

Introduction

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IN TODAY'S WORLD, spiritual needs are experienced, expressed, and defined in a wide variety of ways. "Spirituality" may refer to a person's individual experience within a religious tradition such as Christianity or Buddhism. But more often than not these days, people do not feel their spiritual practices and beliefs need to be rooted definitively within a single or formal religious tradition. Others pursue ideas, beliefs, and practices they would call spiritual even though their approach to traditional religious questions (such as the existence of God, heaven, hell, and reincarnation) would be described as atheist or agnostic. It is arguably the case that one cannot effectively study contemporary religious life in North American and European societies without grappling with the increasingly well-defined cohort of "spiritual but not religious" people (not to mention the related groups of "spiritual but not necessarily religious" and "spiritual but definitely not religious" individuals).

In an earlier volume, *Religious Understandings of a Good Death in Hospice Palliative Care*, edited by Coward and Stajduhar (2012), the research team focused on the way those hospice patients and clinicians who are members of traditional religions understand the notion of a "good death." Setting out these traditional understandings was an important task. The current book focuses on the kinds of existential and spiritual questions posed within hospice palliative care contexts by persons

whose search for meaning has taken them beyond traditional religions such as Christianity, Islam, and Buddhism. For such persons—and they are, arguably, a rapidly growing cohort—“spirituality” is more important or more attractive than “religion.” Such dying persons may describe themselves as atheists, agnostics, or in the increasingly popular terms of “spiritual but not religious” (SBNR) or “spiritual, definitely not religious” (SDNR). Some may define themselves as secular, humanists, or followers of New Age movements. However, regardless of the ways people disavow any formal links to or interest in a single religious perspective, many will still speak of spiritual needs as they approach their own deaths.

In this book, we acknowledge the difficulty of defining “spirituality.” For our purposes, however, we suggest the following operational definition: “Spirituality” relates to an individual’s pursuit of wholeness, well-being, transcendence, and oneness with the universe, whereas “religion” typically denotes an institutionalized system within which the individual’s experiences are thought to unfold and be regulated. In discussions of spirituality in hospice palliative care, there is a tendency to contrast “spirituality” with the term “religious” in a way that frames religion as stifling the free development of spirituality by trapping it under dogma and tradition. The assumptions underlying this contrast are given careful critical analysis in chapter 1, “Hospice and the Politics of Spirituality.” Also, to help in understanding the many ways the term spirituality is used in relation to hospice care, we include two personal essays by Patrick Grant and Elizabeth Causton, chapters 6 and 7 respectively. The intimate style of these chapters provides insights into persons who live outside of religious tradition yet feel it is worthwhile to share their experience of life and how they hope to be cared for when they are dying. But first, let us briefly retrace the developing use of the term spirituality within the founding of the hospice palliative care movement.

In the 1960s in London, England, Cicely Saunders introduced a new way of treating the terminally ill, which she called “hospice care.” Saunders, a trained nurse, social worker, and medical doctor, held that humans should be able to die with dignity and at peace. This viewpoint originated from her

medical experience as well as her religious commitment as a Christian. Saunders developed a program for care of the dying based on three key principles: pain control, a family or community environment, and an engagement with the dying person's most deeply rooted spirituality. Although the hospice movement began in a Christian context, it was clear from the start that there was to be no "forcing of religion," and openness to all religions and understandings of spirituality was encouraged. While the first two of Saunders's principles have been well studied, the third, engagement with the dying person's most deeply rooted spirituality, has been largely ignored in recent years. Our first volume sought to fill that gap for religious people. This second book is focused on those whose loyalty to a particular religious framework or institutions is of no importance at all, or of secondary importance to their individual spiritual journey. The aim of both books is to help doctors, nurses, administrators, social workers, psychologists, chaplains, and volunteers in hospice palliative care address the "spiritual pain" that often parallels and accompanies "physical pain" in the care of dying persons.

In Saunders's view, a good death honors the whole of life—material affairs, human relationships, and spiritual needs (2006, 266). She further defines a good death as "attention to the achievements that a patient could still make in the face of his physical deterioration and awareness of the spiritual dimension of his final search for meaning" (1981, ix). Spiritual needs are defined by Saunders as follows: "'Spiritual' concerns the spirit of higher moral qualities, especially as regarded in a religious aspect with beliefs and practices held to more or less faithfully. But 'spiritual' also covers much more than that—the meaning of life at its deepest levels as understood through our patients' different religions." As Saunders puts it, "The realization that life is likely to end soon may well stimulate a desire to put first things first and to reach out to what is seen as true and valuable—and give rise to feelings of being unable or unworthy to do so. There may be bitter anger at the unfairness of what is happening, and at much of what has gone before, and above all a desolate feeling of meaninglessness. Herein lies, I believe, the essence of spiritual pain" (Saunders 1988, 218). In Saunders's

understanding, “spiritual pain” is parallel and interpenetrates with “physical pain.” Indeed, Saunders coined the term “total pain” to take into account a broader conceptualization of pain to include physical, psychological, social, emotional, and spiritual components (Clark 1999). Our approach is theoretically guided by Saunders’s conceptualization of “total pain,” but with a focus on spiritual pain and an acknowledgment that spiritual needs have to be addressed in hospice palliative care for a good death to be realized.

