries between life and death throughout the world. Nigel Barley, who has written an accessible account of the range of cultural practices surrounding death (1997), describes his alarm and confusion when an African informant tells him that his wife “died” that morning, in the midst of a conversation asking him for a cigarette. In reality, she had been, in Western terms, “unconscious,” but the
Dowayo tribe in Africa make no distinction, either linguistically or conceptually, between death-like states that are reversible (what we might call coma, persistent vegetative state, or perhaps suspended animation) and that which continues permanently. This view of death provides a sharp contrast to biomedical definitions that assume irreversibility. (Although it is important to remember that even in the West, belief in resurrection calls the finiteness of death into question for many and forms a core of religious belief.)

Studying ideas of death, of course, also reveals views on life and what it means to be human (Kaufman and Morgan 2005). The idea of social death is intimately tied up with notions of personhood, and who counts as a person within a society. Social death has utility in analyses at both ends of the human lifespan. Anthropologists have observed and documented societies in which full-term infants are not considered fully alive, and thus members of the social group, until they have survived the first month of life (perhaps not by chance the period of highest vulnerability for a newborn) and received a name in a formal naming ceremony. Those who die before naming are not considered fully human—we might say that the social group does not recognize the infant’s personhood—and thus do not warrant ritual attention, such as the funeral or elaborate mourning rituals accorded to those having full personhood. Such practices are in sharp contrast with contemporary obstetrics practices in the first world, where developing fetuses are named and ultrasound images are exchanged prior to birth. Indeed, the very survival of extremely premature infants in neonatal intensive care units is best understood as an artifact of life and thus already dead, and so infanticide may be allowed. Traditionally in Bariba society (in northeast Benin and northwest Nigeria), certain infants are understood to be witches, and thus mothers are not allowed to grieve the loss because the infant is defined as not human (Sargent 1988).

Social death is also a useful concept for describing practices near the end of life. In some societies, ritual mourning practices may begin before cardiopulmonary death occurs, since the ill or extremely aged person is viewed as meeting cultural criteria for social death. Or those who are very old may be viewed as almost dead. Many have argued that the warehousing of the elderly in sub-standard US nursing homes constitutes a form of social death. In a series of pioneering ethnographic studies of hospital-based death in the United States—in the immediately “pre-bioethics” period—Glaser and Strauss (1965, 1968) described the isolation of the dying as a form of social death.

Arguably the most important example of social death in contemporary biomedicine is the notion of “brain death.” A body maintained in a modern intensive care unit, with heart beating and lungs inflating and deflating, appears to most observers as a living being. Yet a diagnosis of brain death results in that person’s abrupt transition to a socially recognized state of death, and transforms the corpse into a container to house organs awaiting harvesting for another donor. A detailed analysis of the historical development of the concept of brain death, as well as a chronicle of contemporary brain death debates, is found in Margaret Lock’s 2002 study Twice Dead. Lock uses the comparative method to reveal how culture shapes seemingly technical scientific and medical practices. By contrasting Japan and the United States, she reveals how the category of social death can only be understood in cultural context. It might appear at first that the state of brain death follows the straightforward application of a set of technical criteria about the functioning of the human brain. But Lock tells the story of Japanese resistance to organ transplants that require the use of a brain-dead patient because in Japan, the core site or physical location associated with personhood is the heart, not the brain. Lock makes it clear that the story is not simply about “traditional beliefs” and reveals that many features of contemporary Japanese society—including distrust of the medical profession—play a role in widespread resistance to organ harvesting from brain-dead donors.

NEW RITUALS OF DYING
For most people in the wealthy, developed world, the idea that death is an evil to be prevented at all cost, including with the use of aggressive therapies like the totally implantable artificial heart, is commonplace. Buoyed by past successes, the arc of medical practice has extended to the moment of death, which increasingly is seen as a process to be stopped whenever possible (Callahan 2000). As new technologies became available, seeing a patient in cardiac arrest necessitated an action. Resuscitation, or attempts at resuscitation because of the technique’s limited efficacy, became routinized and normalized in the moments before death (Timmermans 1999). By the late 1960s, within the sphere of biomedicine “dying” became defined as a problem in need of a solution.

In the United States, the outcome of the many commissions, legal cases, and academic discussions, as described by Jonsen in the Birth of Bioethics (1998), has been a set of novel, autonomy-based practices that seek to enhance the self-determination of the dying. These practices also aim to protect patients from the abuses of overzealous physicians “programmed” by their instrumental training to over-treat, prolonging the dying process. They include:

1. formal implementation of advance care planning (and execution of advance directives), institutionalized by
WHEN CAN HUMAN LIFE START?  

What differences make a difference?  

Thus far, only broad cultural responses to death have been considered. With increased border crossing and South/North migrations across the world, how should we address cultural difference in bioethics? (Marshall and Koenig 2004). Turning to contemporary biomedicine, a substantial body of research documents the relevance of ethnic or cultural and religious differences in the experience of death and dying and in clinical approaches to end-of-life care (Long 2005; Volandes et al. 2008; Finley, Kristjansdottir, and Forgeron 2009; Blank 2011; Coolein 2012). However, health researchers and clinicians generally do a poor job of making clear analytic distinctions among the key elements of difference, in answering the question, “What makes a difference?” When we talk about cultural difference, do we mean a patient or family’s voluntarily adopted and expressed ethnic identity, their nation of origin if recent immigrants, their race as assigned by a government enforcing discriminatory laws such as segregation or apartheid, or their adoption of specific health-related practices such as diet or use of medicinal herbs? In health care research there is considerable confusion in terminology, particularly with regard to the use of the term race.

