

Caring for the Whole Person in Palliative Care

April 12

Today, I admitted Candy Harris to our home-care agency. Candy is a 42-year-old woman who until a month ago worked as a nurse with developmentally delayed children. She has been married to Ron for the last 20 years; a picture taken of them at their Senior Prom sits on a bookshelf. They have two children aged 5 and 8 years and live in a new neighborhood development. She seemed so sad when I arrived, but I would be, too, if I were in her situation. I find admissions like this so

difficult; she is close to my age and we are so similar in other ways.

She tells me the history of her disease in a very matter-of-fact way. For the 9 months prior to her diagnosis, Candy had noticed increased flatus that had not gotten better, despite alterations in her diet. For the 2 months prior she said that she had little appetite, but still had gained 5 pounds. She felt bloated all the time and the waistbands of her clothes were tight. Her mother started menopause in her early 40's and died at age 56 of breast/ovarian cancer. Candy thought that

her symptoms were related to the early start of menopause and so decided to visit her nurse practitioner for a physical exam and pap smear.

Given Candy's symptoms and her positive family history of cancer, the nurse practitioner ordered an abdominal CT scan in addition to a complete physical work-up. An ovarian mass was detected and Candy was scheduled for a laparotomy. Stage III ovarian cancer was diagnosed. The surgeon was able to use cytoreduction to decrease the tumor volume to <2 cm in diameter, and the oncologist suggested platinum-based combination chemotherapy. She was in shock that all this was happening to her so fast. The children were really too young to completely understand what was going on and her husband insisted that they were going to "fight this."

Candy had just finished her third cycle of chemotherapy. She is very weak and in need of home health-care support. Candy was sitting in a chair in the living room when I arrived. Her hair had all fallen out and her eyes were red, as though she had been crying, and she was holding a rosary in her hand. One section of the wall was covered with get-well cards; she referred to this area as her "prayer wall." As I was assessing her, she burst into tears and told me that she thinks "God is punishing her for something" and that this is why she

has cancer. This was not the first time that I have heard this from a patient. Believing in the importance of atoning for her sins, Candy has been attending mass whenever she has the strength, praying the rosary regularly, and asking the church congregation to pray for her. She has gone to confession and received the "Sacrament of the Sick." She also admitted that she wanted to "cover all of her bases" and that she has turned to holistic interventions in addition to her chemotherapy so that her body, mind, and soul will also heal. After her initial diagnosis, she researched complementary interventions for cancer and started on a macrobiotic diet with additional B12 and D vitamins.

Candy receives Reiki twice a week and is seeing a therapist weekly. She said that she and her husband use mental imagery and relaxation techniques to imagine her body defenses as a powerful source to annihilate the cancer cells. Candy said that she has so much to live for, that she has a lot of good friends, a loving husband, and great kids. She really doesn't know what she has "done wrong" but she asks for God's forgiveness and hopes to get on with her life.

As a nurse, I marvel at her will to live and her determination to beat this disease. She seems to draw her strength from her religion and her relationships. Her strength is an inspiration to all who care for her.



Culture and Spirituality as Domains of Quality Palliative Care

Deborah Witt Sherman

Key Points

- Culture and spirituality structure human experience, values, and behaviors.
- Spirituality provides a sense of connection to self, others, nature, and God and is important in crisis and illness.
- Cultural competence involves knowledge of your own and other cultural groups.
- Cultural assessment has several areas to be addressed.
- Palliative care addresses the cultural and spiritual needs of patients and families.
- Spirituality and religiosity help individuals to cope with serious illness and play a role in the dying process.
- Suffering is a part of the human condition and is experienced in physical, emotional, and spiritual ways.
- Suffering is reciprocal involving not only the patient but also his/her family.
- Hope plays a role in promoting spiritual well-being.
- Health professionals must learn how to conduct a spiritual assessment and have conversations about spiritual and religious issues.
- Spiritual care discovers, reverences, and tends to the human spirit.
- Knowledge of spiritual and religious perspectives on death informs spiritual care.
- Spiritually and culturally competent care requires self-reflection and self-care of health professionals.

Case Study: Mrs. Martinez is an 84-year-old Latino woman, who has progressive pain and weakness due to sensory neuropathy, secondary to diabetes and arthritis. During the course of her illness, she has maintained her independence and good spirits. Mrs. M. believes that her faith in God has enabled her to endure her chronic pain. She states “Sometimes I pray when I am in deep, serious pain. I pray and all at once the pain gets easy. I feel it has helped me more than the medication. I believe in God. He is my guide and protector.” Mrs. Martinez lives with her daughter, son-in-law, and grandchildren.

They are a source of comfort and support and are very concerned about her well-being. Unfortunately, Mrs. Martinez recently had a stroke, which resulted in left hemiplegia. After an initial hospital stay, her family insisted that they care for her at home. On a visit to their home, the healthcare professional observes a shrine of Mary in the front yard, as well as crucifixes and pictures of Jesus in every room. In addition to traditional medications prescribed by her physician, Mrs. Martinez takes herbal remedies in an attempt to restore her health. The healthcare professional acknowledges the cultural and spiritual values and beliefs of Mrs. Martinez as considerations in providing quality palliative care.

Introduction

Culture and spirituality are among the most important factors that structure human experience, values, behaviors, and illness patterns. As a system of shared symbols and beliefs, culture supports a person’s sense of security, integrity, and belonging and provides a prescription for how to conduct life and approach death (End of Life Nursing Education Consortium (ELNEC), 2001). Every culture has a worldview or construct of reality that defines the individual within that reality. Patients’ cultural backgrounds are therefore fundamental in defining and creating their reality and determining their purpose in life (Ersek, Kagawa-Singer, Barnes, Blackhall, & Koenig, 1998). A transformation of identity begins when an individual is diagnosed with a terminal illness. Cultural rituals provide the sacred elements that support patients and families during times of illness and transition. Specific rituals assist individuals and families in coping with death, which is the final transition in life. The rituals of death change the identity of the patient from the living to the dead, and also the identity of the family member, for example, from spouse to widow or widower (Kagawa-Singer, 1998). Culture provides a framework of expectations about communication with others including health professionals and the role of family, and influences the dynamics of decision making regarding health issues and the dying process itself (Barclay, Blackhall, & Tulksy, 2007).

Spirituality plays a vital role in times of crisis and illness, as it provides a sense of connection to self, others, nature, and God, and is a means to cope with loss, grief, and death (Weaver, Flannelly, & Flannelly, 2001). Life-threatening illness is a crisis on many levels—physical, psychological, familial, social, and spiritual (Doka & Morgan, 1993). Given the uniqueness and individuality of each person, even people of the same culture and spirituality may have different

backgrounds, experiences, needs, concerns, and interpretation of illness. In addition to the individuality of the person, the nature of the life-threatening illness may be different and the person may be at different points in adapting to the reality of the disease. Spiritual and cultural concerns may permeate the illness experience or may arise at any point across the illness/dying trajectory. For patients and families who are experiencing life-threatening illness, the concerns may be of suffering that may take multiple forms relative to the mind-body-spirit. It is now recognized that the uncertain and long-term nature of many life-threatening illnesses pose the potential for pain, alterations in body image, and confrontation with death, which may lead to spiritual distress. The renewed focus on incorporating spiritual care into nursing practice is congruent with nursing’s commitment to holistic practice and the renewed valuing of human experiences that defy scientific description and explanation (O’Neill & Kenny, 1998). Within the past few years, research has shown that religious beliefs and spiritual practices affect the meaning of illness, physical and emotional well-being, coping with illness, and healthcare decisions, particularly for individuals facing life-threatening illness.

Spiritual and cultural competences are central tenets of palliative care. As a philosophy of care, palliative care combines active and compassionate therapies to support and comfort individuals and families who are living with life-threatening illness. Palliative care strives to meet the physical, psychological, social, and spiritual expectations and needs, while remaining sensitive to personal, cultural, and religious beliefs and practices (National Consensus Project, 2009). Undergraduate-prepared nurses and advanced-practice nurses must become spiritually and culturally competent in the care they offer across the illness/dying trajectory. Such care is critical to enhancing the quality of life and quality of dying and to supporting the intrinsic dignity of patients and their families.

Understanding Culture

Culture is defined as a way of life, which provides a worldview, fundamental in defining and creating a person's reality, determining his/her meaning and purpose in life, and providing guidelines for living (Ersek et al., 1998). As cultural perspectives evolve, changes are evident in the beliefs, values, and attitudes of a cultural group or its members. Cultures are not monolithic, but rather there is a range of potential responses to each issue in every cultural group. Thus, there may be within-group variations, such as those attributed to acculturation differences, as well as to differences related to age, education, geographic location, and social context (Kagawa-Singer & Blackhall, 2001; Barclay et al., 2007). It is important to inquire whether an individual patient adheres to the beliefs and practices of his/her cultural group, rather than assuming that he/she holds the same values and beliefs (Crawley, Marshall, Lo, & Koenig, 2002).

Although culture is often identified with ethnicity, it is a far broader concept, which encompasses the components of gender, age, sexual orientation, differing abilities, educational level, employment, and place of residency (ELNEC, 2001). As examples, cultures may value male children more than female; the young more than the old, heterosexuals rather than homosexuals, the educated and employed more than the uneducated or unemployed; individuals with stable domiciles more than the homeless; and the healthy more than the physically, emotionally, or intellectually challenged. The diversity of the population with regard to many of these factors may increase their vulnerability in terms of perceived cultural status. Concepts of culture and ethnicity may be useful for making generalizations about populations; however, if they limit appreciation of the unique differences of people and are used to predict individual behavior, they may lead to stereotyping (Koenig, 2002).

Cultural background also relates to issues of power, decision making, language and communication, sources of support within the community, degree of fatalism or activism in accepting or controlling death, maintaining hope, and even views of the patient and family about death (Sherman, 2001). Cultural differences are further evident in terms of the relationship between the older adult and his/her family. In certain cultures, the older person is viewed as the patriarch or matriarch of the family who has the final word in personal and family matters. In other cultures, the older person defers decision making to members of the family, as interdependence among the family and community members is more valued than individual autonomy (Ersek et al., 1998). Dependent on cultural expectations, families may believe that it is their duty to protect the patient from bad news, which is believed to burden the individual or cause emotional distress or harm. Full disclosure of diagnosis

and prognosis to the patient may therefore be considered harmful by families (Barclay et al., 2007). As the cultural diversity of patients and practitioners in the United States continues to increase, there is a risk for cross-cultural misunderstanding surrounding care at the end of life. Cross-cultural understanding and communication techniques increase the likelihood that both the process and outcome of healthcare are satisfactory for all involved (Kagawa-Singer & Blackhall, 2001).

CULTURAL PERSPECTIVES IN HEALTHCARE

Understanding the cultural backgrounds of patients is fundamental to the development of a trusting and supportive relationship between patient, family, and healthcare professionals, and essential in developing a plan for healthcare that is consistent with their cultural expectations and health beliefs. Andrews and Boyle (1995) discussed three types of health belief systems: magico-religious, biomedical, and holistic. In the magico-religious paradigm, a person believes that God or supernatural forces control health and illness. In the biomedical paradigm, to which most Americans subscribe, illness is believed to be caused by a disruption in physical or biochemical processes that can be manipulated by healthcare. In the holistic paradigm, health results from a balance or harmony among the elements of nature and illness is produced by disharmony. Examples of the magico-religious system is a Haitian patient who believes that his symptoms are caused by spirits, or the Mexican American who uses herbs, oils, incense, or religious figurines to drive away evil spirits or to relieve gastric pains. In the biomedical system, Americans or Europeans seek cure of illness through advanced medical technology and pharmacologic management. Based on the holistic belief system, a Chinese woman may attribute her headache to a stagnation of Qi, believing in the need for balance between Yin and Yang, while a Native American patient may wear a bag of herbs around his neck blessed by the medicine man to maintain his strength (Grossman, 1996).

Recognition of these health beliefs systems is evident in the healthcare practices of many cultures. The health beliefs of the African American, Chinese, Asian Indian, Latino and Hispanic, and Native American will be discussed on the basis of recent studies or cultural inquiries and provide a framework for offering culturally competent Hospice and palliative care to members of these cultural groups. The only truly accurate way to know what individuals believe in or the effect that their culture or religion plays in their life is to ask them. The following information will guide the nurse regarding areas to be assessed.

Cultural Perspectives of African-Americans

Within the African-American culture, there is a strong sense of community and of the importance of family, friends, and the church community as sources of support. The extended African-American family consists of mother, father, children, grandparents, aunts, uncles, nieces, nephews, and cousins with a willingness to accept all relatives regardless of their circumstances (McDavis, Parker, & Parker, 1995). Older adults are prized in the African-American family and they play key roles in the family, church, and community. Many grandparents accept the responsibility for rearing their grandchildren, while the parents of those children work or receive higher education. Children are taught to take care of their parents and to be devoted to them. In addition, older African-American family members play a significant role in passing on cultural values, customs, and traditions to the children (McDavis et al., 1995).

With respect to healthcare, African-Americans are often distrustful of the healthcare system, given a history of oppression from slavery and racism. Common themes of justice and respect have reinforced the importance of self-determination. In a study of attitudes, values, and questions of African Americans regarding participation in Hospice Programs, Taxis (2005) identified three main barriers: 1) a lack of information about Hospice and inaccurate assumptions regarding Hospice care; 2) cultural barriers resulting from an avoidance of discussions regarding end-of-life planning; and 3) institutional barrier resulting from a mistrust of the healthcare system. Bullock (2006) reported that even using a faith-based promotion model of advanced care planning, 75% of the 102 African-American participants refused to complete advance directives. The participant's decisions were based on such factors as spirituality, view of suffering, dying, and death, social support networks, and mistrust of the healthcare system. For African Americans, advance care planning conflicts with their beliefs and attitudes about fighting to the end, not giving up hope, and enduring suffering. In a study of 473 adults (220 blacks and 253 whites), Ludke and Smucker (2007) found that relative to whites, blacks were significantly less likely to consider Hospice if they were near the end of life even if their doctor recommended its use. However, blacks who had a prior exposure to Hospice and who trusted their doctor were more willing to consider Hospice.

Since family is central to the care of the dying, and with the assistance and supportive relationships established with church members and neighbors, there is a decreased need for outside support (Sherman, 2001). Given strong family loyalty, there is reluctance to hospitalize family members. As a measure of respect and devotion, elder African-Americans are placed in nursing homes only as a last resort (McDavis et al., 1995).

In the African-American culture, death is integrated into the totality of life. Ancestor worship involves the communion with the living dead through memories, and the deceased are remembered by name. When the deceased are no longer remembered by people alive, they become part of the anonymous dead, but by this time their spirit has been reborn in a new child (Sherman, 2001)

To explore the meaning of death and the experience of grieving, Abrums (2000) conducted life history interviews of nine church-going women, ranging in age from 19 to 82 years, from a small black storefront Baptist church in the Pacific Northwest. The findings indicated that the women in the church had been taught to be strong in the face of death and to handle their grief "head on." The women believed that they would one day be reunited with their loved ones. The terminology of dying was through use of the words "passed on," "passed away," or "died." Participants described many spirit visits for the purpose of offering warnings or as direct messages. Belief in an afterlife was sustained by day-to-day experiences of visions or messages from another world. It was believed that God spoke to them in many ways through premonitions, perceived as the voice of God. There was strong perception of the journey of life in which there was a job to do on earth and a purpose to one's life. No life was in vain. Time was needed to prepare for death and to make peace with God as dying individuals. Participants also described the importance of hope, acceptance, and responsibility to comfort the dying and the bereaved. Abrums (2000) concluded that health professionals should learn to value the spiritual beliefs and grieving behaviors of members of other cultures, rather than viewing them as maladaptive. Supporting the dying and their family in their beliefs is important in providing spiritual care. Verbal recognition of specific actions taken by family to support the dying provided a sense of comfort and support to the family in their grief. The people in this storefront church were often comforted by the recognition that God sustained them in times of adversity and God would protect their loved ones. This acknowledgment of the family's belief system by health professionals can augment the healing process during times of loss and grief.

Cultural Perspectives of the Chinese

In the Chinese culture, the primary theme related to social structure is the centrality of the family. From the centrality of the family arise cultural expectations, such as: 1) duty to family manifested by respect and reverence for parents; 2) conformance to family and societal norms and especially not bringing shame to the family; 3) family recognition through achievement; 4) emotional self-control manifested through reserved and formal public verbal and nonverbal

communications; 5) family disagreement, or demands, kept to a minimum; 6) collectivism evidenced by people keeping a focus on the family and community over self; and 7) humility manifested by a lack of striving for individual achievement but achievement that is related to the family (Kemp & Chang, 2002).

