

Cultural Diversity, Spirituality, and End-of-Life Care

James W. Green

America is becoming more ethnically and racially diverse. By 2050, there will be no single majority. Whites will still dominate politically and economically, but they will share minority status demographically with Latinos, Asians, African Americans, and immigrants from South Asia, the Middle East, and probably most other points on the globe. Latinos, Asians, and African Americans combined will be about 54 percent of the total population by the end of the fifth decade.¹ One response to that emerging reality has been a call for culturally appropriate health care for minority patients and their families, “cultural competence” in medical consultations and at the bedside. Although competence in cross-cultural work remains difficult to define or evaluate, for those who work with the dying, diversity is a very real issue.

“Spirituality” in end-of-life care is a parallel conversation that has been a topic in the professional journals of nursing since the late 1980s and for good reason. Nurses, as well as chaplains, are the professionals most ob-

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viously present with the dying and their families. Palliative care has emerged as an area of medicine where matters of spirituality have a place. And like cultural competence, spirituality is difficult to define and difficult to evaluate. Moreover, the presence of death adds urgency to spiritual questions of ultimate value. Expressions of faith and trust are invoked by the explicitly religious and by the many Americans who prefer to call themselves "spiritual but not religious." Our multi-denominational and sometimes contentious religious history assures some level of diversity, and the expected arrival of more people of Hindu, Buddhist, Muslim, and other loyalties simply adds to the mix already here. There is a link, then, between that demographic diversity and spirituality. One does not exist without the other, and neither stands alone.

The aims of this essay are to explore the connection between spirituality and diversity and to propose ways end-of-life care providers can usefully respond to their culturally varied patients and, in so doing, acknowledge the spiritual dimensions of that work. The argument is in three parts: (1) how Americans generally think about death and what it leads them to expect when it is near; (2) how the culture of hospitals, the place where most of us will die, shapes that experience; and (3) how minority patients and families bring their own expectations into that setting. I will preface that discussion with some comments on how cultural competence in health care has been typically understood and propose an alternative understanding. I will turn then to its application in multi-cultural settings and the implications for spiritual care. Underlying this exploration is a distinctive, anthropological idea of what a culture is, something more interesting than the unfamiliar beliefs and customs it is sometimes thought to be.

WHO SPEAKS OF DEATH?

It is a misleading cliché that America is a death-denying society. Death is on display daily. It is a fixture of newspaper stories and primetime television. Tragedies and mayhem abound. Obituaries are one of the most favorite features of newspaper readers. Most of these deaths are, of course, "other people's," almost generic and at a safe remove. Personal death, our own or that of someone we know and care about, is the problem. Dying people are usually sequestered in institutions at the end of life, which is something

fairly recent. Their invisibility is not the problem—the problem is the absence of a suitable language for discussing what is happening to them.

Historically, the institutions of religion provided rhetoric of dying and death, through their texts, rituals, prayers, and functionaries. But their influence waned, especially in the second half of the twentieth century, as doctors and scientific medicine supplanted priests and ministers as the managers of our exit from this world. Along with that shift, an explicitly humanistic counter-narrative emerged, promoted most famously by Dr. Elisabeth Kübler-Ross in the 1960s. She introduced other physicians and the public at large to her well-known five stage theory of dying. It proclaimed the “good death” a worthy and comforting goal; the stages supplied a vocabulary and a road map for getting there. The initial popularity of her model with health care and social services professionals, and its subsequent availability to the public in inexpensive paperbacks, made her the first modern American guru of death. Others have since added to her perspective, creating our current vernacular model of death.

The core of the model is the familiar American value of individualism with its validation of personal preference, choice, and individual need over communitarian interests or obligations. Kübler-Ross viewed dying as a self-focused psychological struggle to “come to terms” with the inevitable and in so doing experience a unique kind of personal growth. We can die heroically, as obituaries commonly say, after a “brave struggle” or “battle” with a terrible disease. Similarly, Bill Moyers’ impressive PBS documentary about contemporary dying, *On Our Own Terms*, featured the desperate search of patients for their “good death” and a “death with dignity.”² That theme is now common and marketed as well in shopping mall bookstores. “Designer dying,” some critics have called it, promotes going out in the style one prefers.