Throughout the world the lack of consistency in the use of terminology for concepts of race, ethnicity, ancestry, and culture is manifest in the wide variance in terms used to describe individual and group identities. In the United States, terms such as white, Caucasian, Anglo, and European are routinely used interchangeably to refer to certain groups, and black, colored, Negro, and African-American are used to refer to other groups. White-black comparisons are straightforward in contrast to the confused use of terms such as Hispanic and Asian. Both of these labels, one based on linguistic criteria and the other on continental origin, lump together many populations of people reflecting enormous variability in factors related to health and medical care. The terms we use gloss over enormous diversity and are understood differently across the world.

Debates in the scientific literature focus on the appropriate use of terms such as race, ethnicity, and culture. Asking how race is relevant to bioethics, death, and end-of-life care is relevant, but caution is needed whenever the category of race is invoked. Much is “at stake” in how these categories of difference are utilized when conducting research or in designing programs to improve the care of patients, by way of enhancing the cultural competence of health care providers who must aid patients and families in ethical decision making at the end of life. In particular, approaches to conceptualizing disease etiology or health outcomes may have moral significance if one naïvely assumes that culture predicts behavior in a precise way or that something essential or inherent in a certain population leads to poor health outcomes or barriers to health care access (Yasmin 1997; Koenig, Lee, and Richardson 2008).

In the case of black-white differences in infant mortality or homicide rates, for example, how one thinks about causation, and the relative contribution of genes, environment, and social structure, may determine the type of intervention recommended. Meaningful genetic and biological differences do not always map clearly onto social categories of human difference, whether defined as race, ethnicity, or culture. American patients who self-identify as African American generally seek more aggressive care and are underrepresented in hospice services (Crawley, Marshall, and Koenig 2001). If we talk about racial differences about preferences for palliative care services, what exactly do we mean? In the United States efforts to tease apart the independent contributions of race and socioeconomic status when analyzing health care outcomes may be daunting. Studies by Angelo Volandes and colleagues (Volandes, Ariza, Abbo, and Paasche-Orlow 2008; Volandes et al. 2008) suggest that preferences in end-of-life treatment are influenced not by race but by “health literacy.” In these studies, to control for race as a variable, the researchers surveyed two populations—whites and African Americans, and whites and Latinos—about their preferences for aggressive versus palliative treatment; prior to watching a two-minute video about advanced dementia, participants with low literacy (both whites and African Americans) tended to prefer aggressive care more so than did highly literate participants, but after viewing the video, there was no significant difference in distribution of preferences by race or literacy. These results were echoed in the second study comparing white and Latino groups.
Although the dimensions of difference most relevant to end-of-life care are likely to be social or cultural, biological or genetic variation may also be germane. For example, the field of pharmacogenomics tracks individual and group differences in drug metabolizing enzymes to predict response to medications such as chemotherapy or pain medicines. Although classic understandings of human “races” do not correspond to actual genetic variation at the molecular level, there may be gene frequency differences among socially defined populations relevant to pharmacogenomics. It has been known for decades that there is ethnic or cultural variation in the expression of pain or painful symptoms (Zborowski 1969; Garro 1990), the degree of variation in the actual experience of pain—possibly modulated through the action of pain medicines—remains unexplored.

Immigration status is another key category of cultural difference. Recent immigrants provide challenges to the health care system, particularly in end-of-life care. In much of the world, the bioethics ideal of open disclosure of information about diagnosis and prognosis is not the norm (Gordon and Paci 1997; De Trill and Kovalcik 1997; Mol 2008). In fact, patients and families may view the directness about diagnosis that is characteristic of US health care as needlessly and aggressively brutal, violating norms espousing “protection” of the ill. Although for some immigrant groups children may be seen as more in need of protection than adults, much pediatric palliative care literature recommends openness appropriate to the ill child’s age, as preferable to concealment. Procedures governing end-of-life care based on full and open disclosure of prognosis may seem unfathomable to immigrants, but it is perhaps the assumptions of bioethics that are culturally bound. As De Trill and Kovalcik note, “Those who argue that children always should be told the truth about having cancer must recognize that the truth is rather than understood. Lastly, the experience of those immigrants who are refugees from political violence or war adds another dimension. The effects of multiple losses—including the death of multiple family members, and loss of one’s country, one’s entire history—are difficult to predict but clearly shape a family’s response to serious illness and threatened loss. Responses may appear to be overly stoic or overly emotional.

When considering societies with histories of deep racial divisions, it is especially important to separate analytically the concepts of culture, ethnicity, and race from the effects of social and economic status. Historically underserved populations may have special barriers to end-of-life care that have little to do with difficulties in communication and are not related to their identification with a certain set of ethnic traditions. Culturally specific values and beliefs often exist but may not be of signal importance (Kagawa-Singer and Blackhall 2001). In a groundbreaking study, an American physician documented the lack of availability of narcotic analgesics in minority communities such as Harlem (a low-income, historically African American and Hispanic neighborhood in New York City); pharmacies simply did not carry the opiates that are “state-of-the-art” drugs for pain control (Morrison et al. 2000). The American “drug wars,” including the recent battles about the abuse of time-release opiates like oxycontin, are often fought in poor neighborhoods with limited access to legitimate employment. Patients from minority backgrounds may not receive adequate pain control if drugs are not prescribed because of fears of theft or abuse. When members of the health care team are hesitant to prescribe narcotics it may be a legitimate concern based on factual information about a particular family’s drug history, or it may be the exercise of racial stereotyping. The end result is the same: patients may be denied needed pain relief.