Given the traditionally hierarchical and patriarchal family structure of the Chinese, the oldest adult male is the primary decision maker. In family matters, there is significant influence of elders. Health decisions may be made by the family, and are based on what is best not only for the elder patient but also for the family. In general, yes and no questions should be avoided as yes is considered to be the polite answer and is nearly always given.

In China, the primary religion is Buddhism. The essence of Buddhism is the Four Noble Truths, specifically that: 1) all sentient beings suffer; 2) the cause of suffering is desire manifested by attachment to life, security, and to others; 3) the way to end suffering is to cease to desire; and 4) the way to cease desire is to follow the Eightfold path of: knowledge of the Four Noble Truths, right intent, right speech, right action, right endeavor, right mindfulness, and right meditation. It is believed that following the Eightfold Path leads to emancipation from rebirth (Kemp & Chang, 2002).

In the Chinese culture, it is also important to understand the importance of balance of the Yin and Yang, which are complementary forces. A second important concept is that of traditional Chinese medicine (TCM), which is based on channel (meridian) systems, in which various body channels carry vital or life energy called chi. Imbalance or disruption of channels leads to illness and the treatment goal of TCM is to restore balance. A third important concept in understanding Chinese approaches to health and illness is the use of allopathic medicine, as well as TCM.

Issues central to the care of the Chinese at the end of life center around family and communications (Kemp & Chang, 2002). Symptom management may be complicated by patient's and family's reluctance to complain because of respect for others in position of authority. Concerns also center around fears of addiction, desire to be a good patient, and fear of distracting the physician from treating the disease. In some cases, elders may even deny symptoms when asked directly; however, the use of the visual analog scale and numeric rating scale can be used to assess pain. For example, patients may want to keep warm during illness by wearing sweaters or socks in bed and drinking warm liquids and avoiding cold drinks. As death nears, the family may wish to call monks or nuns for ritual prayers (Kemp & Chang, 2002).

Communications at the end of life are also complicated by reluctance to discuss prognosis and diagnosis. Chinese families often withhold information from patients and may pretend that he/she does not know

what is happening. Families believe that discussing end-of-life issues is like wishing death upon the elder, or may lead to hopelessness, especially since terminal illness is not socially accepted. As death approaches, it is believed that a person's final days should be characterized by calm and the patient should not be involved in decision making. The best way to handle the conspiracy of silence is to ask the patient to whom the information should be given and who should make decisions. Families often feel it is their cultural obligation to care for the person who is dying, and, therefore, Hospice services are often refused (Kemp & Chang, 2002).

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Cultural Perspectives of (Asian) Indians

Among (Asian) Indians, extended families are prevalent and elders are highly respected. The husband's parents often move in with family after retirement, when the family decides to have children, or if there is illness. Elders are highly valued, as is their role as grandparents in raising children. Value is placed on independence and privacy in Indian culture, and family issues are discussed within the immediate family before outside help is sought (Bhungalia & Kemp, 2002). Healthcare decisions usually require family input.

Many Indians are of the Hindu faith. The goal of Hinduism is to free the soul from endless incarnation and suffering inherent in existence. The endless reincarnations of the soul are the result of karma or actions of the individual in this present life and the accumulation of actions from past lives.

The caste system is part of Hinduism. In this system, society is divided into four social classes: the highest class is the priest class, or Brahmins, and the lowest class is the laborer class, or Sudras. A person's class is inherited at birth based on his/her karma. Hindu beliefs that may affect patient care include the following:

- Karma or the consequences of one's actions or behaviors, which influences the circumstances of life and may have caused an illness;
- The importance of meditation and prayer; and
- The practice of vegetarianism in which Hindus pray a specific prayer before eating to ask forgiveness for eating a plant or vegetable in which a soul may dwell.

The Indian system of medicine is known as Ayurveda, which means knowledge of life. Indian medicine mixes religion and secular medicine, with more than

80% of people in India relying on herbal remedies to cure or prevent illness. In this system, the root of disease is not always inside the body, but may be related to the environment or other factors. In the Ayurveda system, the body comprises three primary forces, called dosha, specifically the Vata, Pitta, and Kapha. Each represents characteristics derived from the five elements of space, air, fire, water, and earth; the balance between these forces is essential to health. Once there is imbalance between the forces, balance is sought using different therapies, which includes approximately 1400 plants used in Ayurvedic medicine. Most Indians eat two to three meals a day, eating with the fingers of their right hand, and avoiding distractions while eating, such as watching television or excessive talking. Some foods are considered hot and others cold and should not be eaten in combination, as it is believed to affect bodily functions.

With respect to end-of-life care, it is important for the ill individual to complete unfinished business and resolve relationships. Home is the preferred place of death, with many family members present. Symptoms may not be reported, as it is believed that suffering is inevitable and the result of karma. Many seek a conscious dying process without mental clouding from medications. As death approaches, the following rituals are valued:

- A lamp may be placed near the patient's head; turn the body to face east, towards Mecca; sacred ash may be applied to the forehead.
- A few drops of water from the sacred Ganges River may be placed in the dying person's mouth, while a mantra is softly chanted in the patient's right ear.
- Prayer and incense are part of the rituals of the dying process.

After death, family members should be the only ones to touch the body, and ideally a family member of the same sex should clean the body. After the body is cleansed, a cloth is tied under the chin and over the top of the head, and the body is wrapped in red cloth. Embalming and organ donation are prohibited, and there is a preference for cremation. Following the death, religious pictures at home are turned toward the wall and mirrors may be covered. It is believed that for 12 days the soul wanders in the home, trying to let go of life and the material world. During this time, the family prays and chants, and on the 12th day, the soul is reincarnated (Bhungalia & Kemp, 2002).

Cultural Perspectives of Latinos and Hispanics

The cultural group referred to as Latinos refers to individuals of Hispanic background. By conducting 10 focus groups and interviews with 17 gatekeepers in Latino communities, Sullivan (2001) identified Latino

views regarding end-of-life care. The results indicated that many Latinos felt that they could not communicate effectively with healthcare providers due to language barriers, and were not able to understand informed consent even when interpreters were used. None of the Latino participants wanted to die in a nursing home, believing that it is the families' responsibility to care for their relative. Most participants were also not aware of Hospice services or had false information. Although participants expressed diverse views, one third of participants were against the use of life support, particularly if it prolonged the suffering of the patient. Participants also believed that their religious beliefs, especially fatalism and reliance on God, were central to their decision making regarding end-of-life care. There was division among the participants regarding the extent to which they wanted to be informed about a fatal diagnosis, citing that being informed may accelerate the illness. Many Latinos also perceived racial discrimination and cultural insensitivity as barriers to quality care and healing (Sullivan, 2001).

In the Hispanic culture, there are several considerations that relate to quality care at the end of life (Sherman, 2001). It is recognized that in Hispanic culture, there is strong family support and a belief that the dying person should be protected from his/her prognosis. Women show extreme grief or hysteria, while men show little or no grief. Death is often confronted with a humorous sarcasm and is viewed as an equalizer (DeSpelder & Strickland, 1999). Mexican Americans, as well as other Hispanics, are likely to call the priest for the sacrament of the sick, and the bereaved may take shifts being with the deceased person. There is strong support of family as a unit. The funeral is the single most important family ceremony and goes on for several days, as there is the belief that it takes time to grieve. Individuals are prohibited from speaking ill of the person who has died, and the bereaved visit the grave frequently. The day of the dead is celebrated in November and coincides with All Saints' Day, the feast of the commemoration of the dead. Although death is viewed as an adversity, references to dying and death are common in the culture as children play with toys symbolizing death, and the funeral is an important family ceremony. It is a time of celebration with special foods, music, and the decoration of graves. It is believed that the dead return to the world of the living for this special celebration, and families are scorned if they neglect their responsibilities. The bereaved are discouraged from crying too many tears, as excessive grief may make the pathway traveled on by the dead slippery and burden them in the journey (DeSpelder & Strickland, 1999).

Given that cultural values profoundly influence the experience of health and illness for individuals, Martinez (1995) conducted a qualitative study of 14 Hispanic participants, ranging in age from 60 to 89, along

with 6 health professionals and 2 clergy who practice in the community. They perceived health as creating balance in life and as faith that one will be cared for by God, family, and community. Participants held holistic views of self and emphasized the spiritual aspects of life in relation to health. Mental health was described as knowing what is right, living a life consistent with one's beliefs and values, trusting that life will work out, and maintaining faith in God. Caring for self was through caring for others for whom one had responsibility. In dealing with illness, there was a blending of modern medicine and traditional healing remedies. It was also appropriate to include family members in making health decisions.

Cultural Perspectives of Native Americans

For Native Americans, the focus of identity is on the tribe, rather than having simply Native American ancestry. This is important because values and beliefs vary among tribes and the different bands among the "First Nations." There may be similarities in nations originating in the same region, but there are also tribal distinctions (Brokenleg & Middleton, 1993). For many Native Americans, however, life and death are viewed as a natural part of the life cycle and as a part of human existence. Time is considered as a recurring cycle, rather than a linear process. Native Americans are concerned with how this cycle affects people in this life, and death is viewed as a motivation to treat people kindly and lead a good life (Brokenleg & Middleton, 1993; Sherman, 2001).

From a cultural perspective, Native Americans avoid eye contact and are stoic regarding the expression of pain and suffering, and traditional tribal medicines are used (Sherman, 2001). Prayer is a medium through which one might accept the outcome of a situation, and it is not appropriate to question "why" something is happening, as there is an acceptance of the natural order of things (Brokenleg & Middleton, 1993). Death may be forecast by unusual spiritual or physical events. As examples, the sign of an owl may signify that someone close will soon die, and a blue light seen coming from the direction of a dead relative's home or room indicates death (Brokenleg & Middleton, 1993).

Given their reverence for the body in life and death, autopsies and cremation are not acceptable (Sherman, 2004a). Funerals are usually at home, with members of the community expected to stay with the mourners. A death song is sung that represents the summary of a person's life and acknowledgment of death. The dead are considered guardian spirits. After death, the spirit lingers near the site of the death for several days. Native Americans use a funeral pyre and adorn the corpse with flowers, feathers, and skins. For 6 months to 1 year, the name of the deceased is not called, in order to confirm their separation from

the living. All material possessions of the deceased are given away so that the family can begin its new life without the presence of that person (Brokenleg & Middleton, 1993). In the Cocopa tribe, violent grief is expressed until cremation, when they invite the spirits to join them in celebration. In the Hopi tribe, death is kept at a distance because it threatens order and control. The expression of grief remains limited and funerals are attended by few and held privately. For Native Americans, hallucinations in which they see and converse with the dead are regarded as a part of mourning (DeSpelder & Strickland, 1999).

Based on focus groups representing many Native American tribes and conducted by Native American nurses, Lowe and Struthers (2001) identified seven themes representing core principles relevant to health-care. These themes include: 1) caring, which embodies characteristics of health, relationships, holism, and knowledge, and is characterized as a "partnership in healing"; 2) traditions, which refers to: valuing and connection with heritage; respect, which includes characteristics of honor, identity, and strength and refers to the components of presence and compassion; connection, which honors all people, the past, present, and future, harmony with nature, and explores differences and similarities; holism, which includes balance and culture; trust, which is characterized through relationship, presence and respect; and spirituality which includes unity, honor, balance, and healing and includes components of touching, learning, and utilizing traditions to recognize oneness and unity.

DEVELOPING CULTURAL COMPETENCE

A culturally competent healthcare system "acknowledges and incorporates at all levels the importance of culture, the assessment of cross-cultural relations, vigilance toward the dynamics that result from cultural differences, and the expansion of cultural knowledge, and adaptation of services to meet culturally unique needs" (Cort, 2004, p. 68). Achieving cultural competence is a dynamic state in which health professionals gain knowledge of their own cultural and social backgrounds and become aware of the history, traditions, and values of other groups, including understanding the history, food, and lifestyles of people from other countries (Cort, 2004). According to the Schim and Miller, cultural competence model, there are four components of cultural competence:

- 1) Cultural diversity, which is reflected in every aspect of the healthcare system in the United States and recognizes diverse populations with unique values, beliefs, and customs;
- 2) Cultural awareness, which implies knowledge and information exchange regarding health, beliefs,

- and practices specific to various communities, and cultural variations within groups;
- 3) Cultural sensitivity, which requires the recognition of individual attitudes and beliefs and a refinement of communication skills related to active listening, use of silence and touch, conversational distance, language patterns, and the effective use of translators; and
 - 4) Cultural competence, which is the ultimate goal and incorporates diversity (fact), awareness (knowledge), and sensitivity (attitude) into everyday practice and behaviors (Doorenbos & Schim, 2004).

Cultural diversity refers to differences between people based on treasured beliefs, shared teachings, norms, customs, language, and meaning that influence the individual's and families' response to illness, treatment, death, and bereavement (Showalter, 1998). Cultural diversity is evident in the perception of pain, ways of coping with life-threatening illness, and the behavioral manifestations of grief, mourning, and funeral customs (DeSpelder & Strickland, 1999). The acknowledgement of such concepts and their relationships may provide a framework for cultural assessment and an opportunity to provide quality care respectful of differences with regard to cultural expectations and needs. Failure to take culture seriously means that health professionals elevate their values above the values of others, which is culturally destructive rather than culturally skilled (Kagawa-Singer & Blackhall, 2001). Therefore, it is important to support trusting and effective patient and provider interactions through respect, and acknowledgement of cultural diversity and avoidance of misperceptions.

For those experiencing life-threatening illness, several issues are relevant with respect to culture. One such issue is patient autonomy, which emphasizes the rights of patients to be informed about their condition, its treatments, and the right to choose or refuse life-prolonging care. However, this reflects the American beliefs regarding independence and individual rights, which may not be shared by patients and families from other cultures (Kagawa-Singer & Blackhall, 2001). For example, those from Asian cultures may believe that the family as a whole should make decisions regarding the aged individual. This is an example of "family-centered" rather than "patient-centered" decision-making styles (Barclay et al., 2007).

Another issue influenced by culture is responses to inequities in care. When not addressed, this issue may lead to feelings of mistrust regarding the intentions of healthcare providers and a lack of cooperation and collaboration between the patient, family, and healthcare provider. Discussions of the cost of technology and the ineffectiveness of treatment may be perceived by the patient as a devaluation of his/her life (Crawley et al., 2002). As a result, there may be an increased desire for futile aggressive care at the end of life, and

dissatisfaction with care. This issue is relevant to the care of African-American patients and families who are more likely to want aggressive medical care at the end of life and less likely to have Do-Not-Resuscitate (DNR) orders. To address this issue, practitioners can ask directly if the individual trusts someone who is not from his/her same background. Practitioners can work toward addressing inequities in care, or can attempt to understand and accommodate desires for more aggressive care (Kagawa-Singer & Blackhall, 2001).

Furthermore, communication or language barriers may lead to bidirectional misunderstanding and unnecessary physical, emotional, social, or spiritual suffering. It is therefore important to avoid medical jargon, make language simple, check for understanding or hire a trained interpreter. The use of family or untrained interpreters should be avoided, as they may misinterpret phrases, censor sensitive or taboo topics, or filter and summarize discussions rather than translating them completely (Crawley et al., 2002; Flores, 2005).

There may also be differences in religion and spirituality, which may create a lack of trust between the patient and professional from different backgrounds. To create a sense of connection, healthcare professionals need to ask about religious or spiritual beliefs and practices and how the patient could be supported in addressing religious or spiritual needs.

Another issue, which may need to be negotiated, is truth-telling. Individuals from certain cultures may develop mistrust or anger if the healthcare team insists on informing patients about their diagnosis or prognosis against the wishes of their family. Families often believe that such knowledge will result in a sense of hopelessness for the patient, which contributes to their suffering. In this situation, it would be appropriate for the healthcare provider to ask whether the patient would want to know everything about his/her illness, and be cognizant of nonverbal communication when discussing serious information (Kagawa-Singer & Blackhall, 2001).

Consideration should also be given to the issue of family involvement in decision making. Disagreement and conflict between family and healthcare professionals may occur when the family insists on making decisions for patients who have decisional capacity. As healthcare professionals, it is important to identify the key members of the family and involve them in the discussions as desired by the patient. If the patient is capable of making decisions for himself/herself, yet the family requests that information be withheld from the patient and that they make the decisions, it is helpful to conduct a family meeting in which the patient, family members, and healthcare professionals are present. This may provide an opportunity to clarify issues, address conflicts, and provide clarity about the decisions and preferences of the patient.

At the end of life, cultural differences may also exist regarding the desire to enroll in Hospice care. Health

professionals need to understand the feelings and perceptions of patients and families from varying cultural perspectives, and emphasize that Hospice is not a replacement for the family, but as a way of providing resources to support the quality of life for patients and families (Kagawa-Singer & Blackhall, 2001).

