

# Recasting “Spiritual but Not Religious” at the End of Life

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## *Summary*

*Examining end-of-life care clarifies the importance of everyday religion as well as spirituality. They do this because religious experience is more than subjectivity—it is also relational. The task for the spiritual caregiver is to create opportunities for diverse “religiosities” to be voiced without forcing them into “spiritual” versus “religious” boxes.*

Dying in medieval Europe, according to a well-known social historian of the period, was not the confusing, out of control experience it often is for us and many of our contemporaries. Philippe Ariès writes of what he calls the “tame death,” something the medievals knew well.<sup>1</sup> Death he says was often prefigured by visions, signs, or omens and its nearness rarely a surprise. At its approach, well-known ritual procedures were activated including affirmations of faith, confessions, apologies, and forgiveness. They eased the transition to another world. Familiar instruction booklets called *ars moriendi*, the art of dying, contained everything the dying person, family, and friends, and the local priest needed to know. Today we would call them etiquette manuals. In addition, the tame death was a public event, hardly the sequestered occasion it is in modern hospitals and hospice. A fifteenth century English *ars moriendi* recommends that dying should be so well choreographed that “yf it were possyble all, an hole cyte oughte runne hastely to a persone that deyeth” both for moral edification and a good performance.<sup>2</sup>

Even if we suspect that Ariès romanticizes, he nevertheless names a “tamed” possibility that may have once been the norm but cannot be now.

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For us, clinical care at the end of life is more complicated, due in part of the dominance of scientific medicine, the rise of modern, bureaucratized hospitals beginning in the late nineteenth century, the more recent emergence of hospice and palliative specialties, and life spans that are twice those of most people in the fifteenth century. Yet hints of the transcendent still occur at times of dying, though shorn of much of the ritual apparatus that Ariès says helped make dying bearable. Those hints occasionally appear in some of the most scientific of scientific medical journals. Consider this snippet of conversation, reported by a reflective physician, on his encounter with the adult daughter of an older women dying with ovarian cancer. The patient and daughter are African American; I presume from the context of the report that the physician is white.

Doctor: "We're not optimistic."

Daughter: "We understand that *you're* not optimistic, but *we* are."

Doctor: "We want to be realistic."

Daughter: "Well... *we're* looking for a miracle..."<sup>3</sup>

There are two issues here. First, if not comfortable with the idea of miracles, the doctor is surely aware that there is a vigorous discussion on religion and bedside consultations in the medical literature. But "religion" is not the word featured there. The preference is "spiritual" and it has a large following in the end of life literature. The second issue in this brief exchange is racial and cultural. Sensitivity to the needs and interests of patients from varied ethnic backgrounds is, like spirituality, fashionable and frequently flies under the flag of "cultural competence." I will return to the question of cross-cultural capability because I think there is a connection with contemporary usages of the idea of spirituality. But my first concern is the latter. What is meant by spirituality? Why has it become so popular of late? What is "spiritual care" so that we might recognize it when we see it? Or is it best left to those professionals who, on their own, have already developed a strong personal sense of spiritual insight, an elusive quality we all have but in varying degrees?

Whatever spirituality is, or might be, medical interest in the topic is a distinctly modern phenomenon and a growing one. Since 2000, medical and scientific journals have carried almost 7,800 articles on the subject, averaging over 600 per year. While some are authored by chaplains, most are by medically trained practitioners and researchers. Not surprisingly, they rely on questionnaires and surveys, "instruments," to generate quantified results. Some make use of case studies, usually brief and intended to illus-

trate the numbers. There are psychometric “spiritual assessment” tools as well intended to measure how spiritual coping relates to medical outcomes. The Richmond Consortium on Patient Education (RCOPE) and its shortened version, the Brief RCOPE, is an example.<sup>4</sup> These suggest widespread interest in the topic and, not surprisingly, controversies have emerged. First, there is much discussion of what qualifies as “spirituality” and “spiritual care.” This is partly a definitional issue. Definitions are important because they name a topic, setting it up for critical examination, research and, in healthcare settings, possible significance for staff training and bedside care. Second, some researchers have linked the current interest in the topic to sources outside medicine, specifically to trends in the larger secular society, and questioned whether the idea of spirituality has any real medical usefulness at all. If that is the case, we need to rethink what health service professionals believe they are doing when they promote one version of spirituality or another in their work. But do any modern notions of spirituality help us reclaim, in some modest way, the mythos of expectation, hope and personal control, the “taming,” Ariès believes was once there?