The experience of people with sickle cell disease, particularly African Americans, whose pain is often undertreated because of concerns about drug abuse, is another example of stereotyping. Culture thus contributes to inadequate symptom management, but indirectly, through the actions of health care providers, not the essential cultural characteristics of a population. Research in a Los Angeles emergency department documented that Hispanic patients with injuries identical to whites were given less analgesic medication (Todd, Samaroo, and Hoffman 1993). Do patients in such situations have different cultural values about analgesia? Can they exercise full autonomy when faced with decisions about foregoing or withdrawing life prolonging therapies? Surely not, without the assurance of adequate analgesia and palliative care.

Karla Holloway’s Passed On: African American Mourning Stories (2002) reveals vividly how the unique history of blacks in the United States—including the legacy of slavery, Jim Crow policies, and violent death, such as by lynching—shape the experience of death for patients receiving care in hospitals that were segregated two generations ago. Clearly difference is relevant to bioethics; assuming that end-of-life procedures and practices have universal applicability is at best naive and at worst harmful. In addition to the varieties of cultural and social class differences described here, other domains of difference that intersect with culture, such as gender, sexual orientation, disability, and religious background, must also be considered within bioethics (Parens 1998).
CULTURE MATTERS: BIOETHICS, END-OF-LIFE CARE, AND DECISION MAKING

In its report detailing needed changes in care of the dying, the Institute of Medicine has recommended attention to cultural diversity as a national policy objective (Field and Cassel 1998). There is a growing literature based on empirical studies documenting the salience of culture in multiple dimensions of end-of-life care for patients and families (see Crawley, Marshall, and Koenig 2001; Kagawa-Singer and Blackhall 2001; Koenig and Davis 2003; Smith, Sudore, and Perez-Stable 2009). Based on this literature, it is possible to identify the key domains of clinical and ethical significance in caring for patients from diverse ethnicultural backgrounds who are unlikely to survive.

In general, the cultural challenges of end-of-life care can be divided into two basic categories: those that do, and those that do not, violate the health care team’s foundational cultural values, norms that may also be enforced by legal requirements in some societies. In the first category are cultural values or practices that call into question the biomedical goal of combating disease and extending life at all costs. These are critical in end-of-life decision making. A family who refused to allow a potentially curative limb amputation for a female child with osteosarcoma because of beliefs about the need to preserve bodily integrity, and a daughter’s marriageability, would immediately create consternation for health care team members. By contrast, another family who wished to engage a spiritual healer to pray for a successful outcome would not create a cultural crisis, since the family’s desire for a prayer ceremony could easily and effortlessly be incorporated into the clinicians’ care plan.

Generally, issues such as care of the body after death do not provide a fundamental challenge to biomedical values and beliefs; thus customs prescribing particular approaches to post-death care are relatively easy to implement unless they violate laws governing disposal of the body. However, even in post-death care there may be situations that lead to cultural conflict, such as requests for autopsy or organ donation in situations where the wholeness of the body is highly valued. And the domain of grief counseling and bereavement care may or may not elicit conflict. For medical specialists focused on cure, less is “at stake” once a patient has died and can no longer be saved, but conflicts may still emerge over differing definitions of acceptable grieving practices.

FAMILY ROLES AND RESPONSIBILITIES IN SHARED DECISION MAKING

Within the current conventions of bioethical decision making about end-of-life care for a competent adult patient, the decisions are left up to the individual; theoretically, the family or broader community is not critical to the patient’s choices. Autonomy is the primary value at play. In the case of children or the severely mentally incapacitated, where family members become surrogate decision makers, the situation is much more complex. A growing body of research documents how autonomy-focused bioethics practices may not adequately meet the needs of patients from diverse backgrounds (White, Braddock, Bereknyei, and Curtis 2007; Mol 2008; Kon 2010). The value of respect for individual autonomy is not universal. Patients may express confusion and ambivalence when asked to participate in advance care planning about death (Frank et al. 1998).

Disagreements about the goals of care, although rare, are emotionally difficult for all. In many cross-cultural situations, the Western view that individual patients will (and should) make decisions about care may be too narrow. In some societies a social unit beyond the nuclear family may also have considerable decision-making authority. Elders in an extended family or clan group may expect to be involved, and patients may desire this. Integrating extended family or kin groups into care in a hospital, hospice, or nursing home is hard but may be desirable. Gender may play a role as well. In traditional male-dominated societies, mothers may never have experienced the level of decision-making authority automatically granted to both parents in North America or Europe. This may be a source of tension. Similarly, the evolving practice in pediatrics of requesting “assent” to care by older children, especially girls, may create tensions within the family.

A further tension may be created by the ideal “shared decision-making” model of bioethics, which espouses full participation by patient and physician. Tilden and colleagues have documented stress among family members involved in decisions to withhold treatment (Tilden, Tolle, Nelson, and Fields 2001). The impact of family involvement in decisions to terminate treatment has not been studied extensively. Inexperienced clinicians or trainees may present decisions about limiting painful or aggressive procedures, sometimes an opening to a transition to palliative or hospice care, in an insensitive way, making it appear that the family decision makers must give “permission” for futile care to be withheld. Although the family’s involvement in making decisions on behalf of their loved one is expected, few individuals, regardless of their cultural background, are able to do this easily. In fact, the resistance to giving up hope and explicitly limiting therapies found among families from diverse backgrounds may be appropriate. Models of care that do not require that curative therapies be abandoned in order to obtain excellent palliative services may ultimately lessen this problem (Drought and Koenig 2002). Patients or family members should never be told that care will be withheld; rather, the focus should be on meeting the needs of the patient and family. Moreover,
the shared decision-making model is an ideal, and it is subject to contradiction in situ by doctors and patients alike. In a longitudinal study conducted by Koen Pardon and colleagues, eighty-five cancer patients were studied between diagnosis and death: “In half of the cases, advanced lung cancer patients—or their families in cases of incompetence—were not involved in end-of-life decision making, despite the wishes of most of them” (Pardon et al. 2012).

