EPEC™-O

Education in Palliative and End-of-Life Care for Oncology:

Cultural Considerations When Caring for African Americans

Module 16-AA: Spirituality

Quote: "Dying is a spiritual process with medical implications." Gwen London, DMin

ABSTRACT

Spirituality plays an integral role in how the individual with cancer and his/her family adapt to the experience of cancer.

In this module, spirituality, religion, and spiritual coping are defined and contrasted. The historical role of religion and the current demography of religious affiliation in the African American population are reviewed. The importance of spirituality and religion in the everyday lives of African Americans as well as in the lives of those affected by cancer is explored, and compared with the U.S. population as a whole. Spiritual issues of importance to those with cancer, as well as unmet spiritual needs, are discussed. The effects of different types of spiritual/religious coping on quality of life and health outcomes for African Americans and the U.S. population as a whole are described. Recommendations from professional organizations related to spiritual assessment and intervention are presented. Various methods of performing spiritual assessments are outlined, and recommendations for effective culturally sensitive interdisciplinary interventions to alleviate spiritual distress are proposed.

Key words

Spirituality, religion, spiritual coping (positive and negative), spiritual assessment

OBJECTIVES

At the completion of this module, participants will be able to:

- Define spirituality and religion, and explain the difference between them
- Describe the historical role of religion in the African American community
- Identify demographic trends in the religious and spiritual beliefs of African Americans compared with the general U.S. population
- Outline the role that spirituality plays in adjusting to advanced cancer, both in the general population and among African Americans
- Describe methods of performing discipline-specific spiritual assessments
- Formulate pertinent discipline-specific and interdisciplinary spiritual interventions in the plan of care for patients with advanced cancer

DEFINITIONS

Awakenings: Evangelical spiritual renewals which swept the colonies/United States in the 18th and 19th centuries. The First Great Awakening spread from England and Europe to the colonies from about 1730-1760. The Second Great Awakening began in the 1790's,continuing into the 1830's, and saw the rise of evangelical Methodists and Baptists.[1, 2]

Ministry of presence: A form of servanthood characterized by suffering, alongside of/with the hurt and oppressed. Ministry of presence for pastoral professionals means vulnerability to and participation in the life-world of those served.[3]

Religion: Beliefs and practices that center on questions about the meaning of life which may involve the worship of a supreme being. Balboni defines religion as a specific set of beliefs about the transcendent that are shared by a community and are often associated with common sacred writings and practices.[4] London states that religion is structured around doctrines that propose answers to the universal questions of spirituality.[5]

Religious/spiritual coping: How a patient makes use of his or her religious/spiritual beliefs to understand and adapt to stress.[6] Several instruments have been developed to assess religious coping. The one mentioned below, the Brief RCOPE, is a 14-item scale derived from the longer 63-item RCOPE scale that assesses the degree to which patients make use of various religious methods of coping with their current illness, with either a positive or negative frame. Both versions of the RCOPE have been validated, originally in moderately- to severely-medically-ill elderly hospitalized patients, primarily Christian, from the Southeast United States, where 38 percent of the validation sample was non-white.[7]

Positive religious/spiritual coping: A constructive reliance on faith to promote healthy adaptation. Some examples of positive religious coping (based on the Brief RCOPE) are spiritual connection, seeking spiritual support, religious forgiving, collaborative religious coping, benevolent religious reappraisal, religious purification, and religious focus.[7]

Negative religious/spiritual coping: Tends to view illness as a divine punishment and can herald existential crisis. Examples from the Brief RCOPE include spiritual discontent, punishing God reappraisal, interpersonal religious discontent, demonic reappraisal, and reappraisal of God's powers.[7]

Spiritual Reframing: With those who attribute their suffering to God's punishment, an intervention to reframe the idea that God did this to them because they deserved it; substituting the idea that God enters into and can potentially help transform their suffering.[8]

Spirituality: There have been many attempts to define spirituality, but there is no universally accepted definition. In the National Cancer Institute (NCI) Dictionary of Cancer Terms, spirituality is described as having to do with deep, often religious, feelings and beliefs, including a person's sense of peace, purpose, connection to others, and beliefs about the meaning of life.[9] Balboni describes spirituality as an individual's relationship to—and experience of—the transcendent, whether through religion or other paths.[5] According to London, spirituality is a much broader concept than religion, and can be defined as "the inner desire to connect with a higher reality and to experience through that connection a sense of completion and wholeness." It involves the universal search for meaning and is grounded in the awareness that, as humans, we are part of some reality that is greater than ourselves.[10] According to Wright, "Spirituality is concerned with the intangibility of transcendence and the tuning in to something both beyond and within, something deeper, something wider, something bigger."[11]

Case Study Vignette

The patient, Mrs. Washington, is a 54 y.o. African American woman with advanced metastatic cancer who was hospitalized for treatment of sepsis. She has not responded to antibiotic therapy

and is currently bedbound and essentially unresponsive. The patient's family (daughter, two sons, husband, and sister) are gathered around the bed in the hospital room.

The doctor, nurse, and chaplain walk into the room, and begin to discuss options with the family for the continuing care of Mrs. Washington in light of her spiritual values and beliefs. There is discussion between the healthcare providers and the family around the family's belief that a miracle may occur.

Dr. Richard Payne discusses the value of hospice care, and its congruence with African American Spirituality at the end of the video.

The video vignette can be accessed at the following url:

http://www.youtube.com/watch?v=8oWv9TVEQUQ

INTRODUCTION

The United States is generally considered to be a very religious nation, and the African-American population is considerably more religious than the general population on a number of measures; compared with the general population in the United States, a higher percentage of African Americans believe in God, belong to a religion, attend church regularly, and pray daily. A higher proportion of African Americans view spirituality as very important in their daily lives, especially at times of crisis such as serious illness. The vast majority of African Americans in the United States are Christians, and most belong to historically black churches or Evangelical Christian denominations. A small minority of African Americans are Muslims.[12]

Historically, African Americans have been vulnerable to untimely death. For African American slaves, death was often viewed as a release from suffering, and a "going home".[13] Heaven, in the songs of African American slaves, was often portrayed as "just on the other side of the Jordan." The world of nature was a place for spiritual discernment and understanding; even in the darkest of circumstances, "God always makes a way out of no way".[14]

Overcoming struggle and persevering in spite of hardship are also central images in the songs and traditions of early African Americans, as well as contemporary African Americans' writings and oratory.

African Americans commonly rely on their spirituality in positive, constructive ways in order to navigate the vicissitudes of life.[15] This module explores the role that spirituality plays in the lives of African Americans and others faced with advanced cancer.

The Historical Role of Religion in the African American Population

Origins

From the 16th to the 19th century, millions of Africans were brought over to the Americas as slaves; about 645,000 came to what is now the United States.[16] They came from diverse cultures and spoke different languages. Some were Muslim (about 20 percent) and some were Catholics

converted by missionaries in Africa, but most had other belief systems and cultures. Several factors made it difficult for the slaves to hold onto their prior belief systems: the harsh conditions of slavery, the separation from their native land and their families, and the deliberate attempt on the part of the slaveholders to eradicate "heathen" cultures. Yet remnants of their customs survived and were melded into their new lives and belief systems: belief in the curative power of roots and the efficacy of the world of spirits and ancestors, as well as certain rhythms, songs, and dances. [17]

In the 18th and 19th centuries, evangelical movements called "Awakenings" spread from Europe to the New World. The movements stressed the importance of an emotional, personal connection with God, and emphasized that all men could be saved, if they chose to be. Subjective experience was more valuable than intellectual learning and credentials.[18] The forms of worship— enthusiastic singing, clapping, dancing, and spirit possession—seemed familiar to the African slaves and consistent with their former worship patterns and customs.[17] Initial evangelization was conducted at revivals and camp meetings by white missionary preachers such as George Whitefield from England, but many African Americans, free men and slaves alike, joined the evangelical movement and began preaching throughout the country as itinerants, and many also established independent black churches. Sojourner Truth—a former slave who felt called by God at the age of 30 to set out as a free woman—and other African American women also became itinerant preachers. She preached abolition, women's suffrage, and the Gospel, and rose to national prominence and met Presidents Lincoln and Grant. Many of the African American men started their own congregations, in both the North and the South, though distinct forms of worship developed due to the differing conditions in each region. [17]

In the South, slave preachers George Liele, David George, and Jesse Galphin formed a Baptist faith group among plantation slaves and in 1773 became the oldest all Black congregation in America, founded as the Silver Bluff Baptist Church in Aikin County, South Carolina. Both free and enslaved blacks were members. The group later moved to Savannah and—under the auspices of Andrew Bryan, an ordained minister in the Baptist Church—founded the Bryan Street African Baptist Church, which later became the First African Baptist Church of Savannah.[19] Many other African American Christian congregations emerged in similar fashion throughout the South.

Discontent

Initially, slavery was denounced by the evangelical religious movement of the Great Awakening and the Second Awakening. However White Christian ministers began to justify the institution of slavery as acceptable to Christians; they invoked the "good slave" who, by remaining subservient and obedient to his master, would attain heaven. Enslaved blacks rejected this idea as hypocritical and antithetical to Christianity, which should uphold the equality of every man before God. [17]

Slave rebellions in the early 1800's like the one led by Nat Turner in Southhampton County, VA, triggered a reaction: Black worship that was not supervised by Whites or was led by Black preachers was banned in many Southern states. African Americans then organized the "invisible church," creating secret messages to call African Americans to "hush harbors" where they were free to practice an evangelical Christianity comprised of African rhythms, singing, and beliefs. It

was also primarily in the South that many new African slaves were imported to support the burgeoning cotton industry (after the invention of the cotton gin). Both of these trends elevated the importance of traditions and cultures from Africa, compared with the Black churches in the North. [19, 20]

Toward the end of the 18th century, Black churches were started in many areas in the North, such as Philadelphia, Boston, and New York, when White congregations tried to segregate their Black members. When this happened at St. Thomas Episcopal Church, Reverend Richard Allen and Absalom Jones formed the Free African Society in 1787, the first Black mutual aid association in Philadelphia, which was initially non-denominational. Absalom Jones then founded the African Episcopal Church of St. Thomas in 1792, and Richard Allen went on to establish the African Methodist Episcopal Church in 1816. Independent Black Churches established in the North generally more closely resembled their White counterparts. [18]

In 1829, four free Black women, refugees from Haiti, established the nation's first permanent community of Black Catholic nuns in Baltimore, MD. In 1875, James Augustine Healey became the 1st African American bishop in the Roman Catholic Church. [19]

In the early 19th century, many Methodist congregations around the country coalesced into the African Methodist Episcopal Church. Later in the century, the Colored Methodist Episcopal Church and the National Baptist Convention formed. [19]

While many African Americans were drawn to the independent Black churches, many others chose to remain in bi-racial Presbyterian, Congregational, or Episcopal congregations, while others joined newer movements such as the Shakers or the Mormons. [17]

After emancipation, many of the northern Black churches that had actively struggled against the institution of slavery and provided aid to escaped slaves sent missionaries to the South to evangelize among the newly freed slaves, and to bring education and social support to the African Americans there. In the meantime, the number of Southern Black churches was on the rise. Black churches became the center of cultural and social life for African Americans, forming schools, providing for the indigent, doing job training, establishing orphanages and prison ministries, starting newspapers, and supporting each other through the struggles of daily life. [21]

Diversity and Activism

The diversity of religions and cultures found among the original African slaves persisted in America, not only among Christian denominations, but also among other faith traditions.