There is also a plethora of niche marketed titles for Christians, Jews, gay couples, bereaved pet owners, non-believers, and those who say they have had a near-death experience and don’t worry about it anymore. Even in a small but vigorous genre of children’s books available for adults who apparently don’t know quite what to say when a pet or grandparent dies, the focus is on the child’s private suffering with minimal discussion of what parents or other adults might be doing in their own grief.³ Clearly, there are many voices speaking of death for a public eager to know just what to say and do at life’s most fragile moment. The bereavement selection in any

greeting card shop is particularly telling on this point. Much repeated expressions—"words cannot convey"—and conventional sentiments—"our thoughts go with you"—are unwitting confessions of the verbal poverty that surrounds death in an individualistic, consumerist society.

Finding a useful language for comfort and hope in dying is one critical issue. A second one is power. Who is authorized to act in relation to death, and what limits are there on their actions? Legal devices, such as advance directives and durable power of attorney, are useful for managing these issues up to a point. But what of responses to death that are problematic or run counter to what many Americans consider acceptable, such as Oregon's physician-assisted suicide law? Political passions around how choices are made at the end of life should not be surprising, given that individualism and its corollary, choice in the marketplace of services and ideas, are the touchstones of American vernacular culture. In an odd sense, modern medicine is an enabler of that. It has made the timing of death less a matter of fate or of "God's will" and more one of technological management. Timed death makes more choice available than ever before. It also complicates the hunt for a useful language for talking about it. It is the "coming together of three elements: the work and goals of medicine, American individualism, and the market-oriented health care delivery system"⁴ that has created the deep ambivalence regarding death in the hospital culture.

Choice and power are also issues for those whose cultural background does not include individualized dying under modern medical management. In 1997, anthropologist Anne Fadiman published a widely read account of a young patient's epilepsy and her parent's resistance to what her American doctors wanted to do about it. Fadiman's title tells it all: *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures*.⁵ The "collision" was between Lia Lee's genuinely caring physicians and what they felt was necessary for her and the insistence of her parents that traditional Hmong treatment and healers were adequate. The diagnosis the parents accepted was "soul loss," for which herbal medicines and the services of a Hmong shaman were necessary. That conflict made the young patient's death inevitable. The sad story of Lia Lee has become a text widely read by undergraduates and even in some medical schools where it is regarded as a morality tale on behalf of cultural competence. Fadiman's view, her "collision" model which drives the story, is that cultures are something like ships in the night, each one a self-con-

tained vessel of distinctive beliefs, rituals, ethno-medical practices, foods, and clothing distinguishing those aboard one from the passengers on another. A culture in this sense is the shipboard inventory of named and described features that make each community unique. A minority culture is like that too, something “out there” that thrives more or less apart from the mainstream.

I propose an alternative view of culture with implications for spirituality and diversity at the end of life. My argument is that the thing we call “culture” is not the inventory of exotic stuff carried along in a self-contained vessel, or summarily presented as “pointers” in a handy reference book. It is narrative—individual, familial, and communal—enacted at sites where differentials of power are implicitly or explicitly in play. Beginning with the contributions of Kübler-Ross and others, there is a narrative and accompanying vernacular language of death. Terri Schiavo’s death, for instance, generated a distinctive narrative that was a political drama shaped by the courts, religious authorities, activist interest groups, her parents, and her husband. Her doctors had their issues too but rarely spoke out. Close attention to language and power is what cultural competence is about.

CRITICAL JUNCTURES WHERE CULTURE MATTERS

Cultural competence as a professional goal was first developed in the 1980s, in social work and psychology, and has been elaborated since by others in education and health care. Typically, those who promote it emphasize a small number of themes, including attentiveness to the trainee’s sense of self awareness, attitudes toward racial and ethnic others, basic knowledge of cultural differences, and styles of communication in professional settings. Of these, communication skills are the least developed, information about broad cultural differences the most. Books like *Culture and Nursing Care: a Pocket Guide* provide general information and trait lists. For example, the section entitled Death Rituals for Japanese Americans is about one page long and typical of its six entries: “Care of the body: Cleanliness important in preparing the body, and maintenance of dignity and preservation of modesty for viewing the body. Many Japanese Americans of Buddhist or Shinto faith will have the body cremated.”⁶ This description isn’t wrong; it is just too general to be of much help.

