Introduction

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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. The religious basis of hospice care permeates Saunders's whole approach to the terminally ill, and her vision resulted in the founding of St. Christopher's Hospice in 1967 in London. There, Saunders developed a program of care for 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 religious traditions was encouraged. While the first two of Saunders's principles have been well studied, the third, engagement with a person's most deeply rooted spirituality or religion, has not been. Thus, the focus of this book is on the religious understandings of a "good death" in hospice care. Leading scholars of the major religious traditions will formulate their own understanding of a good death, specifically with regard to the "spiritual pain" that often parallels and accompanies "physical pain" in hospice care. These understandings are formulated in terms accessible to people from different intellectual, social, and religious traditions. To ensure that our answers go beyond the theoretical level, a series of real-life case studies from different cultures, religions, and medical challenges are included.

Saunders's biographer (du Boulay 2007) notes that the hospice movement, which Saunders founded, combines the best care that medicine can provide together with an engagement with the dying person's most deeply held spiritual understandings. Saunders uses the term *spirituality* to refer to a person's individual experience within a religious tradition such as Christianity or Buddhism, taking into account its various denominations and institutionalized forms. In this study, we will follow Saunders's approach. "Religious tradition" includes the institutional forms of a religion, as well as an individual's experience within that religious tradition. A person's spirituality is therefore shaped by the interplay between the institutional vehicle and a particular, individual experience. Throughout, we prefer the term *religious tradition* rather than *religion* to signal our recognition that the major religious traditions do not have a single theological, cultural, or institutional identity. Rather, they are highly diverse, and their variety and internal differences will be taken into account throughout. We do not assume that an atheist, agnostic, or someone practicing spirituality outside a religious tradition cannot die "with dignity and peace." This increasingly large group of people (especially in North America; Garces-Foley 2003) also needs to be dealt with in regard to hospice care—which we have planned as a second volume. This book focuses on followers of religious traditions such as Buddhism, Judaism, and Christianity and their understanding of a good death in hospice care—a large enough project in and of itself. The issue of atheist/agnostic/secular spirituality is also a large and important project and needs to be dealt with separately.

The hospice movement began in an Anglo-Christian context and subsequently spread to North America and around the world. In the process, much attention was given to the medical and community requirements for hospice care. Since the early 1980s however, little has been written about the religious dimension, even though this continues to be important in practice. The most effective study of how death is treated by the major religious traditions is *Facing Death: Where Culture, Religion, and Medicine Meet* (Spiro, McCrea Curnen, and Wandel 1996). Part 2 of the volume, "Framing Death: Cultural and Religious Responses," contains excellent chapters on a good death in the Hindu, Jewish, Chinese, Islamic, and Roman Catholic traditions, yet these interesting chapters do not consider hospice care. Within the hospice movement itself, the survey by Saunders and Kastenbaum (1997) of the "state of the art" of hospice development in various cultures and countries around

the world barely mentions religion. In summary, our literature review shows that there is no systematic analysis of how to resolve spiritual pain in the achievement of a good death in hospice care.[1] This, then, is our research question: *What are the religious understandings of a good death in hospice palliative care?* This study fills a significant gap in knowledge and will be an essential tool for the training of doctors, nurses, social workers, psychologists, chaplains, and volunteers for work in hospice care in Canada and worldwide.

The Place of Religion in the Modern Hospice Movement and the Concept of "Total Pain"

Writings during the 1970s and 1980s on the formation of the modern hospice movement tended to describe its religious dimension exclusively with reference to Christianity, with the Church of England as a major player (du Boulay 2007). Although she was open to whatever religious tradition a hospice patient might practice, Cicely Saunders was a deeply committed Christian and a member of the Church of England. In her own writings on the religious dimension of hospice care, Saunders commonly evokes Christian concepts and makes frequent reference to the Bible (Saunders 1988). Yet Saunders held also that hospice should be a place of spiritual growth for both patients and staff, and this growth could occur not only in a Christian context but also in religious traditions other than Christianity, and even in the absence of any religious commitment. As Saunders states: "We are ourselves a community of the unlike, coming from different faiths and denominations or the absence of any commitment of this kind. What we have in common is concern for each individual . . . and our hope is that each person will think as deeply as he can in his own way" (Saunders 2006, 227). Saunders clearly sees how the science of medicine and the wisdom of religion are inextricably related in hospice care. As the Yale University citation for an honorary degree given to Saunders in 1969 says: "You have combined the learning of science and the insight of religion to relieve physical pain and mental anguish and have advanced the humanistic aspects of patient care in all states of illness" (Saunders 2007, 184). In Saunders's view a good death honors the whole of life—material affairs, human relationships, and spiritual needs (Saunders 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" (Saunders 1981, ix).

Spiritual needs are defined by Saunders as follows: "'Spiritual' concerns the spirit or 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 research, then, is theoretically guided by Saunders's conceptualization of "total pain," but with a focus on spiritual pain and an acknowledgment that religious needs have to be addressed in hospice palliative care for a good death to be realized.