VARIED UNDERSTANDINGS OF THE ROLE OF HEALTH PROFESSIONALS OR HEALERS

Just as the appropriate role of parents or family members caring for a seriously ill person may vary, the families’ expectations of the role played by health professionals may differ. In some societies, healers are expected to make a diagnosis almost magically, perhaps by feeling the pulse without asking any questions. Healers may exert considerable power and authority; they may expect and receive deferential behavior. Patients and families schooled in these traditions may be confused by the shared decision-making ideals of conventional biomedical practice. They may lose confidence in physicians who do not appear to know unequivocally the correct course of action but instead ask for the patient’s views. Thus, institutional attempts to enable patient autonomy, such as advance directives, “which are generally accepted in Western Civilization, hold little or no relevance” across nations and cultures (Cox et al. 2006).

In many societies the roles of healer and religious specialist intersect. “Each religious tradition has its own images and ideals of the doctor, in which the individual engaged in healing is defined as enacting some of the highest ideals of the tradition itself” (Barnes et al. 2000). The healer’s role at the end of life may be particularly meaningful, or taking on the care of those not expected to survive may be proscribed, as in the Hippocratic tradition.

Families who have been denied access to health care services may also question the trustworthiness of the “establishment” health system, worried that those in power do not have their best interest at heart. The disparities in morbidity and mortality across US populations suggest that often African American patients receive less intensive care. The irony is that research on end-of-life decision making in adults reveals that minority patients may actually desire more aggressive care near the end of life (Caralis et al. 1997; Tulsky, Cassileth, and Bennett 1997).

COMMUNICATION BARRIERS: THE NEED FOR TRANSLATION

Negotiating the appropriateness of clinical services for patients nearing the end of life is a complex task even when health care professionals, patients, and family members share fundamental goals and assumptions. By no means has a successful “formula” for such communication been established. When cultural barriers exist, particularly those exacerbated by language, the goal of open and effective communication and decision making is exceptionally difficult. Translators may be available only intermittently, and are often poorly trained.

The task of language translation in the arena of ethical decision making for end-of-life care is particularly complex. How does one translate a discussion about a “do not resuscitate” decision to a family with no previous experience of cardiopulmonary resuscitation (CPR)? Or to patients with no prior knowledge of the bioethics tradition of requiring permission not to offer CPR, even to a patient who is actively dying an “expected” death, or may be frail because of extreme old age? What if the language characters representing resuscitation are interchangeable with those suggesting the religious concept of resurrection? Although it sounds odd from the perspective of Western, scientific understandings of death, who would not elect to have themselves or their dying loved one brought back to life if offered the choice in those words? How might medical interventions at the moment of death be understood among practitioners of Buddhism who believe that rituals spoken during the dying process guide the “soul” through dangerous spiritual territory and ultimately determine where and how a person will be reborn? How do you negotiate with a family about the location of death—home versus hospital—against a cultural background where speaking of an individual’s death is thought to bring it about or where certain illnesses cannot be named? (Carrese and Rhodes 1995, 2000). The use of family members as interpreters, which may be unavoidable, may make discussions such as these even more problematic (Smith, Sudore, and Perez-Stable 2009). Family members may see their primary role as protecting others in the family from harm and thus “shield” them from information viewed as harmful. Such shielding is counter to bioethics norms of open disclosure.

Furthermore, models of professional translation, such as those employed in courtrooms where relationships are fundamentally adversarial rather than collaborative, assume that language interpreters should function as neutral “machines.” Health care providers need to be aware that translation services such as those available by phone from telecommunication companies may be based on legal models of interpretation. This stance ignores the interpreter’s potential value in providing information about the family’s cultural background, as well as providing language interpretation. When interpreters are engaged as full partners in providing care, they may aid in negotiations about difficult end-of-life dilemmas (Kaufert, Putsch, and Lavallee 1999). When included as part of the health care team—for example, in programs where native
speakers of commonly encountered languages are employed as bilingual medical assistants—interpreters can also serve the useful function of explaining the culture of biomedicine and its practices, and the seemingly peculiar assumptions of bioethics, to families.

INTEGRATION OF ALTERNATIVE AND COMPLEMENTARY MEDICINE INTO PALLIATIVE CARE

Patients and their families may be subject to strong pressures to utilize “ethnomedical” practices and procedures believed to be efficacious. Recent immigrants may utilize products obtained from their home country. Practices vary widely, including acupuncture, cupping or coining, leveling dietary prohibitions based on “hot-cold” belief systems, Chinese herbal products, Ayurvedic patent medicines, and full-blown rituals such as chanting and the sacrifice of animals. A skilled practitioner creates an open environment in which the patient, family, and perhaps a ritual specialist from the community may openly discuss the appropriate blending of biomedically sanctioned medicines and procedures with ethnomedical products. Although some patent medicines and food supplements are known to be harmful and may actually contain potent pharmaceuticals, the health care team is unlikely to obtain a full accounting of all treatments used for a particular dying patient unless a nonjudgmental attitude is maintained. This may be a challenge when a health care provider must compromise his or her own “ideal” care. For an effective patient-clinician relationship, clinicians must acknowledge the bias of their own medical knowledge, and assume “a basic equality between different healing systems” (Marian 2007).