By contrast, the Association of American Medical Colleges issued a lengthy report in 2005, *Cultural Competence Education*, which moved well beyond trait lists and emphasized specific skills in doctor/patient interaction with admonitions like "Exhibit comfort when conversing with patients/colleagues about cultural issues." The strength of this approach is that it promotes (1) physician knowledge of how patients from diverse groups perceive illness and symptoms; (2) ways of using that information when asking and answering questions; and (3) alertness to how the customary practices of the health care system may be a challenge to patients unfamiliar with it, especially those from minority communities. The emphasis is on narratives in medical settings where the opacity of medical practices and routines are a given. To see how this operates in end-of-life care, I look briefly at four critical areas (there are others, of course) to suggest something of what cultural competence means in practice. Following that, I take up spirituality which I understand to be one dimension of such practice.

Patient Autonomy

Patient autonomy is one of the keystones of American health care, valorized both in law and popular culture. Informed consent and advance directives are two parts of a larger configuration that includes Kübler-Ross' "good death," "death with dignity," death "on our own terms," the myriad ways people grieve and "celebrate" a departed life, and the search for "closure" so the bereaved can "move on." How these are expressed in speech and behavior varies with individuals and within ethnically distinct communities.

Ronald K. Barrett, an African American psychologist at Loyola Marymount University, is well known for his research on end-of-life issues in the Black community. He suggests that something a bit different than the overt individualism of patient autonomy operates in these communities. Elders, he says, are highly esteemed and even when families are scattered, adult children are expected to contribute to their well being, whether the elder is a parent or a more distant kin. Obligations extend widely because collateral, self-help networks within families are common. Everyone is expected to help a failing elder even if their own resources are slim. In addition, fictive kin can be included in this group, contributing material support and counsel in decision making. "Potential fictive kin are close family friends, adopted or foster children (including those informally fostered), neighbors, and fellow church members. Black elders in nursing facilities who have no living relatives sometimes

describe these individuals as “family.” Obviously, this can complicate things when critical health decisions are being made since in many institutions only blood kin or kin by marriage have the authority to make medical decisions. Yet this flexibility in who counts as “family” works well because it disperses obligation and multiplies potential sources of help. In addition, decisions, including critical ones on medical intervention, are made communally, some of these “outsiders” expecting to be included. “For many African Americans,” writes Barrett, “this is a creative way they survive and maintain a sense of community and family even in situations where there is no family.⁸ Sometimes, he argues, the expectations of patient autonomy may have to yield to family interest, even when the understanding of who is family and who isn’t may not accord with the views of outsiders. Patient autonomy, as recognized in American law and practice, does not concur with this broader view of family. Nor does it fit the worldview of autonomy and family. American expectations of autonomy are outside the global norm.

Inequity and Trust

Because so many minority individuals and groups have been marginalized economically and politically, their distrust of mainstream institutions extends to health care as well. Underfunded facilities of the recent past continue to foster suspicion of medical institutions among African Americans. The fact that minorities are as much strangers to hospital culture as anyone else adds to the fragility of the relationship. In a survey of minority perspectives on the “good death” in modern hospitals, one focus group respondent told a researcher, “I think that, in the African American community, there was a time when sometimes people from [our] race could not get basic health care, and so the whole suggestion that everything isn’t going to be done for their loved one reminds them...that [the] culture is again saying we are less than white people.”⁹

A recent survey reported in the *Journal of the American Medical Association* compared Whites and African Americans on the kind of hospital care they wanted. Aggressive care at the end of life was favored by 15 percent of Whites, 42 percent of African Americans. Similarly, 16 percent of whites wanted cardiopulmonary resuscitation (CPR) when they were in terminal stages, 37 percent of African Americans preferred it.¹⁰ As could be anticipated, physician tact and treatment suggestions are, with minority patients and families, a potential mine field. This is especially so when further treat-

ment seems futile (“futility” a bioethical issue well discussed in the medical literature) or when families are not of one mind on critical decisions. Needless to say, discussions or even hints of physician-assisted suicide, legal in Oregon but occurring elsewhere under the euphemism secondary or “double effect,” are out of the question. If being attentive to narrative is one of the critical features of cultural competence, then, clearly the narratives of physicians and nurses are as important as the narratives of patients themselves.