Although there may be diversity in terms of desires, preferences, and expectations across cultures, there are also similarities. In a study of the needs and experiences of non-English-speaking Hospice patients and families in an English-speaking country, McGrath, Vun, and McLeod (2001) found, based on focus groups which included Indian, Filipino, Chinese, and Italian cultural groups and their caregivers, that participants from all groups expressed the same issues. These included the importance of support from families; the pressures on family members to care for relatives at the end of life; lack of knowledge about Hospice and palliative care services; lack of choice in how they wished to care for their family member; difficulty in talking about dying; and desire to care for a family member at home.

In providing quality palliative care for patients and their families, consideration should also be given to the following principles of culturally sensitive care (CSWE Faculty Development Institute, 2001). The first principle is to *be knowledgeable about cultural values and attitudes*. Healthcare professionals should attend to a patient's needs in a sensitive, understanding, and non-judgmental way, and respond with flexibility as much as possible. The second principle is for healthcare practitioners to *attend to diverse communication styles*, including spending time listening to the person's needs, views, and concerns. The third principle is to *ask the patient for his or her preferences for decision making* early in their care. As a fourth principle, it is important to *recognize cultural differences and varying comfort levels* with regard to personal space, eye contact, touch, time orientation, learning styles, and conversation styles.

The fifth principle is to *use a cultural guide from the patient's ethnic or religious background* to clarify cultural problems or concerns if communication with the patient or family is unclear. If necessary, ask the older adult to identify a family spokesperson and respect the appointment made by patient, even if the person is not a family member or does not live nearby. If the elder's preference is for family involvement, family meetings are opportunities to identify family's needs and concerns, and an opportunity for the family to understand the patient's goals of care and end-of-life wishes.

A sixth principle is to *get to know the community, its people, and resources* to identify the availability of social support and needed resources. Healthcare professionals may establish relationships with key community resources to assist the seriously ill older adult and his or her family. As a seventh principle, health practitioners should *create a culturally friendly physical environment*

by designing facilities with artwork or pictures valued by the cultural groups to whom care is most commonly provided. Written materials should be available in the language of patients to enhance their understanding of their disease and treatment options and provide their sense of partnership in making healthcare decisions.

As an eighth principle, it is appropriate for the health professionals to *determine the acceptability of patients being physically examined by a practitioner of a different gender*. Patients should also be asked if they would want to have a family member present during the physical examination. Recognize that symptom recognition, as well as its reporting and meaning, may vary based on the patient's cultural background. A ninth principle is for health professionals to *advocate for availability of services, accessibility in terms of cost and location, and acceptability of services* that are compatible with cultural values, and practices of the person.

Lastly, the tenth principle is for health professionals to *conduct a self-assessment of their own beliefs* about illness and death and how they influence one's attitudes; how significant are culture and religion in health professionals' personal attitudes toward death; what kind of death would they prefer; what efforts should be made to keep a seriously ill person alive and the disposition of their bodies; and what is their experience of participating in rituals to remember the dead.

Having considered the importance of a comprehensive cultural assessment, it is also valuable for health professionals to have knowledge of the principles of culturally sensitive care. With this knowledge and understanding, health professionals are able to develop a culturally appropriate plan of care that addresses the cultural needs and expectations of patients and their families and supports their trust of health professionals and satisfaction with healthcare.

In providing culturally sensitive care, DeSpelder (1998) also suggests that health professionals listen for and mirror the language patterns based on an individual's culture. Small differences in language, such as saying "passed away" or "passed on", can indicate much about the speaker's experience. For example, "passed away" may describe the deceased from the survivor's perspective, whereas "passed on" may imply a belief in life after death. Nurses also can attend to the cultural needs of their patients by gathering information about distinctive rituals, practices, and beliefs, particularly an understanding of what is meaningful to the individual person. This assessment involves listening, observing, and asking about practices of patients and families that may be unfamiliar to the nurse. Furthermore, nurses can determine the strengths an individual draws on when encountering death, dying, or bereavement, such as internal resources provided by the individual's belief system or past experiences; and external resources, such as the comfort provided by cultural customs (DeSpelder & Strickland, 1999). As nurses

interact with patients and families from diverse cultures, they have the experiential opportunity to learn about cultural values, expectations, and needs regarding illness, dying, and death. In caring for patients and families at the end of life, nurses can enhance the quality of life and quality of dying by promoting a respectful and peaceful death through the recognition of their spiritual and cultural needs.

Cultural mistrust is a dynamic that has implications not only for individual healthcare providers but also for administrators of healthcare systems (Cort, 2004). Measures carried out by Hospices to overcome cultural mistrust may include 1) hiring competent African-American staff and minority volunteers; 2) respecting differences in cultural preferences; 3) conducting public education campaigns, by television or community and local organizations, newsletters, and church presentations; 4) involving African-American pastors in capacities that permit them to serve as bridges of trust between their communities and the healthcare system; and 5) avoiding perceptions of injustice and inequality by promising only the services that can be delivered (Cort, 2004).

Cultural competency is a set of academic and personal skills that allow practitioners to increase understanding and appreciation of cultural differences between groups (American Medical Student Association, 2001). Practitioners need to appreciate and accept cultural differences, to learn to culturally assess a patient to avoid stereotyping, and to explain an issue from another's cultural perspective. Areas of dissonance between patients and healthcare providers include historical distrust, varying interpretations regarding disability, the influence of family structure on decision making, and differences in willingness to treat diseases without symptoms, such as high cholesterol, or appreciating illness even when there are no observable manifestations.

Cultural competence entails listening with sympathy and understanding, acknowledging and discussing differences and similarities between perceptions of illness and its treatment, recommending treatments while remembering the patient's cultural perspectives, and negotiating and compromising when worldviews are in conflict (American Medical Student Association, 2001; Crawley et al., 2002). In improving the relationship between the health professional and the patient across cultures, it is important to maintain non-judgmental attitudes towards unfamiliar beliefs and practices, and to determine what is appropriate and polite caring behavior. It is respectful to begin by being more formal with patients, addressing them by their surname, rather than by first name. Recognize that it may be a sign of disrespect to look directly into another's eye or to ask questions regarding treatment. Shaking of the hands as a form of introduction, although valued in American culture, may be inappropriate by a female when

introducing herself to an Orthodox Jewish or Muslim male (Grossman, 1996). Furthermore, a firm handshake may be interpreted by members of Native American tribes as aggressive or rude.

Asian-Americans may tend to have subtle and indirect communication styles that rely heavily on nonverbal cues, such as facial expression, body movements, use of physical space, and tone of voice. For example, a patient may bow his head or may disengage from you if he is in disagreement with the plan of care (Grossman, 1996). Nodding of the head in Asian or Hispanic populations may be merely a social custom, showing politeness and respect for a person in authority rather than a sign of agreement. Given this possibility, the healthcare provider may then ask specific questions that require the patient to express his/her feelings and wishes (Crawley et al., 2002).

It is important to ask questions to explore the patients' beliefs about health, illness, and prevention. Accept the fact that many patients use complementary therapies as well as Western medicine, and not discount the possible effects of the supernatural on health. As health professionals, it is important to have knowledge of the patient's family and kinship structure to help ascertain the values, differing gender roles, issues concerning authority and decision making within a household, and the value of involving the family in the treatment (Grossman, 1996). Discussion with patients and their families may also involve the importance of food and eating as potentially enhancing a sense of community and as a way of supporting customs and heritage. Such information can assist the healthcare team in providing appropriate dietary instructions. For examples, Islamic law forbids Muslim patients to ingest alcohol, or pork or meat from animals that are not appropriately slaughtered. Jewish patients may observe the laws of kashrut, which prescribe specific ways of food preparation and prohibit the eating of pork, shellfish, and wild birds. Individuals from Cuban backgrounds may prefer a diet that is high in calories, starches, and saturated fats, and modification of such a diet may mean just adhering to a modest serving size (Grossman, 1996).

Nurses' Cultural Self-Awareness and Development of Cultural Competency

By being aware of their own feelings, attitudes, preferences, and biases, nurses can be more in touch with themselves, acknowledging their right to their own beliefs, but not allowing those values and beliefs to take precedence over those expressed by patients and families. In order for nurses to care effectively for patients from diverse cultural groups, they also must be willing to learn about the cultures of their patients and presuppositions. The first step is to find educational

sources that provide information about the various cultures, while recognizing that there are individual differences even within the same culture because of differences in social stratum, personal experiences with illness and death, and individual preferences and values. By asking someone of a particular culture to help them understand the taboos and meanings of experiences and events, nurses can actively learn about other cultures. Nurses must also recognize that losses have different meanings from person to person and culture to culture and may be viewed as major or minor.

The key to accommodating cultural diversity is for nurses to understand their own values, beliefs, and customs related to the celebration of life, and coping with illness and death. Irish, Lundquist, and Nelsen (1993) suggest that health professionals assess the degree in which they are proactive in their attitudes and activities toward diversity by asking themselves the following questions:

- Have I actively sought information to enhance my own awareness and understanding of multicultural diversity?
- Have I consciously pondered my own attitudes and behaviors as they either enhance or hinder my relationships with others?
- Have I evaluated my use of terms or phrases that may be perceived by others as degrading or hurtful?
- Have I suggested or initiated workshops or discussions about multicultural diversity?
- Have I openly disagreed with racial, cultural, or religious jokes, comments, or slurs?
- Have I utilized in my work setting appropriate occasions to discuss the multicultural climate in the organizations with my colleagues and with institutional administration?
- Have I complained to the author when I see a broadcast, advertisement, or newspaper article that is racially, culturally, or religiously biased? (p. 45)

Furthermore, DeSpelder (1998) suggests that healthcare professionals develop end-of-life cultural competence when they reflect on their own attitudes, beliefs, and practices toward dying and death. Nurses may explore for themselves:

- their own beliefs about death and what influenced these attitudes;
- how significant religion is in their attitudes toward death;
- what kind of death they would prefer;
- if diagnosed with a terminal illness, whom they would want to tell;
- what efforts should be made to keep a seriously ill person alive;
- how they would want their bodies to be disposed; and

- what their experience is of participating in rituals to remember the dead.

Cultural Assessment

Developing cultural competency requires that nurses listen carefully and gather cultural information. The patient's background may provide clues about a person's beliefs; however, these are only assumptions unless validated by asking patients about their beliefs, needs, expectations, and wishes. Knowledge about a person's cultural group should serve only as a starting point or guideline in assessing individual beliefs and behaviors (Kagawa-Singer, 1998; Lipson, Dibble, & Minarik, 1996).

In conducting a cultural assessment, there are several areas to be addressed:

- Identify the birthplace of the patient.
- Ask a patient about his/her immigration experience.
- Determine his/her level of ethnic identity.
- Evaluate the degree of acculturation as evidenced by his/her use of the English language, the length of time in the United States, and his/her adaptation.
- Determine his/her family structure.
- Identify the use of informal networks and sources of support within the community.
- Identify who makes decisions, such as the individual patient, the family, or another social unit.
- Assess his/her primary and secondary language.
- Determine the person's verbal and nonverbal communication patterns.
- Consider gender and power issues within relationships.
- Evaluate the patient's sense of self-esteem.
- Identify the influence of religion or spirituality on patients' and families' expectations and behaviors.
- Ascertain the patient's perceptions regarding discrimination or racism.
- Identify cooking and dining traditions and the meaning of food.
- Determine the patient's educational level and socioeconomic status.
- Assess attitudes, beliefs, and practices related to health, illness, suffering, and death.
- Determine patients' and families' preferences regarding location of death.
- Discuss expectations regarding healthcare.
- Determine the degree of fatalism or activism in accepting or controlling care and death.
- Evaluate the patient's knowledge and trust regarding the healthcare system.
- Assess the value and use of pharmacologic, nonpharmacologic, and complementary therapies.
- Discuss how hope is maintained (American Medical Student Association, 2001; ELNEC, 2001; Ersek et al., 1998).

UNDERSTANDING SPIRITUALITY

Spirituality and religiosity are often fundamental to the way patients face chronic illness, suffering, loss, dying, and death. Spirituality and religiosity are integral to holistic care and are important considerations, particularly since spirituality may be a dynamic in the patient's understanding of his/her disease and way of coping. Religious convictions may also affect healthcare decision making (Puchalski, 2001a). Spiritual ideas are fundamental to palliative care since both are concerned with non-abandonment, the value of interpersonal relationships, and recognize the value of transcendent support (Purdy, 2002).

Although spirituality and religion are often used interchangeably in common conversations, spirituality is a broader concept than religiosity. Spirituality comes from the Latin word *spiritus*, which refers to breath, air, and wind. Spirituality refers to the energy in the deepest core of the individual. It is the integrating life force that allows us to transcend our physical being and gives us ultimate meaning and purpose in life (Conrad, 1985). Spirituality represents the harmonious interconnectedness with self, others, nature, and God, and can also be communicated through, art, music, and relationships with family or the community (Puchalski & Romer, 2000). Spirituality further involves a melding of the individual's past, present, and future (Hicks, 1999). Even individuals who have no specific religion or faith background are spiritual beings and can have spiritual needs.

Spirituality, as a concept, also includes references to the soul, as well as spiritual needs, perspectives, and spiritual well-being. Moberg (1984) conceptualized spiritual well-being as encompassing a horizontal dimension that refers to a sense of purpose and mission in life and life satisfaction, and a vertical dimension that refers to a sense of well-being in relation to God. Downey (1997) describes spirituality as the awareness that there are levels of reality not immediately apparent and that there is a quest for personal integration in the face of forces of fragmentation and depersonalization. Therefore, spirituality is that aspect of human beings that seeks to heal or be whole (Puchalski, 2001b).

Moore (1992) has discussed the individual's spiritual quest, which is a process of "re-sacralization" of the self and the world in which we live. Individuals are embarking on spiritual journeys to discover the transcendent in daily life and in interpersonal relationships. The spiritual need is one of finding the mystery and sacredness of daily existence. Wink (1999) believes that individuals are searching for meaning outside of the confines of their religion. This is particularly important for individuals who are aging and who may be experiencing a chronic, debilitating, or life-threatening illness and who are questioning the meaning of not only their life but also their suffering. Within this context, the spirit of the person seeks to transcend suffering

through the virtues of love, hope, faith, courage, acceptance, and a sense of meaning in the encounter with death (Arnold, 1989).

Throughout a person's lifetime, and particularly as people age, religion and spirituality assist them to confront their finitude and vulnerability; to uncover meaning, value, and dignity in illness and death; to establish connection with others and a higher life force; and to find hope, love, and forgiveness in the midst of fear and despair. As such, spirituality engenders serenity and transcendence, thereby buffering stress (Doka, 1993).

As a chaplain, Ryan (1997) emphasizes the five fundamental spiritual needs of all people, which include: 1) finding meaning in life, particularly during adverse circumstances; 2) the need for a relationship with a higher life force or transcendent being; 3) the need to transcend the sources of suffering; 4) the need for hope no matter how difficult life can be; and 5) the need to have others who share our life journey and care for us. As one example, a 68-year-old woman with advanced breast cancer revealed her spiritual need when she stated "I only wish there was one person in this world who could tell me that they love me."

Religiosity is one means of expressing spirituality as are prayer and meditation (Puchalski, 1998a). Religiosity refers to beliefs and practices of different faiths and an acceptance of their traditions, such as Catholicism, Eastern perspectives, Islam, Judaism, and Protestantism. For many people, religion forms a basis for meaning and purpose in life, and provides the moral codes by which to live. As illness can call into question the person's purpose in life and work, spiritual and religious issues often arise. Seventy-eight percent of Americans indicate that they receive comfort and support through religious beliefs and have greater trust in health professionals who ask them about their spiritual or religious needs (Koenig, 2002; Ehman, Ott, Short, Ciampa, & Hanson-Flaschen, 1999).

Spirituality and Palliative Care

Even as the physical body declines, healing, which means to make whole, can occur as spiritual needs are identified and spiritual care is given to restore a person to wholeness. Healing can be accomplished through the spiritual journey of remembering, assessing, searching for meaning, forgiving, reconciling, loving, and maintaining hope (Puchalski, 1998a). Holistic care, including care of the soul or spirit, is important to quality palliative care, whose goal is to enhance a person's quality of life across the illness trajectory. People do want their spiritual needs addressed at the end of life and feel that health professionals should speak to patients about their spiritual concerns (Gallop, 1997). Furthermore, elder individuals who are dying express the need for companionship and spiritual support,

particularly human contact, and to have the opportunity to pray alone or with others (Nathan Cummings Foundation, 1999).

When providing palliative care for patients and their families, it is important to remember the following principles (Doka & Morgan, 1993):

- Each person has a spiritual dimension.
- Illness and death can be opportunities for spiritual growth.
- Spiritual care may be different for each individual dependent on his/her religious or cultural background.
- Spirituality is supported through formal and informal ways, such as religious practices, secular practices, symbols, rituals, art forms, prayer and meditation.
- Care should be offered in settings that accommodate the needs of religious or spiritual practices and rituals, and promote spiritual work.

