

# THE HOSPICE MOVEMENT: SPIRITUALITY WITHIN THE UNITED STATES' HEALTH CARE SYSTEM

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*With the elderly population growing, there is a great need to improve the quality of end-of-life care. Traditionally, the healthcare industry has focused on the pathology-oriented medical model when assisting terminally ill patients. This focus can lead to patients feeling depressed, anxious, and hopeless about the dying process. By incorporating spirituality into the dying process, the hospice movement diverged from this medical model, but the role of social workers is often divided between these two very different paradigms. This paper discusses spiritual practice theories that hospice social workers can use to benefit the well-being of terminally ill patients while working within the current health care system.*

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The history of the American hospice movement reveals the importance of spirituality in end-of-life care. In the early hospice movement beginning in the fourth century, care for the dying was almost solely driven by religious communities that promoted spiritual well-being during a patient's last phases of life. What differentiates the hospice movement today from these earlier efforts is the implementation of modern medicine (Garces-Foley, 2003). Within this new medical context, a question arises for social workers: How can we effectively work within the current medical model, which places value on curing, deficits, and pathology, and still attend to the patient's social, emotional, and spiritual comfort in an increasingly secular society? This paper will seek to answer this question by exploring current theories and practices social workers can employ to promote the well-being of patients with terminal illness by focusing on spirituality in hospice care.

## Choosing Hospice Care

Today more than 3,200 hospices have been established in the U.S. ("Brief History of Hospice Movement," n.d.). Types of hospice care vary from independent, to nonprofit, and for-profit. The National Association for

Home Care and Hospice (NAHC) noted that in 2000, one in four terminally ill individuals in the U.S. received hospice care (NAHC, 2002). The majority of patients receiving hospice care are elderly, with more than 79% age 65 or older and only 3.9% of hospice patients under the age of 45 (NAHC).

Race and social class play a significant role in identifying patients most likely to use hospice services. NAHC (2005) asserted that although utilization of hospice services has increased among all racial and economic groups over the past decade, white, middle-class patients are still more likely to use hospice assistance than other groups. Blacker (2004) suggested that many vulnerable populations, including refugees, immigrants, those with severe physical and mental disabilities, and people of color, continue to be underserved during end-of-life situations. Barriers to hospice care may include a lack of knowledge concerning end-of-life options and the limited number of hospice services available in some local communities. In addition, different views on death and dying shaped by philosophical, spiritual, and social beliefs often lead to lower rates of hospice use by different cultural groups. For example, Sullivan (2001) asserted that many Latinos would not choose to be cared for in nursing homes or hospices due to their strong cultural emphasis on familial responsibility, privacy, and modesty.

With the growth of hospice care since the 1970s, an increasing number of Americans are choosing hospice as an option for themselves and their loved ones. Cicely Saunders, a social worker and founder of the first modern hospice in 1974, and Dr. Elisabeth Kubler-Ross, who wrote the groundbreaking book, *On Death and Dying*, both brought the topic of dying to public attention. They did so during a time when the medical community viewed terminal illness as something to be controlled rather than a condition that required relief. Saunders and Kubler-Ross illustrated how the medical community all too often ignored and abandoned the emotional needs of a dying patient, once it became apparent that the patient could not be cured (Raymer & Reese, 2004).

According to Tyrer and Exley (2005), the most common reasons patients choose hospice care over hospital facilities are the support and care available to families, the patient's wishes to die at home, and the inability of medical interventions to cure the patient. NAHC (2005) also suggested that hospice policies that allow patients to stay with family in the comfort of their own home and policies that encourage family members to take an active role in the treatment of their loved one lead patients to prefer hospice care over hospital or nursing facilities. In addition, when compared to trained nursing and

hospital services, hospice is a more cost-effective option for eligible patients with a life expectancy of 6 months or less to live (NAHC). Hospice services are covered by both the Medicare Hospice Benefit under Medicare Part A, and the Medicaid Hospice Benefit. In addition, most private insurers will cover portions of hospice services. Since the majority of hospice recipients are 65 years of age or older, they qualify for entitlement services under the Medicare Hospice Benefit, resulting in almost no out-of-pocket costs to the patient (“Caring Connections,” n.d.). Due to its increased accessibility and cost-effectiveness, hospice use rose 20% from 1992 to 2000 (NAHC). Today, as a greater number of elderly patients seem to be choosing hospice as the baby boom generation continues to age, a focus on end-of-life care by the healthcare system is imperative (Nakashima & Canda, 2005).