Truth Telling and Bad News

Prognostication is one of the occupational hazards of medicine. That is especially so where estimates of the length or quality of remaining life are the issue. The topic is approached several ways. One is to suggest a different treatment regimen in the hope that trying something new might make the difference between a bad and less bad outcome. Nicholas Christakis writes that with prognostication, “Physicians and patients alike often have unrealistic hopes” and that an “optimistic presentation appears more sensitive and respectful....It is also seen as more professional and proper.”¹¹ Another strategy is statistical: “Most patients at this stage of your disease have about a 50–50 chance of living out a year.” Christakis says doctors feel they are on firmer ground when their guesses are backed by numbers and research. However, most doctors and patients accept that hard numbers are something of an illusion. They imply accuracy and some measure of control. While the intent is virtuous, the effect is not. It amounts to an “ethos of beneficent silence,” eliminating any apparent need for further, perhaps disheartening, discussion when frank, compassionate conversation is what some patients might want to have.¹² This becomes even more challenging when the patient is of an unfamiliar ethnic or racial community.

But there is more than honest talk in good cross-cultural communication. Rules of etiquette apply about telling and receiving bad news. Medical truth telling with patients nearing the end of life is not common in world cultures. It was not common in this country either until the 1970s. Prior to that, withholding information was felt to be “humane” as it “protected” the patient. It was thought that too much honesty might encourage hopelessness. Writing on the decorum of death talk in the 1950s and 1960s, sociologists Barney Glaser and Anselm Strauss described what they called verbal games of “mutual pretense” and “closed awareness” at

the bedside, the living as well as the dying talking past the obvious.¹³ That pattern is, in fact, still a common one. In one study of delivering bad news in four American ethnic communities, researchers found that about 65 percent of African Americans as well as Whites believed doctors should tell patients truthfully when a cancer is probably fatal; about 45 percent of Mexican Americans and just 35 percent of Korean Americans agreed. When asked who should make a decision about life support, 60 percent of African Americans and almost 70 percent of Whites thought it should be the patient; among Mexican Americans, it was about equally split at 45 percent between patient and the family. Korean Americans felt strongly, 55 percent, that such matters are a family prerogative.¹⁴

This latter finding is not unusual, particularly among Asians. In a related study, one respondent said to the researcher that “there is a lot of pressure in the [Hawaiian] Chinese culture to take care of your own and also be a part of the person’s process. So I think my ethnicity expressed itself in that my sister and I went to every medical appointment with my mother and even sat in the room with the doctors.” The feeling was strong that the adult sisters could better handle bad news and make the necessary choices. Not that their mother wouldn’t have known she was dying. “Denial” was not the issue. Rather, their intent was to relieve her of the burden of weighing hard choices; for them that was an act of caring.¹⁵ In some Asian families, the oldest son would take that responsibility, again out of a desire to relieve a parent of a burden, not to soften the truth.

Crossing Borders

Knowing whom to talk to and what to say, and asking if one does not, is the obvious starting point. That is not very difficult, and it does not require much prior knowledge of what people in community X or Y believe. It requires instead a subtle realignment of the traditional power relationship between care providers and care receivers. H. Russell Searight and Jennifer Gafford offer a short but wise list of bedside openers that I have modified here slightly. Others have made useful suggestions too, but I like their approach for its honesty and economy.¹⁶

1. Some people want to know everything about their medical condition, others do not. Do you have a preference?

2. Do you usually make your own medical decisions or does someone help you with that? Is there someone you would like to have here to help you now?
3. Would you be more comfortable if I spoke with your (spouse, brother, son, daughter, and so forth) alone?
4. Is there anything you want me to know about your (family, religious faith, community) that might be helpful for us both?
5. Sometimes people are uncomfortable discussing these things with someone of a different race or background. Do you have any feelings about that which would be helpful for me to know?