W.D. Fard was a silk merchant who settled in Detroit and promoted Islam among African Americans; in 1934, Elijah Muhammad assumed leadership of the Nation of Islam. [19]

Gandhi's precepts on the use of non-violence as an agent of social change were brought back to the United States in 1937 by Howard Thurman, a Baptist pastor and educator, among whose students was Martin Luther King Jr. [19]

African American churches have incorporated much more civic and political activism into their ministries than have other churches, from the period of slavery through emancipation and the civil rights movement to the present day.

Throughout history, the church has provided a haven and also social and practical supports to African American individuals and families that were not available to them in society at large. African Americans have turned to the church in times of crisis, including at the time of dying. Faith communities often provide a primary source of support for African Americans with severe life-threatening illnesses such as cancer. [10]

Many African American churches maintain these helping functions to the present day, and several have developed specialized ministries for those struggling with end-of-life issues and concerns. [13]

RELIGIOUS DEMOGRAPHY OF THE AFRICAN AMERICAN POPULATION

Compared with the general population, African Americans are considerably more religious. Eighty seven percent of African Americans identify with a religious group, with most (59 percent) belonging to historically black Protestant churches. [12] (See Table 1)

Table 1: Religious affiliation of African Americans

Affiliation	Percent
Historically black Protestant churches	59 (40 percent Baptist)
Evangelical Protestant churches	15
Mainline Protestant churches	4
Catholic church	5
Muslim	1
Other	4
Unaffiliated	12 (19 percent of those older than 30)
Atheist/Agnostic	<1

Source: Pew Forum: A Religious Portrait of African-Americans[12]

Nearly eight in ten African Americans say religion is very important in their lives (compared to 56 percent among all U.S. adults). Even 72 percent of unaffiliated African Americans say religion plays at least a somewhat important role in their lives, and over half say it plays a very important role. More than half of African Americans attend religious services at least weekly, 76 percent pray at least daily, and nearly nine in ten are absolutely certain that God exists; 55

percent interpret scripture as the literal word of God (versus 33 percent of the general population), 83 percent believe in angels and demons (vs. 68 percent) and 84 percent believe in miracles (vs. 79 percent). Religious commitment is somewhat higher in African American women than men.[12]

About 1 percent of African Americans are Muslims, many of whom belong to the Nation of Islam while a significant but smaller proportion identify with Sunni Muslims.[12, 14] The Muslim and Christian faiths have many beliefs in common. Both are monotheistic religions that trace their ancestry to the patriarch Abraham. Christians believe that God is merciful, and Muslims believe that Allah is a God of Mercy. Muslims believe that we die only when Allah wills it, and many Christians believe that God determines the timing and circumstances of death. Both faiths believe in a judgment day or day of reckoning, bodily resurrection after the day of reckoning, and life after death, with rewards for the faithful and a return to God or Allah. Both faiths refer to apocalyptic writings about events on the earth that will lead to an end to earth as we know it, followed by the creation of a new earth.

Of course, there are differences as well. Muslims believe that Muhammad, who lived around the turn of the 7th century CE, is the greatest and last prophet and the messenger from Allah. Christians, who believe that Jesus is God, do not believe in Muhammad. Muslims do not believe that Jesus is God, though He is viewed as a prophet; Muslims do not believe in the Christian doctrine of the Trinity of God. Muslims put more emphasis on formal prayer, called salaat, and are obligated to pray five times daily, at specified times, in a specified format. However like the Christian faith, the Muslim faith also encourages informal prayer.[14] There are also cultural differences in traditional religious rites between (and within) each faith, and differences in the prescriptions and proscriptions about diet and clothing.

It is important for healthcare providers to know that there are prohibitions against caregivers of the opposite sex providing medical care for Muslim men and women. It is important for seriously ill Muslims to have same-sex providers who are respectful of their faith practices.[22]

Many African Americans hold conservative views on such ethical issues as abortion, euthanasia and homosexuality.[12]

IMPORTANCE OF SPIRITUALITY/RELIGION TO THE PERSON WITH ADVANCED ILLNESS

General population

Several empirical studies document the importance of spirituality and religion to patients with serious illnesses such as cancer. Koenig found that intrinsic religiosity (the motivation behind religious belief and action as measured by the Hoge Scale) was significantly and independently related to the time to remission of depression in a group of hospitalized, depressed elderly patients.[23] Ayele et al. found that 86 percent of hospitalized and long-term care patients used religious activities to cope with their problems.[24]

In a qualitative descriptive study of 8 post-stroke patients, Robinson-Smith found that prayer was used for coping after a stroke, and that participants described prayer as indispensible to their recovery. Themes included: reaching toward God and asking for help, praying with increased intensity and focus, finding strength and being unburdened and comforted through prayer, and connecting with God, nature, family, friends and self.[25]

Levin reviewed the results of three national surveys, The Myth and Reality Aging survey, the second Quality of American Life survey, and the Americans' Changing Lives study; he found evidence for the salutary effect of religious involvement on: life satisfaction, depressive symptoms, happiness, chronic anxiety, emotional adjustment, coping, self-esteem and mastery, subjective health, physical symptoms, and functional disability. He also cited epidemiologic studies showing that certain aspects of religious involvement may extend life.[26]

In a literature review of the impact of religious commitment on health status, Matthews found a large proportion of published empirical data suggesting that religious commitment: plays a beneficial role in preventing mental and physical illness, improves coping, and facilitates recovery from illness. He found the literature compelling enough to recommend that family physicians:

- routinely assess how the patient utilizes religion in handling illness,
- inquire how the health provider can support the patient's faith,
- encourage the patient to make use of health-promoting religious resources from the patient's own religious tradition, and
- refer the patient to clergy or chaplaincy as an adjunct to standard medical care.[27]

Meisenhelder surveyed a national sample of 1,014 church lay leaders, and found that the frequency of prayer was significantly related to higher mental health scores, and concluded that prayer may prevent or mitigate depression and anxiety.[28]

Steinhauser investigated factors of importance at the end of life among a national random sample of 340 patients with advanced illness; being at peace with God was ranked second in importance, only marginally behind pain control.[29]

African American population

Christian African Americans have been shaped by the cruelties of slavery to their ancestors, as well as their ongoing experiences with racial discrimination and oppression. Many view God as an all-powerful father figure in control of humans at all times and in all situations. Christian African Americans throughout history have embraced the thought that they are children of God, and that God will ultimately reward them for their suffering. God's objective for His children may not always be liberation, but rather survival, and positive meaning can be found even in bad situations.[30]

Hamilton conducted in-depth interviews with 28 African American breast and prostate cancer survivors, and found that many viewed themselves as having a close personal relationship with God, who provided support through presence, healing, taking away worries, and by sending

others to help when needed. Many expressed the view that God would give them no more than they could handle, and they reported that He helped them to cope with pain, symptoms and worries. God was viewed as being in control of the situation—whatever happened was viewed as His will. In fact, many of these cancer survivors reported "turning it (the cancer/situation) over to God" and believing that whatever was asked for would be granted (known as "claiming" the healing), that God would heal them. God was also seen as the provider of the medical treatments, and was responsible for the knowledge of the doctors prescribing the treatment. For some African Americans, especially those who considered cancer as a stigma, God was the first—and at times only—confidant with whom they talked about their situation. This population of cancer survivors also felt it was extremely important to repay God through service to others.[31]

Steffen et al. found that among African Americans with high blood pressure (BP), higher levels of religious coping lowered BP levels when awake and asleep. The association was not found in Whites. African Americans also typically scored higher than Whites on measures of intrinsic religiosity and report using higher levels of religious coping.[32]

Matsuyama et al. conducted focus groups to compare African Americans and Caucasians in their perceptions and beliefs related to cancer care. They found a lot of commonality in the experiences regardless of ethnicity, but there were also differences: African Americans were more likely to: report increased religious behaviors, believe that healthcare providers demonstrate care with simple actions and provision of practical assistance, and use church and community information sources instead of solely relying on healthcare providers for information.[33]

SPIRITUAL ISSUES IN ADVANCED CANCER

The spiritual needs of the patient with advanced cancer include the need for belonging; the need for relationship to self, others, and a higher power; the need to explore meaning in life; and the meaning of suffering and death. These needs may be expressed in the form of questions such as those listed in Table 2.[10]

Table 2: Questions experienced by patients with severe illness or cancer

Who am I?
What do I really believe?
What are the things that I value in life?
Is this all there is to life?
What are the things that give my life meaning?
What have I contributed by this life that I have lived?
What are the things that I have left behind that are good?
What are the mistakes that I have made?
What are the things that I have left undone?

What is the state of my relationships?
What are the things that I have left unsaid?

London [10]

Recognizing the fundamental importance of spiritual care as a component of quality palliative care, the Archstone Foundation of Long Beach, California in 2009 organized a Consensus Conference of interdisciplinary palliative experts.. The goal of the Consensus Conference was to identify points of agreement about spirituality that apply to health care and to make recommendations that would advance the delivery of quality spiritual care in palliative care.[34]

The panel identified spiritual issues that arise in the care of the seriously ill patient and family. (see Table 3)

Table 3: Spiritual issues identified by the Consensus Panel

Spiritual Issues
Existential concerns (that is, questions about meaning and worth)
Abandonment (by community, friends, family, God)
Anger (at God and others)
Concerns about relationship with deity
Conflicts or challenged belief systems
Despair/Hopelessness
Grief/Loss
Guilt/Shame
Reconciliation
Isolation
Religious-specific; for example, ritual needs, inability to take part in religious practices
Religious/spiritual struggle; for example, religious or spiritual beliefs, the community not helping with coping, etc.; loss of faith or meaning

Consensus Conference Report [34]

According to the consensus panel, a spiritual issue becomes a diagnosis in need of intervention when the issue:

- leads to distress or suffering,
- causes a psychological or physical diagnosis (such as depression, anxiety, chronic pain), or
- affects the ability to address a physical problem (for example, the patient refuses needed medical interventions for religious reasons).[34]

According to Chaplain Wright, a significant spiritual injury is considered to be present if the person states that he/she experiences any of the following feelings "often" or "very often:"

- Guilt over past behaviors
- Grief or bereavement
- Life has lost its meaning or purpose
- Despair and hopelessness
- Anger and resentment blocking peace of mind
- Doubts or disbelief in God
- Fear or worry about death
- Life or God has treated you unfairly[35]

Such spiritual disequilibrium can occur on a continuum of intensity or severity from ***spiritual concerns*** (defined as "the potential disruption of one's beliefs, assumptions, or values that occurs when one's valued relationship with one's self, others, ideas, nature, higher power, art, or music is threatened or challenged.") through ***spiritual distress*** ("the disruption of one's beliefs, assumptions, or values that occurs when one's valued relationship with one's self, others, ideas, nature, higher power, art, or music is threatened or broken.") to ***spiritual despair*** ("the dissolution and/or disintegration of one's source of meaning and hope, leading to one's feeling little to no hope of resolution.")[36]

Spiritual distress can be felt by the patient and/or the patient's family, and can manifest as struggling with end-of-life decision-making, having questions and concerns about the afterlife, or being involved in an incessant search for meaning and an understanding of suffering.[10]

Unmet spiritual needs

The Coping With Cancer study was a federally funded, multi-institutional, multi-investigator, longitudinal investigation examining factors associated with the well-being of advanced cancer patients and their families. The study generated numerous research projects analyzing such areas as:

- ethnic disparities in end-of-life care;
- effects of discussion of prognosis on patients, families, and health providers;
- factors predictive of patient preferences for end-of-life care;
- how those preferences and actual care received impact quality and cost of care; and
- factors influencing survivor/caregiver adjustment after death of a patient.