The need to integrate alternative and complementary medicine into palliative care is not limited to patients from particular ethnocultural communities. For example, research documents that a large percentage of Americans have utilized “alternative” medicine in the recent past (Eisenberg et al. 1998), with prayer being the most widely utilized practice. Eighty-two percent of Americans believe in the healing power of personal prayer (Barnes et al. 2000).

THE MEANING OF PAIN AND SUFFERING

End-of-life care has as a primary goal the relief of pain and suffering. Cultural difference is relevant to pain management in multiple ways. The effectiveness of symptom management may be lessened by economic barriers to medicines or special treatments. Cross-cultural research has documented differences in the way people experience and express pain (Garro 1990). What is considered an acceptable way to express painful symptoms? Is stoicism rewarded? Are there gender differences in outward discussion of painful symptoms? Spirituality may have an impact on the meaning of suffering and hence on the management of symptoms. A study of infants and children with a rare genetic disease (recombinant 8 syndrome) in Spanish-speaking longtime residents of the American Southwest revealed the complexity of suffering in this community. The experience of affected children in the devout Catholic families was thought to mirror Christ’s suffering, providing meaning to an otherwise unexplainable tragedy.

DEFINING THE BOUNDARY OF LIFE AND DEATH

Biomedical definitions of death, including the concept of brain death, appear to be clear cut. However, when examined closely considerable ambiguity remains. Even among biomedical professionals one frequently hears confusion in language when speaking, say, about an organ donor who is technically brain dead but may appear to be as “alive” as adjacent patients in an ICU. These brain-dead bodies experience a second “death” once organs are retrieved for transplantation and ventilatory support is removed (Lock 2002). It is thus not surprising that patients and families can also become quite confused about states resembling death, including brain death, the persistent vegetative state, or coma (Kaufman 2000; Kaufman et al. 2011).

Disputes arise when a patient meets the biomedical criteria for “brain death,” but the family refuses to allow withdrawal of “life” support. Joseph Fins describes two clinical negotiations about withdrawing life support from children defined as brain dead (1998). In one case, the hospital team engages the family’s orthodox rabbi and other religious authorities in a complex series of negotiations, respecting throughout the family’s view that the patient is not truly dead and that only God can declare death. A more contentious case involves an African American family who maintains a stance of mistrust toward the health care establishment in spite of every effort on the part of the clinical team. The family’s past experience shaped its understanding of the team’s intentions in spite of great effort to gain their trust. Disputes such as these are the “hard” cases, revealing cultural clashes that cannot be ameliorated simply by motivated clinicians, ethics consultations, sensitivity, or excellent communication skills, although clearly those things may keep conflict to a minimum or may keep small cultural disputes from erupting into major pitched battles.

Conflicts may arise about the care of the body after death, particularly the question of autopsy, since in some societies the body is considered inviolable after death; its contents sacred and necessary for the individual’s appropriate survival into the afterlife. These cultural practices were most fully developed in Egyptian dynasties, where funeral practices and preparation for life after death—including mumification and building of elaborate tombs—consumed the society’s symbolic attention and material resources. The acceptability of autopsy, or other uses of the body following death, is deeply sensitive
to cultural and religious prohibitions. Knowledge about the acceptability of autopsy, or requests for organ donation in the case of acute trauma, cannot usually be guessed by “reading” a family’s background. Furthermore, different ethnocultural groups may have varied understandings of the nature, meaning, and importance of cognitive impairment in a patient. In a society where social relationships are a core value, esteemed more highly than individual achievement, disabilities that affect intellectual functioning but do not interfere with the affected person’s role in the family may be more readily “accepted.” By contrast, in some societies severely handicapped people may experience a form of social death, isolated from the broader community.

ACCEP TANCE OF HOSPI CE PHILOSOPHY
Utilization of hospice care programs is not identical across racialized US populations. African Americans utilize hospice services at a lower rate than do European Americans. Home death is often considered an ideal within the hospice philosophy. A good death is often characterized as one that takes place at home, surrounded by family and/or friends, with pain and symptoms under control, spiritual needs identified and met, and following appropriate good-byes. Traditionally, this ideal good death required giving up curative interventions. In the 1970s, when hospice care became a viable alternative in the United States following its creation in the UK, aggressive end-of-life interventions became commonplace, and efforts to secure patient participation in decision making were not yet fully realized. Thus, the home became a refuge from the ravages of hospital death. Even though the strict implementation of a six-month prognosis requirement for hospice is changing, it remains difficult to predict the terminal or near-terminal phase of common illnesses, particularly cardiac, pulmonary, and metabolic conditions, in contrast with cancer. Acknowledging that death is near may be particularly difficult. Home death may not be valued in ethnocultural groups where it is considered inappropriate, dangerous, or polluting to be around the dead. Among traditional Navajo, the dying were removed from the hogan dwelling through a special door to a separate shed-like room to avoid the catastrophe of a death occurring in the hogan, which would then have to be destroyed. Burial practices were organized to make certain that ghosts could not find their way back to the hogan, and family members did not touch the dead body. This task was relegated to outsiders. These issues remain salient for those practicing in the US Indian Health Service (Carrese and Rhodes 1995, 2000).