Clearly, this is just a beginning but the questions start a conversation that is important and will become more so as treatment and care proceed. The first addresses individual preferences, the next three aspects of the patient's cultural background that may be relevant to the medical situation, and the last honestly identifies a racial or cultural difference and asks how that might be relevant. The questions are useful for doctors but also for nurses, social workers, and chaplains. Implicit in each is exactly what ethnographers do when they work in an unfamiliar culture: start a narrative to generate useful descriptive information while also, as in the final question, acknowledging differences in power that might shape the relationship. That is accomplished in a non-threatening way but, more to the point; this style of inquiry allows the patient to take the role of the cultural insider who is also a teacher, the professional presenting himself or herself as an interested learner. The credentialed experts temporarily become, as Ruth Behar eloquently put it, "vulnerable observers."¹⁷

Cultural competence begins when those who are the technical experts can comfortably let that brief role reversal occur. Aside from generating information, this approach softens stereotypes and builds toward a genuinely compassionate relationship. Although I have used the term "cultural competence" throughout this essay, I do so with a disclaimer. Having had something to do with coining that expression in a book published in the 1980s, I now wish I could rope it back in and bury it in that deep, dark abyss where all bad habits of scholarly jargon go. The idea that anyone can be "competent" in someone else's culture is absurd and serves only to inspire an unseemly hubris. "Cultural humbleness" is a better term and particularly appropriate for religiously oriented caregivers. Humility is a neces-

sary virtue in order to be present as ‘vulnerable observers’ with people from diverse cultures at the end of a life.

SPIRITUALITY

In a detailed and insightful analysis, religious studies scholar Lucy Bregman argues that the term “spirituality” is as popular and seemingly useful as it is because it is largely content-free. It is, she says, an “everyone everywhere” concept with a wonderful ambivalence that hints of timeless profundity. “Spiritual but not religious” is the best known instance of this convenience. Bregman adds the useful insight that the term “spirituality” also has a political dimension, not usually appreciated by “spiritual but not religious” adherents. That particular usage began with the Enlightenment, among individuals (mostly intellectuals) seeking to preserve a sense of the transcendental as the persuasive power of established religion was under attack by scientists and humanists. The result is a growing and diverse assemblage of ideas, propositions and thinkers under the expanding tent of spirituality⁸.

Unhooked from time and place-bound moorings, the focus on spirituality suggests something universal in the human breast to which we all have access, an oddly essentialist idea in an allegedly postmodern, relativistic, anything goes time. Lucy Bregman found at least 92 definitions of spirituality in current usage. These definitions can be arranged into just a few types: (1) transcendence understood generically, lacking any named or implied higher power; (2) a quality of relationship to a higher power, named but sometimes unnamed; (3) personal experiences said to be other-worldly; purpose in life and the ways one discovers and pursues it; and (4) the life force generally. Examined in more detail, Bregman concludes that most definitions are but shards of religious material extracted from other traditions—a “forgotten” or romanticized past, ancient tribal lore, or eastern religions transmitted to Westerners through adepts—reassembled into what she calls “quilted identities,” bits of this and of that, more or less cohering. These are spiritualities without dependence on what one would think of as an enduring tradition. They are, she adds, very much a post-1980s phenomena, lodge awkwardly between humanistic psychology viewed as an ethos and religion in a broad, generic sense. That conceptual muddle afflicts efforts to identify a clear spiritual focus for end-of-life care⁹.

One way to find some clarity in this is to set aside vague notions of the spiritual and spirituality and look instead at what people who work with the dying actually do. I have outlined some of the possibilities elsewhere and so want to focus here on one study I find suggestive.²⁰ A critical incident study conducted in a British hospital with patients from everywhere on the globe identified four kinds of “spiritual care.” (The fact that one of the researchers traces her family to India is important since she brought a built-in cross-cultural sensibility to the study.) Nurses were asked to describe patient encounters where they felt some kind of spiritual care was involved.