Spirituality and Health

Physicians, psychologists, and other professionals are researching the role of spirituality in healthcare. Research indicates that spirituality is related to mortality, coping, and recovery, since people with regular spiritual practices tend to live longer, utilize health beliefs in coping with illness, pain, and life stress, and have enhanced recovery from illness and surgery (Puchalski, 2001a). A systematic review of the literature during the 20th century revealed, based on 724 quantitative studies, a significant relationship between religious involvement and better mental health, greater social support, and less substance abuse (Koenig et al., 1992). In a study of religious coping in 850 hospitalized patients, a significant inverse correlation ($p < .001$) was found between religious coping and depressive symptoms (Koenig et al., 1992). In another study examining the speed of recovery from depression of 87 medical inpatients, Koenig (1998) reported that of nearly 30 baseline characteristics, intrinsic religiosity was 1 of only 5 independent predictors of the speed of recovery.

In a study of religiosity, Bergan and McConatha (2000) reported that religious affiliation and private religious devotion increased with age across the lifespan. Based on a sample of 2025 community-dwelling elder residents, it was found that religious attendance provided a persistent protective effect against mortality, even after controlling for the most potential confounders, such as social support, health status, and physical functioning.

Studies also indicate that those who are religious or spiritual have lower blood pressure, fewer cardiac events, better result following heart surgery, and longer survival in general (Koenig, 2002). Furthermore, spirituality counteracts stress-related physiologic states that impair healing and facilitates coping with chronic

pain, disability, and serious illness by enhancing a sense of control that interrupts the cycle of anxiety and depression (Koenig, 2002). Those who participate in religious services express less loneliness and isolation as they receive support from others and believe that God is with them.

Religion or spirituality also facilitates coping with chronic pain, disability, and serious illness by providing an indirect form of control that helps to interrupt the cycle of anxiety and depression. For some individuals, prayer provides a form of control by believing that through prayer they can influence their medical outcome, while, in contrast, others deliberately turn over to God their health situation (Koenig, 2002). The belief that God is with them provides relief from loneliness and isolation. Individuals who attend religious services also have an opportunity for socialization and support from others, while praying for others in need often provides a distraction from one's own pain (Koenig, 2002). These findings are supported by more recent reviews of the literature by Okon (2005) who conducted a review of the spiritual, religious, and existential aspects of palliative care, and by Sinclair, Pereira, and Raffin (2006) who provide a thematic review of the spirituality literature regarding palliative care. Both articles provide comprehensive discussions related to differences between religion and spirituality, spiritual assessment, instruments to measure spirituality, correlates to health, and spiritual interventions.

In terms of health consequences, religious involvement has been associated with improved attendance at medical appointments, greater adherence to medical regimens, and improved medical outcomes. Studies indicate that those who are religious or spiritual have lower blood pressure, fewer cardiac events, better results following heart surgery, and longer survival in general (Koenig, 2002). Furthermore, religious or spiritual practices are believed to influence sympathetic and parasympathetic nerve pathways connecting thoughts and emotions to circulatory and immune system changes, and counteracting stress-related physiologic states that impair healing (Koenig, 2002).

Interested in religiosity and spirituality, Heintz and Baruss (2001) conducted a study based on a sample of 30 people whose mean age was 72.6 years. While some religious behaviors, such as frequent religious practice, prayer, and church attendance were correlated with some dimensions of spirituality, many of the scores on the Expressions of Spirituality Inventory were independent of self-reported religious behaviors. These results reinforced the differences between the concepts of religiosity and spirituality.

In a qualitative study of 41 male and female residents aged 66–92 years, most of the older adults believed that a higher power was present in their lives, which supported them constantly, and was perceived

as protecting, guiding, helping, teaching, and healing them (Mackenzie, Rajogopal, Meibohm, & Lavizzo-Mourey, 2000). God was perceived to work through the mundane world, such as through the work of physicians, loving friends, and helpful strangers. Many felt that their relationship with God formed the foundation of their psychological well-being. The authors concluded that the subjective experience of spiritual support may form the core of the spirituality-health connection for older adults.

The Role of Religiosity and Spirituality in Coping with Serious Illness

As patients are faced with chronic or serious illness and eventually near death, they may experience despair, with spiritual and religious concerns intensified or awakened (Lo et al., 2002). The patient may struggle with the physical aspects of the disease, as well as the pain related to mental and spiritual suffering. They may ask “Why did this happen to me?” “Why is God allowing me to suffer?” “What will happen after I die?” “Will I be remembered or missed?” or “Will I be able to finish my life’s work?” (Puchalski, 2002). True healing requires an answer to these questions as healing can be experienced as acceptance of illness and peace with one’s life (Puchalski, 2001a).

It is through spirituality that people find meaning in illness and suffering and are liberated from their despair. Spiritual care changes chaos to order, and seeks to discern what if any blessings might be revealed in spite of and even through tragedy (Purdy, 2002). As people are dying, they want to be listened to, to have someone share their fears, to be forgiven by God or by others, and believe that they will live on in the hearts of others or through their good works (Puchalski, 2002).

In a study of 19 individuals with advanced cancer, Thomas and Retsas (1999) learned through in-depth interviews that people with cancer developed a spiritual perspective that strengthened their approach to life and death. As cancer progressed, participants described the transaction of self-preservation by discovering deeper levels of understanding self, which incorporates a higher level of spiritual growth, spiritual awareness, and spiritual experiences.

Individuals at the end of life also express spiritual needs. Based on a qualitative study of nine Hospice patients, Hermann (2000) reported their need for religion, companionship, involvement, and control to finish business, experience nature, and the need for a positive outlook. Participants perceived spirituality as a broad concept that may or may not involve religion and that spiritual needs were closely linked to the purpose and meaning in life. In studying older patients approaching the end of life from advanced heart disease, it was

found that 24% of the variance in their global quality of life was predicted by their spirituality (Beery, Baas, Fowler, & Allen, 2002).

Taylor and Outlaw (2002) conducted a qualitative study to understand the use of prayer among persons with cancer ($n = 30$) and recognized that individuals with cancer use prayer to cope with their illness. Participants viewed prayer as personal communication involving or allowing transcendence. The communication or prayer was initiative and receptive. The initiative aspect of praying was to talk to God, get in touch with God, or beseech God, while the receptive aspect of prayer was characterized by phrases like being quiet, being accessible, and listening to God. For these individuals, prayer meant being constantly conscious of God and coming into that higher intention in life. Participants’ illness increased their awareness of the inadequacy of relying on self and the need to rely on a greater power. They described prayer as an active cognitive process, while others described prayer as a more passive process or as “prayer of the heart.” Assistive strategies for praying included constructing a prayer, writing a prayer, relaxing, reading religious material, and how one prayed depended on the purpose of the prayer. Some individuals prayed about healing, or that “God’s will be done.” Many prayed for forgiveness or to be a better person. Most prayed for family and friends who needed peace and support, and also included thanks and praise in their prayers that they were given another day to live. Through the process of prayer, many individuals believed that they benefited, whether their prayer was answered or not. From prayer, they expected that the “best will happen,” or that they will receive comfort, forgiveness, or salvation. As health professionals, the implications for prayer are that clinicians can help by fostering a condition and environment conducive to prayer and can facilitate patient’s use of prayer, which is unique to individuals.

In a phenomenological study of spirituality and life-threatening illness, Albuagh (2003) interviewed seven participants who had either cancer or heart or lung disease for at least 1 month. Participants described a sense of comfort from aspects of spiritual life, such as belief in support from God, feelings of not being alone, and the power of prayer. The participants expressed a trust in God, believing that God would provide the means to get through the experience either by restoring their health or through death. The strength of their spiritual beliefs, feelings of being blessed despite or through the illness, and a deeper meaning to life after facing life-threatening illness were described. The study supports the need to acknowledge patients’ spirituality and assist them in meeting their spiritual needs.

Through a qualitative study involving 28 African-American and European-American adult patients with cancer and their caregivers, Taylor (2003) examined participants’ expectations of nurses in meeting their spiritual needs. Participants identified six approaches of

nurses in addressing spiritual needs: 1) showing kindness and respect; 2) talking and listening; 3) prayer, such as offering verbal prayer or saying, “You are in my thoughts and prayers”; 4) connecting with authenticity and genuineness; 5) quality temporal nursing care, such as coming back to check on the patient; and 6) mobilizing religious or spiritual resources. The authors concluded that nurses need to consider their role in spiritual care and educate the public about their role as holistic healthcare providers.

The effects of spirituality on well-being of people with lung cancer were studied by Meraviglia (2004). Based on a sample of 60 adults who were predominately Caucasian and women, it was found that higher meaning-in-life scores were associated with higher psychological well-being and lower symptom distress. Prayer was positively related to psychological well-being, explaining 10% of its variance. Regression analysis indicated that meaning in life mediated the relationship between functional status and physical responses to lung cancer and explained 9% of the variance in symptom distress. The author concluded that this study supported the importance of providing spiritual care for patients with cancer.

Lorenz, Shapiro, Cleay, Asch, and Wenger (2005) examined religiousness and spirituality among HIV-infected Americans. Based on a sample of 2266 patients receiving care for HIV infection, 80% reported a religious affiliation and the majority indicated that they rely on religious or spiritual means when making a decision or confront problems. Women, older patients, and non-whites were more spiritual, but the clinical stage of the disease was not associated to religiosity or spirituality. It was concluded that religious or spiritual organizations should be used to support patients diagnosed with HIV infection.

Mako, Galek, and Poppito (2006) reported that of the 57 patient with advanced-stage cancer in a palliative care hospital, 96% reported spiritual pain due to intrapsychic conflict, interpersonal loss, or conflict in relation to the dying. Depression was correlated with the intensity of spiritual pain but not with physical pain or severity of illness. The authors conclude that unaddressed spiritual pain contributes to overall suffering.

Based on a study of 50 adult Hospice patients, Prince-Paul (2008) also reported strong positive correlations among spiritual well-being, communicative acts, and quality of life at the end of life (QOLEOL), when controlling for physical symptoms, explaining 53.5% of the variance.

Spirituality or Religiosity During the Dying Process

The attitudes an individual holds regarding the dying process and death are embedded in his/her cultural

and religious values. Values affect the way individuals conceptualize death and behave in relation to death (Meagher & Bell, 1993). Many people return to the religious legacies of their childhood during the dying process since it may have been the first time that they heard about death and learned about Christian resurrection (Satterly, 2001).

At this time, it would be important to explore guilt as central to a person’s religious pain, as well as the concept of forgiveness from his/her religious perspective. Religious rituals for cleansing or religious doctrine may allay feelings of remorse and guilt, providing for renewal of the soul and redemption. In supporting elders in spiritual pain, it may also be helpful to consider the concept of love. Most religious traditions provide a hopeful belief in the unconditional love of God, as well as reinforcing how unconditional love can be allowed to self, especially when an individual may have previously engaged in self-criticism or self-hatred (Satterly, 2001).

As individuals approach death, Doka (1993) identified the spiritual need of individuals to die in a way that is consistent with their self-identity. For example, if a person’s approach to life has also been to remain in control and “not give up the fight,” then it would be expected that they may not want to forego aggressive therapies, even if the chances of cure, or remission are low. Their spiritual need may be to continue to fight the disease. For those who are dying, Doka (1993) also emphasizes the spiritual task of finding hope that extends beyond the grave, as one seeks a sense of symbolic immortality. Individuals often need to feel that they are leaving a legacy, whether through having children or being remembered through their contributions to community, or through artwork, music, or their writings.

Suffering and Spirituality

Suffering is a part of life and the human condition, with suffering either personally experienced in a physical, emotional, social, or spiritual way, or experienced as witnesses to another’s suffering. Cassell (1982) defines suffering as “the state of severe distress associated with events that threaten the intactness of a person” (p. 639). Suffering can be defined as the endurance of, or submission to, affliction, pain, or loss. Suffering is usually psychological, as a result of distressing circumstances that arise in the process of living, but can also be the effects of physical pain. Cassell (1982) believes that many aspects of a person can be sources of, or be affected by, suffering, such as personality, character, the past, relationships, life experiences, roles, one’s rights and responsibilities, family, and cultural background.

According to Kahn and Steeves (1996), suffering is a private-lived experience of a whole person, unique to each individual. As such, suffering cannot be assumed present or absent in any given clinical condition or situation because suffering is dependent on the meaning

of the event or loss. The experience of suffering is also both intrapersonal and interpersonal because it involves the person's own coping with suffering and the caring of others (Kahn & Steeves, 1996). Although we may not find answers about why we suffer, as a part of the human family we build relationships, communities, and society to reach out to one another to relieve suffering and sustain us in our struggle (McGann, 1997).

Suffering varies with the type of disease, type of personality, and the relationship between these factors. "The loss of physical integrity and the impending destruction of the unity of one's person can cause profound suffering" (DeBellis et al., 1986, p. 6). Within the context of illness, suffering can occur because of unfavorable prognoses, loss of function, disability, the complexity of treatment, failure to achieve relief of symptoms, the expense of treatment, and the effects of disease on all social relationships and economic security (DeBellis et al., 1986).

Millspaugh (2000a), as a chaplain, describes suffering as spiritual pain which involves an awareness of death, loss of relationships, loss of self, loss of purpose, and loss of control, which can be lessened by life affirming and transcending purpose and internal sense of control. The loss of self involves fears about death, loss of independence, loss of body image, loss of a God who can be bribed, and loss of relationships to others. It also involves loss of the established self. As spiritual pain is often marked by a sense of being alone, the task of the practitioner is to earn the person's trust and to walk with him or her by being present with the belief that a greater Spirit is at work—a joining of spirits which provides the sufferer with a sense of being understood, and feeling a sense of control in the situation (Millspaugh, 2005b).

Although, suffering and pain often are referred to interchangeably, they are not identical. In some cases, they are both present; at times, one exists without the other. The transition from pain to suffering can occur when pain is unrelieved and out of control or when the source of pain is unknown. The persistence of pain and uncertainty therefore can increase suffering exponentially. Yet, suffering can continue even when pain is controlled. Based on a sample of 177 end-stage cancer patients who had an expected life expectancy of less than 1 month to live in a Hospice, Adunsky, Aminoff, Arad, and Bercovitch (2008) found, using the Mini-suffering State Examination, that there was a low level of suffering, despite maintaining a constant rate (68%) of the use of opioids at admission and the last week of life. The reduction of the level of suffering in end-of-life cancer patients, in the face of pain needs, may be attributed to the medical and nursing care offered through Hospice care.

At the end of life, suffering may also be exacerbated because of protracted or chronic illness, multiple simultaneous diseases and comorbid conditions, recurrent

disease, and awareness of mortality. Because suffering has to do with a personal understanding of the physical, emotional, and spiritual self and their interrelationships, we learn about suffering only by the ways in which an individual expresses an awareness of the threats to his/her personal wholeness (Smith, 1996). Chochinov, Jack, Hassard, McClement, and Harlos (2006) in validating the Dignity model, reported on the basis of 211 patients receiving palliative care that "not being treated with respect or understanding" and "feeling a burden to others" were the issues most identified as having an influence on dignity. In a logistic regression model, "feeling life no longer had meaning or purpose" was the only variable which predicted overall sense of dignity. Addressing these issues is believed to be the cornerstone of dignity-conserving care.

Using heuristic research, Wayman and Gaydos (2005) explored the question, "what is the experience of self-transcending through suffering?" Four people were interviewed who self-identified themselves as self-transcending. The themes were presented linearly but participants were able to move freely between themes. Participants identified a *turning point* in their suffering when they turned from self-identification with their suffering, as it became a part of their lives but not who they were. This was a wake-up call and invitation to change. Then there was a *pause*, in which there was a forced pause in all activity due to treatment. This pause was followed by *confrontation* with their experience of suffering and their response, accepting their suffering for what it was. Participants *surrendered* to a new truth, which led to *extraordinary experiences* of peace and interconnectedness. These experiences became the *touchstones of change* as they reminded themselves of the lessons of suffering and the changes they had made. Participants were changed after transcending their suffering, valuing their lives more, and became more truly who they really were. Their transcending encouraged an unfolding of the hidden, with their inner selves becoming more congruent with their outer selves. This led to the desire for meaningful work and a sense of gratitude for the experience. Their humility grew as they honestly assessed themselves. The experience of self-transcending is the patient's struggle and life journey, which can be supported when nurses facilitate opportunities for pause and reflection, and give reassurance and compassion which facilitate a patient's sense of wholeness and well-being.

In a study of terminally ill patients ($n = 96$) on palliative care units and Hospice, Schroeffer (2007) identified four critical events as motivating individuals to consider hastening their death: specifically perceived insensitive and uncaring communication of a terminal diagnosis, experiencing unbearable physical pain, unacknowledged feelings regarding treatment, and dying in a distressing environment. In order to address these

issues, the authors recommend changes in policies and practices that promote time for communication by health professionals coupled with appropriate training in communication skills. It is further recommended that support be offered by members of the interdisciplinary team to reduce suffering and take a proactive rather than reactive approach to end-of-life care.