Balboni analyzed whether spiritual care from the medical team impacts medical care received and quality of life at the end of life, and whether outcomes varied according to styles of religious coping.[37] Among the 230 study participants (61 percent White, 19 percent African American, 17 percent Hispanic), 88 percent of patients considered religion to be at least somewhat important (68 percent very important) in coping with cancer. Among African American participants, 89 percent reported that religion was very important. Spiritual needs were minimally or not at all met by:

- their religious congregation in nearly half of the group as a whole and slightly more than half of the African American participants;
- the medical system in 72 percent; and
- both in 42 percent.

Almost half of the group as a whole had not even received a pastoral care visit. High levels of religiousness were found to be associated with wanting all measures to extend life, and this occurred more commonly among African American participants.

SPIRITUAL COPING AND ITS EFFECT ON QUALITY OF LIFE

Frameworks for understanding the role of spirituality in relation to coping

Many studies (most of them observational) have examined the effect of spirituality/religion on health outcomes of patients with serious illness. Comparing studies is difficult because there is no uniformity or consensus on what is being measured. Several frameworks have been conceptualized to attempt to understand the role that spirituality plays in the overall well-being of individuals. Some examples are presented below:

Gall et al.[38] describes a framework based on a transactional model of stress and coping that can provide a "scaffold" to organize and understand the explosion of research in the area of religion, spirituality, coping and health. (see Figure 1)
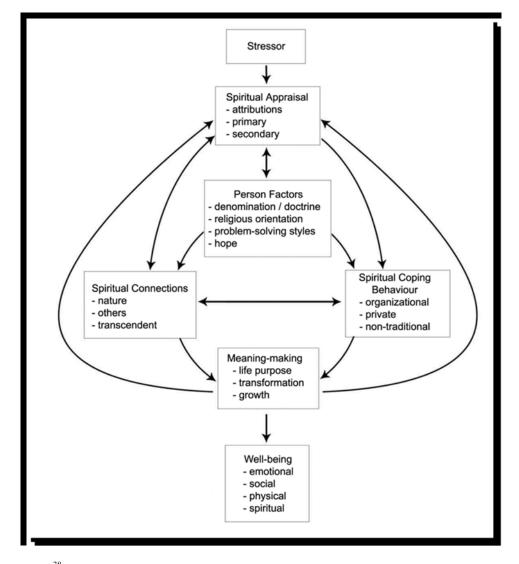
Figure 1: The Spiritual Framework of Coping

Adapted from Gall [38]. © 2005, Canadian Psychological Association. Permission granted for use of material.

An initial stressor prompts the individual to search for a spiritual cause of the stressor and also to identify specific spiritual resources that may be used in response to the stressor. This level, in turn, interacts with personal factors, such as individual religious/spiritual beliefs, problem-solving styles (for example, self-directive, deferring, or collaborative), and hope. Personal factors refer to spiritual connections to nature, others and the transcendent. Personal factors also include spiritual coping behaviors, which may be organizational, private or non-traditional, such as prayer, sacred scripture, song, and meditation. These all coalesce to inform meaning-making for the individual, such as defining life's purpose or generating personal transformation and spiritual growth. How this process unfolds has profound impact on individual well-being in all areas: emotional, social, physical and spiritual.[38]

Pargament proposed another framework (the RCOPE), which he used to develop a measure of religious coping. He postulated that there are five key religious functions:

1. Find Meaning
2. Gain Control
3. Gain Comfort and Closeness to God
4. Gain Intimacy with Others and Closeness to God
5. Achieve a Life Transformation

To achieve these functions, individuals can use several coping strategies including active, passive, and interactive coping methods, as well as problem-focused and emotion-focused approaches. These strategies were then used to devise and test factors sorted into positive and negative coping scales. These were tested and found to have predictive value for better or worse adjustment to illness.[7]

Different types of spiritual coping, and evidence of positive/negative effects on quality of life (QOL) and length of life

Earlier foundational studies, using broad measures of religious coping such as the presence or absence of religious behaviors (such as attending services, the frequency of prayer), found a positive correlation between increased religious behaviors and quality of life, but did not attempt to examine the multi-factorial nature of spirituality and how different aspects of spirituality impact health outcomes. [39, 40, 41]

More recently, studies on the relationship of spirituality to health have explored the multifaceted nature of spirituality in the individual, and how various facets impact health decisions and outcomes.

In developing RCOPE, Pargament identified numerous religious coping items, which he categorized as being positive or negative.[8] (See Table 4) Researchers have found numerous correlations between the type/degree of religious coping and health-related outcomes:

- The majority of patients with advanced cancer use primarily positive religious/spiritual coping, an approach even more emphasized among African Americans. [15]

- The use of primarily positive religious/spiritual coping (for example, seeking spiritual support, benevolent religious reappraisals) by patients was associated with improvements in health, function, mood, quality of life, and better spiritual outcomes, although there was also an association with patients who used positive religious coping having more physical symptoms than those who did not. [15] The use of positive religious coping strategies by caregivers was associated with more satisfaction with care giving, though more burden was also reported.[42]

- The use of some of the items included in negative religious/spiritual coping (for example, punishing God reappraisal, interpersonal religious discontent) by patients predicted declines in health and quality of life, risk for depressed mood, and spiritual struggle. [8, 15] The use of primarily negative religious coping strategies by caregivers was associated

with poorer quality of life, more burden, increased likelihood of major depressive or anxiety disorder, and lower levels of social support, optimism and self-efficacy. [42]

- Patients with advanced cancer who use a high level of positive religious coping were nearly three times as likely to receive intensive life-prolonging care near death.[8] This is problematic, since aggressive end-of-life cancer care (compared to hospice care) has been associated with worse quality of life and more physical and emotional distress for patients with cancer, and for their caregivers carries an increased risk of major psychiatric disorders (such as post-traumatic stress, prolonged grief disorder).[43, 44]

Table 4: Positive and negative religious coping items from the RCOPE

Positive coping items	Negative coping items
1. Looked for a stronger connection with God	1. I've been wondering whether God has abandoned me
2. Sought God's love and care	2. I've been feeling that the cancer is God's way of punishing me for my sins and lack of devotion.
3. Sought help from God in letting go of my anger	3. I've been questioning God's love for me.
4. Tried to put my plans into action together with God	4. I've been wondering what I did for God to punish me like this.
5. Tried to see how God might be trying to strengthen me in this situation	5. I've been wondering whether my church has abandoned me.
6. Asked forgiveness for my sins	6. I've been thinking that the devil made this happen.
7. Focused on religion to stop worrying about my problems	7. I've been questioning the power of God.

Pargament [8]

True et al. explored 3 types of spiritual coping among cancer patients:

1. Collaborative religious coping, or seeking control through a partnership with God or a higher power.
2. Active religious surrender, defined as actively giving up control to a higher power.
3. Seeking spiritual support, or searching for comfort and reassurance through love and care of a higher power.[45]

In this study, African American patients were more likely to report a belief that their fate was in the hands of a higher power, were more likely than Whites to:

- use spirituality to cope with illness,
- turn to a higher power for support,
- believe in divine intervention
- desire all life-supportive measures
- not have advance directives in place.

SPIRITUAL ASSESSMENT

Why do a spiritual assessment?

The belief systems of patients and families have been found to have a major impact on treatment decisions. For instance, in a study of patients with lung cancer, faith was cited as the second most important factor influencing treatment decisions, after oncologist recommendations.[46] Effective spiritual coping can improve the patient's quality of life, help him/her to deal with the effects of disease, help ameliorate distressing symptoms, and help improve their spiritual well-being, including helping them to find meaning and hope. Lower rates of depression, better mental-health status, better physical health, stress-related growth, spiritual growth, and reduced rates of mortality are also related to effective spiritual coping. [8] Ineffective or negative spiritual coping, or unmet spiritual needs, can lead not only to existential distress but also to uncontrolled physical symptoms, declining functional status, and even early death.[47, 48]

Is spiritual assessment acceptable to patients and families?

McCord et al. administered a questionnaire to 921 respondents who were patients at one of four family practice residency training sites to determine when it is appropriate for physicians to inquire about spirituality or religious beliefs, the reasons why patients want physicians to know about their spiritual beliefs, and what they want physicians to do with the information. One in five patients was African American.

- 83 percent wanted physicians to ask about spiritual beliefs in at least some circumstances, such as in the setting of life-threatening illness, serious medical condition, or loss of a loved one, in order to promote better understanding between the physician and the patient.

- About two in three patients believed the information would affect the physicians' ability to encourage realistic hope (67 percent), give medical advice (66 percent), and change medical treatment (62 percent).[49]

In a similar study of 214 (35 percent African American) consecutive patients visiting the pulmonary outpatient practice at the Hospital of the University of Pennsylvania, two in three respondents favored including in the medical history a question like: "Do you have spiritual or religious beliefs that would influence your medical decisions if you became gravely ill?" Sixteen percent reported that they would not welcome such an inquiry. Only 15 percent recalled being asked this information by the healthcare provider.[50]

In a study of 203 family practice adult inpatients in Kentucky and North Carolina, over 75 percent of patients wanted their physicians to consider their spiritual needs, 37 percent wanted physicians to discuss these needs with them more frequently, almost half wanted their physicians to pray with them, and 68 percent reported that their physicians never discussed religious beliefs with them.[51] Similarly, in a survey of inpatient rehabilitation patients, 75 percent felt that their religious and spiritual beliefs were important, over half desired pastoral counseling, 45 percent thought too little attention was paid to their religious and spiritual beliefs, and nearly 75 percent said that no one from the health care staff ever spoke to them about spiritual and religious concerns.[52]

In contrast to the above studies, a pilot study of spirituality and care of 14 African American prostate cancer patients revealed that 75 percent had spoken with their doctors about their spiritual and religious beliefs, and that more than half of the physicians had solicited their patients' spiritual beliefs; one third reported their physicians had been in contact with their clergy (less than the two-thirds who reported a preference for their doctor and clergy to be in contact with one another).[53]

Recommendations of professional groups related to spiritual assessment and intervention:

A number of regulatory, credentialing, and professional organizations in healthcare have addressed the importance of spirituality in the care of patients and families. Standards of practice, regulatory requirements, and ethical directives have been developed to encourage respectful and culturally competent care and spiritual assessment, and interventions. (See Table 5)