#### WHAT COUNTS AS SPIRITUALITY?

Trying to answer a question like this is, for my purposes, more distracting than helpful. Theologians may find this familiar territory, but in the health care literature what qualifies as spirituality is diverse and often nebulous. Definitions abound, held to be important as guides for medical research and training, yet running through this same literature is a frequent complaint that no one yet has found a really good definition. Many are proposed and I have chosen several to illustrate the problem.

In 1999, the Association of American Medical Colleges declared that: “The concept of spirituality is found in all cultures and societies. It is expressed through an individual search for ultimate meaning through participation in religion and/or belief in God, family, naturalism, rationalism, humanism, and the arts.”<sup>5</sup> This observation was part of a larger report promoting good communication in medical settings, a significant goal for medical school training. Several themes found in other attempts at definition are immediately apparent here. Spirituality is a feature of all societies and, by implication, a capacity of all human beings. It is a human universal and a cross-cultural fact. Its essence is the search for meaning, a topic often proposed in medical and psychological studies. What anchors this search,

however, is open-ended and could be almost anything. The definition lacks enough clarity to be useful as a research or training goal.

A second example comes from a journal on family practice:

Although definitions and expressions vary, in general *spirituality* is a search for what is sacred or holy in life, coupled with a transcendent (greater than self) relationship with God or a high power or universal energy. *Religion* is seen as focusing more on prescribed beliefs, rituals, and practices as well as social institutional features...<sup>6</sup>

Here a “high power” is paired with “universal energy,” far more abstract than the multiple features listed in the first definition and suggestive as well of an ideological stance derived from recent sources. In addition, this definition repeats a theme common to many in the literature—the contrast between spirituality and religion. Like the first definition, it offers a generic trait list of open-ended cultural categories—belief, ritual, practices, and institutional features—which may be interesting in themselves but suggesting little in the way of conceptual guidance or clarity.

Other efforts to define this elusive concept seek to identify its critical features through large-scale literature reviews. Several recent ones have appeared but the most comprehensive is that of chaplain Shane Sinclair and co-writers physician Jose Pereira and nurse Shelley Raffin, appearing in a 2006 issue of the *Journal of Palliative Care*. They identify a wide range of themes recurring in journal articles and remark that, “most of this literature is theoretical and opinion based, focusing mostly on the conceptualization of a term that seems to escape attempts to confine it to a simple standard definition.”<sup>7</sup> These definitional attempts plague journal discussions focusing on topics as varied as the relationship of spirituality to religion, how spirituality relates to health, how spiritual care is best provided, its therapeutic uses, spiritual coping, the role of religion at the end of life, the spiritual and religious preferences of care providers, and the adequacy of professional training in providing spiritual care. The Sinclair team observes that while these thematic threads are beneficial, they provide a finite and somewhat skewed understanding of spirituality.

An additional limitation plagues some of these studies. Many rely on quantitative data rather than qualitative material typical of ethnographies based on open-ended interviews and theory-driven participant observation. Some use carefully calibrated “instruments measuring spirituality in end-of-life populations” but their findings often repeat the general and open-ended topics mentioned above. Where there is no specific or standardized definition, the usefulness of that statistical data is hard to know.<sup>8</sup>

## CRITIQUES BEYOND MEDICINE

It is worth noting that the current fascination with spirituality is not new, although the modern elaboration of it is. The topic has long been part of the American scene, from the Great Awakenings of the past to the still familiar practices of regular Sunday observance, Bible reading, meditation, communal and private prayer, and dramatic conversions. In an impressive history of souls and spirituality in American intellectual life and in popular culture, Leigh Schmidt suggests that ‘spirituality,’ as the term is often used now:

[W]as invented through a gradual disentanglement from these model Protestant practices or, at minimum, through a significant redefinition of them. Only through some disassociation from those earlier Protestant habits does the term *spirituality* come to be distinguished from religion.<sup>9</sup>