Reciprocal Suffering of Patients and Family

Within the context of life-threatening illness, suffering, in the form of physical, emotional, social, and spiritual distress, often becomes an experience not only of the patient but also of the family caregivers, as the suffering of one amplifies the distress of the other (Foley, 1995). Family members, like patients themselves, are in transition from living with the disease to anticipating the death of their loved one from the disease (Davies, Reimer, & Marten, 1994). They fear that death will occur in their absence, and may therefore refuse to leave the patient's side for even a moment. There is also a strong compulsion to attend to the patient's every need with disregard for their own needs (Klein, 1998). As the patient's illness progresses, the needs of the family also intensify and change, with both the patient and family caregivers potentially experiencing a significant compromise in the quality of their lives (Sherman, 1998).

Although family members may express the rewards of caring for terminally ill relatives, such care can have major psychosocial and physical effects, including heightened symptoms of depression, anxiety, psychosomatic symptoms, restrictions of roles and activities, strain in relationships, and poor physical health (Higginson, 1998). As witnesses to the patient's pain and suffering, family caregivers may also experience a sense of powerlessness, and are often frightened and confused by the dramatic physical and emotional changes they perceive in their loved one as the disease progresses (Loscalzo & Zabora, 1998).

Coyle (1995) gives examples of suffering, such as when patients experience despair, loneliness, and vulnerability; feel trapped by fear and bewilderment; experience loss and worry about treatment decisions; worry about being a burden; have financial concerns; experience abandonment; or fear dying yet are weary of life, and experience pain or the loss of hope. Families suffer as they assume the responsibilities of caregiving, watch the patient's deterioration, become exhausted, neglect their own needs, experience uncertainty about goals of care, and become anxious about the place of care. The suffering of family members also occurs because of fear of the dying process and the experience of the loss of life as it was, the person they knew, and of hope, as well as guilt in wanting death to come soon.

There are also many conflicting emotions and adjustment tasks, including conflict among feelings of loss, sadness, guilt, difficulty in knowing how to talk with the person who is dying, and worry about dying and death (Beeney, Butow, & Dunn, 1997). Furthermore, the family caregiver must adapt to changes in family roles and responsibilities, while attempting to meet the increased emotional needs of other family members and performing standard family functions (Doyle, 1994). Given that 25% of caregivers lose their job due to caregiver responsibilities and nearly one third of families lose their major source of income or their savings, families also experience significant financial burdens (Lederberg, 1998). This may lead to feelings of anger, jealousy, and an increase in the family caregiver's own needs because of heightened psychological distress. In addition, there is often a loss of social mobility, as well as social abandonment by friends, which negatively impact on the quality of life of family caregivers (Lederberg, 1998).

From a spiritual perspective, family members may question the meaning of the illness and suffering. They often spend considerable time reviewing painful aspects of the past with feelings of regret for disagreements, conflicts, or failures and a wish that relationships with the patient and with each other were somehow different. Buck and McMillan's (2008) study of the unmet spiritual needs of caregivers of patients with advanced cancer, emphasizes that, based on a sample of 110 caregivers of Hospice home care patients, the highest spiritual needs of caregivers related to outlook such as seeing smiles, thinking happy thoughts, laughing, and being with family. Caregivers' unmet total needs were predicted by caregivers' outlook, caregivers' religion, and the patient's distress score. To reduce caregiver suffering, it was concluded that healthcare providers must be aware of the needs for positive thinking, reminiscing of happier times through story telling or the use of pictures, and that chaplains may offer comfort through the reading of religious texts and speaking with caregivers about spiritual issues.

With each family member's unique experience of the stress, families may find it difficult to come together to effectively cope with the imposed life changes (Sherman, 1998). In their search for meaning, patients and families affirm spiritual values, change life priorities, and examine how the experience of illness has contributed to their personal growth. Like their dying loved one, they live day to day to make the most of the present as they prepare for death on practical, cognitive, emotional, and spiritual levels (Davies et al., 1994). The hope is that through palliative nursing care, both patients and family members can transcend their reciprocal suffering and experience growth as they face the challenges of life-threatening or terminal illness (Sherman, 1998).

The Care of Those Who Are Suffering

Cassell (1982) believes that the ways to relieve suffering are, first, through the assignment of meaning to the injurious condition or event and, second, through transcendence, which is the most powerful way of restoring an individual's personhood to wholeness. Watson (1986) proposes four generic meanings of suffering, which include *correction* in which an individual is being corrected of his/her wrongdoing; *affirmation* in which a person is affirmed of his/her "rightdoing" and the ability to be a role model for others; *naturalism* in which the individual is experiencing general human destiny; and altruism in which an individual's suffering will have benefit to others. In caring for those who are suffering, health professionals may help individuals come to a healthy, maintainable higher meaning to their suffering. From a theological perspective, Smith (1996) discusses the religious response to suffering and the possibility of transcendence of suffering through intellectual, ethical, and experiential dimensions of religion. The intellectual dimension involves the realization of some transcendent meaning, which connects the suffering person with some greater reality and delivers the individual from the threat of meaninglessness that is raised by illness and pain. The ethical dimension of religious life provides a perspective regarding how to interpret and respond to suffering. Suffering may be seen as a test of one's virtue or fidelity to God, a test of the worth of religious commitment, or as an opportunity of personal transformation. Within the experiential dimension of religion, the life of oneself and others and of the relationship of these lives to each other and to God are contemplated. The religious experience of suffering may therefore enable an individual to provide redemptive relationships with others, including God, and experience transcendence.

In caring for the suffering, Spross (1996) believes that the role of the nurse is one of coaching. "Coaching is an interpersonal intervention that requires the therapeutic use of the self, involving one's mind, past experience, words, heart, and hand-to comfort those who suffer" (Spross, 1996, p. 201). In coaching, the nurse

- establishes a trusting partnership;
- assesses those who are at risk for suffering or who are vulnerable;
- reassures patients that although their suffering may not disappear, they will not be abandoned;
- identifies factors that may be eliminated or modified to alleviate suffering; and
- intervenes to facilitate expression of feelings, find meaning in suffering, and help patients and families redefine the quality of life.

Spross (1996) states that the ability to alleviate suf-

fering or find meaning in the experiences of suffering depends on the intrapersonal and interpersonal qualities of the nurse. The nurse must be self-accepting, be secure in his or her own self-concept, and feel confident in strengthening others. As coach, the nurse values others and communicates that the individual's feelings, goals, and opinions are respected, while conveying that the person is trustworthy, responsible, capable of self-direction, and able to identify relevant goals and find meaning in life.

Watson (1986) believes that nurses and other health professionals can relieve suffering in six ways: first, by being a companion to sufferers by identifying the pain of their losses, and exploring the circumstance and extent of the loss; second, by listening for statements of meaning from sufferers and allowing the person's natural instincts and energy to surface the issue of higher meaning; third, by valuing any self-disclosure on meaning that a sufferer offers, by analyzing the meaning of the statements and learning what the statement reveals about the sufferer's view of him- or herself; fourth, by encouraging the sufferer's interpretation of their own experience; fifth, by validating the sufferer's interpretation of his/her own experience while clarifying the meaning, seeking further definition of the meaning, and offering alternatives for reframing the meaning; and last, by identifying supportive resources and hoping for the sufferer to extend his or her identity and meaning in the future.

In alleviating the suffering of others, Bird (1986) offers seven principles to be considered within the context of nursing practice:

- 1) Remember that institutions do not dehumanize patients; staff members do.
- 2) Assume responsibility for morale whenever you are in the chain of command.
- 3) Be a whole person yourself, with a healthy sense of humor and attitude.
- 4) Do not add clinical ineptitude to the further suffering of patients.
- 5) Be empathetic rather than sympathetic to patient's needs; otherwise, human suffering can emotionally devastate one.
- 6) Offer holistic care and well-chosen words to allay suffering.
- 7) Determine to touch the life of at least one patient daily with some depth.

Halifax (1999) believes that healthcare providers, patients, and families can go to the root of their own suffering and transform the suffering into inherent wisdom. As a Buddhist, she reminds health professionals to come to the caregiving relationship with loving kindness, compassion by being in touch with one's own and others' suffering, joy in the well-being of others, and equanimity.

The Role of Hope in Spiritual Well-Being

Cousin (1979) reminds us that death is not the ultimate tragedy of life, but rather being separated from our connection with others, and separated from a desire to experience the things that make life worth living, separated from hope. Spirituality may help people to cope with their dying as it may offer hope. In early illness, the hope may be for the cure of the disease and treatment, and later on for the hope of prolongation of life. When cure is not possible, hope may be to see a loved one, to have a day without pain, to celebrate a certain life event, or have the time to travel or complete unfinished business. Eventually, hope may be for a peaceful death. It may be hope that allows seriously ill individuals to find courage and strength to transcend their suffering, and teach others how to die with dignity.

In redefining hope for the seriously ill or the dying, Corr (1991) distinguishes between hope and a “wish,” stating that hope is grounded in reality, while wish is not. Mitchell (1997) offers a definition that hope is not a belief that something is going to go well, but rather that it is a belief that whatever happens will make sense, no matter how it turns out. For patients who are dying, hope may be defined as “an inner life force that helps each dying person to live life until the moment of death” (Parker-Oliver, 2002). Indeed, hope may be defined as the positive expectation for meaning attached to an event, recognizing that individuals shape their hopes by finding new meanings for living (Parker-Oliver, 2002). Hope allows for a sense of control and promotes an active rather than passive participation in life’s events. Even in dying, people have the hope to discover new meanings.

The challenge for healthcare professionals is therefore to help individuals find hope as they search for meaning in their illness, suffering, and death. This can happen as professionals assist individuals to identify key relationships, facilitate caring relationships, and encourage the opportunity to heal relationships and complete unfinished business. Byock (1997) encourages the completion of relationships by saying “I forgive you,” “Forgive me,” “I love you,” “Thank you,” and “Good-bye.” Through the encouragement of short-term, attainable goals, hope can also be promoted as well as by recognizing and encouraging a sense of determination and courage in the face of adversity. Gum and Snyder (2002) conclude that hope can be maintained when providers provide clear information, control symptoms, and maintain functionality.

Hope can also be found within the context of spirituality as spiritual beliefs systems hold hope for happiness, and a promise of an afterlife. Spirituality offers hope for living on in the world through a connection with others, traditions, and rituals and through establishing legacies. Hope can also be easily discovered by just asking

the patient what is meaningful to them and what they want to do with the remainder of their lives. Based on a study of 69 participants, age 65 or older, Theris (2001) reported a significant difference in hope based on the religion of participants. Based on a one-way ANOVA and Scheffe tests, Catholic participants expressed greater hope than those of the Jewish faith, and another significant difference existed between participants of the Protestant and Jewish faiths. There was also a significant, positive correlation between spirituality and level of hope ($r = .73, p = .000$). In a multiple regression analysis, which was used to test for the combined contribution of spirituality and connectedness with others to levels of hope, only spirituality emerged as a significant predictor of hope. The authors concluded that connection with oneself and connection with a higher being was especially important in the maintenance of hope in nursing home residents. Such results are consistent with the findings of Buchanan (1993), who reported, based on a sample of 160 older adults who were depressed and nondepressed, that higher levels of spirituality, hope, health, and social support were positively correlated with meaning in life, and that there was an inverse relationship between meaning in life and depression.

Based on qualitative studies of elder Hospice patients, Herth (1992) found that hope facilitated the transcendence of the present situation and movement toward new awareness and enrichment of being, while Duggleby (2000) found that hope was a process of enduring suffering through a trust in a higher power and making meaning of their lives. Despite the stage of illness and a situation of poor prognosis, practitioners can provide hope and a positive outlook by discussing goals of care, offering symptom control, providing supportive resources, and promising the patient that they will not abandon them (Barclay et al., 2007).

For those who are dying, the focus of hope changes from a hope in the future or a redefinition of the future, to a hope on living day to day. The focus of hope for those with advanced disease is also hope for no more suffering, life after death, and hope their families will not suffer when they are gone (Duggleby, 2001). At times, the most important way to provide hope is by listening attentively and being physically present, which convey a sense of value and affirmation of worth. Hope is then gained that they will not be abandoned and isolated (Duggleby, 2000). Hutchings (2007) conducted a qualitative study of eight people who were dying, guided by Parse’s Theory of Human Becoming. The interviews illustrated that persons at the end of life still envision hopes and possibilities despite declining function and decreased energy. Such findings help health professionals understand that dying patients co-create meaning day by day while emphasizing the importance of bearing witness to the struggles, joys, and hope of dying persons.

The concept of hope in palliative care was also examined by Fanos and colleagues (2008), based on 16 patients diagnosed with amyotrophic lateral sclerosis (AML). Although there was no significant relationship found between hope and functional status, qualitative interviews revealed that patients with AML have hope related to cure, social support, spiritual beliefs, adapting to changing capacities, and the possibility of living in the moment as well as self-transcendence. It was concluded that there was a range of themes from narcissism to altruism with a heightened concern for others and that the palliative care team can play an important role by promoting discussions regarding hope in its many forms.

Learning about Spiritual Assessment and Caregiving

Health professionals need to be attuned not only to their own cultural beliefs but also to their own spirituality before participating in spiritual care. Personal preparation for spiritual caregiving includes the professional's self-evaluation of personal spirituality; reviewing personal beliefs, opinions and biases; understanding the meaning of spirituality; becoming aware of how one's own religious beliefs influence caregiving; and establishing a trusting patient-provider relationship (Hermann, 2000).

As in the care of all patients and families, health professionals caring for patients and their families must learn the specific techniques for addressing spirituality in clinical practice, including how to conduct a spiritual assessment. This also requires that the health professional be totally present and open by listening actively to spiritual issues (Hermann, 2000). Learning spiritual assessment and caregiving can also occur through a combination of teaching/learning strategies, including small group discussions, reflective writing, storytelling, use of poetry, case presentation and discussion, panel discussions with chaplains, patients, and healthcare practitioners, role playing with standardized patients, and attending lectures on the role of spirituality in healthcare (Puchalski, 2001b).

In providing spiritual care, healthcare professionals must remember that religion is only one way of enhancing spiritual well-being. Conversations about life, love, hope, trust, and forgiveness may renew the spirit of both patients and healthcare providers. Although the perspectives of health professionals is of personal value in one's role as a health practitioner, it is important to be non-judgmental, never imposing one's own beliefs and values on the patient or family, always remembering that it is the spiritual or religious perspective of the patient or family that is important. Indeed, the therapeutic value of the self will be recognized through listening, presence, and non-abandonment.

Millspaugh (2005b) suggests that in providing spiritual care for individuals who are suffering, practitioners must be able to maintain boundaries, empathize, contain their own suffering, focus and attend to the sufferer's agenda, use theology, as well as the social and behavioral sciences to inform assessments and interventions, and engender a sense of security and comfort.

Conversations about Spiritual or Religious Issues

Conversations regarding spiritual needs often begins with the use of open-ended questions, such as "Do you have any thoughts about why this is happening to you?" Practitioners can also encourage the patient to say more by such statements as "Tell me more about that?" When exploring spiritual concerns, practitioner should acknowledge and normalize patient's concerns by comments, such as "Many patients ask the same question," and responding with emphatic comments, such as "That sounds like a painful situation" (Lo et al., 2002).

Pitfalls in discussions about spiritual or religious issues near the end of life often occur by trying to solve the patient's problems or resolve unanswerable questions; going beyond the practitioner's expertise or role in providing spiritual care; imposing one's beliefs on the patient; or providing premature reassurance, which may appear superficial or deter the disclosure of other important issues or emotions (Lo et al., 2002). When patients inquire about the religious background of the practitioner, they may be inquiring to determine whether it is safe to talk about spiritual or religious issues, or they may prefer to talk to someone who shares the same religious faith. However, practitioners may answer the question regarding their religious background, but need not explicate on their religious or spiritual beliefs (Lo et al., 2002). If the patient asks for details, it is appropriate to refocus the conversation back to the patient.

In addition to clarifying the patient's spiritual concerns and needs by following spiritual cues, and exploring emotions with emphatic support, healthcare professionals may also do the following:

- Make wish statements, such as "I also wish you were not ill."
- Identify common goals for care and reach agreement on clinical decisions.
- Mobilize support for the patient and family from family, church members, or the community (Lo et al., 2002).