CULTURE, GRIEF, AND MOURNING
Bioethics practices generally focus on decision making prior to death. Clinical interventions to aid the bereaved—increasingly seen as essential services to be provided to patients and families—must take into account cultural differences. It is critical to acknowledge that Western ways of grieving and disposing of the body are not universally accepted as the “right” way. It is also likely that biomedical theories of grief and mourning, including definitions of normal, are inappropriately based on Western behavioral norms. For example, a standard way in the West of dealing with grief is to talk about one’s experience, one’s relationship with the deceased, and one’s feelings. But in some cultures, talking may disrupt hard-earned efforts to feel what is appropriate, and to disrupt those efforts may jeopardize one’s health. In some cultures, talk is acceptable, but one must never mention the name of the deceased person. In other cultures, talk is acceptable as long as it doesn’t focus on oneself. Even in the West, however, not everyone is open to talking. It is important not to label those who do not openly express their emotions as pathological. In fact, the concept of pathological grief is primarily a Western construction. A mother in the slums of Cairo, Egypt, locked for seven years in the depths of a deep depression over the death of a child is not behaving pathologically by the standards of her community (Wikan 1988).

There is enormous variation in what is considered appropriate behavior following death. The ideal among traditional Navajo is to express no emotion, while in tribal societies a death may be met with wild outpourings of grief, including self-mutilation (Barley 1997). In contrast to clinical notions of pathological grief, in some Mediterranean societies widowhood was considered a permanent state of mourning, and mourning clothes were worn for years, if not decades. In a compelling book titled Consuming Grief, Beth Conklin describes how native Amazonians assuage their grief by consuming the body of their dead kin (2001). A number of anthologies provide examples of the range of cross-cultural variation in post-death management (Jackson 1976; Counts and Counts 1991; Huntington and Metcalf 1991; Nelson 1993; Young 1997).

THE NEED FOR CLINICAL COMPROMISE: A CHALLENGE FOR BIOETHICS
Respecting cultural difference may offer a profound challenge to health care practitioners’ most fundamental values. In perhaps the best text explaining the cultural dynamics underlying the treatment of a critically ill patient, Anne Fadiman, in The Spirit Catches You and You Fall Down (1997), offers a detailed account of how the physicians caring for a young Hmong child with life-threatening, difficult-to-control epilepsy ultimately fail her because of their desire to offer her “state-of-the-art” care identical to that offered to their other patients. Through her detailed ethnographic account, Fadiman reveals how in this case the physician’s quest for the “perfect”
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treatment is the proverbial “enemy of the good.” The parents of the child, Lia Lee, were refugees from the American war in Southeast Asia, illiterate in their own language, with ideas about the cause of epilepsy and its appropriate treatment that were completely at odds with the views of the Western health care team. They were not, however, the only participants in the exchange shaped by cultural background and context (Taylor 2003a, 2003b). Fadiman’s work documents the culture of biomedicine, explaining with great clarity how the physicians’ uncompromising dedication to perfection kept them from negotiating a treatment regimen acceptable to all.

Often in cross-cultural settings it is imperative to learn to compromise one’s own clinical goals in order to meet the patient “halfway.” Fadiman’s book recounts the profound miscommunication between the pediatricians and family physicians involved in Lia’s care, the Lee family, and the broader Hmong community in California. When her parents are unable to carry out a complex regimen of anti-epilepsy drugs, the child is turned over to the state’s child protective services agency, provoking a profound and deepening spiral of tragedies. In the end, the physicians wish they had compromised their goals and prescribed a more simple medication schedule. Ironically, the parents’ observation that the medicines were making Lia sick proved true in that one of the antiepileptic drugs contributed to an episode of profound sepsis that resulted in Lia’s persistent vegetative state. After its publication, a number of American medical schools assigned this book as a required text in cultural sensitivity training. Its power lies in revealing both sides of a complex equation: a Hmong enclave transported to semi-rural California and a group of elite, Western-trained physicians and health care practitioners caught up in a drama they cannot understand, not because the Lee family’s cultural practices are so esoteric but because they fail to recognize how their own cultural assumptions and deeply held values limit their ability to help the ill child.

THE CULTURE OF BIOMEDICINE AND BIOMEDICAL DEATH REFLECT FEATURES OF US SOCIETY

In the United States, national efforts to improve end-of-life care often include the notion that cultural change is essential for reform to be successful (Moskowitz and Nelson 1995). Yet, what this cultural change would look like and what barriers to change exist remains unclear. National public awareness campaigns such as “Last Acts” or the “Project on Death in America” have used a variety of strategies to change the culture of dying in America, including working with the media. For example, one strategy has been to sponsor scriptwriting conferences to encourage widely viewed television programs to include realistic stories about patients near the end of life. In fact, one episode of a popular prime-time medical drama focused on end-stage cystic fibrosis. Many narratives created for television convey the idea that a comfortable, pain-free death is possible and should be demanded by patients and families as an essential feature of a comprehensive health care system. More true-to-life portrayals might convey the important lesson that physicians and other caregivers may forgo their most aggressive efforts at cure without abandoning patients.

Unfortunately, these efforts at promoting cultural change ignore a fundamental and problematic social fact—a profound cultural resistance to foregoing high technology interventions and giving up hope for recovery. Narratives of hope and recovery compete with stories of patients abandoning efforts at cure after a valiant struggle with disease.

Empirical bioethics research by Barbara Koenig and others revealed that patients from minority backgrounds, in particular recent immigrants, seemed to lack a sense of the widely accepted narrative structure of end-of-life care that English-speaking, middle-class European American families understood more readily. In particular, the idea that patients and families would make an explicit choice to abandon curative therapy, followed by the “limiting” of aggressive interventions like intensive care and cardiopulmonary resuscitation, did not seem to be a story many minority patients understood. Recent Chinese immigrant patients could not answer questions that presupposed a transition from curative to palliative goals; it was simply beyond their experience (Hern et al. 1998). In their worldview, doctors do not stop treating patients. Efforts to change the culture through engagements with the media—encouraging op-ed pieces in newspapers, scriptwriting workshops, and so forth—may educate potential patients about existing approaches in palliative and hospice care.