Table 5: Healthcare organizations addressing spiritual issues in care delivery

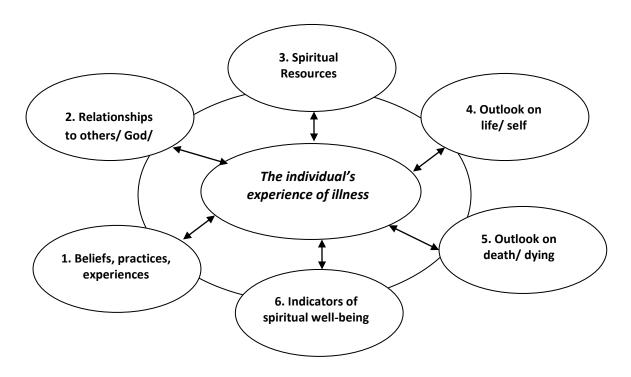| Organization	Statements/ Policies
American Medical Association	Statement on end of life care: Patient's spiritual goals should be given priority
American Society of Clinical Oncology	Policy statement on cancer care during last phase of life: Optimize quality of life through meticulous attention to…spiritual needs of patient and family
Nursing Code of Ethics (US)	Enable patients to live with as much spiritual well-being as possible
International Council of Nurses Code of Ethics	Promote environment in which spiritual beliefs of patients and families are respected
National Association of Social Workers	Endorses the biopsychosocial-spiritual perspective. Recognize spiritual factors that influence decision-making. Have essential knowledge of spiritual needs and how to address them.
Association of Professional	Standards of practice include standards for assessment and delivery of

Organization	Statements/ Policies
Chaplains	spiritual care, and standards for teamwork and collaboration
Centers for Medicare and Medicaid Services	Addresses spiritual assessment and interventions in hospice, long term care, and complex case management
Joint Commission	Requires spiritual assessment be performed and spiritual care be offered and available to all hospitalized patients; standards for hospice and home health
National Consensus Project for Quality Palliative Care	Clinical practice guidelines: IDT* includes professionals with skill in assessment of and response to spiritual and existential issues for patients/families
National Quality Forum	Preferred Practices for Palliative Care include 4 related to spiritual care: development of spiritual care plan, use of structured spiritual assessment, provision of information about and spiritual care services, IDT* includes trained spiritual counselor
National Consensus Conference Recommendations on Improving the Quality of Spiritual Care as a Dimension of Palliative Care	Key areas: spiritual care models, spiritual assessment, spiritual treatment/care plans, inter-professional teams, training/certification, personal and professional development, and quality improvement.

Refs. 54, 55, 56, 57, 58, 59, 60, 61, 62, 63 *IDT= Interdisciplinary team

Instruments/Tools for spiritual assessment

Many instruments have been developed to assess spirituality. Some of these instruments are used in research and have been psychometrically tested, while others have been developed as practical tools to help the clinician obtain a spiritual history. Among the instruments developed for use in research, the Perspectives of Support From God Scale (PGS) [30] was specifically developed to be used in research with Christian African American cancer survivors; PGS focuses on the support believed to come from God as opposed to support that comes from a religious community, clergy, or health care providers. [30] Other research instruments include a measure of religious coping (RCOPE[8]), the Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale (FACIT-sp),[64] and the Multidimensional Measurement of Religiousness/Spirituality (MMRS) for Use in Health Research.[65] (See Figure 2 for cross-cutting themes across varying instruments)

Figure 2: Model of themes occurring in cross-cultural measures of spirituality, and their relation to the illness experience

Adapted from Selman et al.[66]

Clinical practice: The 3 types of spiritual assessment that are pertinent to interdisciplinary healthcare providers are *spiritual screening*, *spiritual history*, and *formal spiritual assessment.*

Spiritual Screening is a quick triage to determine if the person is experiencing serious spiritual crisis and needs immediate referral to a board-certified chaplain (board certification requires 1,600 hours of clinical pastoral education) An example: "Are spirituality or religion important in your life? How well are those resources working for you at this time?"[34]

Spiritual history uses a broader set of questions to capture pertinent information about needs, hopes and resources. There are many spiritual history tools that have been developed to aid care providers in the field (see Table 6); for example, FICA,[67] SPIRIT,[68] FACT,[69] and HOPE.[70]

Table 6: Comparison of several spiritual history tools

FICA	SPIRIT	HOPE	FACT
F – Faith and Beliefs	S – Spiritual belief system	H – Sources of Hope, strength, comfort, meaning, peace, love and connection	F – Faith (and/or Beliefs, Spiritual Practices)

FICA	SPIRIT	HOPE	FACT
I – Importance and Influence	P – Personal spirituality	O – Role of Organized religion for the patient	A – Active (and/or Availability, Accessibility, Applicability)
C – Community	I – Integration with spiritual community	P – Personal spirituality and Practice	C – Coping (and/or Comfort); Conflict (and/or Concern)
A – Address	R – Ritualized practices and restrictions	E – Effects on medical care and end-of-life decisions	T – Treatment Plan
	I – Implications for medical care		
	T – Terminal events planning		
Puchalski[67]	Maugans[68]	Austin[70]	LaRocca-Pitts[69]

One instrument that was developed specifically for oncologists to explore the spiritual and religious concerns in adults with cancer is the Oncologist Assisted Spiritual Intervention Study (OASIS) Patient-Centered Spiritual Inquiry (See Appendix 1). In this exploratory study of 118 consecutive patients in an oncology group practice, oncologists felt comfortable using the spiritual exploration with 85 percent of patients and over 75 percent of patients felt the questions were "somewhat" to "very" useful. At 3 weeks, the intervention group (those who had been interviewed about their religious/ spiritual concerns) had greater reductions in depressive symptoms, more improvement in QOL, and improved sense of interpersonal caring from their physician than those who had not been interviewed. [71]

(See Appendix 1 for additional information on Spiritual Assessment instruments)

The NCI Spirituality in Cancer Care (PDQ®) summary for health professionals has a helpful table comparing several of the assessment instruments for: spirituality, purpose, characteristics, and level of psychometric development.[72]

Formal Spiritual Assessment, generally conducted by a board-certified chaplain, is a more extensive process of active listening to a patient's story that identifies and addresses spiritual issues in greater depth. [34]

Importance of spiritual self-awareness among Healthcare Providers

Various authors have supported the premise that it is importance for the health care provider to engage in introspective exploration of his/her own spirituality before attempting to assess the spirituality of the patient or family. This should help the provider understand the nature of belief

systems and they can relate to a patient's spirituality.[73] It is also imperative that the health providers avoid unintentionally imposing their religious beliefs and values on patients, thereby threatening or disregarding strongly held beliefs by the patient and family.[74]

Team spirituality

Sinclair et al. performed a qualitative autoethnographic exploration of the idea that a palliative interdisciplinary team has a collective spirituality. He found that participants conceived of spirituality as inherently relational and transcendent, and related to integrity, wholeness, meaning, and personal journeying. Spirituality was further described by team members as being wrapped in caring, manifested in small daily acts of kindness and love that are embedded within routine acts of care giving. He further found that a team's collective spirituality was evident and palpable when they were present, which stems from common goals, values, and belonging.[75]

INTERVENTIONS

Spiritual interventions and quality of life

Several studies have shown that attention to the spiritual needs of patients and families actually improves the quality of life for patients and also satisfaction with care among both patients and caregivers. Additionally, Balboni et al.[5] found that among 343 patients with advanced cancer (37 percent non-white) who were "high religious copers," those who indicated that their spiritual needs were largely or completely supported by the medical team were nearly 5 times as likely to receive hospice care and 5 times less likely to receive aggressive care at the end of life, compared with those who were not supported in this way. This finding contrasts with previous studies, where those using a high degree of religious coping have been found to utilize significantly more aggressive care near the end of life than those who do not use such a style. Greater support from the medical team, as well as receipt of pastoral care services, was also associated with a nearly 5-fold improvement in quality of life. In a related study, Song and Hanson explored the end of life care preferences of 51 African American dialysis patients in a number of presented scenarios, and found that those who had more positive, adaptive well-being scores in the spiritual dimension of the Self-Perception and Relationship Tool (S-PRT) were more likely to choose comfort care over more aggressive life-sustaining treatment.[76]

Recommended Spiritual Interventions

The Consensus Conference on Improving the Quality of Spiritual Care as a Dimension of Palliative Care mentions several examples of spiritual health interventions that fall into the categories of therapeutic communication techniques (for example, compassionate presence, and reflective listening), therapy (such as meaning-oriented therapy or referral to a spiritual care provider), and self-care (such as journaling or exercise). [34] (See Table 7)

Table 7: Examples of Spiritual Health Interventions from Consensus Report

Type of intervention	Examples of specific interventions

Type of intervention	Examples of specific interventions
Therapeutic communication techniques	1. Compassionate presence 2. Reflective listening, query about important life events 3. Support patient's sources of spiritual strength 4. Open-ended questions to elicit feelings 5. Inquiry about spiritual beliefs, values and practices 6. Life review, listening to the patient's story 7. Continued presence and follow-up
Therapy	8. Guided visualization for "meaningless pain" 9. Progressive relaxation 10. Breathing practice or contemplation 11. Meaning-oriented therapy 12. Referral to spiritual care provider as indicated 13. Use of story telling 14. Dignity-conserving therapy
Self-care	15. Massage 16. Reconciliation with self or others 17. Spiritual support groups 18. Meditation 19. Sacred/spiritual readings or rituals 20. Yoga, tai chi 21. Exercise 22. Art therapy (music, art, dance) 23. Journaling

Adapted from Puchalski et al.[34]

In a study of the types of social support important to African Americans with cancer, participants mentioned that several practical spiritual activities were valued and helpful, including the presence of others, offers of prayers, and assistance to continue religious practices (for example, being given audiotapes of services to listen to, or being brought communion).[77]

London suggests that people should be encouraged to pray and talk to God about the decisions they are facing—if this is important to them—but should be discouraged from thinking that there is only one right decision. She suggests that it is more helpful to guide people to a gentle understanding that God is invested in a thoughtful, loving process rather than in particular outcomes. She further asserts that the antidote to acute afterlife concerns is acceptance of God's forgiveness and love. This can be modeled in the attitude of the spiritual caregiver (such as a chaplain or other member of the interdisciplinary team providing spiritual care). [10]

Some basic skills and techniques in providing spiritual care include:

- Empathic presence. Listen actively in a calm and non-judgmental way, and acknowledge suffering.
- Normalization of experience. Help patients and families realize that, while their experience may be unique, it is normal, and they are not "going crazy."
- Life review. Help the person to define purpose in their life and self-worth, to establish a personal legacy, to forgive themself and others, and to arrive at closure with the past.
- Exploration of sources of hope and meaning. Help to provide a larger framework of meaning to help the patient/family uncover their own meaning and sources of hope.
- Affirmation of sources of strength and comfort. Name and affirm the positive qualities seen in the patient/family (for example, resilience, wisdom, knowledge, grace) and help the patient reflect on prior ways they have found comfort, coping, and strength, as well as suggesting new strategies.
- Reframing. Help the patient/family see things from a different, more positive perspective within the person's own belief system/religious tradition, and focus on spiritual gratitude and blessing.
- Diversional and life-affirming activities. Help connect the person with sources of life, joy and laughter, and to reconnect with the sacred and transcendent.
- Prayer, rituals and observance of religious practices. Encourage the patient/family to utilize their spiritual or religious practices to find meaning, strength, and comfort.[78]

Some practical guidelines for spiritual care by non-chaplain health care professionals are listed in Table 8.