One type the researchers identified they called a “Personal” style. Said one nurse to an interviewer, “I tried to be as honest as possible and discuss the thoughts and feelings of ‘meaning of life’ and ‘why her’ to a degree that I felt comfortable with...the patient and family appreciated ‘honest’ answers and grew to trust the staff as we didn’t make any false promises.” Her approach included honest, frank exchanges, kindness, and a controlled level of personal involvement in the experiences of the patient and her family. It was holistic in a genuine way, involving counseling and trust, and the nurse expressed a sense of personal satisfaction in knowing the patient well and something of her background.

A second style was “Procedural.” These nurses preferred to follow established routines and were willing to provide whatever was institutionally available. “On admission it was apparent that the patient was Church of England and went to church every Sunday. They spoke openly about their religious beliefs...I felt the patient would like to see the Chaplain in the hospital.” This nurse and others who relied on a Procedural approach did the practical things—finding a chaplain, rabbi or *imam*—and did so efficiently. They were secure in this, largely shielded from the more intensive engagement of Personalistic nurses, and felt they had done their professional duty. They were also quick to “size up” patients culturally and racially, to make conventional judgments about who and what they were, and to act on superficial impressions. Their obligation extended no further.

Some nurses explicitly adopted a “Cultural” approach but were usually frustrated by doing so. Among their coworkers, they knew the most about the cultural background of patient communities and ably determined patient wishes and those of visiting family and friends. They sought expert advice from community religious leaders and took practical measures, such

as care in dietary preferences. Said one, "Clients who wish to pray to Mecca may have the curtains pulled around, be given a side ward or taken to the mosque on D floor...customs of different cultures and religions are recognized as they arise and every effort made to accommodate requests." These nurses had a strong sense of beneficence and ethics. But their efforts were undermined by a fear that they would never know enough. They were equally frustrated by lack of peer interest and little administrative support. The latter made them particularly vulnerable to doubt about the value of their best efforts.

A fourth, but less common, approach the researchers labeled "Evangelical." One nurse commented, "We both shared similar religious beliefs...I told the patient despite his past life that there is a God who cares and promised forgiveness for those who believe and ask forgiveness." These nurses actively sought out co-religionists among the patients, wanted to reaffirm a shared faith, and occasionally pressed their views on others. They enlisted the chaplains where they could and several urged parents to baptize their sick infants in the neonatal ward. Clearly, these practices, while perhaps helpful with fellow believers, run up against professional ethics as generally taught and, likely, hospital policy as well.

Given such variation in practice, what might we make of spirituality and cultural competence in service settings? What can individual professionals do and what institutional procedures might help them do it? My suggestion is that spirituality does not stand alone either as subject or a practice. Whenever and however spirituality manifests itself, it always derives from a specific, historical tradition, a cluster of beliefs, practices and insights that in their transmission say as much about their social origins as they do about transcendence. How could human spirituality be otherwise?

As much as I appreciate the broad scope of the recommendations of the Association of American Medical Colleges, no one can learn and do all the useful things they suggest. Few of us have the time or energy to study whole cultures, let alone the multiplicity of them in a modern hospital—nor is that necessary. What I have proposed is something more focused. Thinking of culture as narrative and power rather than a handy list of traits, the first step toward cultural competence is knowing something of the critical junctures where patient beliefs and expectations (vernacular culture) and hospital/professional beliefs and expectations (institutional culture) are likely to connect and/or collide. At the end of life, the topics I have addressed—

inequality and trust, patient autonomy, and others as well—are relevant to the medical service in question. Other areas of professional care such as pediatrics, gerontology, or psychiatry will have their own list of appropriate topics. Once identified, practitioners seeking cultural competence can formulate their own set of questions after the manner of those suggested by Searight and Gafford. The idea is to learn from patients something of their world view, their concerns and their needs, regarding them as cultural guides on the presenting issue. Careful, sensitive questioning will, over time, produce that information and it will be useful in developing culturally responsive treatment plans. What does it take to get there?