Leigh cites one of grand elders of American spirituality, Walt Whitman: “I should say, indeed, that only in the perfect uncontamination and solitariness of individuality may the spirituality of religion come forth at all.”<sup>10</sup> Institutions and traditions, in Whitman’s view, were dead and deadening entities and he vigorously challenged their presumed authority, most vividly in the opening line of one of his best known poems: “I celebrate myself, and sing myself...” That theme was subsequently graced with scholarly endorsement by the philosopher William James. Religious sensibilities were, for him, the “feeling, acts, and experiences of individual men in their solitude, so far as they apprehend themselves to stand in relation to whatever they may consider the divine.”<sup>11</sup> This emphasis, as it has continued in modern expressions of spirituality, was on something uniquely individual, pre-cultural, “apprehended,” and contextualized in whatever framework one might prefer.

Thus Whitman remains contemporary, despite the fact that his poem was first published in 1855, much reworked, and given its present title, “Song of Myself,” in 1881. Religious writer Diana Butler Bass, describing what she calls *Christianity after Religion*, asserts that we favor such an “expressivist” point of view; we are heirs of Whitman and James who now dominate from the shadows the twenty-first century American religious landscape. It is one, she says where:

[O]bligatory group identity—whether of nation, family, or church—[is] replaced...with a new sense of individual authenticity and the ‘right of choice’ based on personal fulfillment. External authorities gave way to internal ones, as we moved away from conformity to social structures toward the authentic self in society.<sup>12</sup>

That this transformation has happened is neither good nor bad, she says, it just is. The challenge is to use it to make wise choices. I will suggest at the end a choice, applicable to clinical encounters with the dying.

Others see this distinctively American spirituality less charitably and they have compelling reasons. Lucy Bregman, a religious scholar, says the term is a "glow word," essentially empty of content. Its vacuousness is precisely its attraction. "'Spirituality' has become a 'glow word,' such as 'growth' and 'process' and 'relationship'" and, we could add, "authenticity."<sup>13</sup> It is open-ended and has multiple functions: it can be a substitute for institutional religion or inherited traditions; designate a private space of "faith;" or assert a "spiritual core" which everyone has, discoverable through a "journey" of earnest seekership. In any of these capacities, it can mean whatever the speaker wants it to but one clear theme stands out. *It is non-relational*. It need not involve others. It is about an inner self, some deep and mysterious center we all have. Social context, tradition, standardized codes, doctrinal themes, and texts and rituals are neither relevant nor necessary. Says Bregman, "Religion, in this view, is a secondary category: it organizes and provides a cultural framing for this underlying core of 'spirituality.' Religion is not universal, nor is it necessary to our humanity; spirituality is both."<sup>14</sup>

Given the gradual disenchantment with and exit from traditional institutions of religion, largely a post-World War II phenomenon and one coupled with the expansion of free market consumerism with its emphasis on choice, "spirituality" fills a vacant niche created by the drift away from denominational affiliation. Choice, preferences, and "what works" at the individual level became primary, sometimes drawing on a language of skepticism or of humanistic psychology (Maslow's "self-actualization," for example) and exemplified in contemporary church shopping and the attractions of megachurches, which forego denominational identities.

Spiritually also works well where immigrants bring new and sometimes unfamiliar traditions, enormously complicating "wholistic care" in medical settings, especially at the end of life. While we generally expect immigrants to learn English and downplay their traditional language, Bregman notes we do not expect them to change their religious persuasion. And generic spirituality, especially at the bedside, seems a comfortable accommodation to this religious pluralism, even an expression of a generous cosmopolitanism. Thus its attraction in the US and the UK, which have received many immigrants.