One cultural barrier is particularly difficult to surmount. Before physicians can recommend palliative care and before patients and families agree to it, in the current biomedical system one must first accept the possibility that death is imminent or at least that one’s likely survival is seriously limited. Eventually, reform efforts to introduce palliative care early in a trajectory of disease or illness may decrease the need for patients or families to embrace their own death in order to make a clear transition between curative and palliative modalities of treatment. But it is unlikely that the tension caused by the need to balance conflicting goals will ever dissipate totally (Callahan 2012).

Even if one embraces the narrative of limiting aggressive treatment and adopting comfort care, including attention to spiritual and interpersonal goals, as a good idea “in principle” for those facing death, there still exists the radically difficult and jarring transition itself, the need to imagine you or your family member as now taking
center stage in a particular end-of-life narrative. It is no longer theoretical but real. The resistance to seeing oneself (or a loved one) in this role is considerable and may prove insurmountable for many. A set of powerful cultural narratives operates to feed this resistance and encourage its perpetuation. Consider, as one example, the heroic narratives of successful research and triumphant cure that are much more often portrayed by the media than stories of failed therapy and excellent end-of-life care (Koenig 2001). The content of public relations materials produced by medical centers and ads published by drug companies conveys powerful cultural metaphors that are directly counter to the mundane realities of palliative care, often focused on managing symptoms such as constipation. Hospital ads suggest that it is vital to “keep shopping” and eventually you will find the program offering the experimental or innovative therapy that will lead to cure. The heroic search for cure is celebrated in media accounts such as the film Lorenzo’s Oil or news accounts of a family seeking gene therapy to cure their child’s severe, life-limiting genetic illness (Canavan disease). A full analysis of the culture of dying in the United States must acknowledge these powerful counter images.

It is important to bear in mind that such stories and advertisements are features of a particular political economy of health care. Unlike providing palliative care, which does not generate an economic surplus for hospitals, administering chemotherapy generates profits even when the likelihood of its success is low or nonexistent. One recent study documents that curative chemotherapy is often given very close to the end of life, when its use may be futile (Emanuel et al. 2001). This is not to suggest that individual physicians are primarily motivated by financial gain when they prescribe chemotherapy that they know has little chance of success. The full picture is a much more complex mix of faith in research, trust in therapeutic rituals as opposed to inaction, genuine prognostic uncertainty, and unwillingness to acknowledge the likely poor outcome of patients one knows well. But it is critical to acknowledge that the economic structure of US health care has up to now created few barriers for the use of advanced life-prolonging therapies such as chemotherapy, or days in an intensive care unit, at least for those with insurance or access to government-funded programs. The most intensive services often generate the highest profits. By contrast, hospice and palliative care programs are often supported by philanthropy; providing excellent palliative care is at best revenue neutral and more often a money loser for medical centers. Thus, the political economy of health care supports the aggressive use of technology until the last possible moment, often leading to its overuse. Culture shapes the realities of care at many levels. It remains to be seen whether efforts to reform health care can successfully alter this dynamic.

CONCLUSION: BIOETHICS, CULTURE, AND GLOBALIZATION

The experiences of death are culturally constructed within particular social and historical moments. A full account of death within bioethics must take into account the network of human relationships within which behaviors and practices associated with death and mourning are situated. A cultural analysis of the rituals and symbols evoked by death and dying also suggest the powerful role of social and economic conditions that necessarily define and constrain death experiences, including decision making, the treatment of bodies, and reactions to grief. Viewed from a cultural perspective, death practices provide an important foundation for understanding the meaning of human suffering in response to loss.

Cultural analysis using ethnographic methods provides unique insights into the nature of bioethics practices that have become the new rituals of dying. These insights will be of increasing use in the context of a globalized biomedicine, which moves bioethics practices into multiple settings around the globe, often quite different from the social and historical context that shaped their development (Marshall and Koenig 2004). When implemented in societies characterized by an increasing degree of cultural diversity, the limitations of these practices, and their cultural roots and sources, are revealed. Cultural analysis—particularly studies that highlight the response of ethnically different others to bioethics practices—is incomplete if not augmented by attention to the political economy of health care. Cultural variability does not determine one’s views about death. Rather, we are all shaped by culture, and in turn contribute to dynamic change.

There is a naïve hope that cultural competency training will lead effortlessly to improved outcomes in end-of-life decision making. It may under some circumstances, but significant cultural difference inevitably brings with it true conflicts that may not be resolved, even with ideal, open communication and mutual respect. In some situations, the distance between families and the health care team may be too profound to overcome in spite of considerable efforts by all. Anne Fadiman recounts that a physician involved in the care of Lia Lee lamented that even if it had been possible to send the Lee family to medical school with an interpreter, the difference in worldviews separating a refugee Hmong family from mainstream biomedical pediatrics would remain insurmountable.

How one thinks about culture matters. A serious flaw in current cultural competency training in biomedical settings is a simplistic and unsophisticated account of culture itself. It is almost as if there is a belief that culture codes for—and predicts—behavior in the same way that DNA codes for a certain protein. Reductionist approaches to education in how culture matters in bioethics will inevitably fail because, at best, they teach a few general
clues that must be verified through interaction with a family and, at worst, they model an unsophisticated approach to culture that leads to simple stereotyping, thus doing more harm than good (Taylor 2003a, 2003b). Educational techniques and programs that emphasize an interpretive approach to understanding cultural difference are more likely to be successful.