Saunders began her work in hospice as a social worker. On an interdisciplinary team in palliative care, it is the role of the social worker to elicit the big picture, to explore and validate the larger context in which the patient and family experience illness, death, grief, and loss. This holistic perspective also includes a strength-based assessment in which the patient’s and family members’ personal and collective resources are identified and maximized as their journal unfolds. It is also often the role of the social worker to normalize the emotional investment of his or her colleagues in the work, providing support and grief education as needed while encouraging self-care and the setting of healthy boundaries. Although Saunders, in the 1960s, was operating out of a distinctly Christian worldview, and though the vast majority of those served by her movement (in the UK, USA, and Canada) would be Christians, the pioneers of hospice sought from a very early period to make hospice palliative care available to the growing communities of non-Christians in Western societies. One example of the way this was accomplished is evident in the work of Sister Anne Munley, a health care researcher and Roman Catholic nun who used a typology based on William James’s psychology to accommodate the various forms of religious experiences of terminally ill people in hospice care (Munley 1983). Although she sought to make hospice palliative care accessible to non-Christians, in fact all of her examples are from the Christian tradition, a limitation of the existing research (most of which deals with people who happen to be Christian) and perhaps also a reflection of the deep roots of the Christian perspective in our thinking about death and dying.

A further and more recent development within the American hospice movement has taken Munley's interest in inclusiveness one step further and sought to accommodate the now rapidly growing number of people in the West who are interested in forms of spirituality that are unmoored to any single religious tradition (Bradshaw 1996). Perhaps ironically, this broader effort to open up a space within hospice palliative care for people who espouse often dramatically divergent approaches to religion and spirituality has in fact created a quite distinctive, consensual, and yet perhaps constraining view of spirituality. Bradshaw argues that in order to adapt to the American secular and religiously plural culture, the notion of spirituality in the hospice movement "has come to mean a universal dimension of human life, shared by agnostics and atheists as well as traditional religious people" (1996, 415). Indeed, it is this understanding of spirituality that has increasingly come to dominate academic thinking in nursing and medicine generally—and not just in hospice palliative care. The clinical consensus around the definition, function, and universal nature of spirituality (Chiu et al. 2004; McBrien 2006; Paley 2009) raises issues that are given critical assessment in chapters 1 and 2 of this book.

In chapter 1, "Hospice and the Politics of Spirituality," Kathleen Garces-Foley critically examines how understandings of spirituality and religion must be interpreted in relation to each other, especially when we consider that spirituality is often implicitly framed as "good" or at least unproblematic and religion is often framed as "bad" and problematic. Such dichotomies create confusion and undermine the ability of hospices to care for patients who describe themselves using those terms. Garces-Foley uses a review of hospice literature and her own experiences as a hospice chaplain in California (1998–2002) to show how "religion" has been downgraded in favor of "spirituality." There is also the opposite danger when religion/spirituality thinking becomes polarized and those on the "spirituality" side may be excluded. In this chapter, the author argues for a greater awareness of the way the concepts of spirituality and religion are used in hospice palliative care discourse. The portion of the title "the Politics of Spirituality" calls attention to

the fact that spirituality, like religion, is a culturally constructed category promoted by particular people with particular goals. The analysis offered explains why “spirituality” has largely replaced “religion,” understood traditionally as the framework for addressing spiritual care of the dying in North America, especially the United States. Garces-Foley observes that in this new approach to spiritual care, the winner is clearly spirituality and the loser is religion, especially Christianity—but she maintains that hospice itself also loses a great deal as a result. If hospice staff training and clinical practice demonstrate a bias toward spirituality and against religion, that bias will seriously limit the reach of the hospice palliative care movement when many, if not the majority, of North Americans see religion and spirituality as interrelated. By the same token, the growing cohort (19–25 percent) of those who identify themselves as humanist, atheist, agnostic, or SBNR must also be engaged in terms that make sense to them. Careful listening by hospice caregivers, with openness to all approaches, is clearly required.