## INDIVIDUALIZED SPIRITUALITY

But is this open-ended and individualized spirituality really helpful in places where cultural pluralism is a fact of life? (And, I would add, where native populations are already religiously and denominationally pluralistic.) I suggest, following Bregman, that in these settings a non-specific, generic, and “glowing” spirituality is convenient as filler for what is sometimes alleged to be “cultural competence.” Tony Walter, a sociologist of the end of life, believes that is the case and for good reason. “Wholistic care” for the dying is an idea originating with Cicely Saunders in the early days of the hospice movement. The understanding then was that we are all spiritual to some degree, thus attending staff should be capable of rendering spiritual care as part of other services. Typically, that care was described as a “search for meaning,” a common theme in the palliative literature and one derived from Saunders’ reading of Viktor Frankl and his influential *Man’s Search for Meaning* (1959).<sup>15</sup> While noble in intent, Walter argues that spiritual intervention of this kind is more accurately understood as a therapeutic discourse. Moreover, it is a particular kind of discourse, one peculiar to a distinctive and small group of people. It is “promoted in the secular health care facilities of the English-speaking part of the Protestant world. It is rarely found in Catholic, profoundly religious, or non-English speaking countries.”<sup>16</sup> In addition, a generic spirituality is attractive because it helps resolve an organizational issue: how to best manage care facilities where multifaith traditions are represented and staff often lack familiarity with them. Thus much of the medical discussion of the topic appears in journals for those most directly concerned with this challenge: nurses, palliative care providers, and chaplains (Regarding chaplains, see Tabitha Walther, *Reflective Practice* 29).<sup>17</sup> Lacking usable cross-cultural information, Walther argues that spiritual care can be so loosely conceived that “It can be provided by anyone to anyone.”<sup>18</sup> That is what makes the idea “glow.”

The recency of this concept, occurring among a distinctive category of people with a view of the matter very different from its earlier (medieval, for example) manifestations, ought to alert us to the fact that it is what anthropologists would recognize as a “culture bound” category. It is not expressive of something common to us all but rather has a specific cultural location. Its origins are British and American, both consumerist and dominantly Protestant societies, in which individualism is a core value and priority often goes to the “needs” of individuals, not individuals as participants in communities. As a discourse, it appeals to persons who tend to be well educated and

in their personal lives are moving away from institutional (mostly Protestant) religions. Despite the claims of its proponents, the term does *not* refer to a universal human sentiment. It is *not* universally applicable to human suffering. In their cultural diversity, human beings have many and sometimes peculiar (to us) ways of thinking about "existential pain" and the ending of life. If those were not enough reasons to question the utility of this notion of spirituality, I suggest one more.

In one of the larger surveys of the uses of spirituality in medical discourse, Vachon, Fillion, and Achille abstracted from 71 journal articles the dominant conceptual themes occurring over a ten year period.<sup>19</sup> Of eleven identified, five were especially popular.

- First was meaning and purpose, often characterized as a quest or "journey" (a frequent term) to plumb the ultimate significance of one's time on earth.
- Second, self-transcendence—The dying may arrive at "a sense of connecting authentically with the inner self."<sup>20</sup>
- Third, transcendence generally, a connection with a "higher being" which for some is God and for others something else. The choice is up to the individual who suffers, and "it refers to a dimension that transcends the physical, social and material world."<sup>21</sup>
- Fourth is communion and mutuality, the fulfillment of the self in God or in some aspect (perhaps nature) of the grand design of the Universe.
- Fifth is Faith, and what these authors discovered about that is worth noting: it could be God or the Divine but doesn't have to be. It could be faith "in a higher order system. For instance, beliefs such as believing destiny or believing that each event has a purpose are considered forms of spiritual belief."<sup>22</sup>

Is it too much to suggest that these vague characterizations are analogous to, and perhaps have their origins in, various elements of American popular culture? They bring to mind Kubler-Ross and her mantra of "growth" while dying; the frank and loveable Morrie of Mitch Albom's 1997 bestselling *Tuesdays with Morrie*;<sup>23</sup> and the imagery and texts of any number of commercial bereavement cards.

My argument is that these notions of spirituality and their eleven dominant themes, while apparently exhaustive of the literature, do not name anything that could be called a valid or even scientific description of reality. They are rather statements of ideology. They spring from recent and known historical sources; their proponents are invested in a particular way of looking at the world ("post-modern," perhaps); and the preferred "instruments" of discovery which generate statistical outcomes, descriptively accurate or not, lend a scientific gloss to an implied promise of clinical usefulness. In staff encounters



with sometimes perplexing patients, I suspect these themes have standing because they simplify some of the real complexities of dying in culturally and religiously pluralistic settings. To push this a little farther, one might even argue that contemporary notions of spirituality are an *elitist* ideology as well, given their social origins and popularity in communities that are largely white, professional, and dissociated from older, denomination-centered traditions.