Hospice Palliative Care as a "Philosophy of Care"

Definitions of hospice and palliative care have continued to evolve since the inception of the modern hospice movement. Currently, there is no single agreed-upon definition. The diversity of meanings associated with the terms *hospice* and *palliative care* and the lack of agreement among scholars and clinicians has resulted in conceptual confusion in the field (Billings 1998). Hospice has been closely linked with grassroots volunteer movements, whereas palliative care has been more commonly associated with medical and professional care (Downing and Wainwright 2006). For some, hospice is equated with respite and care provision in free-standing facilities, or with care in the community. Palliative care has most typically been associated with care in hospital-based settings (Downing and Wainwright 2006). Twycross (1980), a leading physician scholar contends, however, that "hospice is a concept of care rather than a particular type of institution" (36), and the World Health Organization (2002) refers to

palliative care as an "approach" to care. While multiple connotations of the terms *hospice* and *palliative care* exist, it is now commonly understood that hospice and palliative care are not institutions or "places" of care. Rather, hospice palliative care is a *philosophy of care* that "embodies the active total care of an individual" (Daaleman and VandeCreek 2000) and their family members (Doyle, Hanks, and MacDonald 1999; Ferrell and Coyle 2006). It is this philosophical approach to defining hospice palliative care that guides our research.

Use of the Term Modern Biomedicine Rather Than Western

We use the term *modern biomedicine* rather than *Western biomedicine* (with its European scientific worldview) to acknowledge that various worldviews and belief systems exist within the religious traditions. We contend that Westernized beliefs and approaches alone are inadequate to helping us gain religious understandings of a good death in hospice palliative care. We also recognize that the approach of modern biomedicine has been exported around the world, and now functions side by side with alternative medical approaches such as that of the traditional Buddhist monk healers who offer much of the hospice palliative care in Thailand (see chapter 9).

Overview of the Book

Today, many of those involved in the hospice palliative care movement worldwide may know little of the details of Cicely Saunders's life and the early development of hospice care in England from the 1950s forward. For those who would like to know more, chapter 1, written by Michael Wright and David Clark, offers a more detailed recounting of Cicely Saunders's life, her vision for the founding of St. Christopher's Hospice in London in the 1960s, and the subsequent spread of hospice palliative care around the world in the 1970s and 1980s. Although founded by Saunders essentially within an interdenominational Christian context, Wright and Clark recount how by the 1990s the religious dimension of the hospice movement was being newly described in Jewish, Buddhist, and Indigenous (Australian Aboriginal) terms.

The purpose of this book is to expand and make more inclusive the religious understandings of a good death in hospice care. In part 1,

leading scholars of Hinduism, Buddhism, Islam, Judaism, Christianity, and Chinese religion examine how Cicely Saunders's conception of a good death in hospice palliative care may be understood within each religious tradition. Each of these chapters includes a brief introduction to the religious tradition, the concept of a good death latent in this religious tradition's texts and practices relevant to hospice care, narrative case studies exemplifying the approach of the particular religion, and the identification of special issues such as the position of women and children. A response of each religious tradition to the question of how to treat persons who are suffering from dementia or Alzheimer's disease (a rapidly increasing problem in hospice palliative care) is included in each chapter of part 1. Our goal, in each of these chapters, is to offer to hospice and palliative care clinicians an understanding of how Cicely Saunders's goal of a good death may be realized within each religious tradition. These chapters in part 1 also make a contribution to religious studies of dying and life after death (e.g., Coward 1997). The new knowledge presented in these chapters is a clear understanding of how a good death is to be conceived and practiced in palliative situations. For many of the religious traditions, this specific focus on the good death in hospice care is new knowledge and thus is a contribution to the self-understanding of the process of living and dying well in each religion.

Part 2 contains six case studies of real-life hospice palliative care examples involving Thailand's Buddhist monks, the Ugandan way of living and dying (with HIV/AIDS), Punjabi (Sikh and Hindu) extended-family hospice care, caring for children in hospice palliative care, and interfaith chaplaincy in hospice palliative care.

A glossary and index have been provided to aid a busy reader who may want to read about one religion or one case at a time. For example, a reader who wanted to focus on Buddhism could choose to read chapter 3, part 1, on Buddhist perspectives of a good death, followed by chapter 8 on Buddhist hospice care in Thailand, which includes a case study from a Thai hospice centre. Likewise, someone interested in Hinduism could focus on part 1 of chapter 2 on as well as the Punjabi case study described in part 2 of chapter 10. But our hope is that the contents are sufficiently interesting that most readers will want to read right through the whole book. And, as we mentioned earlier in our introduction, for those wondering why we have left out atheists/agnostics and those who follow some form of spirituality rather than a religious tradition, our second volume (forthcoming) will explore understandings of a good death in atheist/agnostic and spirituality-based hospice palliative care.

Note

1. The Association for Clinical Pastoral Education has been a leading organization for clinical counseling and chaplaincy teaching in the United States since 1967. However, a review of its publications and programs indicates no particular attention given to the topic of a good death in hospice or palliative care.

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