### Social Work Practice in Hospice Care

Social workers involved with hospice are part of a team of physicians, nurses, counselors, home health aides, clergy, therapists, and trained volunteers (NAHC, 2005). Together they offer support and emphasize a holistic framework that places attention on palliative as opposed to curative care. The hospice team relies on the skills and knowledge specific to each discipline in an effort to organize a unique and supportive plan beneficial to each patient and family (NAHC). Blacker (2004) noted that social workers have a unique role on the hospice team, which is to assist patients and families managing complicated psychological, medical, social, legal, and ethical decisions associated with end-of-life issues. Also, social workers serve as patient advocates on the hospice team by assisting the patient in navigating through complex medical and social systems. When developing a model for hospice care, Saunders conceptualized professionals working as a team comprised of many fields of study, since Saunders herself assumed the roles of social worker, physician, and nurse. The current model for hospice care, similar to social work practice, suggests that collaboration is essential for boosting the physical, mental, and social conditions of the patient (Parker-Oliver, Bronstein, & Kurzejeski, 2005).

Although social workers hold a distinct place within the interdisciplinary hospice team, Batten (1997) suggested that the social worker’s role in a hospice setting is often variable and unclear (NAHC, 2005). While providing patients’ psychosocial and spiritual care is an essential and standard aspect of hospice service, social workers do not exclusively

perform these tasks, but share the responsibilities with nurses, clergy, and volunteers. As Reese (2001) explained, “although hospice philosophy holds that all members of the team address spirituality, sometimes spirituality is considered the chaplain’s domain. Social workers may do the initial spiritual assessment, but not intervention with spiritual issues” (p. 149). Therefore competition may arise between social workers and chaplains regarding their core responsibilities. In addition, turf issues may also surface between social workers and nurses concerning the task of completing psychosocial assessments. Often, social workers in hospice settings perceive that nurses are assuming this duty, which is specifically assigned to social workers, creating high levels of frustration and conflict within the interdisciplinary team (Parker-Oliver et al., 2005). Although the role of the social worker is not clearly defined within many hospice settings, social workers’ diverse knowledge of intervention strategies can decrease conflict and motivate change within the hospice team (Parker-Oliver et al.). By working to assess and respond to the needs of the interdisciplinary team, social workers can improve the cooperation, communication, and success of the hospice team and enhance hospice service to patients and their families.

### Spirituality in End-of-Life Care

Nakashima and Canda (2005) argued that while the hospice movement has played an important role in improving terminal care by providing a holistic approach, the leading philosophy of patient care is still embedded in a pathology-oriented medical framework. This medical approach can lead patients to feel depressed, anxious, and hopeless about the dying process. The current medical model does not address a patient’s spiritual concerns, such as questions about the origin and purpose of life and the meaning of suffering (Reese, 2001). While the hospice setting incorporates different religious and spiritual elements to address spiritual issues, social work as a profession has historically fought traditional religious paradigms that often blame individuals for their problems. As a result, social workers have successfully shifted the profession’s attention to the person-in-environment context (Bullis, 1996). Therefore, social work in hospice may differ from the current orientation of many in the social work profession. Hospice work requires social workers to attend to the spiritual dimension of a person, which is vital in understanding how patients define their environment during their final days (Garces-Foley, 2003). Nakashima and Canda maintained that

spiritual practices offered by social workers in a hospice setting can provide profound support for patients to heal, grow, and feel more comfortable in the last stages of life.

### *Transpersonal Social Work*

Reese (2001) argued that focusing on spirituality when working with the terminally ill can act as a source of strength for patients. Reese claimed that, when faced with death, all adult patients can achieve a stage of spiritual growth. This stage, called transegoic, occurs when “ordinary life is infused with a sense of the sacred. Heightened empathy, compassion, and moral standards naturally arise as the individual experiences a profound connection with others” (p. 137). Although the transegoic level of consciousness is not an automatic development during the last stage of life, Reese contended that a smooth shift into the transegoic stage can support a comfortable death by reducing death anxiety and increasing social support. She pointed to the need for hospice social workers to incorporate transpersonal theory as a foundation for practice technique to assist dying patients and their relatives make the transition to the transegoic stage (Reese).

Application of these transpersonal techniques may help patients take full advantage of the time that remains and to live in as much peace as possible during their last phase of life. An example of one transpersonal technique is teaching meditation practice as a way to support spiritual growth and relieve stress. Specific meditation techniques include “paying attention” and “intentional breathing” (Reese, 2001, p. 152). Paying attention supports awareness by encouraging patients to take pleasure in a shower or appreciate each moment with a loved one. Intentional breathing is a technique that helps patients to diminish stress by repeating a mantra while concentrating on their breathing. Other transpersonal techniques used to help transegoic stage development are movement mediation, group chanting, dream interpretation, music and art therapy, acupuncture, and keeping a journal (Reese).

### *Focusing on a Patient's Resiliency*

Nakashima and Canda (2005) conducted a qualitative study that examined the opinions of older adults who had positive experiences during their last stages of life. From their findings, the researchers concluded that in order to promote the psychosocial and spiritual well-being of terminally ill patients, social workers need to create intervention plans to help patients identify their internal and external resources that have helped them cope

with adversity in the past. Through this process, patients will re-live past experiences of resiliency, which can lead to a more positive and peaceful death.