Anne Bruce and Kelli Stajduhar offer an assessment of how to approach spirituality in hospice palliative care nursing in chapter 2, “Spiritual Care in Nursing: Following Patients’ and Families’ View of a Good Death.” They begin with a historical and theoretical analysis showing that spiritual care has been a core component of nursing care even before Florence Nightingale. Bruce and Stajduhar locate their discussion in the early Christian and humanistic values that have shaped nurses’ understanding of spirituality and the philosophical and theoretical underpinnings of the nursing discipline. They then examine how spirituality is diversely defined in the nursing literature and the challenges of these views for providing the conditions for a good death. Questions surrounding an assumed universality of spirituality and who should provide spiritual care are also explored. While Bruce and Stajduhar find no consensus on the definition of spirituality in the nursing literature, they argue that understandings of spirituality and good death must be ultimately defined and determined by patients and their families. They acknowledge that understanding spirituality, respecting religious traditions, and recognizing the growing cohort of SBNR people and the unique perspective that each individual

holds is inherently complex. In the face of this challenge, nurses, in caring for the dying, need to engage in a reflective process to scrutinize their own beliefs and assumptions and how these can influence the care they provide. They will then be better able to listen to and understand people as unique individuals and so move away from the mechanistic view from biomedicine that influences modern-day nursing practice. This reflexive process allows nurses to recognize that they ought not to make assumptions about what is meant by spirituality for any individual person. Thus, the spiritual worldview of the patient directs the response of the nurse in providing palliative care. This is consistent with the accepted practice in hospice palliative care for treating physical pain—that is, that pain is what the person experiencing it says it is. Similarly, “spirituality” is what the dying person says it is, and it is that spirituality to which the nurse must respond in providing care. This individualized approach to defining spirituality is shown to be in line with Cicely Saunders’s view of spiritual care as a concern for each individual and expresses a hope that each person will be able to think as deeply as he or she can and in his or her own way as death approaches.

In chapter 3, “Religion, Spirituality, Medical Education, and Hospice Palliative Care,” Paul Bramadat and Joseph Kaufert focus on the education of doctors. Unlike nursing, where engagement with spirituality and religion has been present from the beginning, in medical schools and residency programs it is just since the 1980s in North America that there has been an effort to respond in some way to spirituality and religion. In medical education and practice (especially in psychiatry and hospice palliative care), spirituality is understood to relate to an individual’s pursuit of wholeness, transcendence, oneness with the universe, and well-being. The first half of the chapter outlines the way in which in the modern Western scientific rationality and secularization have provided the context for medical education—a context that is antagonistic to religion and other nonscientific worldviews. However, as the authors show, over recent decades, medical training has been challenged by major critiques from feminism, multiculturalism, alternative medicine, and the Internet. In response, medical schools and

residency programs have incorporated new forms of training that address medical humanities, bioethics, and studies of the social determinants of health. The chapter concludes with three case studies involving end-of-life scenarios used in medical education and assesses the way in which the patient's spirituality was handled in each case. The authors conclude that in spite of the presence of medical humanists in medical education, the case studies reveal a "hidden curriculum" reflecting a culture of scientific pragmatism in which it is difficult to engage in serious reflection about the spiritual dimensions of human health. With this in mind, say the authors, it is important for palliative care or hospice physicians to grapple with the ways in which the institutions in which they work and the meta-narrative of medical education have influenced the care of patients.

Chapter 4, "Research and Practice: Spiritual Perspectives of a Good Death within Evidence-Based Health Care," by Shane Sinclair and Harvey Max Chochinov, reviews empirical studies of the relationship between spirituality and health care at the end of life. Within evidence-based health care, spirituality is generally considered to be a universal dimension of human health, which is individually determined and expressed through nonreligious and religious means. Spirituality, as defined by the patient, has been shown to have a positive effect on factors associated with a good death. A difficulty is that while patients desire to have their spirituality addressed during their dying process, clinicians and health care systems sometimes seem reticent to do so. Three core elements of spiritual care delivery that are identified by palliative care patients as most important include being present, recognizing the shared humanness between practitioner and patient, and incorporating aspects of the patients' spirituality into the care plan. Spiritual issues are found to be as important as biomedical needs among patients facing end of life. With this in mind, the authors devote much of their chapter to palliative care-focused empirical studies of patient spirituality, spiritual distress, and spiritual pain. A careful review of dignity, as an essential aspect of spiritual distress in a good death, is presented along with a detailed discussion of the Patient Dignity Inventory as an empirical measure for clinical enhancement of the end of life. Finally, the authors note