#### RECOVERING EVERYDAY LIVED RELIGION

There are two routes out of this modernist cul-de-sac of spirituality, one conceptual and one centered on how we as chaplains relate to the dying and their families. I begin with the conceptual. As indicated, the dominant mantra of contemporary spirituality is “spiritual but not religious.” That expression implies an expanding space between spiritual intent and whatever it is anyone might want to label “religious.” I suggest this dichotomy is not helpful despite its seeming obviousness. A small number of religious scholars have proposed, and are documenting, what they call instead “everyday or lived religion.” Everyday religion is the activity within the alleged gap between spirituality and religion. There is as yet no definition of the idea (and maybe there should not be). Sociologist of religion Nancy Ammerman suggests we look closely into that gap and ask:

*How does religion operate in the modern world? When and where do we find experiences that participants define as religious or spiritual? Where do we see symbols and assumptions that have spiritual dimensions, even if they are not overtly defined as such? Where are traditional religions present beyond their own institutional walls, and where are new religions gaining a foothold.<sup>24</sup>*

It is often in these liminal spaces, including dying, where many people encounter everyday religion.

Robert Orsi, a well-known scholar of twentieth century American Catholicism, supplies a clear example of lived religion. He writes how a hospital aide struggled without success to find a vein in the frail hand of his dying mother. Finally a surgical nurse was called in and she completed the procedure effortlessly. The latter revealed the secret of her technique: “Oh, I always say a prayer to St. Jude before I start looking, and he never fails me.”<sup>25</sup> Of course, St. Jude, patron saint of lost causes; he can and does intervene when called upon. This was not in a Catholic hospital and those in the room apparently heard her comment as unexceptional. “Religion,” writes Orsi, as his example suggests, “is the practice of making the invisible visible, of con-

cretizing the order of the universe, the nature of human life and its destiny" and it makes those things "visible and tangible, present to the senses in the circumstances of everyday life.<sup>26</sup> Everyday religion is the sometimes abrupt conjunction of mythos and subjectivity as lived experience.

In other settings and other traditions, anthropologists and the ethnographically inclined have also described occasions of "concretizing the order of the universe" in everyday, sometimes mundane, affairs.<sup>27</sup> Examples include the popularity of divining and diviners in Muslim areas of West Africa,<sup>28</sup> snake handlers in Appalachia,<sup>29</sup> modern-day apparitions of the Virgin Mary on the Internet,<sup>30</sup> and reading the fate of departed souls from stains on skulls exhumed from a Greek cemetery.<sup>31</sup> This writer's experiences include the wildly joyous *qawalli* performances at the tombs of Muslim saints in Pakistan, and whispering gratitude into the gold plated ear of a Buddha-like St. James in his Cathedral at the end of the Camino in Spain's Santiago de Compostella. Readers will have favorites of their own.

This emergent interest in "everyday religion" challenges the simplistic bipolarity of all claims of "spiritual but not religious." Orsi's theme of making the invisible visible transforms my somewhat random list of such practices into a coherent assemblage, the lot illustrative of a common theoretical principle, and even suggestive of a clinical application. Everyday religion is not a sideshow of quirky superstitions, heresies, or ethnographic oddities. It is how most people experience and speak of religion most of the time, with or without reference to historic creeds, with or without backing from institutional authorities. Everyday religions, including that of the nurse attending Orsi's mother are, he says "practices of presence," the mundane moments when people encounter their gods through the immediacy of material objects and events. *They do this because religious experience is more than subjectivity—it is also relational.*

This opportunistic open-endedness means that the occasions of presence can be unexpected, dynamic, or seemingly unlikely. That happens when the dying report seeing a predeceased spouse inviting them to cross over, and among the grieving who at troublesome moments sense the dead are near, like St. Jude, offering a little help.<sup>32</sup> It is what motivates survivors to stand at a grave and recount for the deceased current news about the family.<sup>33</sup> There is nothing unusual or particularly unorthodox about this. Considered from an existential rather than theological perspective, it is how people struggle to make sense when everyday sense-making doesn't seem to work. Unlikely practices endure because they empower. Snake handling, visits to a

diviner, saving water from Lourdes, or sensing a holy presence in a brilliant sunset—any of these can be understood as “practices of presence.” They can be thought of as well as components of “a cultural technology of hope.”<sup>34</sup> This characterization suggests an active rather than merely representational sense of presence. How, then, can care professionals engage a “technology of hope” in service to dying persons and their families?