In situations when the patient or his/her family is praying for a miracle even in medically futile situations, the role of health professionals is to respect their

beliefs and remain supportive by trying to understand their worldview and the role their beliefs have in coping. Criticism or confrontation will lead to distrust and close the dialogue between healthcare professionals and the patient. When older patients and their families feel that they can talk to health professionals about their religious or spiritual beliefs, there is greater chance that they will accept what the professional is saying. A response may be that “Sometimes God answers our prayers for healing in interpersonal ways that may ultimately be more important than physical healing” (Koenig, 2002, p. 492.)

Conducting a Spiritual Assessment

Holistic care involves not only assessment of physical, emotional, and social needs, but also of spiritual needs and expectations. A spiritual history is a history about a person’s values or beliefs that explicitly opens the door to conversations about the role of spirituality and religion in the person’s life (Puchalski & Romer, 2000). Although it is not the health professional’s responsibility to solve spiritual problems or provide answers, health practitioners need to conduct a spiritual assessment to identify when a patient or family member is experiencing spiritual distress. It is important to create an environment that nurtures the patient’s exploration of spiritual needs and concerns and supports them in their search for answers. A spiritual history or assessment should be completed with each new patient visit and on annual examinations, as a part of taking routine history taking (Puchalski, 2001b). A spiritual history inquires about the role religion or spirituality plays in the patient’s ability to cope with illness. Affiliation with a religious or spiritual community is important for many individuals and serves often as an extended family for many adults, especially those who live alone or have limited family support (Koenig, 2002). In taking a spiritual history, Puchalski (1998b) suggests that the acronym FICA be used:

- “F” refers to faith as identified by the question “What is your faith or beliefs and do you consider yourself religious or spiritual?”
- “I” refers to influence which is assessed by the question “How does your faith or spirituality influence your medical decisions?”
- “C” refers to community and is related to the question “Are you a part of a spiritual or religious community?” and
- “A” refers to addressing spiritual concerns as exemplified by the question “Would you like someone to address your spiritual needs or concerns?”

A spiritual history is important not only in identifying ways individuals may cope with adverse life circumstances, but also to examine potential negative

effects in which religious beliefs are a source of distress and emotional turmoil (Koenig, 2002). Religious pain is a condition in which the patient feels guilty over the violation of the moral codes or values of his/her religious tradition. This may arise due to major transgressions such as abortion, adultery, overt cruelty, or from minor transgressions such as not seeking a second opinion or failing to take better care of one’s self. As a result, the patient may feel that that God is disappointed in his/her past or present behaviors, actions, or thoughts (Satterly, 2001). Feelings of guilt are often accompanied by a fear of punishment from God, that God does not love them, or has abandoned them in their time of need.

Individuals may believe that future punishment from God can be avoided if enough self-pain is endured here and now (Satterly, 2001). Such may be the case for individuals who refuse pain medications, and may warrant spiritual exploration by members of the palliative care team. Chaplains have the knowledge and skills to discuss spiritual issues related to a patient’s perceived need for pain and suffering and they may provide an alternative perspective concerning the patient’s perception of either a punishing or forgiving God. In some cases, a patient may refuse to speak with the chaplain or clergy because he/she is angry with God, thereby rejecting religion or spirituality as a source of comfort. It is important for healthcare professionals to recognize that religious or spiritual pain is highly personal and deeply subjective, and does not have to make “sense” to the professional in order for a patient to experience it (Satterly, 2001).

Religious beliefs may also influence an individual’s decisions about medical treatments, particularly if they become seriously ill, such as decisions related to cardiopulmonary resuscitation or withholding or withdrawal of life-prolonging treatments. Medical therapies may also be refused if a patient is a Jehovah’s Witness or Christian Scientist; in such situations, health professionals need to understand the patient’s viewpoint and show respect for his/her beliefs (Koenig, 2002).

As another approach, Highfield (2000) uses the letters from the word “SPIRIT” to remember question appropriate to a spiritual interview, specifically:

- S Spiritual belief system (religious affiliation);
- P Personal spirituality (beliefs and practices of affiliation that the patient and family accepts);
- I Integration with a spiritual community (role of the religious/spiritual group; individual’s role in the group);
- R Ritualized practices and restrictions (beliefs that healthcare providers should remember during care);
- I Implications for medical care;
- T Terminal events planning (impact of beliefs on advance directives; contacting the clergy).

Spiritual assessment further includes assessment of personal beliefs, sources of meaning and hope, values, belief in an afterlife, and sense of connection to self, others, nature, and God. Health practitioners begin to address spirituality by asking such questions as “How are your spirits?” “How do you define your spirit?” “What nourishes your spirit?” or “How have you relieved your spiritual pain in the past?” (O’Connor, 1993). For adults with life-limiting or threatening illness, valuable questions to explore include the following:

- Are you suffering in physical, emotional, social, or spiritual ways?
- What is the meaning of illness and suffering?
- Do you see purpose in your suffering?
- Are you able to transcend your suffering?
- Are you at peace, or feeling hope and despair?
- Do your personal beliefs help you to cope with anxiety about pain, and death and provide a way for achieving peace? (Puchalski & Larson, 1998)

Hermann (2000) further asks in a spiritual assessment such questions as “What gives your life meaning and purpose?” “Do you have goals you would still like to achieve?” “How has your diagnosis changed the meaning of your life?” “What kinds of things do you hope for?” and “To whom do you turn for help?” Practitioners should also observe for objective data such as signs of depression, flat affect or refusal of treatment, presence of religious, spiritual or inspirational books or other literature, or jewelry (Hermann, 2000).

Health professionals may recognize spiritual pain as the person expresses sorrow or grief, verbalizes a sense of meaninglessness or emptiness to life, fear and avoidance of the future, sense of hopelessness and despair, anger towards God, as well as isolation of self and others (Matthews, 1999). It is important to realize that indications of spiritual pain can be both verbal and nonverbal, and that just as physical pain may change in nature and intensity over time, so too can spiritual pain change over time. As death approaches, new spiritual issues may arise, which may or may not be accompanied by spiritual pain (O’Connor, 1993). Furthermore, although health professionals may wish to alleviate spiritual pain, it is important to recognize the meaning and value of experiencing pain from the patient’s perspective. Some individuals may believe that pain will lead to salvation or as a way of coming closer to God.

Instruments to Measure Spirituality

In the past several years, there has been a focus on the role of spirituality, as distinct from religion, in coping with illness. However, there remains a dearth of well-validated, psychometrically sound instruments

to measure aspects of spirituality (Peterman, Fitchett, Brady, Hernandez, & Cella 2002). One instrument that is a psychometrically sound measure of spiritual well-being is the Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being (FACIT—Sp). This instrument comprises two subscales, one measuring a sense of meaning and peace and the other assessing the role of faith in illness. The FACIT-Sp has convergent validity with five other measures of spirituality and religion in samples of early state and metastatic cancer diagnoses, as well as documented reliability. A total score can be obtained.

A second spirituality assessment instrument with clinical utility is the Paloutzian and Ellison’s Spiritual Well-Being Scale, which has also been administered to 70 family members caring for a relative with life-limiting illness. This 20-item instrument yields three scores: a total score of spiritual well-being (overall score); an existential well-being score, which relates to feelings about meaning and purpose in life, feelings about the future, and sense of well-being; and a religious well-being score which represents a sense of support and connection with God (Kirschling & Pittman, 1989).

Such instruments are of value in conducting research studies that explore the relationships of spirituality and quality of life for patients on palliative care. By identifying a patient’s or family member’s sense of spiritual well-being or spiritual distress, spiritual interventions may be provided to maintain or improve spiritual well-being and, hopefully, the quality of life and quality of dying as perceived by patients and family members.

Spiritual Caregiving

“Spiritual care is so much more than religious care. Spiritual care discovers, reverences, and tends the spirit—that is the energy or place of meaning and values—of another human being” (Driscoll, 2001, p. 334). In providing spiritual care, health professionals express the capacity to enter the world of others, to respond to fears, concerns, and feelings with compassion, and bear witness to the physical, emotional, social and spiritual dimensions of their suffering. As adults age, healthcare professionals can provide an opportunity to find intrinsic dignity, which is the dignity that comes from being a human being with inherent value and worth. By reviewing past life experiences, health professionals can assist the individual to reflect on their life accomplishments, the value of their relationships with others, and to forgive or be forgiven by others, and to say goodbye. Support can be given to patients to complete unfinished tasks or goals, and make peace with themselves or with God.

During hospitalizations, health professionals may ask if the person would like to speak with the clergy

or chaplain or have the opportunity to attend a hospital worship service. Patients may also be asked if they would like someone to pray with or for them or have spiritual reading materials. Prayer has been identified as the most frequently reported alternative treatment modality of elders, with women and blacks using prayer as a coping strategy significantly more than men and whites (Dunn & Horgas, 2000). At times, if the patient is of the same faith background as the health professional, the patient may request prayer. However, prayer is appropriate only when the patient wants it and will be comforted by it (Koenig, 2002). Prayer should not be prescribed because the risk is that the intention is not patient-centered, but provider-centered, and in that context prayers offered by health professionals may be viewed as coercive (Koenig, 2002). The existing religious or spiritual beliefs of the patient should be supported and encouraged, yet the end of life is not the appropriate time to introduce new or unfamiliar spiritual beliefs or practices (Koenig, 2002). In a study of 30 individuals with cancer, Taylor, Outlaw, Bernardo, and Roy (1999) reported that several individuals described hesitations about petitionary prayers for particular things, cure, or for themselves, and described inner conflicts about releasing control to God.

If a person is not religious or does not want a health professional to address religious issues, spiritual conversations around hope, love, courage, and forgiveness can occur in the provider-patient relationship (Koenig, 2002). Patients and health professionals of different faith backgrounds can appreciate the commonalities of basic human needs, such as love and hope, and explore issues of coping and what it means to live with an illness. Although health professionals can assess spiritual needs and address uncomplicated spiritual issues, caring and listening is the intervention, not giving advice or trying to address spiritual problems (Koenig, 2002).

Addressing spiritual problems is the role of the chaplain or clergy, as a member of the interdisciplinary team. The chaplain is a healthcare professional who has been trained to offer spiritual care to all people of any or no religious tradition and whose primary focus is the spiritual needs of patients, families, and staff (Driscoll, 2001). Like other members of the palliative care team, chaplains are alert to the expressed needs of the patient. As counselors, they take time to listen, discern the significance of the words spoken, intuit what is the importance of what is unspoken, and affirm the value of shared silence (Purdy, 2002). Often, spiritual support is listening to rhetorical questions, wanting an honest hearing of the question, rather than an answer. Patients may want to explore with chaplains whether God exists, the meaning of mortality, what Heaven is like, who goes to Hell, the integrity of doubt, the possibility of a miracle, the need to forgive, or the loneliness of suffering (Purdy, 2002). Patients and their families experience spiritual support when interdisciplinary team members

actively listen to their anxiety and allow discussion of the question, "Are we doing the right thing here?" (Purdy, 2002). Health professionals can also provide support by silent witnessing, and presencing, as well as serving as a liaison with other health professionals in addressing physical, emotional, and spiritual needs (Hicks, 1999).

Humor also has an effect on the spiritual aspect of healing, as many patients find humor "spiritually uplifting." As an element of spirituality and a coping method for spiritual growth and healing, humor can be transcendent, momentarily removing one from an isolated state to join in surprise at ludicrous human situations (Johnson, 2002). In a study of nine women with breast cancer, participants stated that they looked for meaning in their lives through spirituality and humor, as humor helped them to laugh at themselves and life. For some, it appeared that God had a sense of humor and that finding humorous moments was a step to recovery as humor heals and gives hope to survive the moment (Johnson, 2002).

Health professionals can also encourage patients to socialize with friends, family, and children, as well as encouraging them to help others, even if only by active listening. Supporting others often preserves a person's meaning in life and sense of usefulness. Adults can also pass on their legacy to others by recording personal histories, telling stories, and reminiscing about the past. Conducting a life review by asking questions, such as tell me about tranquil times in your life, chaotic time, what was your childhood like, what obstacle you overcame, what have you achieved, what are your fondest memories, help individuals to recontextualize and reframe mistakes and failure, allow forgiveness of self and others, reclaim an unlived life, and take advantage of current opportunities to participate in enjoyed activities (Jenko, Gonzalez, & Seymour, 2007). If the person is isolated, the health practitioner can suggest his/her watching spiritual or religious television programs or provide an opportunity to enjoy his/her favorite sacred or secular music, or other forms of art (Hermann, 2000). Practitioners may encourage opportunities for patients to experience nature in whatever ways they can, such as a walk or wheelchair ride in the garden or courtyard, or as they sit outside feeling the air and warmth of the sun.

Spiritual uplifting in the present moment can also occur as the practitioner attempts to create meaning and a source of pleasure in the present moment. As one example, a bed-bound patient with Parkinsonism found a moment of meaning and pleasure in the day by retelling to the nurse practitioner a story from his childhood, while anticipating a favorite meal to be brought in by his family the following day. Spiritual care can also involve "making meaning" through other forms of life review, such as looking at old photographs or personal memorabilia, reading old letters, or diary entries. By

such efforts, healthcare professionals can acknowledge the individuality of a person and promote his/her sense of connection to self, others, and nature, thereby supporting his/her spirits and sense of well-being.

Chochinov and Cann (2005) reinforce not only general approaches to spiritual care, such as those offered by palliative care and psychotherapeutic approaches, but also specific approaches, such as relief of symptoms, as well as exploring guilt, encouraging forgiveness of self and others, and complementary practices that promote healing. Other supportive interventions include music and art and supportive-affective programs that focus on the spirit, emotions, and relationships.

Spiritual support may also be available through Parish nursing, which expands home health and public health provider roles. Parish nursing uses the faith community as a cooperative means of successful health promotion and maintenance for the older adult (Boland, 2000). In a survey of parish, oncology, and Hospice nurses, the most frequently identified spiritual interventions were referral, prayer, active listening, facilitation and validation of patient's thoughts and feelings, conveying acceptance, and instilling hope (Sellers & Haag, 1998).

SPIRITUAL AND RELIGIOUS PERSPECTIVES ON DEATH

Losses in life often challenge our faith and philosophical systems. Those who experience loss and grief may differ regarding religious and spiritual perspectives from which they seek answers, search for meaning, and to which they turn for ritual, comfort, and support (Doka & Davidson, 1998). Understanding the ways that spirituality or religiosity facilitates or complicates the adjustment to loss and grief is a critical task to those involved in palliative care.

Death from a Jewish Perspective

Judaism began when the descendants of Abraham's grandson Israel were enslaved in Egypt. Moses led them to Palestine. During this time, Jewish law, known as the Torah, was divinely revealed to Moses. The Sabbath is celebrated from sunset on Friday to sunset on Saturday evening. The Sabbath is the day of rest. The degree to which a Jew observes the Sabbath and other rituals depends on whether he or she is Orthodox, Conservative, or Reformed. (Sherman, 2004a). The focus of those of the Jewish faith is on life and its preservation and in fostering and establishing religion in the life of people on earth, rather than focusing on the world beyond. The Jewish faith offers consolation in death by affirmation of life. Sickness and death are viewed as neither punishment nor reward. Death is not considered evil but rather inevitable and natural, as it comes from God

and should not be feared. Jewish teachings are that the soul exists before the body comes into existence and continues to live on after the body is dead. Although the Orthodox believe in resurrection, this belief may be figurative rather than literal (Grollman, 1993).

Jewish death practices help the bereaved to realize that the loved one is dead and to gradually fill the void in a constructive way. The memory of the deceased must be perpetuated. Although Jews are usually buried, cremations are also done. A religious rite is the rending of mourners' clothes, signified by the cutting of a black ribbon that is pinned to the mourners' clothing in the funeral chapel or cemetery. This signifies the loss of a loved one. The Jewish funeral is a rite of separation, in which the casket actualizes the experience. The rabbi recites prayers expressive of the spirit of Judaism and the memory of the deceased. Shiva refers to the 7 days of intensive mourning beginning right after the funeral. The bereaved remain at home and condolence calls are made to pay respects to the family. The shiva candle burns for 7 days and the family prepares the meal of consolation, known as *seudat havra'ah*. Following shiva comes the 30 days of *sloshim*. During this time normal activities are resumed but entertainment is avoided. If a parent dies, the mourning continues for an entire year. The mourner's prayer is called the *Kaddish*, which is recited during the weekly Sabbath as a pledge to dedicate one's life to God, acknowledge the reality of death, and affirm life. The anniversary of the death is called *yahrzeit*. The *Kaddish* prayer is recited and *yahrzeit* candles are again kindled (Grollman, 1993).

Death from the Roman Catholic Perspective

In Catholicism, it is believed that Jesus experienced suffering, grief, and death. Jesus's death and the death of all others are viewed as a part of God's divine providence. As sinners, human beings experience the tragedy of death, yet are beneficiaries of its forgiveness and liberation. In Catholicism, resurrection is integral to death. Catholics believe that Christ died and rose from the dead, and that faith will allow them to see death as an entry into life with God. Confession and communion are important rituals conducted by priests. The sacrament of the anointing of the sick provides bodily and spiritual renewal and has replaced the term "the last rites," which was viewed as a harbinger of death.