many studies that indicate that the health care providers' qualities (e.g., compassion, respect, and spiritual empathy) at the bedside of palliative patients are equally or even more important than medical knowledge or skills. Interestingly, as is often reported by hospice nurses, working with patients in palliative care is also seen to have a positive impact on the spiritual lives of health care professionals. The authors of this chapter find that while the relationship between spirituality and health care may at times seem vague, and while (as Garces-Foley's chapter establishes) it may be problematic to juxtapose spirituality too simplistically against religion, a convincing body of evidence clearly attests to the significance of one or another forms of spirituality to patients' experiences of a good death. Whatever spiritual perspective patients embrace, spirituality appears to enhance the possibility of a good death, while buffering factors that diminish it. While empirical evidence provides important data demonstrating the influence of spirituality in hospice palliative care, the most compelling evidence comes from the dying themselves, who consistently identify spirituality as vital to their end-of-life experiences.

Chapter 5 focuses on chaplains and other hospice palliative care staff members who feel unsure as to how to relate to patients that self-describe as SBNR, atheist-agnostic, or other nonreligious categories. In his chapter "Hospice Chaplains, Spirituality, and the Idea of a Good Death," Wilson Will, a former hospital chaplain, argues that the philosophical components of chaplaincy training position chaplains to work with spiritually diverse populations including those who are SBNR. Support from such a clinical practitioner, firm in his or her own beliefs, yet cosmopolitan in spiritual outlook, can assist persons seeking to integrate a spiritual outlook into the hospice palliative care journey. Will details practical guidelines for helping atheist-agnostic or SBNR patients to explore their own views on human existence and the dying process within a safe and supportive environment. These include a discussion of the ethics involved in working with members of these populations, supportive approaches to pastoral communication (nonjudgmental listening and interpretation), spiritual screening tools for helping to identify and talk about SBNR worldviews, and

suggestions for working with children and other family members (especially when the patient's spirituality may diverge from that of his or her family). The chapter concludes with a discussion of how chaplains can help fellow staff members to process their own thoughts about spiritual diversity among the dying and the anxieties they may feel about those whose spiritual beliefs differ from their own. Will argues that it is important that the collective outreach of the care team be consistent in its spiritual messages and aims, and here chaplains can help by offering workshops for staff members on care for SBNR atheist-agnostic patients. Will summarizes his analysis by noting that "the ideal chaplain is the spiritual equivalent of an ethnobotanist: someone familiar with the tools and taxonomies of a wide range of spiritual systems and movements, from the structured to the eclectic, who can appreciate the beliefs and practices that SBNR patients and others hold."

The majority of the chapters in this book provide scholars—who may or may not be sympathetic to the cohort the book is addressing—with opportunities to use their ethnographic, philosophical, or empirical evidence to develop and advance theories about the many issues associated with the role of "spirituality" within modern hospice palliative care. In the final section, we offer two personal views about end-of-life care by authors who hold atheist and nontraditional views of spirituality. Patrick Grant, in chapter 6, offers his atheist understanding of life and death and of how hospice professionals might care for someone like him at the end. Grant writes that "none of us is ever quite as we are defined, and we remain to some degree opaque to ourselves and to one another." In caring for each other while dying, as in life, something escapes—and the absence, paradoxically, is our best opportunity for meeting one another authentically. Grant concludes, "The inarticulate in itself summons a recognition at once tragic and compassionate, beyond the consolations that can be given a voice. Yet neither does such recognition dispense with the voice that, taken to its limit, acknowledges the deeper human claim that always escapes it, and which, once recognized, can then also inform what might be spoken." In a similar vein, Elizabeth Causton's "Spirituality Unhinged" offers a passionate description of the

author's transition from her early life as Lutheran to her adoption of a more open-ended form of spirituality. Causton, a hospice social worker and counselor, seeks to move beyond all categories, including "spiritual but not religious," and shares her hope at the time of death for a fellow "explorer" to be there with her to hold her hand and listen to her, rather than a professional "detective" who, through questions weighted down with assumptions, is trying to classify her approach to death.

These chapters can be read singly or in the order proposed so as to gain a better understanding of how to approach "spirituality" in the provision of hospice palliative care. One of the frustrations shared by so many of the contributors to this book is the fact that while the nursing and medical literatures have been exploring spirituality for roughly two decades now, critical interdisciplinary assessment of this emerging concept and its applications is still in its infancy. Regardless of the approach readers take to the book, it is our hope that it will stimulate among clinicians, scholars, policy makers, and present and future hospice patients a greater interest in the complex and dynamic ways spirituality has emerged in hospice palliative care as an umbrella concept, an alternative to tradition, and an alternative tradition in itself.

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