#### NAVIGATING THE EVERYDAY

My word choice—navigating—is intentional. That term is beginning to appear in some corners of medicine including work with minorities and with cancer patients. One group of researchers speak of “navigating the knowledge landscape” of patients as a goal of their clinical programs.<sup>35</sup> There are few explicit applications of this idea to suffering at the end of life. But one good model for thinking about that comes from the ethnographic work of Dennis Klass, a psychologist of religion who developed along with others a theory of bereavement called *Continuing Bonds*. It was an alternative to older Freudian models of grief and to the spread in popular culture of the idea of “grief work” with its prescriptive “journeying” through stages of resolution, closure, and “moving on.” To test this, Klass undertook a long-term ethnographic study of a self-help community of parents whose children had died.<sup>36</sup> He discovered they had little interest in closure and that whatever passed for spirituality they preferred to express through concrete things brought to group presentations for discussion. These included photographs, favorite toys, and various mementos. There was also real interest in invented rituals that incorporated deceased children into family gatherings and holidays.

Klass noticed in these activities three critical elements of his continuing bond model. There was a sense of connection to a transcendent reality, however conceived; active and repeated verbal exploration of the pain of a child’s death; and a community in which that pain and the reality of a death was openly acknowledged. Over time most parents created an enlarged space in their personal life where their bond with the child evolved from a memory to a social reality. The goal was learning to live in new and unexpected ways with what Klass calls a “durable memory,” essentially a reconstructed sense of identity. It is that memory which is the basis for the continuing bond. A deceased daughter, her father’s former running partner, is sensed as a presence, a companion, as he puts in his miles. A grieving mother keeps her son’s

bicycle in her study and she still sees him near it, holding a puppy. A couple out for an evening walk encounter an unusual butterfly and accept that as a sign that their deceased child is in a better place. Each is an everyday moment which, in Orsi's terms, is a "practice of presence." These parents feel no need to frame their experience as somehow spiritual rather than religious.

How might a model like this come to the rescue of bedside clinicians trying to work with their profession's diffuse and apparently undefinable spirituality? How might it work for chaplains helping the dying (and their family) clarify their sense of what is important now and what is at stake given the circumstance? Here I tweak Klass' model slightly. He says, "the criteria for the health of an interpersonal bond are the same whether the bond is between living people or between living people and dead people."<sup>37</sup> That being so, why should we wait until after a death to begin building the bond? Here is a project for providers who want to move beyond the stale imagery of spiritual and/or religious. Those who are soon to leave this world might have a lot to say about what is important to them, what they think their legacy might be, and how they want it remembered and honored. In what he described as the "complex interactive web of bonds and meanings," Klass lists numerous entry points for launching a bond-building project.

As an alternative to spirituality's inner journeying, Dennis Klass offers a larger, more contextualized concept of earthly and transcendent interconnections. His topics include family and community, the meaning of one's life and impending death, a sense of the transcendent, and visions of how the universe works. Clearly, this involves more than occasional one-on-one conversations between care providers and dying patients. At some point, family and perhaps friends must join the project. Chaplains in particular could facilitate that occasion. Klass' themes for inquiry (with my modifications) are:

- Identifying family and community affiliations where legacy-maintaining activities will continue.
- Acknowledging new challenges for the living once the dying person is gone.
- Naming and describing memories likely to take on a durable character and reasons that they are significant. These will probably vary among family members and that adds to the richness of the story-line.
- Ritual actions that can be observed, both formal and informal, and how they help make memories durable.
- Identifying material objects associated with the dying that can function as evidence of a life soon to be gone.