LEARNING VULNERABLE OBSERVATION

Just as the broad sweep of any particular culture cannot be the focus of this endeavor to develop cultural competence, neither does generalized “cultural awareness” training produce much that is useful. My experience is that staff retreats, often mandatory, have little or no impact. Indeed, they can backfire. Some attendees won’t want to be there; some don’t need to be there; many will find it interesting but are left wondering what to do about it after they leave. Generally, there is little in the way of administrative follow-up and one has the feeling that these sessions are useful mainly for meeting regulatory requirements. Sometimes the lure is a remote and pleasant location, an equally bad idea because it reinforces the notion that cultural awareness is something of an “extra,” good as lip service but not really central to the core tasks of the institution.

A better approach is to convene the handful of individual doctors, nurses, counselors or chaplains who have a need for cross-cultural information and who want to work on the topic long term. As a small team of learners and providers, their strategy is regular discussions of cases and the critical cultural issues each presents. Such meetings could occasionally host translators, community religious leaders, and minority members of the professional staff, not to discuss “their culture” but to offer insight on puzzling issues in the caseload. Compiling that information and making it available to others who share the interest is one way to establish institutional memory. Any such handbook would be no more than a list of helpful suggestions and the context of the specific cases from which they were derived. There is ample precedent

for doing this, in physician Ira Byock's work on end-of-life care and in the analytic principle of casuistry long advocated by bioethicist Albert Jonsén.

What makes any of this spiritual? Recall my suggestion that the term culture in its anthropological sense has to do with narratives constructed in settings where power is unevenly distributed. "'Culture' is not a 'thing,'" argues medical anthropologist Janelle Taylor, "somewhere 'out there,' that books are 'about.' It is a process of making meanings, making social relations, and making the world that we inhabit, in which all of us are engaged—when we read and teach, or when we diagnose and treat....The meanings that we make set the course for the actions that we take; they matter enormously."²² Spirituality is a way human beings create meaning, something they are prone to do at times of existential reflection or of threatening crisis. They respond with the resources they have on hand, making sense if they can of events that seem arbitrary, hurtful, and meaningless.

Cultural competence is a way of enabling that by establishing harmonious, workable relationships with patients, clients, and parishioners when they need it most. It is working with, not through, differences of race, tradition, language, and power. Palliative care physician Stuart Farber and his co-researchers found that good primary care doctors play three roles: consultants who provide technical advice, collaborators seeking to understand the patient's experience, and clinicians who as guides use "personal intuitive knowledge of patient and family to facilitate everyone's growth when providing end of life care."²³ Religious leaders play parallel roles. They may be ethical consultants whose way of advising aims to help people discover their deepest longings and values. Religious leaders are committed to understanding the experience of being sick or dying from the patient's perspective. And religious leaders guide people at the end of life to a deeper awareness of the presence of God.

Cultural competence, rightly conceived, is the capacity to enter into the experience and suffering of others, surely with empathy but also as a critical, analytical exploration of all that everyone brings to the encounter. It is a way of "looking through a glass darkly," finding there the astonishing diversity of ways humans salvage what they can from the inevitable presence of death.²⁴ What could be more spiritual than that?