Table 8: Guidelines for Spiritual Care by Non-Chaplain Health Care Professionals

Guidelines	Actions
Listen more than talk	- Encourage patient and family to give voice/tell stories - Explore/don't probe - Help the persons feel "heard"
Practice being present	- It is ok to say, "I don't know, but I'm here, I hear your pain" - Monitor your own need to "do something"
Avoid judgment of beliefs, practices, or emotional responses	
Refrain from prosyletizing or imposing your own beliefs	- Be aware of your own beliefs and biases - Be careful: Even if you share the same religious tradition, beliefs and practices vary widely
Avoid discussion of religious doctrine, dogma, and complicated theological questions	- Usually the person is not needing an intellectual or theoretical explanation - Usually the person needs comfort and reassurance
Avoid religious clichés	Such as "It's God's will" or "God never gives you more than you

Guidelines	Actions
	can bear"
	• These are not usually comforting
Respect patient and family spiritual framework and practices	• Provide care in keeping with them
Respect patient and family privacy in this area	
Let the patient and family invite you to participate in their religious observances or practices	• Rather than you initiating prayer, ritual, scripture reading, etc.
Coordinate and collaborate as a member of the IDT	• Follow the plan for spiritual care agreed upon by patient, family, and the team

From Module 14: Religion, Spirituality, and End of Life Care. Part IV: Basic Skills and Techniques
http://endoflife.northwestern.edu/religion_spirituality/skills.cfm#Guidelines

Some studies by Emmons suggest that a focus on blessings and what a person is thankful for can have emotional and interpersonal benefits.[79]

The longer a person searches without resolution for meaning and an understanding of suffering, the more likely the person is to manifest mental and physical illness.[48] At times, even in the face of an unresolved search for meaning, a person may find that the mere fact that they have survived in the face of the unthinkable indicates their emotional strength and resilience, which could lead to a greater understanding of self and a new and broader perspective on the nature of God. In such a case, the role of the spiritual caregiver is to "bear witness" to the suffering.[10]

Role of the Interdisciplinary team (IDT)

All members of the IDT should be skilled at doing a spiritual screening history. All members of the IDT should be proficient in compassionate presence and active listening.[34] London asserts that the most important skill that a provider of spiritual care must possess is the ability to listen without judgment.[10] All members of the IDT should have knowledge of options to address spiritual issues, including spiritual resources and information, and members should know when to refer to a board certified chaplain. All team members should have a broad minimum level of knowledge/training in the spiritual/religious values and beliefs of various cultures that may influence medical decision-making. Chaplains should have comprehensive training and knowledge in addressing sources of spiritual suffering. Board certification involves at least 1,600 hours of clinical pastoral education.[34]

Puchalski et al.[80] recommend a collaborative interdisciplinary model of spiritual intervention outlining the roles of the different members of the healthcare team, including recommendations of relevant, authoritative professional bodies for each.

Physicians: Physicians should practice "compassionate presence," take a spiritual history, and formulate a spiritual treatment plan, including appropriate referrals (for example, meaning-centered psychotherapy/counseling, spiritual care professionals, spiritual directors, parish nurses,

pastoral counselors, music thanatologists, art or music therapy, meditation, yoga/tai chi, spiritual support groups). Physicians need to become comfortable with uncertainty.

Nurses: Nurses should develop a caring relationship of trust with the patient and family that includes the integration of spirituality, in order to facilitate health and healing. A part of developing trust with the patient and family is teaching in a respectful way. The nurse should convey caring, dignity and respect by: touching with tenderness during personal care; exhibiting sensitivity to pain and discomfort and intentionality when assessing and assisting with basic activities of daily living (ADLs); and providing a safe, supportive, and peaceful environment.

Spiritual assessment should be conducted as part of the nursing history, including the impact of the illness on the patient/family and their ability to cope, challenges to their sense of meaning and purpose, limitations for engaging in important spiritual/ religious practices, and their sense of connectedness. Nurses should strive to identify spiritual distress and to implement appropriate interventions, such as spiritual support, hope installation, spiritual growth facilitation, religious ritual enhancement and cultural brokerage. Compassionate presence and active listening are essential components of the spiritual interventions delivered by the nurse. Nurses often play a pivotal role by communicating a patient's needs and preferences for spiritual care to other collaborators.

Social Workers: Social workers should be reasonably knowledgeable about religious diversity in the U.S. As with other members of the interdisciplinary healthcare team, social workers should be adept at compassionate presence and listening with empathy. In addition, the social worker should assess the patient's and family's psychosocial network, help draw in appropriate resources, and draw out the patient's deeper spiritual questions.

Chaplains: The role of the chaplain is to attempt to help others—through words, acts and relationships—experience the reality of God's presence and love in their lives, and to listen attentively to their concerns. The chaplain is the interdisciplinary team member who provides in-depth spiritual counseling. The chaplain works with patients on issues of meaning and purpose, helps them with issues of existential distress and suffering, and seeks to engage the sufferer and to reframe his/her perspective of suffering in the context of life's incongruities. At the most fundamental level, the chaplain serves as a witness to a patient's story, mirrors unconditional love, and conveys and maintains hope. Although it is beyond the scope of this module to go into depth about the chaplain's role, the U.S. Navy Chaplain Corp has developed a handbook for the provision of spiritual care to persons with post-traumatic stress syndrome and traumatic brain injury that may have applicability to patients and families struggling with cancer. [3] (See Appendix 2 for a table listing various recommended chaplain interventions.)

Balboni et al. [5] conclude that chaplains play an essential role as professional providers of spiritual care, but that other medical providers also play crucial roles, which include performing spiritual assessments, recognizing spiritual needs, and making pastoral care referrals.

Interdisciplinary Team: After each team member has made an assessment, it is crucial for team members to share and compare, to discuss whether the religious/spiritual coping strategies of the patient are a healthy or unhealthy factor in the care of the patient, and to decide who on the team

is best suited to address pertinent issues with the patient. Interdisciplinary healthcare professionals interact with each other to develop and implement the spiritual care plan for the patient in a fully collaborative model. [80]

Psychological Interventions useful for addressing spiritual issues

Some therapies utilized by professional counselors have shown promise as effective interventions for those with serious existential or spiritual concerns. Two of these therapies, Acceptance and Commitment Therapy, and Dignity Therapy, are described briefly below. Currently, the evidence-base for these therapies is preliminary, based on small observational studies, and they have yet to be studied in the U.S. population (these studies took place in Spain, Australia, and Canada). Further studies should clarify their usefulness in American patients, including African Americans, who are experiencing spiritual distress.

Acceptance and Commitment Therapy (ACT)

Karekla describes an innovative psychological intervention, Acceptance and Commitment Therapy (ACT), that is sensitive to a person's belief system and establishes an open environment for the person to discuss his/her religious and spiritual beliefs and how he/she utilizes these beliefs in everyday life.[81] Initially, the patient's values are explored (including spiritual and religious values) and subsequently the patient is helped to accept any experience they have no control over in light of these values, and to then commit to take actions consistent with their values.[82]

Dignity Therapy

Dignity Therapy is a brief, individualized psychotherapeutic intervention designed specifically to engender a sense of meaning and purpose in patients nearing death. Patients are invited to address issues that matter most to them and to identify how they would most want to be remembered after death. Themes explored include generativity, continuity of self, role preservation, maintenance of pride, hopefulness, aftermath concerns, and the tenor of their care. Chochinov et al. found this intervention to be highly acceptable to patients, with 75 percent reporting a heightened sense of dignity, nearly 70 percent reporting an increased sense of purpose and heightened sense of meaning, and close to half reporting an increased will to live. Achieving these goals was associated with a reduction in suffering among patients. Approximately 80 percent of patients reported that it had already helped (or would be helpful to) their family members.[83]

When the patient or family expects a miracle

The situation in which the patient and/or family expects a miracle in the face of irreversible decline in the patient's status can be very challenging for the health care team, especially when the family bases medical decision-making on the assumption that a miraculous recovery will occur. DeLisser recommends a practical approach for the health care team to follow when the family is expecting a miracle:

1. ***Explore the meaning and significance of a miracle to the family.*** In addition to clarifying what the issues are, a "listening first" approach conveys to the family that the healthcare team is sincere in wanting to know what the family's perspectives are, and demonstrates respect for their beliefs. It also provides a non-confrontational way to begin a discussion. The expectation of a miracle may reflect a belief in divine intervention, grounded in faith and perhaps enhanced by personal experience. Alternatively, the family may not understand the patient's diagnosis and prognosis. On the other hand, it may simply be an expression of hope or optimism for the possibility of recovery. Or it may reflect the family's distrust of the healthcare system, and may be a manifestation of a belief that further treatment would be effective, but is being withheld for some reason, such as expense or prejudice.

2. ***Provide a balanced, non-argumentative response.*** The information obtained above is then used to frame a response. If the anticipation of a miracle is an expression of hope or optimism, it might be pointed out that there are other types of healing besides physical healing that can occur, and alternative sources of hope besides hope for a cure. Patiently listen to expressions of hope while continuing to gently, and truthfully convey the patient's condition. If the expression of a miracle reflects distrust or anger about deficiencies in care, attempt to reestablish trust by assuming responsibility (if appropriate) and apologizing for the previous deficiencies. If the expectation of a miracle truly represents a belief in divine intervention, don't argue the validity of the belief. Instead, emphasize non-abandonment, cite professional obligations to institute only those medical treatments that are appropriate and effective, the obligation to avoid causing needless burden and suffering, and the obligation to follow the patient's preferences for treatments if they are effective. At times, reframing the meaning and manifestation of the miracle with care and sensitivity (for example, the miracle may be that estranged family members have been brought together, or that the patient's life becomes an inspiration to other family members) may be helpful, as might the suggestion that if a miracle is to occur, physician actions will not prevent it.

3. ***Negotiate patient-centered compromises while practicing good medicine.*** Is it important to the family that the patient remain on life support to allow another family member to be present at the time of death? This would likely be an important goal for the patient, and, when possible, should be accommodated. Negotiate compromises to bring the care team and the family's goals into closer alignment; for example, continuing pressors in a patient who has irreversible decompensated heart failure at the family's request, but negotiating that CPR will not be initiated if cardiac arrest occurs.[84]

The healthcare team should not presume that they should be trusted by the family, but the team should work diligently and compassionately to provide the optimal care to the patient and to address sources of suffering for both the patient and the family. This approach will likely be successful in facilitating a relationship of trust between the healthcare team and the family, and will help the family come to acceptance of the prognosis of their family member. The chaplain member of the healthcare team can provide an invaluable role in these types of discussions and negotiations.[30]

Spirituality and Professional Boundaries

It is unethical for the physician or other members of the healthcare team to proselytize to the patient and family who are under their care. The patient and family should never feel pressured to accept the beliefs of the treating clinician. Also, on the issue of praying with a patient, the following are recommendations of T.F. Dagi, a neurosurgeon and ethicist:

- Physicians and (other health professionals) should not pray openly with a patient without his or her explicit request and permission.

- If the patient/family requests that the physician/health professional pray with them, the health professional can join in the prayer, but the prayer should be led by the patient/family or an identified religious leader distinct from the treating medical team whenever possible so as to avoid even an appearance of religious coercion.

- Physician/health professional-led prayer is acceptable only when pastoral care is not readily available, when the patient is intent on prayer with the health professional, and when the health professional can pray without having to feign faith and without manipulating the patient.

