Chapter 3
Culturally-Sensitive Approaches to Dying: Muslims and End-of-Life Care

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ABSTRACT
Transformations in understanding the dying process include a focus on the holistic life of the individual, particularly understanding and respecting ethnic and religious variations in the dying process and end-of-life care. This is vital to ensure the dying process is considered a “good” one. Health services professionals are often lacking in culturally-appropriate training for dying patients that ranges outside pain management and physical symptom maintenance. Dying, however, does not just happen to the physical body. It is necessary to care for a patient’s religious, social, and psychological selves as well. This chapter focuses on healthcare practices for professionals involved in end-of-life care, particularly for Muslim patients. Emphasis is placed on the role of cultural and religious understanding in providing patients and their families with a good dying experience.

INTRODUCTION
Historically, dying was considered a personal, family-focused experience. It was only recently that we moved the dying experience into the institutionalized hospital setting (Kellehear, 2007). Since families are no longer the primary end-of-life caregivers, many dying patients experience a sterile, medicine-focused dying process (Kaufman, 2005). At any stage of life, previous research has stressed the importance of caring for the whole individual as a person, as opposed to solely focusing on their physical ailments (Morgan & Yoder, 2012; Zamanzadeh et al., 2015). This holistic model of health care, which emphasizes the mind, spirit, and emotions along with the body, is also a main tenant of hospice, which seeks to make the end-of-life experience as personal and positive as possible (Hospice Foundation of America, 2018; Zamanzadeh et al., 2015). For Muslim patients, then, making sure to incorporate religious and
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ethnic beliefs is a top priority in experiencing a good death, particularly when certain beliefs may contradict or challenge normative, Western approaches to end-of-life care (Harford & Aljawi, 2013).

The purpose of this chapter is to provide insight for end-of-life caregivers and health care professionals who encounter dying Muslim patients and their families. The overarching research question asked: “What are the cultural and religious gaps for treating Muslim patients during end-of-life in the United States?” This chapter assesses current policies and practices for end-of-life care to determine the availability of and focus on Muslim tradition during the dying process. Any cultural and religious gaps discovered will aid health care providers in delivering a good dying experience for their patients and their families. With over 1.8 billion Islamic followers and approximately 3.5 million of them residing in the United States, health care providers are likely to encounter Muslim clients (Badawi, 2011; Stephenson & Hebesky, 2018). Being prepared for and able to provide for these clients at the end of life is the focus of this chapter.

BACKGROUND

Transformations in End-of-Life Care

Prior to our relocation of the dying to medicalized settings, much of our end-of-life care and experiences occurred at home (Kellehear, 2007). When the majority of caretaking was provided by loved ones or close friends, cultural and religious beliefs of the dying could easily be incorporated into their last days. Historically, this made for what was known as the “good death,” or “dying that permits one to prepare for death with the cooperation of family and the community” (Kellehear, 2007, p. 86). Recent transformations into a scientifically-focused, death-denying society means that Americans are afraid of death and often sequester it away into the sterile unknown of the hospital setting (Chapple, 2010; Kaufman, 2005). We have moved past the quest for a good death into that of a “managed death,” one that is, ideally, staved off until the last possible minute, with doctors having tried everything to save their patient (Chapple, 2010). Not only does this mean the dying patient is vulnerable to unnecessary, even painful procedures, but their dying process now becomes an unseen experience, away from friends and family (Chapple, 2010; Kellehear, 2007). This also means the dying experience is more medicalized, often at the expense of the patients’ own wishes and needs.

Challenges to this curative method of dying do exist, however. The hospice model used today traces back to Dame Sicily Saunders, who opened the first hospice center, Saint Christopher’s Hospice, in England in 1967. The American hospice movement began seven years later in New Haven, Connecticut at Connecticut Hospice (National Hospice and Palliative Care Organization [NHPCO], 2009, p. 2). Hospice’s main focuses include compassionate care at the end-of-life and death with dignity. These include pain management (palliative care) and, ideally, dying on one’s own terms (NHPCO, 2009, p. 2). The emphasis now is on caring for the patient instead of curing them and includes a team of workers caring for all aspects of the dying patient. This includes their social, psychological, and religious health and wellbeing, along with the physical. Unlike palliative care, which should be included in all medicine, hospice is reserved for those who meets the following requirements: (1) the patient must be diagnosed with a terminal illness and six months or less to live; and (2) the patient and/or family has elected for palliative (relief from pain) care instead of curative care (Vitas Healthcare, 2019).