Examples of a patient's internal and external resources might include spiritual attitudes, unique skills, talents, and relationships with others that can be shared with the social worker through narrating events of past resiliency. By storytelling past positive experiences, patients can create meaningful narratives of living and dying. Findings from Nakashima and Canda's (2005) study also indicated that strong spiritual or religious relationships in the community strengthen the ability for individuals to cope during stressful situations. A strong connection to the church, involvement in prayer, or attending spiritual rituals all promote spiritual practices and beliefs and strengthen the ability of individuals to thrive and benefit in adverse circumstances (Nakashima & Canda).

### *Buddhist Approach to End-of-Life Care*

While social workers need to focus on a patient's resiliency and spiritual strengths to promote the well-being of terminally ill patients, Garces-Foley (2003) argued that it is also important to create a nonsectarian spiritual language, along with nonsectarian social work practices, to aid in a patient's positive end-of-life experiences. Garces-Foley pointed out that over the past 20 years, Buddhism and hospice have created a mutually valuable relationship based on the attraction to nonsectarian language of spirituality, the craving for realistic techniques of coping with death, and the potential capacity of Buddhism to meet this need.

During the 1980s, the American hospice movement was searching for a spiritual language that was not associated with a particular religious denomination and that would be appropriate for clients of different ethnic, religious, or cultural backgrounds (Garces-Foley, 2003). In addition, hospice was becoming a mainstream option for terminally ill patients. Around this same time, Buddhism was expanding in popular culture through advocates of Buddhist practice who used books, Buddhist centers, conferences, and trainings to raise public awareness of Buddhist philosophies. Through this increased social consciousness, leaders of the hospice movement became aware of Buddhist wisdom towards death and dying and discovered that Buddhism offered an appropriate nonreligious language to use within hospice practice (Garces-Foley).

Within Buddhist philosophy, there are many teachings and applicable

practices that speak specifically to end-of-life issues. As a result, many religious and non-religious people who are searching for supportive practices during the dying process turn to Buddhism as a guide to dying and post-death rituals. Buddhist teachings present meditation practices for both the patient, whose objective is to begin to let go of life, and the caregiver, whose objective is to develop compassion. For either patient or caregiver, these practices permit the increase of a sense of power in times when people often feel powerless. In contrast to the view of medical institutions, which view death as a failure, Buddhist practices present a means to a successful and positive death, which can be accomplished through discipline during meditation practices (Garces-Foley, 2003).

Patients who are receiving hospice services may be attracted to Buddhist teachings on death and dying, but are not necessarily converting to Buddhism. Instead, religious and nonreligious hospice providers and patients are borrowing Buddhist practices to enhance their own religious ideals and practices. Garces-Foley (2003) called this type of melding of religious practices “religious mixing or combination” (p. 342). Through this process of religious selection, people can maintain their personal religious backgrounds while selecting aspects of Buddhism that seem appealing and applicable in their daily spiritual practices. With the establishment of Buddhism within the modern hospice movement, social workers have access to a unique spiritual language and applicable meditation practices that support positive spiritual end-of-life experiences for patients of diverse religious backgrounds.

### The Future of Spirituality in Hospice Care

In addition to learning spiritual techniques and approaches, there is also a need for hospice social workers to be trained in spiritual assessment and intervention. Wesley, Tunney, and Duncan (2004) suggested that even though the Joint Commission on Accreditation of Healthcare Organizations includes spiritual assessment in its principles, it does not offer precise guidelines for social workers. Furthermore, the social work profession needs to define what constitutes standards of spiritual care, as little social work research exists concerning spirituality and terminal illness (Wesley et al.).

In addition, Reese (2001) suggested that there are inconsistencies among social workers to define, identify, and address spiritual issues. She proposed that social work education needs to focus attention on the various spiritual

beliefs about dying that exist within our society. Social workers also need to come to a consensus and create suitable documentation of spiritual interventions that can effectively monitor and evaluate the effectiveness of various approaches. Lastly, Reese noted that it is important for social work education to address the social worker's personal beliefs about death and spirituality, which may influence their willingness to address spiritual matters with clients.

### Conclusion

Social workers' use of spirituality in a hospice setting can greatly enhance and promote a patient's well-being during their last stages of life. As a result of the work of Saunders and Kubler-Ross, the topic of dying has been brought to public attention ("Brief History of Hospice Movement," n.d.). There is now a critical need for social workers to move away from the current pathology-oriented medical model (Nakashima & Canda, 2005). Hospice social workers need to incorporate spirituality to support patients' ability to emotionally heal, grow, and feel more comfortable in their last stages of life. Transpersonal social work, focusing on the resiliency of terminally ill patients, and incorporating a Buddhist approach to death practices are all types of spiritual practice theories that social workers can use to benefit the well-being of people with terminal illness. Spirituality training for social workers employed at hospice settings, as well as addressing spirituality and hospice in graduate social work programs, are also necessary to support the hospice movement's use of spirituality in end-of-life care. Even with all of the existing theories and lessons for social workers to understand and apply when working with dying patients, Reese (2001) put it simply when she said, "in the end, the people who are dying will teach us these lessons more often than we will teach them" (p. 158).

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