- Secular health professionals can respect the patient's beliefs and accommodate requests for joint prayer by gently declining to actively pray and instead listening respectfully as a patient prays.[85]

In the essay, "Religion, Spirituality and Medicine: Application to Clinical Practice," Koenig (a researcher in the effect of religion and spirituality on health) recommends the following:[86]

- Physicians should acknowledge and respect the spiritual lives of patients, and always keep interventions patient-centered. This may involve obtaining a spiritual history in those with illness that threatens life or way of life.

- Physicians should not "prescribe" religious beliefs or activities for health reasons.

- Physicians should not impose their religious beliefs on patients or initiate prayer without knowledge of the patient's religious background and likely appreciation of such activity.

- Physicians should not provide in-depth religious counseling to patients, as this is best provided by trained clergy.

It is important for all members of the interdisciplinary healthcare team to practice within their competencies when it comes to spiritual care, and to refer patients and families to the appropriate expert when care beyond the competency of the team member is required.

SUMMARY

Addressing spiritual issues is part of the standard of care for health professionals caring for patients with advanced cancer and their families.

Spirituality is a vital part of the lives of African Americans, who, on the whole, rely on religious coping to a greater extent than the general population to deal with cancer in their lives.

There is a rich religious and spiritual diversity among the African American community, and healthcare providers should avoid making assumptions about the spiritual beliefs and practices of the individual patient and his/her family.

The interdisciplinary health professional should address sources of spiritual distress for African American cancer patients with sensitivity and with attention to issues that are of the most importance to the individual patient and family, with the goal of reducing suffering and improving quality of life.

Key take-home points

1. Spirituality plays a vital role as African American patients and their families adjust to serious illness, including cancer.

2. Failure to assess and address the spiritual needs of those with cancer or other serious illness can lead to spiritual distress, and adversely affects quality of life, medical outcomes, and decision-making for the general population with cancer, as well as for African American patients with advanced cancer and their families.

3. Standards for quality palliative care include competent, discipline-specific, and interdisciplinary spiritual assessment followed by appropriate interventions to relieve the spiritual suffering of patients and families dealing with serious illness. All healthcare providers caring for those with serious illness should, at a minimum, screen all their patients for spiritual distress and refer appropriately for intervention.

Appendix 1: Spiritual Assessment Tools

FICA (Puchalski & Romer, 2000)

F – *F*aith, Belief, Meaning: "Do you consider yourself spiritual or religious?" or "Do you have spiritual beliefs that help you cope with stress?"

I – *I*mportance or Influence of religious and spiritual beliefs and practices: "What importance does your faith or belief have in your life? Have your beliefs influenced how you take care of yourself in this illness? What role do your beliefs play in regaining your health?"

*C – C*ommunity connections: "Are you part of a spiritual or religious community? Is this of support to you, and how? Is there a group of people you really love or who are important to you?"

*A – A*ddress/*A*ction in the context of medical care: "How would you like me, your healthcare provider, to address these issues in your healthcare?"

HOPE (Anandarajah & Hight, 2001)

H – Sources of hope, meaning, comfort, strength, peace, love, and compassion: "What is there in your life that gives you internal support? What are the sources of hope, strength, comfort, and peace? What do you hold onto during difficult times? What sustains you and keeps you going?"

O – Organized religion: "Do you consider yourself as part of an organized religion? How important is that for you? What aspects of your religion are helpful and not so helpful to you? Are you part of a religious or spiritual community? Does it help you? How?"

P – Personal spirituality/practices: "Do you have personal spiritual beliefs that are independent of organized religion? What are they? Do you believe in God? What kind of relationship do you have with God? What aspects of your spirituality or spiritual practices do you find most helpful to you personally?"

E – Effects on medical care and end-of-life issues: Has being sick (or your current situation) affected your ability to do the things that usually help you spiritually? (Or affected your relationship with God?) As a doctor /health professional, is there anything that I can do to help you access the resources that usually help you? Are you worried about any conflicts between your beliefs and your medical situation/care decisions? Are there any specific practices or restrictions I should know about in providing your medical care?"

SPIRIT (Abridged: Maugans, 1997; Ambuel & Weissman, 1999)

*S – S*piritual belief system: "Do you have a formal religious affiliation? Can you describe this? Do you have a spiritual life that is important to you?"

*P – P*ersonal spirituality: "Describe the beliefs and practices of your religion that you personally accept. Describe those beliefs and practices that you do not accept or follow. In what ways is your spirituality/religion meaningful to you?"

*I – I*ntegration with a spiritual community: "Do you belong to any religious or spiritual groups or communities? How do you participate in this group/community? What importance does this group have for you? What types of support and help does or could this group provide for you in dealing with health issues?"

*R – R*itualized practices and restrictions: "What specific practices do you carry out as part of your religious and spiritual life? What lifestyle activities or practices do your religion encourage, discourage or forbid? To what extent have you followed these guidelines?"

*I – I*mplications for medical practice: "Are there specific elements of medical care that your religion discourages or forbids? To what extent have you followed these guidelines? What aspects of your religion/spirituality would you like me to keep in mind as I care for you?"

*T – T*erminal events planning: "Are there particular aspects of medical care that you wish to forgo or have withheld because of your religion/spirituality? Are there religious or spiritual practices or rituals that you would like to have available in the hospital or at home? Are there religious or spiritual practices that you wish to plan for at the time of death, or following death? As we plan for your medical care near the end-of-life, in what ways will your religion and spirituality influence your decisions?"

FACT (Larocca-Pitts, 2008)

*F – F*aith (or Beliefs): "What is your faith or belief? So you consider yourself a person of faith or a spiritual person? What things do you believe that give your life meaning and purpose?"

*A – A*ctive (or *A*vailable, *A*ccessible, *A*pplicable): "Are you currently active in your faith community? Is support for your faith available to you? Do you have access to what you need to apply your faith (or your beliefs)? Is there a person or a group whose presence and support you value at a time like this?"

*C – C*oping (or *C*omfort); *C*onflicts (or *C*oncerns): "How are you coping with your medical situation? Is your faith (your beliefs) helping you cope? How is your faith (your beliefs) providing comfort in light of your diagnosis? Do any of your religious beliefs or spiritual practices conflict with medical treatment? Are there any particular concerns you have for us as your medical team?

*T – T*reatment plan: If patient is coping well, then either support and encourage or reassess at a later date as patient's situation changes. If patient is coping poorly, then 1) depending on relationship and similarity in faith/beliefs, provide direct intervention: spiritual counseling, prayer, Sacred Scripture, et cetera, 2) encourage patient to address these concerns with their own faith leader, or 3) make a referral to the hospital chaplain for further assessment.

Consensus Panel of the American College of Physicians recommends the following 4 questions be included in a spiritual history:[60]

1. "Is faith (religion/spirituality) important to you in your illness?"
2. "Has faith been important to you at other times in your life?"
3. "Do you have someone to talk to about religious matters?"

4. "Would you like to explore religious matters with someone?"

Oncologist-Assisted Spiritual Intervention Study (OASIS) Patient-Centered Spirituality Inquiry

1 Exploring Spiritual/Religious Concerns in Adults with Cancer

Health Care Provider Action	Possible Patient Response	Health Care Provider Reply
Introduce issue in neutral inquiring manner.		"When dealing with a serious illness, many people draw on religious or spiritual beliefs to help them cope. It would be helpful to me to know how you feel about this."
Inquire further, adjusting inquiry to patient's initial response.	Positive-Active Faith Response	"What have you found most helpful about your beliefs since your illness?"
	Neutral-Receptive Response	"How might you draw on your faith or spiritual beliefs to help you?"
	Spiritually Distressed Response (e.g., anger or guilt)	"Many people feel that way. What might help you come to terms with this?"
	Defensive/Rejecting Response	"It sounds like you're uncomfortable that I brought this up. What I'm really interested in is how you are coping. Can you tell me about that?"
Continue to explore further as indicated.		"I see. Can you tell me more (about…)?"
Inquire about ways of finding meaning and a sense of peace.		"Is there some way in which you are able to find a sense of meaning or peace in the midst of this?"
Inquire about resources.		"Whom do you have to talk to about this/ these concerns?"
Offer assistance as appropriate and available.		"Perhaps we can arrange for you to talk to someone./ There's a support group I can suggest./ There are some reading materials in the waiting room."

Health Care Provider Action	Possible Patient Response	Health Care Provider Reply
Bring inquiry to a close.		"I appreciate you discussing these issues with me. May I ask about it again?"

http://www.cancer.gov/cancertopics/pdq/supportivecare/spirituality/HealthProfessional/page5

Adopted from Kristeller et al. [61]

Appendix 2: Chaplain interventions

General	Specific	Specialty
Intentional ministry of presence	Clinical use of prayer	Spiritual mantram repetition
Spiritual reframing	Healing rituals	Creative writing
Focus of spiritual gratitude & blessings	Confession – guilt & forgiveness work	Interventions Below Require Special Training:
Meaning-making	Percentage of guilt discussion (What percent of guilt does person actually deserve?)	Sweat Lodge – Apache Warrior Ritual
Grief work	Life-review – Spiritual autobiography	Psychic Judo – going with the negative emotion
	Scripture paralleling/ Education	Interpersonal psychotherapy
	Reframing God assumptions – Examining harmful spiritual attributions	Trauma incident reduction
	Encouraging connection with a spiritual community	

From: Spiritual Care Handbook on PTSD/TBI

http://healthcarechaplaincy.org/userimages/Spiritual%20Care%20PTSD%20Handbook1.pdf

Health Professional Resources

National Cancer Institute: Spirituality in Cancer Care (PDQ®
http://www.cancer.gov/cancertopics/pdq/supportivecare/spirituality/HealthProfessional Accessed 6/27/12.

African American Outreach Guide. Caring Connections, NHPCO in collaboration with Duke Institute on Care at the End of Life. 2008
http://www.caringinfo.org/files/public/outreach/African_American_Outreach_Guide.pdf Accessed 6/12/12.

Association for Clinical and Pastoral Education: Racial, Ethnic, and Multicultural Network
http://www.acpe.edu/REMNetwork.html accessed 6/27/12.

Association of Professional Chaplains Standards of Practice
http://www.professionalchaplains.org/index.aspx?id=1210   Accessed 6/27/12.

Center to Advance Palliative Care www.capc.org Accessed 6/27/12.

EndLink Resource for End-of-Life Education: Module 14: Religion, Spirituality, and End-of-Life Care http://endoflife.northwestern.edu/eolc_religion_spirituality.cfm   Accessed 6/27/12.

FACT Spiritual Assessment Tool http://www.pastoraljournal.findaus.com/pdfs/ar2.pdf Accessed 6/27/12.

FICA Spiritual History Tool http://www.gwumc.edu/gwish/clinical/fica.cfm   Accessed 6/27/12.

Institute on Care at the End of Life, Duke Divinity School
http://divinity.duke.edu/initiatives-centers/iceol Accessed 6/27/12.

Spiritual and Religious Care Competencies for Specialist Palliative Care. 2003. Marie Curie Cancer Care hospices. David Mitchell and Tom Gordon.

Spiritual Competency Resource Center. Assessing Spirituality.
http://www.spiritualcompetency.com/recovery/lesson7.html Accessed 6/27/12.

Standards for Hospice & Palliative Care Chaplaincy. 2nd ed. 2006. Association of Hospice and Palliative Care Chaplains.