This last point, material evidence, has been shown to be an important feature of continuing bonds. Called “linking objects,” they include photographs, jewelry, clothing, books, artwork, and toys.<sup>38</sup> Items of this nature are sometimes left at gravesites. (I once saw a grave decorated with an impressive collection of empty hot sauce bottles.) Roadside memorials are another, more recent variant. Physical reminders are important because they grant place and power to the absent self.

What is useful about this list is how it serves to direct a care provider’s inquiry and can generate new questions to pursue. Over time, repeated discussions generate a rich description and fuller context for a life lived, in effect a personal mini-ethnography. As a counseling strategy, it has the added benefit for providers of bypassing unusable notions of spirituality and pretensions of cultural competence with patients and families from unfamiliar traditions. If this seems unduly time consuming for professionals who are busy enough already, there are those in medical circles now working with something like it. Known as SDM (Shared Decision Making), it “entails a model of collaboration between patients and their clinicians to reach agreement about a health decision...[which] incorporates patient’s needs and values into decisions, and aims to improve the patient-clinician dialogue about decisions.”<sup>39</sup> If this is empowering for cancer patients, as it seems to be, it might work as well for those who know their days are literally numbered. That is a worthy project for nursing and chaplaincy.

#### EVERYDAY RELIGION: PRACTICAL AND DURABLE

I offer two final comments about this way of doing things. First, it’s practicality. The idea of a mini-ethnography as part of a medical consultation is not unusual. The continuing bond approach as outlined here parallels much of what physician-anthropologist Arthur Kleinman advocated in work with patients of many and varied backgrounds. “When we are ill,” he said, “we all have in our minds an Explanatory Model of what is happening to us.” He developed a short list of questions, now widely used, to access a patient’s understanding of what is going wrong inside their body. It is an interview technique, he says, “that tries to understand how the social world affects and is affected by illness.”<sup>40</sup> His larger issue, as is true of the continuing bonds model, is discovering what is at stake for the patient and those around him or her. Spiritual suffering, Walter notes, is really “biographical pain.” Learn-

ing something of that takes us to the heart of suffering, dying and, perhaps, spirituality but in a more focused, contextually meaningful sense.

This is already familiar territory for most chaplains. Addressing suffering is the critical task of chaplaincy. One observant chaplain has written, "The general mood is that the patient story is key to understanding the patient journey and suffering. Without reference to the patient story, any treatment is perceived as less effective."<sup>41</sup> The challenge now is to develop procedures and training protocols so the skill can be refined and taught. Ammerman notes, in reference to everyday religion, "Religious ideas and practices may be present even when they are neither theologically pure nor socially insulated."<sup>42</sup> The clinical task, then, is to create opportunities for diverse "religiosities" to be voiced without forcing them into "spiritual" versus "religious" boxes.

A final, more specifically anthropological concern is: To what general class of human activity does a durable, continuing bond belong? Is it unusual among human societies or is it that in our bureaucratized way of managing death we are the cultural oddity, the outlier? Anthropologist Michal Lambek, in repeated visits to Madagascar, studied spirit cults marked by routine visits of the dead. There he saw a culturally-specific expression of durable bonding, although that was not his term for it. When the cult's dead appeared, they were interested in what the living were doing, how their legacy was upheld, and what they thought was right and what was wrong in the community's affairs. They made their concerns known through religious specialists who knew well the local "practices of presence." Lambek called this ghostly activism "memory as a moral practice."<sup>43</sup> More than simple recall, he argued, memory rehearses, indeed authors, a renewed sense of self, by recreating the past but from the point of view of the present. Memory legitimates identity, constructing it or reconstructing it in therapy and in public ritual. That is exactly what Klass' bereaved parents embraced and were doing. It is what Ariès saw in the long-ago medieval desire for a tame death, a priest and the dying narrating for family and neighbors a lengthy assessment of a life and their collective hopes for themselves and survivors. Together, they framed their part in a grand cosmic process, one where they were not alone or isolated in their private thoughts or doubts. Perhaps that is what many of the dying now would be willing to try, if able and if given the opportunity. The results might be revealing, even useful, for reimagining what the "search for meaning" at the end of life is really all about in the experience of lived religion.

## NOTES

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