Since the second Vatican Council, the Catholic contemporary view places emphasis on risen life. There is a move from a preoccupation with sin and death toward an orientation of blessing for a Christian life. Christians follow Jesus into the mystery of death in order to find a life like his own (Miller, 1993). The funeral becomes

one of thanksgiving and consolation; the funeral mass is offered on behalf of the deceased, aiding them to the other side of death and giving the bereaved the consolation of hope. It is believed that Christ accompanies the dying person to heaven and that dying is an act of faith in God (Miller, 1993).

Death from the Protestant Perspective

In Protestantism, spirituality is viewed as a dimension of humanness, a process of interaction, and an awareness of relationship. Spirituality cannot be lived in the abstract but rather is lived through one's religion, which is regarded as a cultural institution (Klass, 1993). God is viewed as a single being, who spoke to his people through the Bible; God protects but also judges. Each Protestant has a direct and personal relationship with God, unmediated by priest or sacrament. The church is viewed as a voluntary association of believers. The Protestant community is the local congregation or particular denomination supporting interpersonal relationships, yet is often split along racial, ethnic, and social class lines (Klass, 1993). Anointing the sick is accepted by some groups. Although there are no last rites, prayers are given to offer support.

Death is a challenge because it raises the problem of evil and the problem of the meaningfulness of suffering. Suffering and overcoming evil are the core of Protestant teaching. For Protestants, the focus is salvation, which depends on the moral quality of life on earth. Heaven is known in hope, but not as a guarantee. The belief in an afterlife is through experiences of memory and sense of presence and shared community. Although Jesus is a model for physical, emotional, social, and spiritual suffering, the individual faces the cosmos alone. The issue is not how the individual can participate in Jesus's suffering, but rather the individual's accepting the gift of God's grace in Jesus's death (Klass, 1993).

Death from the Islamic Perspective

Islam means submission. Muslim means one who submits. A Muslim is one who submits to Allah, the Arabic word for God. Muslims, Jews, and Christians worship the same God. The founder of Islam is Mohammad, who received a vision while meditating, which later became the Koran. The five pillars of Islam are confession of faith daily in front of witnesses, prayer five times a day, fasting during the month of Ramadan, almsgiving, and a pilgrimage to Mecca. Fasting during Ramadan is not required of the sick. Second-degree male relatives (e.g., cousins or uncles) should be contacted when a person is sick. They determine if a person or family should be told the diagnosis or prognosis. The Islamic teachings encourage Muslims to seek treatment when they are sick including modern medicine, spiritual healing, and traditional healing practices such as recitation

of verses of the Noble Qur'an. They believe in divine predestination and perceive suffering as atonement for one's sins. When asking about the life expectancy of a patient, they are more likely to be comfortable with less definitive answers such as "it is in the hands of God" as Allah determines the time of death (Zafir al-Shahri and al-Khenaizan (2005)).

Death is viewed as the beginning of a different form of life in which there are blessing from Allah. Some families may ask to have the patient face Mecca (East) and his/her head should be elevated above the body. Discussions about death are not usually welcomed. Grief may be expressed by slapping or hitting the body. Same-sex Muslims should handle the body after death; otherwise the individual should wear gloves so as not to touch the body. Islam forbids cremation, and burial should happen as soon as possible (Zafir al-Shahri & al-Khenaizan (2005)).

Death from Eastern Perspectives

Hinduism originated in India, with belief in the cycles of being born and dying in an infinite series of lives or successive creations. Hinduism teaches the belief in karma, which is that every act of a human being, even an internal act, such as desire, has an effect on who that person becomes. One becomes virtuous by good actions and bad by bad actions (Ryan, 1993). A Supreme Being exists in the individual's soul and is the ultimate all.

Originating in India, Buddhism does not include a belief in a God or a soul. Buddhism teaches that suffering is a part of life and that in death there is a transference of consciousness out of the body (Smith-Stoner, 2006). Buddhists believe in karma and rebirth. Karma is the principle of cause and effect. Buddhists train their minds to remain calm and peaceful as death approaches. Buddha taught that a way to overcome ignorance and attain truth is through the path to enlightenment or changed state of awareness called Nirvana. Buddhists believe that the way to Nirvana is through meditation, while others believe it can be attained through faith.

Yet another Eastern tradition is that of Confucianism, which has its origins in China and stresses the importance of improving human relationships. The proper relationship between the living and dead is one of continuous remembrance and affection, through which one attains social immortality. The value of rituals is that they relate the living with the dead. Memories of parents and ancestors are kept through regular remembrance rituals, which also provide a vehicle for the expression of the human emotions of grief and affection.

Taoism has its origins in China. In Taoism, the focus is on nature and remedying society's disorder and lack of harmony. One looks toward nature to discover

the principles of life. Life is viewed as the companion of death, and death is viewed as the beginning of life and part of the living-dying process. Taoism offers a way of transcending the limits of the world, as there are ceaseless transformations where the person is not lost. The yin and yang are the basic principles for all natural change. The yang is the light half, which is characterized as masculine, active, hot, bright, dry, and hard. The yin is the dark half, which is characterized as feminine, passive, cold, dark, wet, and soft. They are viewed as complementary forces that transform into the other. There is no light without dark, evil without good, or life without death (Ryan, 1993).

Many Asian patients—Chinese, Japanese, Koreans—have an Eastern perspective in which formal behaviors are valued. It is believed that to rebel against death reveals a fundamental lack of understanding about life. Therefore, sadness and grief are kept private. Such behavior sets a good example and contributes to one's good reputation (Ryan, 1993). Patients may seek comfort in images, such as Buddha, Krishna, or the Divine Mother, or in repeating holy mantras. Those from an Eastern perspective believe that a person's final dying thoughts may determine one's rebirth.

Spiritual Issues in Death and Dying for Those Who Have No Conventional Religious Beliefs

Religion traditionally has provided a context for understanding and interpreting death. However, individuals who are not religious can still find comfort and meaning through spirituality and by stepping back from the material world (Orion, 1993). Individuals with no conventional religious beliefs often interpret life on the basis of a sense of being a part of a larger whole and from a scientific worldview. There is belief that an individual's life has a beginning and an ending, but the life process is indefinite. Whether the process is defined in terms of social or biological continuity, the brevity of life does not suggest insignificance. A particular life is short and seemingly inconsequential but assumes value and importance as a significant element in the entire ongoing process. Even brief life is viewed as a contribution to the life process.

Those without conventional religious beliefs often consider the present as the real world and take full responsibility for their decisions. There is the belief that immortality occurs by biological immortality such as living on in the genetic pool of one's descendants, or living on in the memories of others or one's contributions to the world (Orion, 1993). The focus is on actualizing human potential. From the naturalistic perspective, death is not avoided or denied. Death is viewed as real, final, and inevitable and a mark of humans' solidarity with nature and the evolutionary process.

Naturalism leads an effort to place the death of an individual in a framework of the process of living and dying, emergence, and extinction. In this framework, death is:

- a working out of the natural law by which all living things die;
- the absorption of the differentiated person in the natural process;
- a contribution to the evolutionary process;
- cessation of life's potential for negative and positive contributions; and
- re-absorption into new ways in nature (Orion, 1993).

Fear of death can be overcome by remembering that everything dies, but existence goes on. When death is seen as part of the natural order or part of the universal condition, it can be tolerated more easily. Life and death are continuous parts of the whole (Orion, 1993).

Given the dearth of studies regarding the perspectives of atheists in palliative medicine, Smith-Stoner (2007) conducted a study of 88 individuals who self-identified as atheists, which is defined as someone who does not accept that there are any Gods, heaven, hell, devils, souls, miracles, an afterlife, or anything else supernatural. Based on an analysis of open- and closed-ended survey questions, the results of end-of-life preferences indicate that participants' view of a good death included respect for nonbelief and the withholding of prayer or any other references to God. However, consistent with a definition of spirituality which includes intrapersonal, interpersonal, and a natural focus, atheists expressed a deep desire to find meaning in their own lives (intrapersonal), to maintain connection with family and friends (interpersonal), and to continue to experience and appreciate the natural world.

Based on a qualitative study, it was also reported that patients with cancer use prayer to cope with their illness. Participants described prayer as an active cognitive process involving talking to God, or beseeching God, while others described a passive process involving listening to God and accepting that "God's will be done" (Taylor & Outlaw, 2002).

NURSES' NEED FOR SELF-REFLECTION AND SELF-HEALING IN PALLIATIVE CARE

Doka and Morgan (1993) describe the caregivers' assumptions and principles of spiritual care. First, nurses represent diverse spiritual or cultural backgrounds and, like patients, have the right to expect respect for their belief systems. Second, nurses should be offered opportunities to explore their own values and attitudes about life and death and their meaning and purpose in life. Third, nurses should be aware that they have

the potential for providing spiritual care, and should be encouraged to offer spiritual care to dying patients and their families, as needed. Fourth, just as all caregivers, nurses should be flexible and realistic in setting spiritual goals. Fifth, ongoing care of the dying and bereaved may cause a severe drain of energy and uncover old and new spiritual issues for the caregiver. Spiritual growth and renewal is, therefore, a necessary part of staff support and a personal priority for each caregiver.

Indeed, in caring for dying patients and bereaved families, nurses may have experiences that create a grief response of their own because they have lost someone in whom they have invested themselves emotionally. Nurses' grief response, like that of their patients, will be influenced by their spiritual and cultural values and beliefs. If accumulated grief is not worked through, the nurse is vulnerable to the same manifestations of unresolved grief as any other individual who has had a loss but failed to complete the grief work (Rando, 1984; Sherman, 2004b). Nurses, therefore, need to resolve their own feelings of loss, with their spiritual convictions supported, sense of failure alleviated, and emotional strength replenished (Rando, 1984; Sherman, 2004b).

In coping with the stress of caring for the dying, Rando (1984) believes that nurses progress through five stages: 1) focusing on professional knowledge and factual information; 2) experiencing the trauma of the patient's illness, often accompanied by guilt and frustration as the nurse confronts the patient's impending death; 3) moving through the pain and coming to an acceptance of the reality of death; 4) identifying the pain and suffering with sensitivity, but freeing themselves from the incapacitating effects; and 5) relating compassionately with the dying person in full acceptance of impending death. In caring for patients in palliative care, nurses must develop an awareness of their own emotional, physical, or spiritual limits, and develop an awareness of their own energy levels. By realizing the need for self-care, acknowledging their own feelings about dying and death and the stresses in caring for the dying that are most troublesome to them individually, nurses can prevent caregiver burnout (Rando, 1984).

In developing awareness and supporting nurses' spiritual well-being, nurse educators may ask their students or nursing colleagues the following questions:

- What expectations do you have about yourself in caring for the dying and bereaved?
- What would define success in your work?
- What are the three most difficult aspects of your work in caring for patients with life-threatening illness?
- What are you doing to help yourself cope with stress and replenish yourself to avoid becoming overstressed?

“Nurses must recognize their stress reactions and symptoms and employ self-care strategies to replenish themselves in physical, emotional, mental, and spiritual ways to overcome the various sources of stress” (Sherman, 2004b, p. 53). In reducing burnout in palliative-care nursing, *physical health* is promoted as nurses care for their bodies by eating well, engaging in restful and relaxing activities, and counterbalancing fatigue by making improvements in lifestyle. *Emotional health* is bolstered by developing a calm mind with peaceful thoughts through such activities as meditation or listening to quiet music, as well as consciously letting go of negative thoughts and emotions. *Mental health* is strengthened by making choices, setting priorities, letting go of conflict, and saying no, while keeping open to new opportunities and possibilities. And *intuitional health* is nurtured by listening to the soul's wisdom and recognizing the need for balance and wholeness.

In overcoming interpersonal stressors, particularly when relations with others are difficult, nurses may find it helpful to reflect on the rewards of their work and the moments in which they have made the greatest difference in the lives of their patients and families. To cope with feelings of grief and loss, nurses can take time to reflect on what happened at the time of the patient's death and lessons learned and speak to colleagues or journal about feelings, perceptions, and experiences (Sherman, 2004b).

Within the context of end-of-life care, and given that spirituality has emerged as a vital component of health, it becomes necessary for nurses to acknowledge their own spiritual beliefs and values and to deal with their own spiritual and cultural issues. Based on a sample of 155 Israeli oncology nurses, Musgrave and McFarlane (2004) reported that nurses' attitudes toward spiritual care are influenced by their spiritual well-being, intrinsic and extrinsic religiosity, and education. In a descriptive, qualitative study of the spiritual care perspectives and practices of 204 Hospice nurses, Belcher and Griffiths (2005) recognized that the majority of the sample stated that they personally expressed their spirituality by attending church and related activities, that there was an openness and level of comfort in being a spiritual caregivers, and that there was no role conflict in spiritual expression. The majority of Hospice nurses learned of the spiritual needs of their patients and families through personal interactions and the support of pastoral counselors or learning from their own personal life experiences. As Hospice nurses, most indicated that they conducted spiritual assessment and recognized the importance of addressing spiritual needs, although their basic educational programs did little to prepare them. It was clear that Hospice nurses value education regarding spirituality, which they believe enhances the quality of care. Clark and colleagues (2007) examined the spirituality of members of a Hospice interdisciplinary team (n = 215). Based on the Jarel Spiritual Well-Being

Scale, the Chameic-Case Spirituality Integration Scale, and the Job Satisfaction Scale, respondents reported high levels of spiritual well-being, self-actualization, and job satisfaction. Structural path analyses revealed that job satisfaction is more likely realized by a model that transforms one's spirituality into processes of integrating spirituality at work and self-actualization.

According to Hunnibell, Reed, Quinn-Griffin and Fitzpatrick (2008), nurses in Hospice and palliative care, as well as oncology nurses, manifest self-transcendence, which is characterized by awareness of the spiritual self, one's relationship to others, a higher being, and find meaning and purpose in life. Based on a sample of 563 nurses (244 Hospice nurses and 319 oncology nurses), both groups of nurses scored high on the Self-transcendence Scale, though Hospice nurses had higher scores. For both groups of nurses, the greater the level of self-transcendence, the lower the nurses scores of burnout, measured by the Maslach Burnout Inventory, as emotional exhaustion, depersonalization, and personal accomplishment. Oncology nurses manifested higher levels of burnout than Hospice nurses, particularly with respect to depersonalization. It was suggested that nurses should be encouraged to connect with other nurses and form support groups to share their experiences. Strategies such as keeping a journal, sharing one's stories, and recognizing positive individual contributions to care may increase sense of worth and reduce professional burnout.

The importance of spiritual care was emphasized in a position statement published by the Hospice and Palliative Care Nurses Association (2007). The statement emphasized the commitment of Hospice and palliative care nursing to compassionate care at the end of life, acknowledging the importance of spiritual care, encouraging support of The National Consensus Project Guidelines for Quality Palliative Care on spirituality, encouraging organizational support in the provision of spiritual care, commitment to education and resources to promote spiritual care, and recognition of the right of individuals to decline spiritual care.

In caring for people with life-threatening and progressive illness, nurses must remain in tune with their own spiritual needs, healing themselves as well as others. To do so, Halifax (1999) suggests a contemplative exercise for nurses to remain centered, renewed, and whole as they care for others. Sitting in a relaxed position, with eyes closed and aware of the rhythm of the breath, the nurse focuses one at a time on each of the following five phrases, which are repeated slowly twice. The nurse then allows the phrase to pass into the background of her or his awareness, moving attention to the breath and to the next phrase. The phrases are as follows:

- May I offer my care and presence unconditionally, knowing that it may be met with gratitude, indifference, anger, or anguish.

- May I offer love, knowing that I cannot control the course of life's suffering or death.
- May I remain in ease and let go of my expectations.
- May I view my own suffering with compassion just as I do the suffering of others.
- May I be aware that my suffering does not limit my good heart.
- May I forgive myself for things left undone.
- May I forgive all who have hurt me.
- May those whom I have hurt forgive me.
- May all beings and I live and die in peace.

Coulehan and Clary (2005) suggest that poetry can play a role in healing, as the written word becomes an instrument of healing, and an opportunity for practitioners to reframe negativity, learn to function in the face of uncertainty, and supports a compassionate presence in the care of the seriously ill and dying. Writing and reading poetry assists practitioners in understanding their own beliefs, feelings, attitudes, and response patterns, and in the process fosters empathic connection and a relationship that heals both patients and practitioners.

Spiritually and culturally competent care, therefore, requires self-reflection and self-care of nurses. Replenishing one's own vessel in spiritually and culturally renewing ways is important in supporting nurses' caregiving potential. For, it is only by doing so that nurses will come to the bedside with the strong healing presence and true compassion needed to alleviate the suffering of patients and their families.