The National Association of Veterans Affairs Chaplains/ Black Chaplains subcommittee
http://www.vablackchaplains.org/ Accessed 6/28/12.

Community and Patient Resources

National Cancer Institute: Spirituality in Cancer Care (PDQ®
http://www.cancer.gov/cancertopics/pdq/supportivecare/spirituality/Patient Accessed 6/27/12.

Handbook for Mortals by Joanne Lynn, Joan Harrold, and The Center to Improve Care of the
Dying. Published by Oxford University Press 1999. ©1999 by Joanne Lynn. Available by order
at: http://www.growthhouse.org/educate/flash/mortals/mor99999.html Accessed 7/10/12.

The Unbroken Circle: A Toolkit for Congregations around Illness, End of Life, and Grief
http://divinity.duke.edu/initiatives-centers/iceol/resources/unbroken-circle   Accessed 6/27/12.

References

[1] Great-Awakening.com. Analysis and Information on the First Great Awakening.
http://www.great-awakening.com/?page_id=12 Accessed 7/10/12.

[2] ushistory.org. 22c. Religious Transformation and the Second Great Awakening. Program Title:
U.S. History Online Textbook. ©2012. http://www.ushistory.org/us/22c.asp Accessed 7/10/12.

[3] Hughes B, Handzo G. Spiritual Care Handbook on PTSD/TBI: The Handbook on Best
Practices for the Provision of Spiritual Care to Persons with Post Traumatic Stress Disorder and
Traumatic Brain Injury. Published by the U.S. Department of the Navy Bureau of Medicine and
Surgery, United States Navy Chaplain Corps. 2009. p.1
http://healthcarechaplaincy.org/userimages/Spiritual%20Care%20PTSD%20Handbook1.pdf
Accessed 7/10/12.

[4] National Cancer Institute Dictionary of Cancer Terms.
http://www.cancer.gov/dictionary?CdrID=489395 Accessed 7/10/12.

[5] Balboni TA, Paulk ME, Balboni MJ, et al. Provision of spiritual care to patients with advanced
cancer: Associations with medical care and quality of life near death. *J Clin Oncol.*
2010;28(3):445-452.

[6] Phelps AC, Maciejewski PK, Nilsson M, et al. Religious coping and use of intensive life-
prolonging care near death in patients with advanced cancer. *JAMA.* 2009;301(11):1140-1147.

[7] Pargament KI, Koenig HG, Perez LM. The many methods of religious coping: Development
and initial validation of the RCOPE. *J Clin Psychol.* 2000;56(4):519-543.

[8] Hughes B, Handzo G. Spiritual Care Handbook on PTSD/TBI: The Handbook on Best
Practices for the Provision of Spiritual Care to Persons with Post Traumatic Stress Disorder and

Traumatic Brain Injury. Published by the U.S. Department of the Navy Bureau of Medicine and Surgery, United States Navy Chaplain Corps. 2009. p.47. http://healthcarechaplaincy.org/userimages/Spiritual%20Care%20PTSD%20Handbook1.pdf Accessed 7/10/12.

[9] National Cancer Institute Dictionary of Cancer Terms http://www.cancer.gov/dictionary?CdrID=441265 Accessed 7/10/12.

[10] London G, Washington R. Spiritual Care Near Life's End including Grief and Loss in the African American Community. Chapter 4 in Payne R, London G, Latson SR, et al. Key Topics on End-of-Life Care for African Americans. 2006. http://divinity.duke.edu/initiatives-centers/iceol/resources/last-miles/papers/04 Accessed 7/10/12.

[11] Wright MC. The essence of spiritual care: a phenomenological enquiry. *J Palliat Med.* 2002;16(2):125-132.

[12] The Pew Forum on Religion and Public Life: A Religious Portrait of African-Americans. Analysis January 30, 2009. http://www.pewforum.org/A-Religious-Portrait-of-African-Americans.aspx Accessed 7/10/12.

[13] Calloway K, London G. End-of-Life Care Ministry in the African American Church. Chapter 5 in Payne R, London G, Latson SR, et al. Key Topics on End-of-Life Care for African Americans. 2006. http://divinity.duke.edu/initiatives-centers/iceol/resources/last-miles/papers/05 Accessed 7/10/12.

[14] Smith P, Abdul-Malik I, Wright J. Theological perspectives on death and dying for African Americans: Christian Perspective and Islamic Perspective. Chapter 9 in Payne R, London G, Latson SR, et al. Key Topics on End-of-Life Care for African Americans. 2006 http://divinity.duke.edu/initiatives-centers/iceol/resources/last-miles/papers/09. Accessed 7/10/12.

[15] Tarakeshwar N, Vanderwerker LC, Paulk E, et al. Religious coping is associated with the quality of life of patients with advanced cancer. *J Palliat Med.* 2006;9(3):646-657.

[16] Wikipedia. The Free Encyclopedia. Slavery in the United States. http://en.wikipedia.org/wiki/Slavery_in_the_United_States. Accessed 7/10/12.

[17] Maffly-Kipp L. African American Christianity, Part. 1: To the Civil War. http://nationalhumanitiescenter.org/tserve/nineteen/nkeyinfo/aareligionc.htm. Accessed 7/10/12.

[18] PBS. Slavery and the Making of America. The Slave Experience: Religion. Production of Thirteen/WNET New York. ©2004. Educational Broadcasting Corp. http://www.pbs.org/wnet/slavery/experience/religion/history2.html. Accessed 7/10/12.

[19] PBS. This Far by Faith. P.1-5. http://www.pbs.org/thisfarbyfaith/timeline/p_1.html. Accessed 7/10/12.

[20] Colorado College, Dept. of Education. African Diaspora. http://www2.coloradocollege.edu/Dept/HY/HY243Ruiz/Research/diaspora.html. Accessed 7/10/12.

[21] Wikipedia, the free encyclopedia. Black church. http://en.wikipedia.org/wiki/Black_church. Accessed 7/10/12.

[22] Crawley LM. Racial, cultural, and ethnic factors influencing end-of-life care. *J Palliat Med.* 2005;8(suppl1):S-58-S-69.

[23] Koenig HG, George LK, Peterson BL. Religiosity and remission of depression in medically ill older patients. *Am J Psychiatry.* 1998;155(4):536-542.

[24] Ayele H, Mulligan T, Gheorghiu S, Reyes-Ortiz C. Religious activity improves life satisfaction for some physicians and older patients. *J Am Geriatr Soc.* 1999;47(4):453-455.

[25] Robinson-Smith G. Prayer after stroke: Its relationship to quality of life. *Journal of Holistic Nursing.* 2002;20(4):352-366.

[26] Levin JS, Chatters LM. Religion, health, and psychological well-being in older adults. *Journal of Aging and Health.* 1998;10(4):504-531.

[27] Matthews DA, McCullough ME, Larson DB, et al. Religious commitment and health status: A review of the research and implications for Family Medicine. *Arch Fam Med.* 2007;7:118-124.

[28] Meisenhelder JB, Chandler EN. Prayer and health outcomes in church lay leaders. *Western Journal of Nursing Research.* 2000;22(6):706-716.

[29] Steinhauser KE, Christakis NA, Clipp EC et al. Factors considered important at the end of life by patients, family, physicians and other care providers. *JAMA*. 2000;284:2476-2482.

[30] Hamilton JB, Carter JK, Lynn MR. Reliability and validity of the Perspectives of Support from God Scale. *Nurs Res.* 2010;59(2):102-109.

[31] Hamilton JB, Powe BD, Pollard AB, et al. Spirituality among African American cancer survivors. *Cancer Nursing.* 2007;30(4):309-316.

[32] Steffen PR, Hinderliter AL, Blumenthal JA, Sherwood A. Religious coping, ethnicity, and ambulatory blood pressure. *Psychosomatic Medicine.* 2001;63:523-530.

[33] Matsuyama RK, Grange C, Lyckholm LJ, et al. Cultural perceptions in cancer care among African-American and Caucasian patients. *J Natl Med Assoc.* 2007;99(10):1113-1118.

[34] Puchalski C, Ferrell G, Virani R, et al. Improving the quality of spiritual care as a dimension of palliative care: The Report of the Consensus Conference. *J Palliat Med.* 2009;12(10):885-904.

[35] LearnWell.org: Continuing Education in Health and Ethics. Spiritual Health: Serving the Whole Person. http://www.learnwell.org/spirit.htm. Accessed 7/10/12.

[36] Hughes B, Handzo G. Spiritual Care Handbook on PTSD/TBI: The Handbook on Best Practices for the Provision of Spiritual Care to Persons with Post Traumatic Stress Disorder and Traumatic Brain Injury. Published by the U.s. Department of the Navy Bureau of Medicine and Surgery, United States Navy Chaplain Corps. 2009. p.18. http://healthcarechaplaincy.org/userimages/Spiritual%20Care%20PTSD%20Handbook1.pdf. Accessed 7/10/12.

[37] Balboni TA, Vanderwerker LC, Block SD. Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *J Clin Oncol.* 2007;25(5):555-560.

[38] Gall TL, Charbonneau C, Clarke NH, et al. Understanding the nature and role of spirituality in relation to coping and health: A conceptual framework. *Canadian Psychology.* 2005;46(2):88-104.

[39] Comstock GW, Partridge KB. Church attendance and health. *J Chronic Dis.* 1972;25:665-672.

[40] Koenig HG, McCullough ME, Larson DB. (2001). *Handbook of religion and health.* Oxford: Oxford University Press.

[41] Pargament KI. (1997). *The psychology of religion and coping: Theory, research, practice.* New Your: Guilford Press.

[42] Pearce MJ, Singer JL, Prigerson HG. Religious coping among caregivers of terminally ill cancer patients. *Journal of Health Psychology*. 2006;11(5):743-759.

[43] Wright AA, Zhang B, Ray A, et al. Association between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA.* 2008;300(14):1665-1673.

[44] Wright AA, Keating NL, Balboni TA, et al. Place of death: Correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. *J Clin Oncol.* 2010;28. Published online: http://jco.ascopubs.org/cgi/doi/10.1200/JCO.2009.26.3863. Accessed 7/10/12.

[45] True G, Phipps EJ, Braitman LE, et al. Treatment preferences and advance care planning at end of life: The role of ethnicity and spiritual coping in cancer patients. *Ann Behav Med.* 2005;30(2):174-179.

[46] Silvestri GA, Knittig S, Zoller JS, Nietert PJ. Importance of faith on medical decisions regarding cancer care. *J Clin Oncol.* 2003;21(7):1379-1382.

[47] Pargament KI, Koenig HG, Tarakeshwar N, Hahn J. Religious coping methods as predictors of psychological, physical and spiritual outcomes among medically ill elderly patients: A two-year longitudinal study. *Journal of Health Psychology.* 2004;9(6):713-730.

[48] Pargament KI, Koenig HG, Tarakeshwar N, Hahn J. Religious struggle as a predictor of mortality among medically ill elderly patients: A 2-year longitudinal study. *Arch Intern Med.* 2001;161:1881-1885.

[49] McCord G, Gilchrist VJ, Grossman SD, et al. Discussing spirituality with patients: A rational and ethical approach. *Ann Fam Med.* 2004;2(4):356-361.