NOTES

1. U.S. Census Bureau press release, *An Older and More Diverse Nation by Mid-century*, August 14, 2008, available at <http://www.census.gov/Press-Release/www/releases/archives/population/012496.html>.
2. *On Our Own Terms: Moyers on Dying*, prod. Public Affairs Television, Inc., presented by Thirteen/WNET New York, September 10–13, 2000, DVD.
3. I have documented how death is presented to children in James W. Green, *Beyond the Good Death: The Anthropology of Modern Dying* (Philadelphia, Penn: University of Pennsylvania Press, 2008). By treating children's books as artifacts, written and purchased by adults who wish to convey in simplified form their own understanding of death, I extracted a number of familiar elements. They include the spiritual presence of the dead among us, heavenly reunions, and a view of nature as sentimentalized, purified, and quasi-sacred. It is encased in a cult of memory, understood by the natives to be something individualistic and psychological but, in my reading, sociological and moral as well.
4. Sharon R. Kaufman, *And a Time to Die, How American Hospitals Shape the End of Life* (New York: Scribner, 2005), 1. A medical anthropologist whose fieldwork was in three California hospitals, her subject was "time and death" both of which are problematic in "the culture that predominates in the hospital and its deep, internal ambivalence about death. That ambivalence arose with the coming together of three elements: the work and goals of medicine, American individualism, and the market-oriented health care delivery system." This is the definitive work on this subject.
5. Anne Fadiman, *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures* (New York: Noonday Press, 1997). The book was favorably reviewed in the *Journal of the American Medical Association* in 1998. I am indebted in part to colleague Janelle S. Taylor and her excellent critique. See her essay "The Story Catches You and You Fall Down: Tragedy, Ethnography, and 'Cultural Competence.'" *Medical Anthropology Quarterly* 17, no. 2 (2003): 159–181.
6. Julien G. Lipson, Suzanne L. Dibble, Pamela A. Minarik, eds., *Culture and Nursing Care: a Pocket Guide* (San Francisco: University of California Nursing Press, 1996), 186. The title received a Nursing Book of the Year Award and went into a new edition in 2005 as *Culture and Clinical Care*.
7. Association of American Medical Colleges, "Cultural Competence Education for Medical Students" (Washington, D.C.: AAMC, 2005), 11, 12; downloadable at <http://www.aamc.org/meded/tacct/culturalcomped.pdf>.
8. R. K. Barrett, "Dialogues in Diversity," *Omega* 52 (2006): 249–261.
9. E. Tong, "What is a Good Death? Minority and Non-Minority Perspectives," *Journal of Palliative Care* 19 (2003): 168–175.
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16. The questions quoted here are adapted from H. Russell Searight and Jennifer Gafford, "Cultural Diversity at the End of Life: Issues and Guidelines for Families and Physicians," *American Family Physician* 71 (2005): 515–522. See also S. J. Farber and others, "Issues in End-of-Life Care: Patient, Caregiver, and Clinician Perceptions," *Journal of Palliative Medicine* 6 (2003): 19–31. The latter reported that patients identified four areas that were significant to them: awareness of the approach of death, coping with everyday routines while keeping up necessary care, changes in personal relationships, and personal experiences that were new and, obviously, challenging.
17. Ruth Behar, *The Vulnerable Observer: Anthropology That Breaks Your Heart* (Boston, Mass: Beacon Press, 1996).
18. Lucy Bregman, "Spirituality: A Glowing and Useful Term in Search of a Meaning," *Omega* 53, no. 1–2 (2006): 5–26.
19. See J. Dyson, M. Cobb, D. Forman, "The Meaning of Spirituality: A Literature Review," *Journal of Advanced Nursing* 26 (1997): 1183. They argue that the provision of spiritual "care in nursing is hindered by the lack of an agreed definition of spirituality and the absence of a conceptual or theoretical framework in which to deliver such care."
20. A. Narayanasamy and J. Owens, "A Critical Incident Study of Nurses' Responses to the Spiritual Needs of their Patients," *Journal of Advanced Nursing* 33 (2001): 446–455. My own overview of the matter is in Green, *Beyond the Good Death*, 197–200.
21. Both these authors are prolific and two useful examples of their work can be mentioned here. Ira Byock, *Dying Well, The Prospect for Growth at the End of Life* (New York: Riverhead Books, 1997), and Albert R. Jonsen, Mark Siegler, and William J. Winslade, *Clinical Ethics* (New York: McGraw-Hill, 2006). The latter is valuable for its four-part model for analyzing cases. Medical indications are the first part; the remaining three involve areas traditionally associated with spirituality: the preferences of the patient, quality of remaining life, and contextual features including religious values and rituals.
22. Taylor, "The Story Catches You and You Fall Down," 179.
23. S. J. Farber, T. R. Egnew, J. L. Herman-Bertsch, "Defining Effective Clinical Roles in End-of-Life Care," *Journal of Family Practice* 51 (2002): 153–158.
24. 1 Cor. 13:12.