Case Study conclusion: Mrs. Martinez's weakness and fatigue progressed, with only a slight improvement in her left sided weakness. She spent the last 6 months of her life in the loving care of her family with the support of Hospice. The nurse continued to address Mrs. Martinez's physical needs, which were increasing pain, constipation, and nausea, while recognizing the multidimensional aspects of her suffering. Mrs. Martinez enjoyed her visits with the Hospice chaplain, who was a Catholic priest. He prayed with her at her request, administered weekly Holy Communion, and anointed her with the Sacrament of the Sick. Like Mrs. Martinez, the family expressed their appreciation for the chaplain's spiritual sensitivity and care. Spiritual support was further offered by the nurse practitioner who recognized the value of life review and sat with Mrs. Martinez and the family as they watched family videotapes and reminisced about special occasions. With help from the nurse, the daughter would take her mother in the wheelchair to sit for short periods in the yard. Mrs. Martinez's face relaxed as she

listened to the birds and enjoyed her watching grandchildren.

Till the very last days of her life, Mrs. Martinez experienced the love and support of her family. Sips of herbal teas were encouraged to give her strength or relieve the nausea. Latino music was played, reminding her of her cultural connection. Members of her church visited and prayer novenas were conducted. Mrs. Martinez died in her own room with her family and the Hospice nurse at her side. The nurse and family discussed the cultural and spiritual practices of the family in preparing for Mrs. Martinez's funeral and plans to celebrate her life.

During a follow-up bereavement visit, Mrs. Martinez's family acknowledged their appreciation for the culturally and spiritually sensitive care received by the Hospice team. Mrs. Martinez's daughter told the nurse that they considered her as a member of their family. This comment reveals the depth of connection that can be established with older patients and their family, and the importance of cultural and spiritual sensitivity in providing quality palliative care.

CONCLUSION

Illness and dying are occurrences that take us to the very core of our being. Although they are intensely personal experiences, they occur within the context of our spiritual and cultural traditions. Culture and spirituality can therefore not be separated from who we are, as they are often the very source of our nourishment and physical, emotional, social, and spiritual well-being. Through sensitive and competent cultural and spiritual care, nurses can protect patients and families from the ultimate tragedy of depersonalization. They will be able to sustain them in a personalized environment that recognizes their individual needs, reduces their fears, and offers them hope and dignity. Sulmasy (1997) believes that “when patients collapse spiritually in the face of illness, a clinician with the right perspective will understand much more acutely how desperate their plight really is and will treat the wounds of such patients with even more liberal applications of the wine of fervent zeal and the oil of compassion” (p. 52). Frankl (1988) reminds us that man is not destroyed by suffering, but by suffering without meaning.

Cultural and spiritual values, beliefs, and practices profoundly influence life and living and death and dying. Identifying cultural and spiritual factors pertinent to a patient's health are critical to the development of a successful plan of care that supports a person's sense of worth, integrity, and the continued actualization of their

potentials. Within the context of culturally and spiritually diverse beliefs and practices, health professionals should preserve beliefs and practices of individuals that have beneficial effects on health, encourage the adaptation or adjustment of practices that are neutral or indifferent, and suggest the re-patterning of those practices that are potentially harmful to health (Leininger, 1995).

Culturally and spiritually competent care requires self-reflection and self-care if healthcare professionals are to be therapeutic. As such, healthcare professionals need to replenish their own vessels in culturally and spiritually renewing ways to actualize their caregiving potential. In doing so, healthcare practitioners can offer a strong healing presence, true compassion, and sensitivity to the cultural and spiritual needs of older patients and their families (Sherman, 2001).

Consideration of the cultural and spiritual backgrounds of patients and attention to their cultural and spiritual needs often enable older patients to live as fully as possible until death, and to maintain or restore quality to their lives. Byock (1997) reminds us that through competent and compassionate end-of-life care, older adults and all other patients can achieve a sense of inner well-being even as death approaches, and that “when the human dimension of dying is nurtured, for many the transition from life can be as profound, intimate, and precious as the miracle of death” (p. 57).

EVIDENCE-BASED PRACTICE

Level IV Evidence: Descriptive, Correlational, Qualitative

Mako, C., Galek, K., & Poppito, S. (2006). Spiritual pain among patients with advanced cancer in palliative care. *Journal of Palliative Medicine, 9*(5), 1106–1113.

Background. Empirical research indicates that the spiritual pain of patients influences the disease process and further understanding of the complexity of spiritual pain is warranted.

Purpose. To explore the multidimensional nature of spiritual pain as it relates to physical pain, symptom severity, and emotional distress in patients with end stage cancer.

Design. Quantitative evaluation of the intensity of spiritual pain, physical pain, depression, and intensity of illness, as well as a qualitative exploration by chaplains of the nature of spiritual pain and interventions identified by patients to relieve spiritual pain.



Plan for Achieving Competencies: Spiritually and Culturally Competent Palliative Care

KNOWLEDGE NEEDED	ATTITUDE	SKILLS	UNDERGRADUATE BEHAVIORAL OUTCOMES	GRADUATE BEHAVIORAL OUTCOMES	TEACHING/LEARNING STRATEGIES
<p>Cultural perspectives regarding illness and death:</p> <ul style="list-style-type: none"> — Native American; — African and African-American; — Hispanic; — Asian; — Cultural values underlying advanced directives and medical decision making; — Research regarding culture and end-of-life issues. 	<ul style="list-style-type: none"> ■ Appreciate varying cultural perspectives of death. ■ Value research in informing cultural care. 	<ul style="list-style-type: none"> ■ Demonstrate sensitivity to cultural beliefs and customs. 	<ul style="list-style-type: none"> ■ Develop a plan of care with the patient and family that addresses their cultural perspectives on death and cultural needs. ■ Critique and utilize research in guiding culturally competent care. 	<ul style="list-style-type: none"> ■ Address conflicts that result from differences in cultural perspectives on death of patients, families, and healthcare providers. ■ Participate in conducting research regarding culture and health-related outcomes. 	<ul style="list-style-type: none"> ■ Have students interview two individuals of diverse cultural backgrounds and compare beliefs, values, expectations, and traditions related to illness and death. Compare the information obtained from information written in textbooks or journal articles. Share findings in class. ■ Critique five research articles related to cultural beliefs and healthcare issues. Synthesize the findings and discuss the implications for nursing practice.
<p>Quality nursing care: Addressing cultural needs of patients and their families—nurses' cultural self-awareness and development of cultural competency—cultural assessment and interventions.</p>	<ul style="list-style-type: none"> ■ Recognize students'/ nurses' own cultural beliefs and values. 	<ul style="list-style-type: none"> ■ Convey unconditional acceptance of patients and families of various cultural backgrounds. ■ Demonstrate the completion of a cultural assessment. 	<ul style="list-style-type: none"> ■ Create an environment which supports cultural beliefs, values, traditions, and rituals. 	<ul style="list-style-type: none"> ■ Develop a comprehensive plan of care which takes into account cultural values, needs, and expectation. ■ Educate other healthcare providers in providing culturally competent care. 	<ul style="list-style-type: none"> ■ In post-conference or seminar, encourage students to express feelings of appreciation regarding their own cultural heritage while introducing the topic of ethnocentrism in connection with the value of cultural diversity. ■ Have students identify who was significant in teaching or transmitting to them their cultural identity and discuss the impact of their identity on their present life. ■ Have students identify how members of their cultural group approach personal or emotional problems. ■ In the clinical setting, conduct a cultural assessment of a patient/family and report findings in post-conference or seminar. ■ In post-conference or seminar, create and discuss a list of behaviors or comments which may be viewed as culturally insensitive based on past, personal, or professional experiences. Role-play compassionate and effective communication regarding cultural issues relevant to palliative care.
<p>Spirituality and culture as factors that structure responses to</p>	<ul style="list-style-type: none"> ■ Affirm nurses' commitment to holistic practice. 	<ul style="list-style-type: none"> ■ Act in accordance with the patients' and families' 	<ul style="list-style-type: none"> ■ Incorporate spiritual and cultural care in nursing practice. 	<ul style="list-style-type: none"> ■ Role-model and expect of others spiritually 	<ul style="list-style-type: none"> ■ Write a position paper about the role of spirituality and culture in providing nursing care.

KNOWLEDGE NEEDED	ATTITUDE	SKILLS	UNDERGRADUATE BEHAVIORAL OUTCOMES	GRADUATE BEHAVIORAL OUTCOMES	TEACHING/LEARNING STRATEGIES
life-threatening illness.	<ul style="list-style-type: none"> Emphasize the value of spirituality and culture in providing end of life care. 	<p>spiritual and cultural values and wishes.</p>		<p>and culturally competent care for patients and families.</p>	
The spiritual nature of the person	<ul style="list-style-type: none"> Value and support the spirituality of human beings. Appreciate the needs of the dying to make peace with life and death. 		<ul style="list-style-type: none"> Provide spiritually competent care to patients and families experiencing life threatening illness by considering spiritual well-being. 	<ul style="list-style-type: none"> Create an environment in which the spiritual nature of people is recognized, valued, and supported. Assist patients and families to find a source of spiritual energy or reaffirm students'/ nurses'/spiritual focus. 	<ul style="list-style-type: none"> Based on the spiritual assessment of a particular patient and family, develop a spiritual plan of care. Review the plan of care with clergy/chaplain.
Suffering as a human condition -Reciprocal suffering of patients and family;—Care of those who are suffering.	<ul style="list-style-type: none"> Acknowledge suffering as a multidimensional experience. Recognize that suffering may be personal or experienced as witness to another's suffering. Appreciate that suffering and pain are not identical. Consider the effect of suffering on health and quality of life of patients, families, and healthcare providers. 	<ul style="list-style-type: none"> Demonstrate therapeutic use of self in alleviating suffering. 	<ul style="list-style-type: none"> Assist patients and family to identify the meaning of suffering and refer to members of other disciplines as appropriate. 	<ul style="list-style-type: none"> Assess the impact of suffering on patient, family, healthcare providers, and community. Implement the role of nurse as a coach in caring for those who are suffering. Support patients and family in achieving some transcendent meaning to their suffering. 	<ul style="list-style-type: none"> Based on a case study, identify the dimensions of suffering and nursing strategies to alleviate suffering.
Spiritual and religious perspectives of death: —Jewish —Roman —Catholic —Protestant —Islam —Eastern perspectives	<ul style="list-style-type: none"> Appreciate varying spiritual and religious perspectives of death. Value research in informing spiritual care. 	<ul style="list-style-type: none"> Demonstrate sensitivity to spiritual and religious beliefs and customs. 	<ul style="list-style-type: none"> Develop a plan of care with the patient and family that addresses their spiritual and religious perspectives on death and associated needs. 	<ul style="list-style-type: none"> Address conflicts that result from differences in spiritual and religious perspectives on death of patients, families, and 	<ul style="list-style-type: none"> Role-play as a way of learning about different spiritual/ religious beliefs and values in a nonjudgmental way. Self-critique attitudes and interaction followed by feedback from faculty and peers. Critique five research articles related to spiritual or religious beliefs and

(Continued)

Table 1.1 (Continued)

KNOWLEDGE NEEDED	ATTITUDE	SKILLS	UNDERGRADUATE BEHAVIORAL OUTCOMES	GRADUATE BEHAVIORAL OUTCOMES	TEACHING/LEARNING STRATEGIES
<ul style="list-style-type: none"> —No conventional religious beliefs —Research regarding spirituality 			<ul style="list-style-type: none"> ■ Critique and utilize research in guiding spiritual caregiving. 	<p>healthcare providers.</p> <ul style="list-style-type: none"> ■ Participate in conducting research regarding spirituality and health-related outcomes. 	<p>healthcare issues. Synthesize the findings and discuss the implications for nursing practice.</p> <ul style="list-style-type: none"> ■ Distribute 3×5 cards and ask the students what happens at the time of death on side one and how that belief serves them on side two of the card. Ask the students to pass the card to another student. They are to take on the belief of the other student as their own. They are now asked how this new belief may benefit them.
<p>Quality nursing care: Addressing spiritual needs of patients and families:</p> <ul style="list-style-type: none"> —spiritual caregiving —spiritual assessment —spiritual interventions and care —educating nurses and physicians regarding spirituality. 	<ul style="list-style-type: none"> ■ Recognize students'/nurses' own spiritual and religious beliefs and values. ■ Value nurses' presence, compassion, and hopefulness in providing quality spiritual care. ■ Appreciate the role of chaplains and clergy in offering spiritual care. 	<ul style="list-style-type: none"> ■ Convey unconditional acceptance of patients and families of diverse spiritual and religious beliefs and backgrounds. ■ Demonstrate the completion of a spiritual history/assessment. 	<ul style="list-style-type: none"> ■ Create an environment that nurtures the the patient's exploration of spiritual needs and concerns. ■ Address patients' and families' spiritual and religious needs through presenting, active listening, unconditional regard, and support of meaningful rituals. 	<ul style="list-style-type: none"> ■ Identify patients and family who are at risk for spiritual distress. ■ Develop a comprehensive plan of care to alleviate spiritual suffering. ■ Educate other healthcare in providing spiritually competent care. 	<ul style="list-style-type: none"> ■ Write a position statement identifying students'/nurses' personal beliefs and assumptions as it relates to spirituality or religiosity. ■ Conduct a values clarification exercise for students/nurses to identify their own spiritual values. ■ Discuss the role of clergy as members of the interdisciplinary team in post-conference or seminar. ■ Discuss illustrative cases where patient's spirituality or religiosity negatively affected their health outcomes and potential spiritual interventions.
<p>Nurses' needs for self-reflection and self-healing in palliative care.</p>	<ul style="list-style-type: none"> ■ Affirm nurses' right to be respected for their belief systems. ■ Acknowledge students'/nurses' personal potential for providing spiritual and and cultural care. ■ Appreciate the potential drain of energy and resurfacing of personal spiritual issues related to care giving. 		<ul style="list-style-type: none"> ■ Develop an awareness of students'/nurses' own spiritual, emotional, and physical limits. ■ Establish a personal plan of care for maintaining health and promoting personal and professional growth. 	<ul style="list-style-type: none"> ■ Assess colleagues at risk for caregiving burnout. ■ Advocate for systems that support students'/nurses' self-care and personal and professional growth. 	<ul style="list-style-type: none"> ■ Write a personal plan of care to address the students'/nurses' physical, emotional, social, and spiritual needs, and strategies to promote personal and professional growth within the next 6 months. ■ Create a suggestion box and contribute one recommended change, which would support the nurses' caregiving potential within the educational setting. ■ Discuss in the classroom, post-conference, or seminar ways in which students/nurses have been able to provide spiritual care and the responses of the individual and family. ■ Beginning with a 5-min relaxation exercise, have students/nurses write a poem asking a transcendent life force for support. Have each student/nurse read their poem, twice slowly.

Sample. 57 patients with advanced cancer in a palliative-care hospital.

Results. 96% reported spiritual pain which was described as intrapsychic (anxiety, loss, regret, interpersonal feeling unwanted and disconnected from others), and in relation to the divine (abandoned by God, being without faith or a religious community). Intensity of spiritual pain was correlated with depression, but not with physical pain or severity of illness. However, a third of participants describe their pain in somewhat physical terms. Those receiving morphine for physical pain were more likely to express spiritual pain. The intensity of spiritual pain was not associated with age, gender, disease course or religious affiliation. The most frequently requested intervention is listening and presence.

Conclusion. Spiritual pain is universal and multidimensional. Alleviation of physical pain by morphine may allow access to underlying spiritual issues. Spiritual pain is communicated through an emotional realm. Though there is overlap between spiritual pain and depression, there is differentiation requiring different interventions. More attention needs to be given to exploring the complexity of pain and of spiritual pain as a factor.

Commentary. This study is of significance to palliative-care practitioners in recognizing that spiritual pain can occur in the absence of physical pain and that dignity conserving interventions are of benefit. This study discussed in the review of the literature Melzack and Wall's theory of pain as a multidimensional construct but did not present a conceptual framework or theory which guided the study. There was no discussion of the inclusion criteria, data collection procedures, or protection of human subjects. The variables were not measured with instruments with reliability or validity. The methods for qualitative data analysis were not described. Paragment et al.'s three dimensions of spiritual pain was used to classify the qualitative data regarding spirituality, which may have limited reporting of other findings that did not fit the three dimensions. The authors conclude that unaddressed spiritual pain may impede recovery and contribute to overall suffering. It is recognized that spiritual pain is associated with anxiety, but the concepts of recovery and suffering were not directly measured. The findings support the need for assessment of spiritual distress and the need for future research, which will inform the identification and implementation of appropriate spiritual interventions.

To identify the knowledge, attitudes, and skills of undergraduate and graduate nurses' behavioral outcomes and teaching/learning strategies, please refer to the Education Plan (Table 1.1).

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