[50] Ehman JW, Ott BB, Short TH, et al. Do patients want physicians to inquire about their spiritual or religious beliefs if they become gravely ill? *Arch Intern Med.* 1999;159:1803-1806.

[51] King DE, Bushwick B. Beliefs and attitudes of hospital inpatients about faith, healing and prayer. *J Fam Pract.* 1994;39:349-352.

[52] Anderson JM, Anderson LJ, Feisenthal G. Pastoral needs for support within an inpatient rehabilitation unit. *Arch Phys Medicine Rehabil.* 1993;74:574-578.

[53] Bowie J, Sudnor KD, Granot M. Spirituality and care of prostate cancer patients: A pilot study. *J Natl Med Assoc.* 2003;95(10):951-954.

[54] AMA Statement on End-of-Life Care. http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/about-ethics-group/ethics-resource-center/end-of-life-care/ama-statement-end-of-life-care.page. Accessed 7/10/12.

[55] ASCO Special Article: Cancer Care During the Last Phase of Life. Adopted February 20, 1998. *J Clin Oncol* 1998;16:1986-1996 American Society of Clinical Oncology 1998. Accessed online on 5/26/11 at: http://www.asco.org/asco/downloads/CancerCareattheEndofLife.pdf.

[56] Code of Ethics for Nurses with Interpretive Statements. © 2001 ANA printed 2005 available online at: http://www.nursingworld.org/MainMenuCategories/EthicsStandards/CodeofEthicsforNurses/Code-of-Ethics.aspx. Accessed 7/10/12.

[57] The ICN Code of Ethics for Nurses 2005. © International Council of Nurses 2006. Accessed online 5/26/11 at: http://www.icn.ch/images/stories/documents/about/icncode_english.pdf.

[58] NASW Standards for Social Work Practice in Health Care Settings. © National Association of Social Workers 2005. Accessed online on 6/27/12at: http://www.socialworkers.org/practice/standards/NASWHealthCareStandards.pdf.

[59] The Association of Professional Chaplains. Standards of Practice. Accessed online on 6/27/12 at: http://www.professionalchaplains.org/index.aspx?id=1210#acute_care.

[60] Centers for Medicare and Medicaid Services. Accessed the following sites with reference to standards for hospice care, long term care, and complex case management having to do with spiritual assessment and care. Accessed 6/27/12. http://www.cms.gov/CertificationandComplianc/07_Hospices.asp. http://www.cms.gov/MinimumDataSets20/Downloads/MDS20Forms.pdf. http://www.cms.gov/SpecialNeedsPlans/Downloads/SPMeasuresUpdate.pdf.

[61] Joint Commission for the Accreditation of Healthcare Organizations. Comprehensive Accreditation Manual for Hospitals. 2008.

[62] National Consensus Project for Quality Palliative Care (2009). *Clinical Practice Guidelines for Quality Palliative Care, Second Edition*. http://www.nationalconsensusproject.org/Guideline.pdf. Accessed 7/10/12.

[63] National Quality Forum: A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report. 2006. http://www.rwjf.org/files/research/txPHreportPUBLIC01-29-07.pdf. Accessed 7/10/12.

[64] Peterman AH, Fitchett G, Brady MJ, et al. Measuring spiritual well-being in people with cancer: the functional assessment of chronic illness therapy-Spiritual Well-being Scale (FACIT-sp). *Ann Behav Med.* 2002;24(1):49-58.

[65] Abeles R, Ellison C, George L, et al. Fetzer Institute in collaboration with The National Institute on Aging. Multidimensional Measurement of Religiousness/Spirituality for Use in Health Research: A Report of the Fetzer Institute on Aging Working Group. 1999. http://www.fetzer.org/research/248-dses. Accessed 7/10/12.

[66] Selman L, Harding R, Gysele M, et al. The measurement of spirituality in palliative care and the content of tools validated cross-culturally: A systematic review. *JPSM.* 2011;41(4):728-753.

[67] Puchalski C, Romer AL. Taking a spiritual history allows clinicians to understand patients more fully. *J Palliat Med.* 2000;3(1):129-137.

[68] Maugans TA. The SPIRITual history. *Arch Fam Med.* 1996;5(1):11-16.

[69] LaRocca-Pitts, M. (2008b). FACT: Taking a spiritual history in a clinical setting. *Journal of Health Care Chaplaincy 15*, 1-12. (NB: Though published in 2009, it is the 2008 edition.) Anandarajah, G., & Hight, E. (2001).

[70] Austin L. Spirituality and medical practice: Using the HOPE questions as a practical tool for spiritual assessment. *American Family Practice.* 2006;63:81-88.

[71] Kristeller JL, Rhodes M, Cripe LD, Sheets V. Oncologist assisted spiritual intervention study (OASIS): Patient acceptability and initial evidence of effects. *Int'l J. Psychiatry in Medicine.* 2005;35(4):329-347.

[72] Spirituality in Cancer Care (PDQ®). Table 1. Assessment of religion and spirituality in cancer patients. http://www.cancer.gov/cancertopics/pdq/supportivecare/spirituality/HealthProfessional/Table1. Accessed 7/10/12.

[73] Smith T, Gordon T. Developing spiritual and religious care competencies in practice: pilot of a Marie Curie blended learning event. *International Journal of Palliative Nursing.* 2009;15(2):86-92.

[74] Ferrell B. Meeting spiritual needs: What is an oncologist to do?. *Journal of Clinical Oncology.* 2007;25(5):467-468.

[75] Sinclair S, Raffin S, Pereira J, Guebert N. Collective soul: the spirituality of an interdisciplinary palliative care team. *Palliat Support Care.* 2006;4(1):13-24.

[76] Song MK, Hanson LC. Relationship between psychosocial-spiritual well-being and end-of-life preferences and values in African-American dialysis patients. *J Pain Sumptom Manage.* 2009;38(3):372-380.

[77] Hamilton JB, Sandelowski M. Types of social support in African Americans with cancer. *Oncology Nursing Forum.* 2004;31(4):792-800.

[78] Module 14: Religion, Spirituality, and End of Life Care. Part IV: Basic Skills and Techniques http://endoflife.northwestern.edu/religion_spirituality/skills.cfm#Guidelines. Accessed 7/10/12.

[79] Emmons RA, McCullough ME. Counting blessings versus burdens: An experimental investigation of gratitude and subjective well-being in daily life. *Journal of Personality and Social Psychology.* 2003;84(2):377-389.

[80] Puchalski CM, Lunsford B, Harris M, Miller T. Interdisciplinary spiritual care for seriously ill and dying patients: A collaborative model. *Cancer J.* 2006;12:398-416.

[81] Karekla M, Constantinou M. Religious coping and cancer: Proposing an acceptance and commitment therapy approach. *Cognitive and Behavioral Practice.* 2010;17:371-381.

[82] Paez M, Luciano MC, Gutierrez O. Phsychological treatment for breast cancer: Comparison between acceptance based and cognitive control based strategies. *Psicooncologia.* 2007;4:75-95.

[83] Chochinov HM, Hack T, Hassard T, et al. Dignity Therapy: A novel psychotherapeutic intervention for patients near the end of life. *J Clin Oncol.* 2005;23(24):5520-5525.

[84] DeLisser HM. A practical approach to the family that expects a miracle. *Chest.* 2009;135(6):1643-1647.

[85] Post SG, Puchalski CM, Larson DB. Physicians and patient spirituality: Professional boundaries, competency, and ethics. *Ann Intern Med.* 2000;132(7):578-583.

[86] Koenig HG. Religion, spirituality, and medicine: Application to clinical practice. *JAMA.* 2000;284(13):1708.

Self-Assessment Questions

Module 16 AA: Spirituality

1. You are visiting Mrs. Jackson, a 34 y.o. African American woman who has just been diagnosed with metastatic breast cancer. You ask her how she is doing and she replies, "Well, you know, this has been a real blow! But I just have to give this over to God, and leave this in His hands. He will help me through this."

   This is an example of:

   ☐ a). collaborative religious coping
   ☐ b). focusing on religion to stop worrying
   ☐ c). over-reliance on God
   ☐ d). active religious surrender

2. African American patients like Mrs. Jackson who rely heavily on spirituality to cope with illness are:

   ☐ a). More likely than White patients to use hospice care
   ☐ b). Less likely than White patients to desire all life-supporting measures as death nears
   ☐ c). Less likely than White patients to have advance directives in place
   ☐ d). Less likely to believe in divine intervention than White patients

3. All members of the interdisciplinary team (IDT) should be able to:

   ☐ a). Perform a formal spiritual assessment on a patient with severe illness
   ☐ b). Utilize dignity-conserving therapy for those with spiritual distress
   ☐ c). Use compassionate presence as a spiritual intervention
   ☐ d). Exhibit intentionality when providing hands-on care

4. Mr. Moss is a 67 y.o. African American with hormone and chemotherapy refractory metastatic prostate cancer who is admitted to the hospital because of altered mental status over the past 3 weeks. He has been losing weight steadily, and can no longer stand or walk. You are meeting with the family to discuss goals of care for this admission. The

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family states categorically that the chemotherapy was discontinued prematurely, and that they know that God will perform a miracle and heal Mr. Moss, if his treatment is resumed.

Your initial response to this statement that God will perform a miracle should be:

☐ a). A miracle is by definition is a very rare occurrence, and it is very unlikely that this will happen for Mr. Moss.
☐ b). Ask if their religion allows for a do not resuscitate order to be written.
☐ c). Ask a chaplain to come by, and meet with the family later to discuss goals of care.
☐ d). Ask the family what they mean by "God will perform a miracle".

Self-Assessment Answers

Question 1. The correct answer is: d)

Mrs. Jackson is exhibiting both active religious surrender, defined as actively giving up control to a higher power, as well as seeking spiritual support, or searching for comfort and reassurance through love and care of a higher power. Both of these types of spiritual coping are more common among African American patients than Whites, according to a study by True et al.[34] Collaborative religious coping, or seeking control through a partnership with God or a higher power, is another coping strategy commonly utilized by African Americans, but does not apply to the example above. This is not an example of "over-reliance on God".

Question 2. The correct answer is: c)

African American patients, especially those who use a high level of spiritual coping, are less likely than White patients to use hospice care, more likely to desire all life-supporting measures as death nears, less likely than White patients to have advance directives in place, and more likely to believe in divine intervention than White patients.

Question 3. The correct answer is: c)

All members of the IDT should be skilled at using compassionate presence and active listening, among other skills. Dignity-conserving therapy is a new psycho-therapeutic intervention that requires special training. Nurses should exhibit intentionality when providing hands-on care. Although all members of the IDT should be able to obtain a spiritual history, it is the chaplain member of the team who performs a formal spiritual assessment on patients.

Question 4. The correct answer is: d)

The initial response to the statement by a patient or family that God will perform a miracle is to explore the meaning and significance of a miracle to the family. "Listening first" conveys respect

and signals that you are interested in the family's point of view. Providing a balanced, non-argumentative response is the next step, followed by negotiating a patient-centered compromise consistent with good medical practice. Although a chaplain may be helpful to the patient and family who is experiencing spiritual distress, abruptly interrupting a goals discussion to send a chaplain who has not been requested by the family is inappropriate. Even though a miracle is a very rare occurrence, little is to be gained by challenging the family's belief in a miracle as a first step, and may undermine trust between the patient/family and health providers.