If one accepts that analyzing the nature of ethical practice, and ultimately improving end-of-life care, is a fundamental goal of bioethics, then bioethics scholars must take account of culture in their work. Culture must be engaged at many levels, not just through a focus on the other. Ethnic and cultural difference in response to bioethics practices—the new end-of-life rituals—must be respected in a sophisticated manner, free of harmful stereotyping. But we must not stop there. Those working in bioethics must engage in a critical analysis of the culture of biomedical science—and bioethics practices—as they move together around the world. And finally, we must be active students of the cultural assumptions underlying bioethics itself, interrogating the foundations of the field.

SEE ALSO Advance Directives and Advance Care Planning; Aging and the Aged; Autonomy; Bioethics; IX. Anthropology of; Body: II. Cultural and Religious Perspectives; Body: III. Commodification; Care, Death, Definition and Determination of; End-of-Life Care; Feminism; Grief, Ethical Implications of; Harm; Hospice and Palliative Care: Professional Education; Human Dignity; Infanticide; Life, Life, Sanctity of; Life-Sustaining Treatment and Euthanasia: I. Ethical Aspects of; Literature and Health Care: Narrative; Pain and Suffering; Pediatrics, Intensive Care in; Race and Racism; Relativism, Cultural and Ethical, Right to Die; Policy and Law; Shared Decision Making; Suicide; Vegetative and Minimally Conscious States; Virtue and Character

BIBLIOGRAPHY
Blake, Deborah. 2000. Unpublished manuscript, Regis University, Denver, CO.
Death


Young, Colin Murray; Pittu Laungani; and Bill Young. 1997. Death and Bereavement Across Cultures. Routledge: London.

The Concept of Natural Death. In no small measure Vedic (Brahmanical) religion (1500–500 B.C.E.), its sequel now called Hinduism, and other Indian religions (Jainism and Buddhism) inherited views of death from the Indo-Europeans. Because life expectancy in the prehistoric world was about thirty years on account of disease, natural calamities, and warfare, people turned to religion for help, performing rituals for health, physical security, longevity, or immortality.

A proto-Indo-European myth about death involves a primordial sacrifice in which Manu (literally, Man), the first priest, sacrifices Yama, his twin and the first king, to create the cosmos, including the realm of the dead. Located to the south, symbolizing warmth, the realm of the dead is described as a paradise where cold, suffering, labor, injustice, evil, darkness, aging, sickness, and death are unknown (Lincoln 1991). According to one Indian version found in the Rigveda (10.13.4)—the earliest and most authoritative Hindu scripture—Manu sacrifices King Yama, who shows the path to where the forebears of old had gone. The Rigveda considers this place either the southern world or the highest region—a paradise with light, beauty, and joy. (In later texts, Yama is demoted to preside over a hell; the fetters that once bound him as the sacrificial victim for creation are now used by him to fetter sinners.) In another early Indian myth the Purushasukta (Rigveda 10.90), Manu, the sacrificial victim, is bound, killed, and dismembered. His mind becomes the moon; his eye, the sun; his mouth, the fire; his breath, the wind; his feet, the earth. Henceforth each sacrifice repeats the cosmogonic one, with animals representing the human victims of earlier Indo-European myths or rituals, to ensure the continued existence of the cosmos. A symbolic reenactment of the cosmogonic sacrifice occurred in the funeral ritual; according to Rigveda 10.16, different parts of a dead person go to various parts of the universe.

The Vedas prescribe a life of 100 years, indicating a desire for longevity and natural death. For those who die a natural death, the funeral ritual (shraddha) will be performed; this will provide them the status of ancestor, ensuring rebirth as a human or existence as a god (hence creating a double buffer against death as annihilation).

Drawing on their pastoral practice of seasonal migration, the Indo-Europeans referred to the dead as traveling along a pathway. In India the Vedas also referred to the paths of the dead. The straight and easy one ascends to a luminous paradise where the gods live; the tortuous and difficult one descended to a dark netherworld. By performing sacrifices and funerals, people gain access to the former (Rigveda 10.2.3). The most common Indo-European image of the dead following a path involves crossing a river or ocean by means of a ferryman by a ferryman, the personification of old age, to paradise.

II. EASTERN THOUGHT

This entry provides an overview of concepts and practices related to death in South, Southeast, and East Asia with special reference to the religions of Hinduism, Buddhism, Jainism, Confucianism, Daoism, and Shinto. Unlike other species, humans can reflect on death. One response to the mystery and fear humans associate with death is to create systems of religious meaning that give purpose to life in the face of death. A corollary of the fact that people can reflect on death is their realization that it is possible for them intentionally to end life. Religion constrains this possibility in the interest of human survival; only a few exceptions to the taboo against killing humans are allowed. Animals, by contrast, cannot decide to kill themselves and seldom kill members of their own species.

Concepts of death in Asian religions include two basic types: natural, for example, death by disease and old age, and unnatural, for example, death by an accident, by the intention of another person (homicide), or by one’s own intention. The latter, here called self-willed death, may be subdivided into three types: (1) suicidal (self-willed death out of depression or passion, an irrational and private act); (2) heroic (self-willed death by warriors—and sometimes their wives—to avoid being killed or captured by an enemy and therefore shamed or to follow a leader in death because of loyalty); and (3) religious (self-willed death as a rational and public act sanctioned by a religion, for example, in cases of terminal illness, in response to debilitating old age, or as a means to achieve heaven or enlightenment).